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**Understanding the experience of mood change and early  
intervention for people diagnosed with bipolar disorder**

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**Submitted for the degree of PhD, Psychology**

**Birkbeck University of London**

## Declaration

I hereby declare that the work presented in this thesis is my own, except where other sources are clearly and identifiably cited.

Joanna Farr

Some of the ideas presented in this thesis were developed through the following papers:

Nizza, I., Farr, J., & Smith, JA. (2021). Achieving excellence in interpretative phenomenological analysis (IPA) studies: four markers of high quality. *Qualitative Research in Psychology* [DOI:10.1080/14780887.2020.1854404](https://doi.org/10.1080/14780887.2020.1854404)

Farr, J., & Nizza, I. (2019). Longitudinal Interpretative Phenomenological Analysis (LIPA). A review of studies and methodological considerations *Qualitative Research in Psychology* 1-19 DOI: 10.1080/14780887.2018.1540677

## Abstract

Bipolar Disorder (BD) is a chronic, severe mental illness characterised by recurring mood episodes of depression, mania or hypomania, interspersed with periods of euthymia (stability). Episode change is a core aspect of living with BD yet qualitative findings in this area derive from a cross-sectional approach that highlights the impact of living with BD episodes rather than the experience and process of mood change itself. No study has examined what it is like to experience successive mood states over time. Nor has any work explored the experience of first BD mood episode and early intervention services, despite their recognised potential to improve outcomes.

This thesis explores the experience of mood change and early intervention for people diagnosed with BD. Two empirical studies are presented, using Interpretative Phenomenological Analysis.

The first study uses a longitudinal approach to explore the experience of three women during BD moods and euthymia. Idiographic trajectories reveal the participants' changing sense of disconnection with self, other people and their environment, along with an ongoing struggle for self-coherency. BD moods are shown to create significant changes in agency, felt connection, temporality and relational balance, leading to confusion and shame.

In the second study, eleven young people are interviewed about their experience of first-episode psychotic BD and NHS early intervention services. Dramatic changes in their sense of interpersonal control during first episode are illustrated and the benefit of existing early intervention provision is highlighted. However, findings also illustrate a complex tension between self-renewal, compromise and risk of relapse during their journey.

Mood change for people with BD is suggested to be all-encompassing and cumulative, creating identity loss and ongoing incoherency during both early and late stages of the illness. The value of existing early intervention provision is illustrated and possibilities for tailoring services to people in this group are proposed.

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### **List of Acronyms**

Acceptance and Commitment Therapy (ACT).....	221
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Bipolar Disorder	

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## Chapter One – Introduction to the Research

*“Which of my feelings are real? Which of the me’s is me? The wild, impulsive, chaotic, energetic, and crazy one? Or the shy, withdrawn, desperate, suicidal, doomed, and tired one? Probably a bit of both, hopefully much that is neither.”*

An Unquiet Mind: a memoir of moods and madness, Kay Redfield Jamison

### Setting the scene

My interest in bipolar disorder (BD) is not based on any personal connection. In fact, prior to exploring this area, my view of BD was mainly based around its representation within the media and celebrity culture. It was only when I started working at an acute adult psychology service in London and began to listen to people’s stories that I began to develop some understanding of what it was like to live with this condition. Most people in the service had lived with BD for several years and had experienced multiple mood episodes. Though I was surprised that the experiences they described seemed characterised more by their heterogeneity than similarity, one aspect that was consistently stressed by people in the service was the all-encompassing nature of episodes of depression, mania or hypomania and their pervasive impact in shaping their ongoing lives. From this insight, I became increasingly interested in exploring the experience of BD mood episodes by entering the world of individuals and elucidating their in-depth and distinctive insights.

This thesis explores the experience of mood change and early intervention for people diagnosed with BD. It comprises of two empirical studies, presented across two parts. The first examines the experience of BD mood change as it occurs during the different states of depression, euthymia (stability) and mania. Reviewing the qualitative literature, it became clear that there was a gap. Experiential studies highlighted several key dimensions of living with BD, but a core aspect that pervaded most areas of people’s lives, was their experience of mood change. Though the experience of symptoms during mood episodes were commonly overwhelming, it was successive changes between highs, lows and euthymic periods that shaped the flow of people’s lives and gave rise to instability. What was striking, however, was that despite the pivotal significance of mood change, qualitative work had yet to examine this dynamic longitudinally.

The absence of experiential longitudinal research on BD was not necessarily surprising. Qualitative longitudinal research is relatively young, having gained momentum at the turn of the 21<sup>st</sup> century, and brings with it additional methodological complexities that need to be crystallised and addressed (Neale, 2021). Indeed, longitudinal interpretative phenomenological analysis (LIPA) has only recently seen an increase in studies and the illustration of core procedures (Farr & Nizza, 2019). The development of the first study of this thesis was therefore an exciting opportunity to expand on this unexplored aspect of BD by using LIPA to examine the experience of mood change for people living with BD.

In Part Two, the exploration of mood change is extended to examine the experience of first episode BD and treatment within NHS early intervention services. My interest in looking in greater depth at this area was given impetus by study one and its insights that spoke strongly of the need to prioritise support for BD earlier and before the escalation of successive mood change. A subsequent literature review highlighted with surprising veracity both the potential for early intervention to help change the course of BD after first episode and the absence of existing studies exploring the experiences of this group. Assisted by my clinical supervisor, I was incredibly fortunate to find two NHS early intervention services working with young people during first episode BD who were willing to support the development and implementation of the study.

## The Chapters

The thesis spans two sections. Following on from this introductory chapter, the first study is presented in Part One (Chapters Two to Six) and explores the experience of BD mood change over time. Part Two (Chapters Seven to Nine) then reports the second study examining young people's experience of first episode BD and early intervention NHS services.

Part One begins with Chapter Two which includes an overview of the characteristics of BD, followed by a review of the literature focusing on the experience of living with BD. The former introduces dominant perspectives on the objective features of BD, including its clinical classification, epidemiological and prognostic characteristics, psychological models and underlying mechanisms. In the latter, five experiential constructs, synthesised from a review of qualitative findings, are described. The wide-ranging impact of episode change is discussed along with the need for longitudinal work to examine the process of change

through time. The chapter concludes with an outline of the aims of Study One to investigate an individual's experience of mood change over time.

Chapter Three provides a description and discussion of the methodology underpinning the study. The core ideas of phenomenology are introduced along with their foundation for the development of different phenomenological approaches in qualitative psychology. The key tenets of interpretative phenomenological analysis (IPA) are described along with its distinctive strengths and suitability for realising the study aims. LIPA is also introduced along with its potential to capture the flow of real-time idiographic change.

Chapter Four presents the Method of the first study. This explores the participants' experience of mood change during different states of depression, stability and mania. An account of each stage of the research process is provided, extending from the development of study design and formation of interview schedules through to data collection procedures and analytic processes. Key decisions around each stage are discussed and a description of the analytic process is illustrated through examples drawn from individual and longitudinal cross-case analyses.

Chapters Five and Six provide an in-depth account of the results. The first section of the results in Chapter Five explores the participants' changing experience during different states over time. Four themes are described within a state-by-state analysis of the participants' trajectories, with each theme focusing on one dimension of their changing experience through time. Verbatim extracts are used to illustrate the experience of participants during each state and to support interpretations. The findings are considered in relation to the wider philosophical literature around agency, temporality, feelings and relatedness, and their contribution to the psychological literature is discussed.

The second section of the results is covered in Chapter Six, illustrating the participants' search for self-coherency over time. Two themes report the participants' ongoing struggle for self-coherency during depression and stability and their mounting sense of confusion, disruption and shame. Each participant's journey unfolds through illustrative extracts that are brought to light through interpretative analysis. Findings are situated within the prevailing qualitative BD literature on identity, confusion and shame and their significance is discussed.

Part Two begins with Chapter Seven which outlines the rationale and method for the second study. This extends the exploration of mood change to examine the experience of first

episode BD and early intervention services. It provides a review of the literature demonstrating the absence of work focusing on either the experiences of first episode BD or NHS early intervention services for this group. The particularities of study design, recruitment and cross-sectional analysis are detailed.

Chapters Eight and Nine report the results of the second study. Chapter Eight presents an in-depth account of the participants' experience of first episode psychotic mania and its aftermath. Two themes are identified, illustrating extreme changes in the participants' interpersonal control during psychotic experiences and an intensity of feeling, leading to a profound loss of self. The results are then situated in the wider literature on first episode psychosis and BD delusions and their novel insights into meaning-making and identity are discussed.

Chapter Nine presents a further two themes that focus on the participants' experiences of early intervention services and managing a new sense of normalcy. The journey towards recovery is illustrated, including piecing together the past, assessing the present and building a future along with aspects of service interventions and style that supported this process. The tension between self-renewal and compromise during wellness are explored and the risk to relapse are highlighted. Key findings are then considered in relation to the wider literature on early intervention for first episode psychosis.

Chapter Ten brings to conclusion the results of both studies by summarising the findings of each study and evaluating their contribution and clinical implications. The importance of study one findings is highlighted in revealing novel patterns of mood change and their interrelationship within and between states. The role of LIPA in demonstrating the complexity of change processes through the formation of idiographic trajectories is also discussed. From study two, the constitutive role of meaning-making and identity during first episode is discussed, as is the possibility to better tailor interventions to this group. Looking across studies, the prominence of identity is emphasised along with the implications for clinical priorities. Finally, the quality of the work is evaluated and study limitations and future research are described.

**Part One: Capturing the experience of bipolar disorder  
through time: investigating change and self-coherence**

## Chapter 2 - Literature Review

### Introduction

With this review, I aim to contextualise my research by presenting a brief overview of the current thinking around bipolar disorder (BD) in terms of its clinical classification, epidemiological characteristics, prognostic trajectory, underlying mechanisms and psychological models. I will then endeavour to situate my first study within the qualitative research in this area that has so far attempted to provide an understanding of people's experience of living with BD. The corpus of qualitative studies exploring this aspect will be reviewed and a synthesis of the key experiential constructs presented along with a discussion of their contribution.

### Overview of the characteristics of BD

#### Classification and diagnosis

Bipolar Disorder (BD) is defined as cyclical affective disorder involving periods of profound disruption to mood and behaviour, interspersed with periods of full recovery or improved function (Vieta et al., 2018). Inter-episode phases of normal or stable mood are commonly referred to as euthymia (Grande et al., 2016). In the absence of approved biomarkers, the BD phenotype is defined solely according to the clinical features set out by two main diagnostic systems: the International Classification of Diseases tenth edition (ICD-10) and the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013; e.g. Grande et al., 2016; WHO, 1993). The ICD-10 is used in most countries in the world, including the United Kingdom, while the DSM-5 is used widely in the United States and in research contexts.

According to DSM-5, bipolar spectrum disorders are classified according to the severity and duration of manic episodes. DSM-5 encompasses a number of sub-types including Bipolar Disorder I (BD I), Bipolar Disorder II (BD II), cyclothymic disorders and other atypical forms (APA, 2013). BD I is diagnosed based on a single manic episode and BD II is diagnosed as a hypomanic episode and at least one episode of major depression over the lifetime. Although a history of depression is not required for BD I diagnosis, the majority of people diagnosed will have experienced at least one or more episodes of depression (Grande

et al., 2016). In contrast to DSM-5, the ICD-10 does not discriminate between BD type I and II (WHO, 1993). Instead, BD diagnosis is determined by two discrete mood episodes of either hypomania or mania and any other affective episode (manic, hypomanic, depressive or mixed) in the past (Phillips & Kupfer, 2013).

Under DSM-5, the primary criteria for both a manic and hypomanic episode is a period of abnormally and persistently elevated, expansive or irritable mood, accompanied by increased activity or energy (APA, 2013). A number of symptoms can be seen ranging from inflated self-esteem to decreased need for sleep, as well as talkativeness, distractibility and flight of ideas. It can also include increased and excessive involvement in activities that have a high potential for negative consequences.

The key criterion that differentiates mania (BD I) and hypomania (BD II) is the severity of symptoms. While manic episode typically leads to impairments to social or occupational functioning and may result in hospitalisation, hypomania is a less severe state and does not lead to significant problems with functioning (Grande et al., 2016). Accordingly, psychosis is estimated to occur in up to 75% of individuals with a manic episode, but does not occur during hypomania (Goodwin, 2007).

Episodes of depression are diagnosed according to the same criteria as major depression (in DSM-5) or depressive episodes (in ICD-10). They typically involve depressed mood, diminished interest in activities, weight loss, decreased energy, psychomotor agitation, insomnia, feelings of worthlessness, difficulties concentrating and suicidal thoughts (Vieta et al., 2018).

Although diagnosis usually follows an episode of mania or hypomania, the first mood episode experienced by people is often depression and misdiagnosis is therefore common (Carvalho et al., 2020). Studies estimate that approximately 40% of people with BD are initially misdiagnosed with depression, while up to 50% of people with a diagnosis of depression may meet the criteria for BD (Angst, 2006). There is, consequently, often a significant delay between the emergence of symptoms and diagnosis or management of BD, estimated to be between 5-10 years (Baldessarini et al., 2007; Dagani et al., 2017; Hirschfeld, 2003). A longer delay between first episode and adequate management of BD has been associated with longer duration of the illness and increased suicide attempts (Altamura et al., 2015; Altamura et al., 2010).

## Epidemiology and burden

BD affects more than 1% of the global population, independent of ethnicity, nationality and socio-economic status and is one of the leading causes of disability among young people (Alonso et al., 2011). In a worldwide mental health survey, the lifetime prevalence of BD was estimated to be 0.6% for BD I, 0.4 % for BD II and 2.4% for the broader spectrum of bipolar disorders (Merikangas et al., 2011). In the UK, it is estimated that 1.3% of the population have the condition (Smith et al., 2013), however, due to the challenges around diagnosis, it is likely that the true prevalence of BD, and particularly BD II, is higher (Fagiolini et al., 2013). While the prevalence of BD I is similar in men and women, in BD II it is more common in females (Nivoli et al., 2011).

BD ranks as the 17<sup>th</sup> greatest source of disability among all diseases worldwide (Vigo et al., 2016) and is a leading cause of Years Lost due to Disability (YLDs) in nearly all countries (Vos et al., 2015). In the 2013 global burden of disease study, BD was the fifth leading cause of disability-adjusted life years (DALYs) among the mental and substance-abuse disorders (Ferrari et al., 2016). As a lifelong and recurrent illness, BD often leads to functional impairment and reduced quality of life that can be more severe than unipolar depression or on a par with schizophrenia (Brissos, Dias, Carita, et al., 2008; Brissos, Dias, & Kapczinski, 2008; Cotrena et al., 2016).

Living with BD often leads to diminished occupational and social functioning (Goodwin, 2007). While it is estimated that 60% of people diagnosed with BD are in employment (Marwaha et al., 2013), unemployment rates are up to 10 times higher than in the general population (Grande et al., 2013). Relationship difficulties are common and people diagnosed with BD experience separation or divorce rates that are 2-3 times higher than the general population (Suppes et al., 2001). People with BD have also been found to experience cognitive deficits that continue during euthymia (stability) and contribute to difficulties with activities in daily living (Burdick et al., 2014; Träger et al., 2017).

People affected by BD have high rates of coexisting psychiatric disorders including anxiety (estimated to be present in 71% of persons with BD), substance use and personality disorders (Carvalho et al., 2020). This not only increases the complexity of diagnosis, but also leads to poorer outcomes (Merikangas et al., 2007). BD is estimated to have the highest suicide rate among affective disorders at approximately 20-30 times higher than the general population

(Dong et al., 2020; Plans et al., 2019). Approximately 7% of people with BD commit suicide and 35-50% attempt suicide at least once (Schaffer et al., 2015).

Nonpsychiatric comorbidities, including metabolic syndrome, migraine and obesity, are similarly more prevalent than in the general population (Fornaro & Stubbs, 2015; Vancampfort et al., 2016; Vancampfort, Vansteelandt, et al., 2013). Combined with suicide rates, the higher rate of physical disease present in this population mean that people diagnosed with BD have approximately twice the risk of death compared to the general population (Hayes et al., 2015; Kessing et al., 2015).

The impact of BD also leads to a considerable direct and indirect financial burden. In the UK, the annual socio-economic cost of BD in 2007 was estimated to be £5.2 billion and is projected to increase to £8.2 billion by 2026 (McCrone et al., 2008).

#### The chronic course of bipolar disorder

BD has a chronic course that usually appears in early adulthood, with a mean age of onset of approximately 20 years (Goodwin, 2007). Prevalence surveys indicate that BD is apparent from the age of 10, reaches a peak in the early 20s and then decreases thereafter (Ferrari et al., 2016). Multiple episodes are common and although pharmacological management of BD usually leads to faster remission, reduced hospitalisations and increased time to relapse, full recovery is often not achieved (Kendall et al., 2014; Yatham et al., 2013). Despite the development of effective mood stabilisers that prevent mania, depression or both (Gitlin & Frye, 2012), studies indicate relapse rates in groups receiving treatment range from 40- 60% over 1-4 years (Gignac et al., 2015b).

In addition to high relapse rates, people experience BD symptoms for approximately half of their time even under treatment (Joffe et al., 2004; Judd et al., 2003; Judd et al., 2002; Kupka et al., 2007). Subthreshold depressive symptoms have been found to dominate the illness course, with one study suggesting that individuals with BD I spend 8.9% of weeks manic/hypomanic and 31.9% depressed (Judd et al., 2002) while individuals with BD II spend 1.3% hypomanic and 50.3% of weeks depressed (Judd et al., 2003) .

Although the inter-episode period has commonly been conceived as asymptomatic, recent evidence suggests that a consistent number of people experience subsyndromal (residual) symptoms even during euthymia (Samalin et al., 2016). In one study, 29% of participants

who reported symptoms when recruited did not fully recover during the entire study period of 24 months (Fagiolini et al., 2009). Another study that examined the time to recovery after a mood episode, found that over their first five mood episodes, approximately 30% had not recovered at 6 months and 10% had not recovered at 2 years (Solomon et al., 2010).

BD has a progressive course which includes a reduction in the inter-episode duration (Kessing, 1998). An increasing number of episodes is associated with a decrease in the likelihood of response to treatment, both biological and psychological (Scott et al., 2006; Swann et al., 1999). The relationship between functional and symptomatic recovery is also complex: a time lag commonly exists, with people who have become asymptomatic continuing to be functionally impaired (Gitlin & Miklowitz, 2017; MacQueen et al., 2001). Evidence conflicts, however, over whether this is influenced by illness duration and episode history. While some longitudinal studies suggest stable cognitive functioning irrespective of mood changes over time, other cross-sectional studies suggest a higher duration of illness leads to greater cognitive deficit (Van Rheenen et al., 2020).

Because of the gradual progression of BD, staging models have been proposed (Berk et al., 2017). In these, BD is proposed to move along a predictable path from prodrome (early signs) to first episode to multiple episodes and then later stage characteristics. While evidence on the validity of a staging model is not conclusive, recent reviews highlight the clinical utility of broadly defining BD as early or late stage and the potential for staging models to aid stage-specific interventions (Kapczinski et al., 2014).

### Mechanisms underpinning bipolar disorder

Bipolar disorder is genetically complex and both genetic and environmental risk factors are understood to lead to the development and maintenance of the illness course and a model within which both gene and environmental risk factors interact is currently seen as the best fit for BD (Craddock & Sklar, 2013).

Genetic epidemiological research strongly indicates that genes affect predisposition to BD and estimates of heritability from twin studies are high (Craddock & Jones, 1999). The revolution in molecular biology and the more recent focus on genome-wide association studies has furthered knowledge of the genetics and possible neurobiological pathways of BD (Gordovez & McMahon, 2020). In a recent genome-wide association study, many genes with small effect sizes, as well as gene sets, were found to contribute to the risk of BD (Stahl et al.,

2019). While these were found to overlap with markers associated with schizophrenia and major depression, none of these genetic markers confers major risk for the development of the illness and only account for 25% of the heritability of BD (Gordovez & McMahon, 2020). Studies investigating the interacting effects of a variation in genes suggest that polymorphisms in candidate genes may also interact with early life stress, childhood adverse events and cannabis use, influencing BD outcomes (Misiak et al., 2018; Rowland & Marwaha, 2018).

While mood disorders were historically believed to result from an imbalance in the monoamine transmitter systems, no single dysfunction has been identified (Goodwin, 2007). More recently, the focus has been on the influence of synaptic and neural plasticity in regions of the brain, such as the prefrontal cortex, hippocampus, amygdala and other areas of the limbic system (Vieta et al., 2018). Neurobiological lines of research lend support to the notion of BD as a progressive illness and have shown that there are changes in brain structure and cell function (Berk, Kapczinski, et al., 2011; Berk et al., 2017). In a subset of patients, the reduced time between episodes and lower responsiveness to treatment has been linked to neurobiological interrelated processes in the brain (Passos et al., 2016). Dysfunction in the activity of the hypothalamic-pituitary-adrenal axis is thought to contribute to pathophysiology and progression of BD, while also being related to environmental risk factors, such as childhood trauma (Belvederi Murri et al., 2016).

In an attempt to explain the cause of BD progression, the “kindling” hypothesis has been proposed. This indicates that alterations in brain plasticity lead to increased responsivity to stressors which, in turn, leads to recurring affective episodes (Post, 2007). The mechanisms underpinning the model may be strengthened if the illness is not treated or if a person is exposed to psychoactive substances or lifestyle risks (Firth et al., 2019).

While the kindling hypothesis emphasises the impact of environmental factors on onset, research in this area is limited. Factors such as smoking during pregnancy and high paternal age are identified as risks, while life events, in particular adverse childhood events and trauma, have been found to both increase risk and contribute to a more severe clinical course (Aldinger & Schulze, 2017). Similarly, drug misuse increases the risk of onset and severity, while medications such as anti-depressants can also trigger elevated mood.

## Psychological models of BD

Psychological models of BD endeavour to explain vulnerability to bipolar mood states in terms of the characteristics and relationships between cognition, behaviour, motivation, attention and emotion. Over the last 30 years, cognitive behavioural models have been developed that highlight the importance of appraisals in understanding interactions between external or internal triggers and BD mood states.

### *Behavioural Approach System (BAS) Dysregulation Model*

The behaviour approach system (BAS) is a psychobiological system that is believed to underlie motivation and approach behaviour (Depue & Iacono, 1989; Gray, 1994). Typically, the BAS is activated by positive external events that elicit satisfaction and associated expectations, and deactivated by negative ones that create dissatisfaction and related expectations (Fleck et al., 2020). The process of activating or deactivating the BAS involves the expression of related emotions and actions that result from a response either towards or away from the event.

According to the BAS-dysregulation model, vulnerability to BD is associated with a dysregulated BAS whereby people are overly sensitive to certain environmental stimuli which leads to extreme fluctuations in activation and deactivation and BD symptoms (e.g. Alloy & Abramson, 2010; Depue & Iacono, 1989). In response to events involving rewards or goal attainment, a trait-like BAS sensitivity over-activates the BAS, leading to increased behavioural approach and manic symptoms, such as higher goal-directed activity and self-confidence (Urosević et al., 2008). In contrast, sensitivity to failure and non-attainment can under-activate the BAS, leading to decreased behavioural approach and depressive symptoms, such as decreased goal-directed activity, energy and loss of interest (Depue & Iacono, 1989; Urosević et al., 2008).

An individual's appraisal of BAS-activating success (e.g. how strongly they feel they will obtain pertinent goals) or BAS-deactivating failure (e.g. how strongly they expect to fail) form their expectations of future success or failure (Urosević et al., 2008). That person's state prior to the event influences appraisal processes which, in turn, influences the BAS state. Extreme appraisals, therefore, can arise from a combination of weak BAS regulation and high pre-event states, resulting in more dysregulated appraisals and a greater severity of bipolar symptoms.

### *The Integrative Cognitive Model of BD*

Like the BAS, the Integrative Cognitive Model (ICM) of BD (Mansell et al., 2007) sheds light on the influence of extreme appraisals in escalating cognition and behaviour, and in the maintenance of affective symptoms. In the ICM, the key interaction is between extreme positive or negative appraisals of a change in internal state that respectively drive ascent or descent behaviours and the expression of affect (Kelly et al., 2017). Some appraisals are seen as particularly relevant to BD, such as positive appraisals of high activation and catastrophic appraisals of mood states (Mansell et al., 2007). Appraisals of changes in internal state and related ascent or descent behaviours are also influenced by beliefs regarding the self, along with past and current experiences. According to the model, alterations in state can precipitate contradictory appraisals. For instance, a change can signify both personal success and imminent catastrophe, precipitating a potentially conflicting response: efforts to achieve success initiate ascent behaviours and efforts to control internal state and prevent catastrophe initiate descent behaviours (Kelly et al., 2012). The former might include increasing activity or risk-taking, while the latter could involve social withdrawal or self-criticism. Further, the process initiates a self-sustaining and reciprocal cycle that drives state changes and escalates BD symptoms.

### *BD models extended from theories of depression*

Other models of BD stem from theories of depression, including the Cognitive Vulnerability Model and the Response Style Theory. The Cognitive Vulnerability Model proposes that cognitive styles, such as negative attitudes and appraisals, lead to bipolar vulnerability (Abramson et al., 1989; Alloy et al., 2006) and negative cognitive styles, that are seen to explain depression, also account for manic episodes. Within this model, the manic defence hypothesis posits that mania arises as a defence mechanism to avoid depression and associated negative cognitive styles (Neale, 1988).

According to Response Style Theory (Knowles et al., 2005; Nolen-Hoeksema, 1991), the process of rumination, whereby a person focuses on their negative state, contributes to depressive symptoms and episodes. Mania is reflected in the depression avoidance hypothesis, whereby extreme distractive behaviour and risk-taking intended to avoid depression lead to mania (Thomas & Bentall, 2002). Mania is also proposed to occur through rumination in response to positive affect which intensifies mood (Feldman et al., 2008).

## Summary

BD is characterised by profound changes in mood, encompasses a heterogenous set of clinical sub-types and has a chronic course involving recurrent episodes, both in the short and longer term. Its adolescent onset is recognised along with its negative impact on cognition and daily functioning. Given that subthreshold symptoms and cognitive deficits often persist during euthymic periods, full recovery between episodes can be hard to achieve. Evidence is not conclusive on the nature of BD's progressive course in terms of duration and impact, and it is not clear whether it progresses in predictable stages over the illness course. Despite considerable progress in the genetics and possible neurobiological pathways of BD, much is still not understood. Most of the inherited risk of BD remains unexplained and the absence of biomarkers means that diagnosis remains reliant on subjective clinical exercises. Appraisals and cognitive styles are believed to contribute to the processual interaction between events, internal states, affective expression and behaviours that are seen to escalate BD episodes.

## Understanding the experience of bipolar disorder

The evidence presented so far endeavours to provide an objective understanding of BD, in terms of its prevalence, clinical features, frequency and duration of episodes, characteristics of the illness course and measures of impact on psychosocial functioning along with genetic, neurobiological and psychological mechanisms. It is this objective view with its reliance on quantitative models and biological markers that has dominated recent reviews of the condition (Carvalho et al., 2020; Vieta et al., 2018). Where this view falls short, is that it is unable to convey what it is like to experience BD from the perspective of people living with it. Qualitative research in this area has gathered pace, however, and there is now a body of work that aims to capture the lived experience of BD through the eyes of people diagnosed with it, focusing on their perceptions and experiences, what matters to them and how this might change over time. The findings from this body of work are likely to provide a different emphasis that can complement and build on existing quantitative work as well as bring to light new areas of significance.

## Review of qualitative experiential literature

Qualitative literature encompasses a range of methodological approaches, underpinned by distinct epistemological positions and priorities, which are used to address different types of

research questions. The choice of methodology used by researchers shapes the particular perspective or insights that become available on the phenomena under study.

Phenomenological approaches including IPA are concerned with investigating the lived experience of phenomena, with IPA taking an interpretative and idiographic perspective. Other key approaches include grounded theory (GT), which aims to inductively develop a theory or model that is grounded in the data; narrative analysis (NA) that focuses on the stories that people tell and how they narrate their lives and discourse analysis (DA) which is concerned with how language and people's interaction construct their reality and social objectives. Finally, thematic analysis (TA) is a flexible method that, depending on theoretical orientation taken by the researcher, is commonly used to investigate people's life experiences and perspectives.

To gain an understanding of how BD is experienced, the phenomenological group of methodologies are most likely to offer appropriate insightful findings because they are concerned with lived experience. However, BD has been researched in several fields, such as psychology, nursing and psychiatry using a range of approaches that also prioritise the exploration of experience and are likely to offer insightful contributions. In view of this, as well as the need to be comprehensive, it seems advantageous to look at all the principle experiential approaches. This encompasses phenomenological approaches, including IPA, GT, TA and NA.

### Qualitative literature search

A literature search was conducted of published qualitative studies reporting peoples' experiences of living with BD mood episodes. This included participant samples with either a formal or self-reported diagnosis of BD I and II and with a history of either mania or hypomania and depression. Mixed states and other BD sub-types were excluded. Studies predominantly focusing on psychosocial interventions, medication and treatment were not included, nor were those focusing on formal self-management interventions and social stigma. Mixed-methods studies that reported qualitative findings were included in the search.

To identify the highest number of relevant studies, two databases were explored, Psychinfo and Web of Science. The searches were completed during December 2020 and included only articles from peer-reviewed journals between 2000 and 2020. The following combination of keywords was used: "Bipolar\*" AND "qualitative\*" AND "interpret\* phenomenological

analysis” AND “phenomenology\*” AND “narrative” AND “thematic analysis” AND “grounded theory”. The search results were screened to identify 41 eligible articles that corresponded to 35 studies.

### Introduction to the corpus

Within the corpus of studies, a proportion of writers endeavoured to examine what it is like for people who are living with BD. While some studies aimed to reveal the range of concerns for people living with the condition, or endeavoured to elucidate its existential meaning, others formulated their enquiry within single constructs or domains such as diagnosis, interpersonal aspects, or the self.

Some distinguished their research by focusing on discrete symptomatic moods, notably mania and hypomania, and a few delimited the boundaries still further by exploring the positives of this experience (Johnson et al., 2016; Lobban et al., 2012; Ouwehand et al., 2018; Ouwehand, Zock, et al., 2019; Russell & Moss, 2013; Seal et al., 2008; Taylor et al., 2015). While the primary focus in this group concerns the experience of mania, two studies also explored hypomania, depression and euthymia (Fletcher et al., 2013; Samalin et al., 2014).

Of the 35 studies identified, 16 employed methods rooted in phenomenology and 10 of those used IPA. Thematic analysis was used in 7 studies, while the remaining portion used either narrative approaches or grounded theory. Studies using thematic content analysis that offered insight into the experience of BD were included as were two studies that used other qualitative approaches.

Design choices framed the focus of the enquiry while also shaping the view that was revealed in the results. The preferred design was cross-sectional with interview data collected at one time point when participants were euthymic, which allowed for a considered and retrospective view of episode experiences. One study collected data at multiple time-points over an extended time-period and synthesised the data for cross-sectional analysis rather than analysing the data longitudinally (Inder et al., 2011; Inder et al., 2010). Though most authors used interviews to gather data, a small number used focus groups, personal blogs or emails. The findings from two of the studies derived from a mixed-methods design that used either a flexible online questionnaire or individual interviews to gather data (Folstad & Mansell, 2018; Sajatovic et al., 2008).

The body of work varied significantly in the purity of its approach: commonly authors included participants' coping strategies as well as experiences of relationships, identity and aspirational issues in their table of themes. Consequently, although the corpus offered valuable insights into the experience of BD, a proportion of studies did not offer a focused or in-depth elucidation of a specific aspect. Even those studies that focused on single areas, such as diagnosis, reported themes relating to a range of constructs that not only informed the immediate area of study but also related to areas evidenced elsewhere in the corpus. Compared to research on other closely related disorders, such as depression or schizophrenia, research on BD is relatively young. Authors may, therefore, have felt the need to highlight the range of pertinent issues at stake for future researchers. Equally, the breadth of findings is likely to be a consequence of the epistemological orientation of researchers and the analytic procedures employed.

The breadth of study findings created challenges to producing an accurate evaluation of the experiential evidence in this area. To tackle this, findings were synthesised into key experiential constructs that would illustrate how the experience of BD episodes is currently understood. This is particularly valuable given that only two qualitative reviews of the experience of BD have been conducted. The first focuses on people's experience of symptoms and diagnosis, while the second identifies the experiences that people diagnosed with BD find distressing (Russell, 2013; Warwick, Mansell, et al., 2019).

All themes were tabled to evaluate their prominence and pattern across studies. A series of experiential areas emerged that reflected substantive experiences and topics. Synthesising the findings facilitated a comparison of perspectives reported in each core area, which allowed a more nuanced understanding and proved vital in identifying gaps in knowledge.

Study design and methodological approach were also examined to help understand how these choices influenced the findings. Where available, the following information was extracted and tabled: aims, methodology, sample size, inclusion criteria, recruitment site, data collected, timing and frequency of data collection, findings and conclusions.

### Experiential constructs

The following main constructs were identified:

- 1) Identity
- 2) Loss of control
- 3) Progress and goals
- 4) Interpersonal experience
- 5) Intensity and extremes during BD moods

Findings from the most prominent area in the corpus, 'Identity', are closely related with the experience of mood states and diagnosis so will be explored together. 'Loss of control' is the second key experiential construct and its relationship with sense of self and self-esteem will be discussed. An inter-related aspect, 'Progress and goals', concerns the disruptive impact of mood episodes on a person's sense of progression, opportunity and identity. The impact of BD episodes on relationships with others, generally reported in standalone themes, will be examined in 'Interpersonal experience'. Finally, 'Intensity and extremes during BD moods' explores the sense of conflict and intensity experienced within high moods and depression.

#### 1) Identity

A significant proportion of the corpus reports the struggle of participants to understand the changes in themselves arising during BD moods. Some studies indicate a tension between changes in episode and sense of self, suggesting that extreme behaviours challenge established self-understandings which can lead to feelings of confusion, self-doubt and loss. (Inder et al., 2011; Jönsson et al., 2008; Lim et al., 2004; Rusner et al., 2009). Changes in self create a sense of disorientation that influences identity construction during adolescence and young adulthood (Inder et al., 2008). Moods became a self-defining and all-encompassing factor in life, creating multiple confusing tensions between a person's sense of self and their perceived condition.

Part of the struggle arises from an inability to decipher aspects of the condition from their own sense of self, precipitating feelings of inauthenticity and self-doubt. Findings highlight the challenge of distinguishing normal feelings from those associated with symptoms as well as the difficulty of explaining feelings to others (Goldberg, 2019; Jönsson et al., 2008). Conversely, outlandish behaviours contradict existing self-perceptions creating a relationship that is difficult to integrate (Inder et al., 2011).

This quote vividly illustrates a sense of conflict brought about by acute episodes, the shock of which instils a loss of self and a struggle to re-establish self-coherence.

You think that you're a king and you're screaming at the top of your lungs... trying to eat your hospital bed... You don't know how to become yourself again... It's like somebody hands you a different driving licence and you're like: 'Well, who is this person?' (Michalak et al., 2006)

The conflict brought about by mood change is also considered in one study to pose an existential challenge to self (Rusner et al., 2009). From this stance, the challenge to understand is not an outcome of BD but constitutive of it: the complexity of mood change becomes unfathomable, bringing confusion over the meaning of experiences that questions a person's understanding of self, others and situations. The struggle to understand is all-encompassing and is described as a daily battle that brings with it a feeling of being misunderstood.

The way that individuals conceive episodes varies. A recent study of internet blogs by people with self-identified BD reports that moods were viewed as an alien monster by some, and as inseparable from self by others (Mandla et al., 2017). The perceived relationship between self and mood is neither linear nor stable and fluctuates: at times, moods are perceived to be inseparable from self, while at others, identity is seen as distinct (Inder et al., 2011; Inder et al., 2008).

The interplay between perceptions of self and mood is complex and changeable, but no work has focused on how this dynamic is experienced by the same person during different episodes through time. And yet capturing this aspect would help to reveal the way identity and mood inter-relate and cumulatively develop within and between episodes and well periods. The incorporation of a longitudinal and idiographic approach can initiate a shift from the prevailing view, that focuses on the shared experiences of participants at a fixed point, to examining the temporal process of self and change as it occurs through an individual's trajectory.

Studies also suggest that the dynamic between self and moods is not necessarily a negative experience. One line of research that aimed to explore the positive experience of living with BD describes a complex and dynamic relationship between self and mood that is neither a struggle or psychologically problematic (Lobban et al., 2012). Participants perceive BD in relation to the self in different ways: some see it as inseparable from themselves, others as associated with contrasting selves and a small minority as an illness that is distinct from self.

For some participants, the conflict between their positive view of BD and the negative illness model becomes a source of confusion. Though currently absent, a longitudinal perspective would help distinguish negative and positive experiences of self and illness and how these experiences might intersect and diverge through time.

One study that focused on the experience of mania for participants who were identified as creative illustrates the surge in creative energy (Johnson et al., 2016). More than half the sample saw creativity as closely intertwined with mania and felt that BD was a gift. A recent mixed methods study examined the motivations for either keeping or switching off BD: two-thirds of participants want to permanently switch off BD, but those who see BD as part of their identity want to keep it (Folstad & Mansell, 2018).

Additionally, people's evaluation of their strategies to manage moods is impacted by the degree to which this cohered to their self-expectations. Specific features of episodes are also perceived and managed in different ways, with positive attributes resulting from symptoms being embraced as integral to self and negative aspects externalised (Cappleman et al., 2015; Fletcher et al., 2013; Mandla et al., 2017). The confidence experienced during hypomania is seen as ego-syntonic and boosting self-perceptions. Compared to hypomania, however, depression is viewed as ego-dystonic, unacceptable and external to the self. Elevated mood is particularly difficult to differentiate from feelings of happiness leaving participants feeling uncertain about the authenticity of their emotions (Goldberg, 2019; Proudfoot et al., 2009).

BD diagnosis influences people's understanding of themselves and their moods, albeit in contrasting ways (Goldberg, 2012, 2019; Inder et al., 2010; Jönsson et al., 2008; Mandla et al., 2017; Proudfoot et al., 2009). One study that focused on a high-functioning group suggests that self-confusion is compounded by a diagnostic label which together undermines identity (Proudfoot et al., 2009). In another study, the initial impact of diagnosis on a group of professionals left them feeling pathologized (Goldberg, 2019).

Conversely, other work reveals the positive impact of diagnosis. In one study participants reacted positively to diagnosis, in that it helped to explain symptoms and facilitated acceptance of the condition (Delmas, et al., 2011). Diagnosis is also seen to relieve confusion (Mandla et al., 2017). One theme, 'The Monster had a name', illustrates the relief brought about by diagnosis after extended periods of confusion over mood episodes, emotions and

behaviours. A good fit between diagnosis and how the participants see themselves and their moods can lead to acceptance (Pallesen et al., 2020).

People's experience of diagnosis is seen to change over time, yet no study has examined how this occurs at different points. In one study of outpatients from a psychiatric clinic, diagnosis both answers and raises questions over cause and triggers, which precipitates the search for information (Jönsson et al., 2008). Participants transitioned from confusion over mood swings to an improved sense of clarity and understanding of their feelings. Even when diagnosis is initially seen to help explain symptoms and life experiences, time is necessary to accept the longer term implications of diagnosis (Delmas, et al., 2011). For some people, it is a precursor to recognising the problem as well as accessing treatment or further support and guidance (Warwick, Tai, et al., 2019).

## 2) Loss of control

The experience of being out of control arises from an inability to predict moods and the struggle to manage behaviours and emotions. Authors highlight a range of relational and contextual factors that compound the experience leading to feelings of helplessness and failure. Being out of control has implications for self-esteem and can reflect an instability in identity arising from changes in behaviour between states. Additionally, Folstad and Mansell (2018) suggest that being out of control is a key reason for people wanting to escape BD. A person's responses to symptoms, combined with their perception of others' responses, contributes to feeling of out of control (Crowe et al., 2012). Symptomatic moods constitute a significant change in participants' lives that cannot be predicted or controlled, creating an unstable experience of their world. The chaos and confusion of symptoms highlighted by studies also raises important questions around the way BD episodes destabilise a person.

Changes in behaviours, such as, outlandish actions and poor decision-making undermine self-control while the reactions of others compound it (Hormazábal-Salgado & Poblete-Troncoso, 2020). Multiple contexts are highlighted by Fernandez et al. (2014) including the participants' contrasting behaviours and an inability to be happy due to symptoms. Other authors describe the relentlessness of instability that defies any hope of control and brings with it an ongoing struggle for balance (Lim et al., 2004). Mood is a defining characteristic of self and is seen as a key controlling factor in life. As a result, participants feel insubstantial in lacking a stable sense of self with which to distinguish themselves (Inder et al., 2008).

While findings in this area highlight the far-reaching effect of episode change on feelings of control, the cross-sectional perspective brings to light the impact of changes rather than the way it occurs through time. Though the wide-ranging effects of change on people's lives are emphasised, its cumulative meaning over time is not clear.

Studies suggest that feelings of failure combined with the loss of control undermine people's view of themselves. Participants describe feeling flawed and unable to meet social norms, even when not perceived differently by others (Crowe et al., 2012). Some express rising self-doubt due to constant symptom surveillance (Fernandez et al., 2014). Feelings of helplessness and inconsistency are also reported to pose a direct challenge to identity (Hormazábal-Salgado & Poblete-Troncoso, 2020; Lim et al., 2004). A range of external factors are also seen to exacerbate the loss of control, including stigma, medication dependency, diagnostic labels, relationships with healthcare providers and disclosure (Crowe et al., 2012; Fernandez et al., 2014; Inder et al., 2008).

Regaining control is seen to alleviate people's fear of episodes and change (Russell & Browne, 2005; Veseth et al., 2012). While formal self-management interventions are not the focus of this review, a selection of studies illustrate strategies, activities and meanings that help people to negotiate change (Cappleman et al., 2015; Veseth et al., 2012). While some participants identified a fixed anchor, such as religion or a social role that grounded them, others highlighted the importance of meaningful activities that provided consistency. Social roles that provide structure and a more positive sense of self are also seen to support mood management (Borg et al., 2011; Tjoflåt & Ramvi, 2013), as is an awareness of bodily, emotional and social signs (Veseth et al., 2012).

A range of barriers to managing moods during euthymia are identified, that encompass personal, familial, social and healthcare domains (Blixen et al., 2016). However, by taking a broad rather than in-depth approach this work tends to separate mood symptoms from responses rather than capturing their personal experiential significance. And yet accessing the way that BD moods and their personal meaning shape euthymic periods could help inform people's negotiation of control when well. Other aspects that hinder self-management are self-stigma, lack of social and financial support, negative attitudes to medication, poor decision-making and the quality of relationships with healthcare providers. Although the structure and confidence gained from employment can support self-management, stress and prolonged work hours can trigger relapse (Borg et al., 2011).

### 3) Progress and goals

For people living with mood instability, the future can seem fragile or even unforeseeable, shaping their aspirations and possibilities. Unpredictable mood change and related disruption affect a person's progress so that their ability to achieve goals can be severely undermined (Inder et al., 2011; Inder et al., 2008; Jönsson et al., 2008; Lim et al., 2004; Russell & Moss, 2013; Tse et al., 2014). Experiences during episodes, however, can either severely limit or enhance a person's capabilities and their related achievements (Lobban et al., 2012).

The difficulty of envisaging a viable future is reported by a selection of authors (Jönsson et al., 2008; Lim et al., 2004; Proudfoot et al., 2009). Failure to control moods in the past prevents perceptions of a manageable future and negative self-efficacy beliefs impedes future mood monitoring (Lim et al., 2004). Other authors emphasise that the fear of relapse contributes to a fragile future (Jönsson et al., 2008). Fear for the future is also reported by authors exploring diagnosis. They emphasise its delimiting impact on expectations (Proudfoot et al., 2009). Factors that contributed to a more hopeful future are also highlighted, including insight, adjustment and the will to fight (Jönsson et al., 2008).

The impact of the past on future perceptions is emphasised by work in this area, but an idiographic and longitudinal approach is required to reveal the temporal flow of experiences within and between episodes and well periods. Capturing the way this unfolds retrospectively and prospectively through an individual's trajectory could help inform how changes in progression and the future are managed over time.

The relationship between identity and mood change can have a bearing on life trajectories and vary according to life stage (Sajatovic et al., 2008; Tse et al., 2014). Older adults' expectations for the future are determined by feelings of hopelessness over managing moods, whereas younger adults anticipate positive selves that bring an improvement in well-being, work performance and role attainment (Sajatovic et al., 2008; Tse et al., 2014). In employment contexts, BD diagnosis is seen as stigmatising and a hindrance, however, findings indicate the value of goal-related activities and employment opportunities in providing meaningful identities and improved self-esteem (Borg et al., 2011; Pallesen et al., 2020).

Symptoms associated with different states are perceived to both disrupt or enhance achievements: depression is seen as a constant interruption in life that increases insecurity

over ability and potential, while mania is an opportunity for relief from incapacity (Jönsson et al., 2008). Mania can enhance existing abilities, leading to greater levels of accomplishment. Heightened energy along with expansive thoughts during mania can also contribute to creative thinking and output (Taylor et al., 2015). Occupational advantages, however, are more in keeping with moderate changes during hypomania, such as confidence and focused problem-solving (Fletcher et al., 2013; Lobban et al., 2012). Indeed, the destructive consequences of mania are illustrated by Russell and Moss (2013): though mania shares a conceptual fluidity with aspects of happiness, such as excitement and joy, its behaviours result in damaged careers and lost opportunities.

Taken together, studies suggest a stark contrast between depressive disruption, manic progress and its destructive aftermath. However, no study has tackled how temporality during different states is interpreted by the same person through time or how it inter-relates with their sense of progress during euthymia.

Residual symptoms between episodes also impacts functioning and impedes attainment (Maassen et al., 2018; Samalin et al., 2014). Emotional instability is seen to impede the achievement education and employment goals during well periods (Inder et al., 2011; Inder et al., 2008), but there is limited understanding of how this struggle interrelates with episodes and accumulates.

#### 4) Interpersonal experience

BD episodes and mood instability both impact and are shaped by people's relationships with others. Changes in mood along with behaviours during episodes lead to relationship disruption, while the perceptions of others' reactions can exacerbate relational tension and aggravate mood states. Equally, supportive others are acknowledged to be pivotal in facilitating mood management and recovery.

##### a) BD moods impact relationships

Challenging behaviours exhibited during elevated moods can result in relationship loss and shame and the mistreatment of others during episodes can exacerbate depressive thoughts (Granek et al., 2016; Rusner et al., 2009; Samalin et al., 2014). Authors stress the detrimental impact of decisions and actions during mania on relationships, as well as discord in intimate relations due to manic hyper-sexuality (Granek et al., 2016; Hormazábal-Salgado & Poblete-

Troncoso, 2020; Lim et al., 2004; Michalak et al., 2006; Owen et al., 2017). In one study, the use of dyadic design leads to valuable insights into the impact of BD on marital relationships highlighting the negative impact of mood volatility, personality change and unpredictable behaviours, along with a lack of physical intimacy (Granek et al., 2016). Other authors describe the struggle to maintain relationships during mood volatility which can precipitate marital break-up and damage parental relationships, while creating feelings of loss and loneliness (Fernandez et al., 2014; Inder et al., 2008; Owen et al., 2017).

Interpersonal disruption creates anxiety and uncertainty over retaining existing relationships and much-needed social support. In turn, feelings of anxiety and fear arising from relationship loss prevent the formation of meaningful future relationships (Inder et al., 2008). Other mood related factors, such as the exhaustion and self-isolation during depression, also pose a constant challenge to maintaining social contact (Owen et al., 2017; Rusner et al., 2009)

Overall, findings point to the need to better understand how the episode-specific behaviours and feelings that impact relationships are experienced at the time. Indeed, accessing this aspect is likely to facilitate the management of relational change during and between episodes. A longitudinal approach, therefore, could bring to light changes in perspective and relational adaptation through time, particularly when combined with IPA that privileges idiographic depth.

Relational interactions are also found to reflect and create emotional dynamics: the negative responses of close others during hypomania and depression are perceived to be unsupportive and critical and lead to increased anger and frustration (Fletcher et al., 2013; Owen et al., 2017). Over time, close others are often perceived as becoming more supportive and accepting. Elevated moods lead to more open interactions that increase relational connection (Lobban et al., 2012). While interactions with others appear to impact interpersonal lives and develop over time, evidence of this dynamic is solely retrospective. An examination of how others are experienced during episodes and how this cumulates would illuminate this aspect.

Increases in self-esteem during elevated moods are also seen to confer social advantage (Owen et al., 2017). One study highlights the contradictory tension between feelings and perceptions of social connection and adaptation during mania and its damaging interpersonal consequences (Russell & Moss, 2013). Though mania heightens senses, bodily energy and

social connectedness, it is also associated with relationship loss, suggesting that contradictory experiences arise from the episode over time. An increase in social connection and the capacity to fulfil social roles is also experienced during hypomania, but without negative consequences (Fletcher et al., 2013; Seal et al., 2008).

#### b) Supportive others and social interactions impact moods and coping

Authors who widen their focus of enquiry to include quality of life and recovery also highlight the supportive impact of significant others on coping and relapse prevention (Cappleman et al., 2015; Fernandez et al., 2014; Hormazábal-Salgado & Poblete-Troncoso, 2020; Michalak et al., 2006; Rusner et al., 2010; Sajatovic et al., 2008; Veseth et al., 2012; Warwick, Tai, et al., 2019). Reliable and empathic close others play a vital part in discussing experiences, supporting self-awareness and facilitating acceptance, all of which can contribute to personal recovery and well-being.

The meaning of a good life with BD is encapsulated by a dependence that empowers, where dependence is guided by voluntary choice and others are trusted and honest (Rusner et al., 2010). The role of others in facilitating mood management comes in many forms. Significant others can prove protective: for example, one participant is able to postpone manic episodes due to the needs of her daughter, while in another study, the love and support offered by the children of parents with BD are seen as life-saving during depressive periods (Tjoflåt & Ramvi, 2013).

The support of family and close others is seen as pivotal in providing feedback on behavioural changes and monitoring symptoms to prevent relapse (Hormazábal-Salgado & Poblete-Troncoso, 2020; Veseth et al., 2012; Warwick, Tai, et al., 2019). During periods of relapse, parental support was seen by young adults as particularly important in encouraging them to engage in activities that were seen to help (Hormazábal-Salgado & Poblete-Troncoso, 2020). At times of suicide risk, significant others are also protective and can facilitate more positive reflection (Owen et al., 2015). Older age-groups gain particular benefit from relational roles and responsibilities (Sajatovic et al., 2008; Tjoflåt & Ramvi, 2013).

Close and reliable others can help process shameful experiences by providing honest appraisals and being present during periods of despair. Their insights can illuminate previous behaviours, creating opportunities to change, as well as help identify early warning signs

(Cappleman et al., 2015; Goldberg, 2019; Rusner et al., 2010). Relational dependence, however, can conflict with the need for autonomy, a dynamic that can vary according to life-stage (Michalak et al., 2006). The role of social support is set against the need for adolescents to establish independence within the family domain.

#### 5) Intensity and extremes during BD moods

When examining the corpus, what was striking was the limited evidence of people's experience during episodes and the relationship between elevated moods and depressive episodes. Moreover, the few studies that did investigate this aspect focused on people's retrospective experience of episodes, rather than gaining insight into how they arise at the time. A prospective view can get help closer to lived experience, thus providing a more immediate view of change. Moreover, IPA's in-depth approach can help provide rich detail into the feelings of participants as they occur during episodes, as well as shedding light on more nuanced aspects of change.

Elevated moods are characterised by an intensity experienced at multiple dimensions that change a person's experience of themselves, others and their environment (Fletcher et al., 2013; Lobban et al., 2012; Ouwehand et al., 2018; Ouwehand, Zock, et al., 2019; Rusner et al., 2009; Taylor et al., 2015; Veseth et al., 2012). One study that specifically explores mania, describes an intensity in perceptual, cognitive and emotional experience that generates the novel ideas and original connections that facilitate creativity (Taylor et al., 2015). Further work on creativity and mania suggests an energy surge that gives rise to creative connections and non-linear thinking (Johnson et al., 2016). Other authors mention a heightened sensitivity to feelings that are understood through creative contexts, such as art, poetry and music (Rusner et al., 2009).

Work focusing on religious and spiritual experiences during episodes, highlight the intensity of divine presence and meaning during mania (Ouwehand et al., 2018; Ouwehand, Zock, et al., 2019). Consequently, elevated moods can be viewed as a gift or blessing in their ability to extend experiences beyond the constraints of normal life, but a curse due to potential psychotic implications (Lobban et al., 2012). Indeed, Goldberg (2019) highlights people's fear of extra-intensity during mania which is experienced as an explosion of destructive feelings and behaviours.

These extra dimensions during elevated moods are apparent in all aspects of life and are perceived to be, in magnitude and complexity, beyond what is seen as a normal life and creating chaos (Rusner et al., 2009). Visual and auditory stimuli are similarly magnified, creating an altered experience of sensory perception, along with changes in temporality. One participant describes an acceleration in their experiencing of phenomena that has no temporal value:

I can experience a hundred things in one second. They flash past. And when I regain consciousness I'm still sitting there smoking. I haven't even taken a puff of my cigarette (Rusner et al., 2009)

A small group of studies report experiences of ecstasy during mania, something that sharply conflicts with the sense of loss and shame described earlier (Russell & Moss, 2013; Seal et al., 2008; Veseth et al., 2012). The conceptual fluidity between happiness and the joy of mania is highlighted by Russell and Moss (2013) who describe it as a state of euphoria that is liberating and physically energising. Comparatively, hypomanic experiences are described in more measured terms and conferred a sense of optimism that provides welcome relief from depression (Fletcher et al., 2013; Seal et al., 2008). Self-confidence is seen as one of the qualities of hypomanic experiences, providing freedom and opportunity for change. Euthymic periods are characterised by disproportional emotional responses, hypersensitivity to the environment, hyperreactivity to stress and emotional intensity (Samalin et al., 2014).

The positivity of mania and hypomania creates challenges for people trying to stabilise themselves (Veseth et al., 2012). Participants report feelings of ambivalence over letting go of mania and battling to establish stability against their desire to experience something extraordinary.

Authors highlight the sense of conflict that arises from opposing episodes, yet they do not systematically elucidate the experiences that bring about conflict or, indeed, what changes (Crowe et al., 2012; Fernandez et al., 2014; Fletcher et al., 2013; Mandla et al., 2017). Fernandez et al. (2014) broadly suggests that depression precipitates negative self-perceptions and frightening experiences including suicidal ideation, loneliness and despair, while mania is experienced as adventurous and as a time of endless energy. The only paper to tackle the experience of both elevated and depressed states focuses on BD II and the contributory role of extreme self-appraisals in driving mood escalation (Fletcher et al., 2013).

Informed by the ICM of BD (Mansell et al., 2007), findings suggest that changes in internal state (mood change, arousal, cognition) lead to conflicting and extreme personal appraisals, driving behavioural responses that precipitate an escalation in mood. Hypomania is viewed as a desirable ego-syntonic characteristic that boosts self-perceptions and confers occupational and social advantages, while depression, in contrast, is seen as an abnormal negative state that is ego-dystonic. Participants expressed an overwhelming fear of depression, eliciting thoughts of a full-blown episode that result in a downward thought cycle. This work, however, struggles to convey the experience of change between states, highlighting the need for a more inductive, holistic and in-depth examination of both elevated and low mood states and their inter-relationship over time. What is currently lacking here is an in-depth approach that can capture and elucidate the root of people's conflict by revealing how change arises and is constitutive of a person's trajectory.

## Summary

Living with BD is all-encompassing and shapes key dimensions of a person's experiential world including their identity, sense of control, view of the future and progress, as well as their interpersonal life. Bipolar episodes precipitate radical alterations in emotional intensity, behaviours and perceptual enhancement. Changes to a person's lifeworld also influence their experience of BD moods and their ability to manage them. Although the aim of this review was to distinguish the key experiential constructs that derive from the qualitative literature, it is apparent that they interrelate and influence each other.

The first and most expansive area identified was identity and its complex relationship with a person's shifting sense of themselves during episodes. The struggle to understand reflects an unstable tension between a person's sense of self and their experience of mood episodes. Overall, findings suggest a complex picture that is highly personal: at times, people struggle to decipher their sense of self from moods, while at others they struggle to accept blatant extremes as part of themselves. People view themselves in relation to their condition, a dynamic that can result in confusion and identity loss. A sharper focus is required to capture how and when the understandable confusion of mood change creates a problematic affront to self. Most evidence focuses on the perceptions of self that result from mood change without elaborating on the experience of self during different moods, a feature that limits our understanding. For example, the revelation that identity can be perceived as both inseparable and distinct from episodes increases our understanding of the impact of BD moods, but does

not get to the root of how or when this occurs or the accumulative meaning over time. LIPA, however, is well-placed to bring a new level of idiographic depth and detail to this area that is currently lacking, along with the personal meaning of change over time.

Feeling out of control shapes the way that people view themselves and manage BD. Mood episodes and change lie at the heart of the loss of control, infiltrating a person's sense of self and their relationships with others. This raises important questions about the way that successive episodes destabilise connections between a person, their identity and others. Though the effect of change is illustrated by cross-sectional studies, an absence of prospective data means it is not clear which specific experiences during bipolar episodes and euthymia people find destabilising and the accumulative nature of those changes. The use of LIPA would provide insight into the process of change as it occurs within individual's trajectory through time.

Closely inter-related with this construct is a person's view of the future that over time can become diminished by mood changes, damaged career opportunities and disruption to personal goals. Conversely, cognitive, perceptual and emotional enhancement during elevated moods can bring periods of increased creativity and achievement. It is, therefore, unsurprising that mood instability challenges a person's ability to stay on track or to envisage a future that is sufficiently stable to attain expected goals. Though authors broadly convey the feelings of uncertainty, hopelessness and anxiety that arise from the impact of mood change on a person's ability to progress, they do not identify which experiences during episodes are unmanageable and how their changing sense of temporality impacts future momentum.

Relational interactions can influence emotional dynamics during episodes and elevated moods may instil more open interactions. Interpersonal disruption and relationship loss is also closely interrelated with a person's changing experience of moods. The way a person's interpersonal world alters during individual episodes, however, is not understood, highlighting the need for an in-depth, longitudinal approach. From this perspective, relational disruption is not solely the outcome of episode behaviours but also arises through fundamental changes in a person's relational experience through time.

Surprisingly few studies focus specifically on people's experience during BD episodes. For the most part, findings illustrate the intensity and enhancement of changes during elevated moods and its impact on different experiential dimensions. It is notable however, that

depression is largely overlooked, along with the relationship of episodes to people's sense of stability during euthymia. To date, no study has examined mood change within and between states or their accumulative inter-relationship over time. The idiographic commitment of longitudinal IPA, however, well-placed to illuminate a person's sense-making of different states and the way that unfolds during real-time and interrelates to their sense of past and future.

## Conclusions and research question

The construct that transcends most areas identified in the corpus is how people understand themselves in relation to their sense of change during and between bipolar episodes. While this is a highly personal and dynamic process that is influenced by specific mood states and contexts, it can lead to identity threat, confusion, loss of control or progress and interpersonal challenges. Although people struggle with the unpredictability of extreme change between episodes, manic and hypomanic moods can be experienced either positively or negatively. While the literature provides insights into the retrospective experience of manic states, no work has examined how change manifests during mania and depression. Given the significance of bipolar mood change to people's experience of themselves and their lives, it is necessary to understand how change is experienced within episodes and euthymia by the same person. This perspective would shed light on the experience of change during episodes and euthymia and reveal its cumulative through time. An understanding of how change occurs during different states would also shed light on the nature of instability and the management of BD moods over time. Therefore, the primary research question of my first study is as follows:

**How do people with a diagnosis of BD experience changes in mood over time in terms of themselves, other people, and their environment?**

Other studies in the corpus have explored the multi-faceted and far-reaching impact of mood episodes, but the focus of this study is on the change that occurs during depression, mania and euthymia and how it interrelates with a person's sense of self, others and their environment. The experience of BD moods is highly subjective and requires a detailed and in-depth approach to elucidate the different ways that it manifests in a person's lived experience of their world. Therefore, phenomenological methodologies, such as IPA, offer an appropriate approach to this endeavour. By being rooted in phenomenology, hermeneutics

and idiography, IPA is uniquely positioned to elucidate idiosyncratic meaning. To access the experience of change and its cumulative progression requires a longitudinal approach that is designed around people's real-time experience. The commitment to real time in longitudinal work not only unpicks when and how different transitions occur but, by looking across them, also reveals their connections and processes. When combined with IPA's idiographic analysis, longitudinal work can reveal nuanced temporal changes that characterise people's trajectories and the way they diverge and converge. In-depth interviews conducted during mood states would also be the best approach to gaining an understanding of real-time change and its meaning over time.

## Chapter 3 – Methodology

In the last chapter, I proposed that my research question lends itself to phenomenological enquiry and that IPA is the best positioned, amongst the range of possible methodologies, to provide rich idiographic insights. In this chapter, I will introduce the core ideas of phenomenology and the way it has formed the basis for different strands of phenomenological approach in psychology. The key tenets of IPA will be discussed, along with its distinctive strengths that will help shed light on this area of enquiry.

Typically, research questions follow from an epistemological position that provides a particular perspective from which to examine phenomena. Similarly, psychological research methodologies tend to be grounded in an epistemological position that holds certain assumptions about what the data can tell us. An epistemological position provides an orientation on how people and the world can be understood, and knowledge can be accessed (Willig, 2013). Different approaches and epistemological positions bring alternative views of a phenomena to light. When considering a methodological approach for a study it is therefore important to ensure that it is consistent with the epistemological position and theoretical underpinnings of the research question (Larkin, 2015).

As demonstrated in the literature review, experiential qualitative methods in psychology have a shared concern with people's experience of phenomena. However, they are characterised by distinct epistemological orientations that lead to the privileging of different perspectives and priorities. Therefore, to produce qualitative research that offers distinctive insights and is also considered trustworthy, it is important to be clear why one methodology is prioritised over another.

### The question of epistemology in human science

The birth and development of qualitative research methods in psychology in the late-20<sup>th</sup> century reflected a growing recognition of the limitations of basing the investigation of human life within the constraints of a positivist paradigm (Banister, 2011). From a positivist perspective, knowledge is objective and 'things exist as meaningful entities independently of consciousness, that they have truth and meaning residing in them as objects' (Crotty, 1998, p. 11). It follows that a meaningful reality does not arise through a person actively relating to and experiencing a phenomena, but is already out there waiting to be passively appropriated.

The objective world, governed by absolute principles, is discoverable through systematic scientific inquiry, bringing accurate and certain knowledge. Inspired by the progress of physical science, the primary endeavour in human science became the creation of a theoretical network of stable concepts and definitions. Although this approach to knowledge formulation was abstracted from human life and their contextual variation in time and space, it was, nonetheless, able to meet the primary aim to explain and predict human events (Polkinghorne, 1986).

Within this prevailing positive paradigm, the psychological endeavour shifted towards the study of measurable behaviours (Ashworth, 2015). Even when the rise of cognitive psychology revived the focus on mental processes, it remained underpinned by the assumption of an objectivist reality. During the 1970s, however, developments in social psychology led to a reaction against the prevailing experimental method of a theoretical science that was criticised for being overly artificial, theoretical, middle-class and therefore unable to address the range of social problems within a diversity of cultures (Banister, 2011). What became apparent were the limitations of the experimental method where a person's own experience of reality, along with the significance of meaning, language and context was overlooked (Ashworth, 2015; Polkinghorne, 1986).

The tenets of philosophical thought that had paved the way for a positivist and deterministic form of human science had not gone unchallenged. One such philosophical tradition started with the ideas of Edmund Husserl (1859-1938) and Wilhelm Dilthey during the late 19<sup>th</sup> century. Phenomenology criticised the objectivist stance of natural science as failing to either recognise or access the constitutive role of subjectivity and consciousness in objectivity (Moran, 2000). Traditional notions of knowledge that claimed a person's mental life is merely a reflection of an objective exterior reality were rejected by phenomenological thinkers, who saw a person's experience as something that arises through their engagement with the world. Objects of research can neither be understood solely in themselves, nor reduced to a subject's conceptual world but only grasped as something fundamentally interrelated (Dahlberg et al., 2008).

Rather than explaining away experience by abstracting it into concepts or philosophical ideas, the priority of phenomenology was to examine the nature of experience as it occurs and in its own terms. As Husserl attests:

Experience is not an opening through which a world, existing prior to all experience, shines into a room of consciousness, it is not a mere taking of something alien to consciousness into consciousness [...] Experience is the performance in which for me, the experiencer, experienced being “is there” and is as what it is, with the whole content of and the mode of being that experience itself, by the performance of going on in its intentionality, attributes to it (Husserl, 1969, pp. 232-233).

This founding principle of the phenomenological tradition provided a new stance for human science.

## Phenomenology

Phenomenology is a philosophical approach to the study of experience and how it constitutes our lived world. Having set itself against the imposition of theory, it never became doctrinaire, but was a way of conducting philosophy that revived the philosophical focus towards the life of the living person (Moran, 2000). Phenomenological philosophers share a concern with human experience, but they bring to light different aspects of it, along with distinct ideas about how phenomenological enquiry can come to understand it.

### Consciousness and transcendentalism

From the outset, Husserl’s primary phenomenological endeavour was to get to the truth of matters by describing consciousness and what is evident in intuition. For Husserl, intuition was primordial knowledge; the way a person comes to know their own experience of a phenomenon in consciousness (Moran, 2000). His focus was the world as lived by a person, their lifeworld, as given in pre-reflective experience (Valle, 1989).

From this perspective, experience cannot be separated from an individual – it is always an experience to *someone* and is made present to them through consciousness. Similarly, consciousness is intentional – it is always directed towards *something*, whether real or imagined. It is, therefore, through intentionality that phenomena appear to a person as their own experience of something and the world is made meaningful (Lewis & Staehler, 2010). For Husserl, the task is to ‘go back to the things themselves’ (Moran, 2000, p. 108) by systematically examining and describing meanings as they are intended and fulfilled in consciousness.

Husserl's philosophical project was led by his reflections on his own experience, with a view to developing a classification of all conscious experiences and pinpointing their essential nature. For Husserl, this could not be achieved from within one's own natural outlook, which includes everyday distractions and preconceptions (Moran, 2000). To access conscious acts requires a move from this viewpoint, referred to as the natural attitude, to one of phenomenological reflection. Husserl developed a series of meditative reductions, including the phenomenological epoché, that enabled him to suspend the natural attitude by bracketing all existing assumptions and preconceptions, and thereby reveal the essential structures of consciousness: the eidos of a phenomenon (Warnock, 1970).

### Hermeneutic and existential phenomenology

A student of Husserl, Martin Heidegger (1889-1976) introduced a different emphasis to phenomenology that signified a move away from transcendentalism and founded the beginnings of existential and hermeneutic phenomenology. Heidegger saw himself as working in the phenomenological tradition, but disagreed with its primary emphasis on internal consciousness. In his major work, *Being and Time* (1962), he reconsidered the principles of phenomenology, while formulating a new philosophical approach to understanding human existence that he termed Dasein. The ontological question of human existence became the challenge for philosophy and was something that could be accessed through the synthesis of phenomenology with hermeneutics (Moran, 2000).

For Heidegger, human life and phenomenology itself was constituted by interpretation and he questioned the possibility of any knowledge outside of an interpretative stance. This stance is not theoretical but rooted in the lived world of Dasein that is caught up in the practical, historical, cultural and lived nature of its being: it's Being-in-the-world. Whereas Husserl saw consciousness as connecting person and world, Heidegger's Dasein is already immersed in an existing world of objects, people and language and cannot be separated from it (Lewis & Staehler, 2010). Things present themselves as available to a person and are meaningful in being related to their purpose in daily life.

This perspective replaced Husserl's notion of intentionality with directedness, where the experience of a person is grounded in the world and always encounters that which has already been meaningfully interpreted (Moran, 2000). Having been thrown into a pre-existing world, Dasein understands itself through the possibilities that appear to it in a particular context.

Although the web of possible meanings tied to a particular context are not necessarily explicit, they make up the background of understanding that makes it possible to interpret something. The possibilities of Dasein's being are therefore not subjective or inner phenomena but are tied to, and constrained by, its worldly situation; its Being-in-the-world.

Like Husserl, Heidegger was concerned with the way in which experience appears, presents itself and is seen through its own manner of appearing: 'that which shows itself to itself' (Heidegger, 1962, p. 51). For Heidegger, the act of appearing has dual significance. While phenomena reveal meanings that can either be true or deceptive, they may also have hidden meanings that are concealed by their mode of appearing.

Manifestly, it is something that proximally and for the most part does not show itself at all: it is something that lies hidden, in contrast to that which proximally and for the most part does show itself; but at the same time it is something that belongs to what thus shows itself, and it belongs to it so essentially as to constitute its meaning and its ground. (Heidegger, 1962, p. 59)

Phenomenology, therefore, is no longer an account of the truth of the appearance of phenomena, but 'is seeking for a meaning that may be hidden within its mode of appearing' (Moran, 2000, p. 229). Whereas Husserl's emphasis was on reduction and description, for Heidegger the way that phenomena were encountered was already interpreted and, therefore, could not be described directly.

Heidegger's conception of hermeneutic phenomenology became the basis for the work of Hans-Georg Gadamer (1900-2002). For Gadamer, the primary focus was the revelatory nature of speech and conversation, the act of understanding that brought to light new and unanticipated understanding through a hermeneutical process. In this, he looked to Heidegger's hermeneutics, emphasising that interpretative work during conversation 'doubles' the 'hermeneutical process' 'because there is one conversation between the interpreter and the other, and a second between the interpreter and oneself' (Gadamer, 2004, p. 403). Paul Ricoeur (1913-2005) developed Gadamer's thinking around empathy and consensus and proposed a dialectical relationship between an empathic and a more critical stance (Langridge, 2007).

While Heidegger developed an existential analytic of human existence, Jean-Paul Sartre (1905-1980) was concerned with the meaning of human freedom (Lewis & Staehler, 2010).

Sartre illustrated how freedom can be a key value at stake between self and other, showing the complexity around choice and the responsibility to act in relation to others as well as the influence of others on one's perception of self and the world (Spinelli, 2005). His existential perspective brought into focus the significance of understanding human experience in relation to the existence of others because our experiences are 'contingent upon the presence and absence of our relationships with other people' (Smith et al., 2009, p. 20).

### Embodiment

While Heidegger highlighted the worldliness of human experience, Maurice Merleau-Ponty (1908-1961) emphasised the embodied relationship between self and world in constituting human awareness. For Merleau-Ponty, the primary phenomenological purpose was to demystify and describe bodily experience as it is embedded in a person's worldly sense of belonging (Lewis & Staehler, 2010). Intentionality encompasses our bodily being; the way a person moves, speaks and interacts within the world (Valle, 1989). From this stance, understanding key areas of human science, notably perception, is inseparable from the constant flow of relations between body and world.

### Phenomenological Psychologies

The outlook and insights of phenomenological philosophers offer a different way to understand and approach the study of human science. Rather than construing people as objects in nature, the phenomenological perspective views person and world as interdependent, co-constitutive and dialogical. From this stance, our world view both structures the world that is experienced and at the same time is structured by the influences of the world upon us (Spinelli, 2005). Subjective experience is no longer introspective or disconnected from objectivity but becomes its foundation and development. The relationship between people, others and their environment cannot be causal or reduced to observable variables (Ashworth, 2003). Instead, human life must be explored holistically and contextually through human experience and the examination of meaning. Participants and researchers are culturally and socially situated, and interpretations cannot be made from an impartial position.

Psychiatry has a long tradition of engaging with phenomenological ideas to expand clinical practice and psychiatric knowledge (e.g. Jaspers, 1963; Minkowski, 1970). In this field, the phenomenological outlook has shifted the emphasis towards understanding psychiatric

disorders rather than attributing cause (Stanghellini & Fuchs, 2013). Diagnosed states, such as schizophrenia or psychosis, no longer represent unintelligible or disconnected transformations, but reflect changes in the relationship between person and world and the possibilities that are available to them. These changes manifest in different realms of experience, such as temporality, embodiment, relationships, affectivity and agency. A mental state can no longer be reduced to rigid, externally observable symptoms or traits, but must be understood through a person's relatedness that is situated in the world and is temporal. While discrete symptoms cannot capture the holistic and dynamic nature of this relationship, a longitudinal phenomenological approach, with its concern for subjectivity and lived experience, is able to bring meanings to light.

While clinical phenomenology methods have been developed to investigate the subjective psychiatric experiences (Parnas et al., 2005), they tend to draw on a theory-lead approach that is structured around psychiatric diagnosis. To find an approach that examines the experience of phenomena in its own terms, however, it is necessary to look to phenomenological psychology.

Because phenomenological philosophy had never set out a systematic scientific phenomenological method, this task was picked up by the work of phenomenological psychologists who adapted concepts from philosophy to meet the aims and parameters of psychological research (Morley, 2012). This involved selecting specific areas of experience and collecting data from participants through empirical materials, such as interviews, then synthesising the data to produce findings. Phenomenological psychology has evolved into a range of approaches that reflect the different emphases of philosophical phenomenology. A defining feature of the field is the distinction between Descriptive (eidetic) and Interpretative (hermeneutic) approaches, which are underpinned by different philosophical assumptions and methods. The differences between these two strands have led to disagreements over what constitutes phenomenological psychology and while much of the debate is rooted in what phenomenology is, it also encompasses differences in how it is operationalised within the field of empirical psychology.

### Descriptive Phenomenology

Descriptive phenomenology was developed by a group of academics at Duquesne University in the US including Colaizzi (1973; 1978), Giorgi (1985, 1997, 2009) and Moustakas (1994).

The most prominent approach, developed by Giorgi (1997), translated the concepts of Husserl's philosophical phenomenology into a programme for psychological research. The aim was to examine conscious experience as it presents itself to a person, with a view to providing a detailed account of those experiences and their essential meaning structures.

A defining feature of this approach is the Husserlian notion of the epoché and the phenomenological reduction. Giorgi (2010) and Moustakas (1994) argued that the validity of any phenomenological method adapted to the human sciences rests on the inclusion of the epoché. In Giorgi's (1997) approach, the epoché is followed by a psychological reduction that involves being open to the psychological aspects of phenomena.

Descriptive approaches generally include a set of analytic procedures that engender a move from the analysis of meaning of individual participants to a broader description of the meaning. Personal meanings that are rooted in individual participant accounts are subsumed into more general overarching structures. Nevertheless, some approaches (e.g. Ashworth, 2003) attempt to retain the individual features of accounts in the final description.

While descriptive phenomenology has been widely used to understand people's experience of mental health difficulties, its position and aims are not consistent with the perspective of my research question which assumes that the experience of bipolar episodes and change is bound up with a person's sense of self, other people and the world. From a hermeneutic perspective, a person's experience is not only situated, temporal and interpersonal, but is always interpreted. The aim, therefore, is not for transcendent knowledge via description of essential meaning, but the meaning of experience as it is lived by an embodied, relational, and situated person, that is revealed through interpretation.

#### Interpretative approaches: Interpretative phenomenological analysis and hermeneutic phenomenology

Interpretative approaches follow the hermeneutic phenomenology of Heidegger, Gadamer and Ricoeur where interpretation is considered a fundamental aspect of our being. From this perspective, a person cannot be separated from their wider social, cultural, and historical context. Like descriptive methods, the quality and texture of a person's experience and its meaning is of key concern but the way that experience shows itself and is seen is distinct. While descriptive approaches argue that 'unified meaning can be teased out and described precisely as it presents itself' (Giorgi, 1992, p. 123), from a hermeneutic stance, meanings do

not present themselves directly, but are conceived through the interpretative nature of human understanding (Langridge, 2007). Experience cannot be captured directly through description as this would deny that both the researcher's and the participant's experience is interpreted.

A core feature of IPA (Smith et al., 2009) is its use of the double hermeneutic, whereby the researcher is making sense of the participant's sense-making of something. IPA not only recognises the interpretative dynamic inherent to experiential understanding, but also the way it operates during the research process (Larkin et al., 2006). IPA's primary focus is those experiences that are important to people and that prompt reflection. Inherent to this is the notion of a self-reflexive and 'sense-making creature' (Smith et al., 2009, p. 33) who is actively interpreting their relationship with things and the world (Taylor, 1985). What turns an event into an experience is the meaning conferred on it by the person that, through their sense-making, brings about changes to their experience of it (Smith, 2019; Smith et al., 2009). The participant's sense-making is fluid and illusive and the phenomenological task is to bring to light that which lies partly hidden within its manner of appearing (Smith et al., 2009).

### *The hermeneutic circle*

Interpretative approaches draw on the hermeneutic circle (Schleiermacher, 1998). While hermeneutics began with the interpretation of biblical texts, it has developed into a more general concern with the nature of understanding and the constitutive role of interpretation (Couzens Hoy, 1999). Throughout history, the hermeneutic circle has been used to describe the process of understanding a text hermeneutically, where understanding is not something linear but involves repeated circular movements between the parts and the whole.

Hermeneutics was seen as the appropriate method for understanding lived experience in the human sciences, including the interpretative interplay between researcher and participant (Dilthey, 1976; Palmer, 1969).

During the research process, the researcher's preunderstandings and assumptions are regarded as unavoidable and constitute their engagement. The researcher therefore enters the circle from a position informed by their presumptions, but by focusing attentively and open-mindedly on the participant, their understanding evolves towards the position of the participant who is situated on the other side of the circle (Smith, 2007). The process is not linear but develops iteratively through a dialogical interplay between a part of the data, the whole and what else is known about the participant, which are mutually illuminating. IPA's

double hermeneutic is illustrated through the hermeneutic circle whereby the interpretative process is dynamic and iterative (Smith, 2007).

Although the requirement for openness in order to reveal the participant's experience is reminiscent of the epoché, the process is different. It is not possible to insulate a person from their preconceptions, but through this process a person becomes more aware of their preconceptions, whilst reflexively engaging with the phenomena itself. As Heidegger attests:

Our first, last and constant task in interpreting is never to allow... our fore-conception to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out the fore-structures in terms of the things themselves (Heidegger, 1962, p. 198)

In IPA analysis, Smith (2007) suggests that the iterative movement between a series of parts and wholes, as well as within and across transcripts, reflects the way meaning emerges through the researcher's pivoting perspective. At the same time, another facet of the double hermeneutic is at play, involving a movement between two positions: empathy and suspicion (Ricoeur, 1970). By engaging empathically with the participant, but also questioning the meaning of their words, the researcher is able to examine a particular experience that is appearing but may be obscured (Smith, 2011c).

For the purposes of investigating a person's experience of BD moods, IPA has much to offer. Not only does its hermeneutic position recognise that an experience is irrevocably immersed with self, others and world, but its use of the double hermeneutic enables the researcher to bring to light the different meanings that arise and transcend the experience itself. IPA's interrogative stance does not assume that participants can easily explain experiences or are aware of their underlying meaning. It therefore offers ways of probing during interview and analysis that can draw out meanings (Eatough & Smith, 2008). At the same time, it recognises the limits of the researcher's position and the challenges of understanding a phenomenon that they have never experienced. While it offers procedures that support understanding, such as in-depth interviewing and an inductive and interrogative interpretative analysis, the process is guided by the primary aim to stay rooted in the participant's experience.

### *Points of divergence and contention*

While interpretative methods generally take the view that a person's preconceptions are part of the phenomena that needs to be interpreted (Packer & Addison, 1989), there are differences in approach, including the way in which they translate interpretative endeavour into methodological practice. While IPA is focused on meaning-making, it also aims to situate this perspective within the field of psychology and inform our understanding of a range of psychological aspects, such as cognition, affectivity and embodiment (Smith et al., 2009). When conducting empirical qualitative research, it is important that a methodology offers a framework to support the delivery of high-quality research that will be taken seriously within the field. IPA therefore includes methodological guidelines that provide a basis for conducting systematic research that is transparent, rigorous and trustworthy, and by which the validity and quality of work can be evaluated (Nizza et al., 2021; Smith, 2011a; Smith et al., 2009). Through this, IPA research can endeavour to not only meet its own benchmarks (Smith, 2011a) but also the criteria for empirical qualitative psychological research in the field (Levitt et al., 2018).

Other interpretative approaches, such as Van Manen (2016) and Öhlen (2003), that do not primarily aim to position themselves within qualitative empirical psychology, advise against the utility of methodological guidelines. Öhlen (2003, p. 565) warns that the formal language of researchers "does not have the power to give life to the mysteries of life". Instead, Van Manen and Öhlen emphasise the need for creative engagement with language, where the researcher engages in the 'free acting of "seeing"' (Van Manen, 1990, p. 79). This approach might include the incorporation of devices, such as poetic condensation, to help engage the researcher at a deeper level of meaning by translating the data into poetic form with the purpose of expressing the emotional tone of the participants' narratives (Willig, 2007).

Since IPA is committed to staying close to the participant's meaning and rooting interpretation in the data, it does not look to creative formats to embellish meaning. IPA's priority is the detailed analysis of meaning-making between participant and researcher within the double hermeneutic. While meaning is revealed through analysis, it is also brought to light through a close examination of participant quotes during the write up (Nizza et al., 2021).

In this respect, IPA's systematic approach and the way it supports validity, trustworthiness and quality make it the appropriate approach for this study. Crucially, it is not prescriptive

and encourages the researcher to push the boundaries of interpretation to draw out depth of meaning. While other approaches advocate comparable levels of interpretative flair, the advantage of IPA for my research question is that its interpretative approach stays rooted in the data.

Recently, contentious claims have been made around the theoretical meaning of phenomenology and the nature of the phenomenological project in psychology (Van Manen, 2017, 2018) that has also sparked criticism from within philosophy (Zahavi, 2019, 2020). In response, however, Halling (2020) has called for a more constructive approach that allows for the practical concerns of phenomenological work in psychology and where the quality of phenomenological research is not solely viewed as a theoretical issue. He advocates a more elemental view of phenomenology and the value of innovation in theory, while criticising the imposition of a dichotomy between the study of concrete experience and the wider exploration of human existence. In evaluating the phenomenological value of a method, he highlights the need to look beyond methodological steps and towards the work itself. The method should be evaluated according to its results and whether its contribution is consonant with the essence of phenomenological enquiry.

### Interpretative Phenomenological Analysis: an idiographic approach

Although IPA's phenomenological and hermeneutical roots are shared with other phenomenological approaches, its idiographic grounding sets it apart. The idiographic commitment of IPA allows for a detailed, inductive and in-depth examination of a particular experience in a particular context. With its detailed approach, IPA aims to produce rich accounts of experiences as well as identify layers of meaning (Larkin et al., 2011). In contrast with a nomothetic approach, where data is aggregated at group level, IPA retains situated and idiographic details at the individual level. This enables the comparison of multiple cases and the illustration of divergence and convergence between cases, while at the same time illuminating new levels of meaning (Smith et al., 2009).

IPA's idiographic analytic approach reflects the detective work involved in hermeneutic phenomenology that helps bring to light that which lies hidden or latent through the close analysis of quotes. In rooting its interpretation in the data, it offers a unique view of individual meaning and the way that might change over time. It is this concern with individual meaning, and the way that this is conferred by the participant, that is of particular

value in approaching my research question. While BD moods have been shown within the wider literature to share similarities, the particular significance for my research question is the way in which this experience and its meaning may diverge over time.

IPA's commitment to idiography elucidates individual meaning and also provides the basis for transparent and well-evidenced research. As a result of the idiographic level of detail, interpretation can be discussed with other researchers and validated, while readers can scrutinise the evidence and come to their own interpretation of the meanings presented. While quality criteria have been developed to ensure rigour in its procedures (Smith, 2011a), the requirement for representativeness, transparency and variability sits comfortably with its idiographic commitment and is mutually supportive.

### Longitudinal Interpretative Phenomenological Analysis (LIPA)

IPA has been used extensively in mental health contexts to investigate a wide range of aspects, such as the experience of psychological distress (e.g. Rhodes & Smith, 2010) and service interventions (e.g. Wagstaff et al., 2018) and the experience of clinicians (e.g. Levinson et al., 2021). In recent years, it has also been used to examine the experience of phenomena over time. In a review that I co-authored in 2018, 66 LIPA studies were identified, focusing on a variety of areas including psychological distress (Farr & Nizza, 2019).

LIPA brings to light the experience of change as it occurs within the real-time flow of subjectivity, thus accessing a closer and more immediate view a person's experience of phenomena. It is therefore consistent with, and helps realise, the key priorities of IPA to get close to a person's experience of phenomena, access 'hot cognition' as well as produce accounts that vividly encapsulate what an experience is like for a person (Smith et al., 2009).

A related concern of IPA is the elucidation of experiential meaning that is embedded in and arises out of a person's sense-making through time. LIPA helps capture and elucidate the dynamic fluctuations of this process through the systematic analysis and comparison of an individual's experience at different time-points, brought to light through the researcher's interpretation. Within this approach, change is no longer free-flowing or situated in the past but is an inherent part of a person's experience of the present that is interrelated with future and past. The key strength of LIPA is its idiographic level of analysis that is able to tease out

and convey each participant's trajectory and thus reveal the experiential process of change as it evolves through a person's sense-making through time.

LIPA studies have used different approaches to capture and present the temporal dynamics of experience and core methods have been established and their key strengths identified (Farr & Nizza, 2019). One resonant example of this approach is Spiers' (2016) exploration of patients' undergoing a kidney transplant. Through an in-depth exploration of each participant's trajectory during the process, findings shed light on the divergences and convergences between the evolving relationship of participants with their donors through time. A further LIPA study by Shaw (2016), that examines the transition of older adults into care, captures the changing relationship between the participants' developing sense of space and place and how this inter-relates with feelings of confinement and opportunity. In the area of psychological distress, a small number of LIPA studies focus on key life events, such as bereavement (DiGiacomo et al., 2013) or the recovery journey from first episode psychosis (Connell et al., 2015a; Dunkley et al., 2015). However, no study in this area has yet focused on a person's experience of different states over time. Given that the aim of this research is to get as close as possible to the experience of change during BD episodes and euthymia, the priority is to capture the experience of change in real time, rather than its perceived retrospective impact.

## Chapter 4 – Study One: Method

Episode change in BD is recognised to impact a person's sense of identity, their ability to be in control and to progress, as well as their relationships with others. The impact of mood instability is acknowledged in the prevailing qualitative literature, but the nature of change itself and how it is experienced through time, within and between episodes is not known. No qualitative study has explored people's experience during different BD moods or how they arise as part of a person's unfolding trajectory over time.

To gain a better understanding of how to manage mood change and its impact on significant aspects of a person's life, it is necessary to gain insights into how change occurs in real-time. To this end, this study will explore people's experience of change during depression, mania and euthymia. As illustrated in Chapter 3, the suitability of IPA for this study is bound up in its idiographic, holistic and interpretative procedures that get closer to participants' experiences of phenomena. A longitudinal design allows examination of the three states of depression, mania and euthymia as they arise through each participant's subjective experience, bringing them to light through the process of analysis.

This chapter will focus on the research process, with a view to illustrating how the study was developed and implemented. It will endeavour to explain the rationale behind the study design, as well as providing a step-by-step illustration of each stage of the research process, from the development of the study design to formation of the interview schedule and ethics application, as well as the data collection and analysis.

### Developing the study and context

The research was developed and implemented in collaboration with the clinical supervisor of the study and his team at an NHS acute adult psychology service in London. The service provided one-to-one and group psychological support for outpatients and inpatients diagnosed with BD. The clinical context for the research was pivotal, enabling participants recruited from the service to access clinical support and providing me with valuable access to clinical knowledge during study development and implementation.

The study focus and design were informed by my practical experience of working with people diagnosed with BD alongside insights from the wider literature. During the study, I worked as an honorary assistant psychologist at the service, assisting clinicians with the delivery of psychoeducation groups for people diagnosed with depression and BD. Through this, my understanding of mental health conditions and knowledge of clinical contexts became less abstract and more rooted in concrete experiences. This helped me to better recognise and assess my own position in the research process and appreciate the position of the service users who were situated in the diagnostic perspective and language of clinical contexts.

The majority of people attending the service had been managing BD for many years and struggled with the impact of changes over time, hindering their ability to engage in psychoeducation and wider psychological interventions. While the changes commonly involved depressive episodes interspersed with sustained euthymic periods, becoming well appeared to involve a complex process of adjustment that was not linear. Though people attending the service might meet objective criteria for remission, this was often accompanied by a sense of not feeling themselves and this seemed to preclude full recovery. It was not easy, however, for them to pinpoint exactly what was causing these feelings. Both my practical experience and the wider literature pointed to the impact of instability, which led me to focus on how people who are diagnosed with BD experience change over time.

## Study design

### Longitudinal design

The aim was to gain a subjective view of how people diagnosed with BD experienced changes in state through time. This requires the examination of change as it appears to the same person through time, rather than as an isolated or discrete event. A person's experience of change unfolds through a temporal flow where each episode is interrelated to what has come before and to what will come after, so that the temporal structure that ties them together shapes the experience itself (Ashworth, 2016). Change is always comparative; a person's experience of one state is inevitably informed by what has come before, as well expectations of the future. For example, a significant change during euthymia cannot be meaningfully separated from the experience of other states that together are constitutive of it. To investigate how change arises subjectively, it is, therefore, necessary to examine a person's

own experience of change, not only during BD episodes, but also when well. Therefore, I proposed to collect data at three time points during depression, euthymia and mania.

IPA longitudinal studies commonly structure time points around a single life-changing event or intervention, with a view to showing how change evolves through an individual's trajectory (e.g. Dunkley et al., 2015; Spiers et al., 2015). The type of change scrutinised in the present study, however, reflects a shift in state that may have already become part of a person's lifeworld over time. Therefore, while the primary aim of this study was to understand immediate change during different states, it was also important to consider the cumulative impact of those changes through time.

#### Data collection decisions: balancing study aims, participant well-being and feasibility

In IPA, there is an assumption that the data collected will tell us about a person's involvement in something of importance to them (Smith et al., 2009). Since the priority of the present study was to elucidate the participants' in-depth experience of change, it was critical that the method of data collection would enable them to reflect upon their feelings and thoughts. Longitudinal IPA draws on a range of data collection methods: one-to-one interviews, focus groups, diaries and drawings have been used to access an in-depth understanding of experience (Farr & Nizza, 2019; Mavhandu-Mudzusi, 2018). When considering the optimal approach, it was necessary to balance the aim to elucidate rich data against other concerns, such as participant well-being and feasibility.

Given the complexities of interviewing people during different states, one-to-one interviews were the best option to achieve study aims. Although the wider BD qualitative literature has predominantly conducted interviews during euthymia, IPA interviews have produced in-depth accounts of people's experience during depression (e.g. Rhodes & Smith, 2010; Smith & Rhodes, 2015). Additionally, clinicians felt that one-to-one interviews would not be a risk to participant wellbeing. Service users who attended psychoeducation groups were generally comfortable talking about their experience of BD during both depressive and high states. While they were accustomed to talking in a group context, focus groups could provide neither the level of privacy nor the flexibility required. One-to-one interviews also had an advantage over diaries or creative methods, in that they did not pose extra or unfamiliar demands on the participant, something that might be hard to achieve during BD episodes.

A further consideration was the feasibility of talking one-to-one with people during manic or depressive episodes which was largely contingent on opportunity, timing and episode severity. While it seemed likely that there would be opportunities to interview during depressive periods, manic episodes tend to be rare, particularly when a person is receiving mood stabilising medication (Gitlin & Frye, 2012). It would not be feasible to interview people during acute or psychotic mania, or severe depressive periods, however clinicians at the service felt that interviews would be possible during more moderate stages of the episode.

### Ethics

During summer 2015, I developed a protocol for the study which was structured around Health Research Authority (HRA) guidelines. An NHS ethics application was drafted on the integrated research application system (IRAS) that provided comprehensive details of study design, rationale, procedures and data management. During this process, I systematically considered key areas of the study procedures including decisions around consent and capacity (see below), the recruitment of participants over time, potential risks and managing data. Prior to submission, the ethics application was reviewed by my academic and clinical supervisors and the protocol subjected to external expert peer review.

The application was submitted in October 2015 for full review by the Camden & Kings Cross research ethics committee. On 30<sup>th</sup> November 2015, I attended the research ethics committee meeting with my academic supervisor and the study aims and procedures were discussed. In January 2016, the committee gave approval for the study (see Appendix 1A). A request for two minor amendments were approved during 2017 and 2019, following a change of clinical supervisor and the need to extend study duration (see Appendix 1B).

### Recruitment

Research was hosted by the Central North West London NHS Foundation Trust. It took place across two sites that formed the basis for participant recruitment and data collection.

Participants were selected purposively through consultation with the clinical team. Individuals who were potentially suitable were identified by their clinician and informed either in person or in writing about the study. To reduce undue influence, the clinicians were not involved in the information-giving and consent-taking process. In addition, the

recruitment materials and procedures highlighted that the therapeutic care of service users would not be influenced by their decision to participate or not.

### Information-giving and consent-seeking procedures

Before asking individuals to participate and before each interview, clinicians were approached to check the suitability of their patients, ensuring that individuals who were distressed or at risk were discounted.

I completed all information-giving and consent-seeking procedures. Potential participants were given an overview of the study objectives as well as the requirements of participants and any potential risks or benefits of taking part. To ensure voluntary consent, all information was provided to participants in writing prior to discussing it in person. Prior to each interview, the terms of the study information sheet (Appendix 1C) and the consent agreement were reviewed and the participant was invited to sign the consent form (Appendix 1D).

To uphold valid consent, the participant's functional capacity to consent was checked prior to participation in each interview. I completed an NHS e-course on informed consent in adults who lack capacity and also attended a Good Clinical Practice course. I felt it was important that the participant did not feel that their capacity was being questioned, so I checked the participant's functional capacity during the information-giving process by asking them to describe the objectives of the study and what they would be required to do.

### Contact with participants over time

After the first interview, the participant was asked whether they would be interested in participating in a second interview at a later stage. If interested, they were asked how they would like to stay in contact. All participants who participated in a first interview showed interest in continuing in the study and chose to stay in contact by phone.

### Participant and researcher safety

Interview procedures were devised to minimise the risk of upsetting participants. These included reminding the participant of their right to not respond to a question, actively monitoring their wellbeing throughout the interview and pausing or stopping should they become distressed. In the event that a participant disclosed suicidal feelings or intention to

harm others, their clinician would be notified by phone and in writing, as would the clinical supervisor of the study who would ensure that it was recorded in the patient's notes.

Interviews were conducted in a private room at the service and clinical support was available to both the participant and myself should any difficulties arise.

### *Participants*

IPA's idiographic and inductive mode of enquiry aims to recruit a closely defined group of participants that can represent a particular perspective in the area of study (Smith et al., 2009). In practice, IPA's homogeneity aims need to be balanced against recruitment feasibility. Given that the potential pool of participants at the service with a BD diagnosis was relatively small, the recruitment criteria were kept broad.

### *Inclusion criteria*

- (i) Diagnosis of bipolar disorder by a mental health practitioner
- (ii) Ability to communicate in English to a standard that enables the interview to be completed without an interpreter
- (iii) Willingness to undergo a short assessment of mood state at the time of interview
- (iv) Aged 18-70

### *Exclusion criteria*

- (i) Co-morbid psychiatric conditions
- (ii) Severe alcohol or drug dependence

### *Sample size*

IPA often uses small participant samples in order to retain an idiographic commitment to the detailed account of a person's experiences (Smith et al., 2009). The challenges of attrition in longitudinal research (Calman et al., 2013), along with the complexity of recruiting participants during unanticipated states lent support to recruiting a small sample. The objective of the study was to report data for approximately 14 participants.

Over the duration of the study, 12 participants were recruited and were interviewed either during stability, depression or mania (please see Table 1. below). The majority of first interviews were conducted during stability (n=8), with others conducted during depression

(n=3) and mania (n=1). Overall, nine interviews were conducted during stability, six during depression and two during mania. One of the depression interviews (Participant: John) did not meet the criteria for depression and was discounted. Longitudinally, three participants were interviewed during both stability and depression and one participant was interviewed once during mania and twice during stability.

Table 1. *Table of participants and interviews*

No.	Name Pseudonym	Gender	Age	Stable	Depressed	Manic
1	Sasha	Female	36	Interview 1		
2	Majid	Male	31		Interview 1	
3	Kaya	Female	26	Interview 1/3		Interview 2
4	Julia	Female	38	Interview 2	Interview 1	
5	Sandra	Female	51	Interview 1		
6	John	Male	35	Interview 1	Interview 2	
7	Caroline	Female	40	Interview 1	Interview 2	
8	Michelle	Female	42	Interview 1		
9	Karen	Female	45	Interview 2	Interview 1	
10	Jessie	Female	35			Interview 1
11	Frank	Male	26	Interview 1		
12	Katy	Female	31		Interview 1	

Levels of attrition during the study were higher than anticipated, as was the period of stability experienced by participants. Despite successful recruitment, the longitudinal aims of the study were not fully realised and the final longitudinal sample was smaller than hoped. IPA's idiographic approach is, however, well-suited to small samples and has widely been used for in-depth case study research (e.g. Eatough & Smith, 2006; Rhodes & Smith, 2010).

Therefore, by drawing on the particular strengths of IPA, I endeavoured to produce an idiographic account of each participant's journey during change.

## The Interview

IPA draws on a semi-structured interview format that engenders an open approach to investigating a participant's experience. A central feature of IPA interviewing is that it is exploratory and encourages the participant to speak freely about their experiences (Reid et al., 2005). A further distinctive aspect of IPA is its use of interrogative probing that helps participants to elucidate in more depth their experience of phenomena.

In longitudinal designs, the decision over whether to use the same or different interview schedules over time has an impact on the type of data collected (Farr & Nizza, 2019). In this study, the same interview schedule was used for each interview. The advantage is that it does not presume the presence of change, but instead invites participants to discuss whatever is relevant at the time, making the interview more participant-led.

### Developing the interview schedule

IPA interviews encourage participants to speak freely about their experience and the role of the schedule is to orientate the interview around the key areas of concern. In developing the schedule there were several aspects to consider. The first step was to identify the key areas that should be included. To examine participants' experiences of their present state, the questions needed to prioritise current feelings and experiences. To grasp their sense of comparative change, it was also necessary to examine their experience of the other two states during each interview. Other key areas included the participants' sense of themselves, other people and their environment.

I then considered the temporal sequence of the schedule and the form of questioning and use of language. Prompts were employed to facilitate depth by encouraging participants to expand on their experience of specific areas of relevance to the research topic. While some of the prompts invited a descriptive response, such as 'How did you manage them over time?', others pointed to the elucidation of meaning; 'What images best describe it?' The latter drew on the participant's metaphorical expressions that can create a bridge to understanding that otherwise might be hard to capture (Shinebourne & Smith, 2010).

In order to gain insight into the participants' current state, the first section of the interview (see Figure 1) focused on how the participant felt at the time, before moving on to explore their experience of others and their environment.

*Figure 1. First section of interview schedule*

1) Could you describe to me how you feel at the moment?

*Possible prompts: Are there particular words that describe it? What images best describe it? Does it have particular associations for you?*

2) Can you describe your daily life at the moment? For example; What do you do? What are your thoughts and feelings?

*Possible prompts: Does this fluctuate over the day?*

3) How do you feel when you're with other people at the moment?

*Possible prompts: Your close relationships? People you know less well? How do you think they see you? How do you see them? Do you always feel like this with other people?*

4) Could you describe how you see the world at the moment?

*Possible prompts: Your world of work? Your home environment? What images would you use to describe it? How does time pass for you?*

5) How do you feel about yourself at the moment?

*Possible prompts: What do you feel capable of? What words would you use to describe it? What images best describe it? Does it have particular associations for you?*

The temporal focus of questions encourages the participant to talk about their current experience, helping them to focus on feelings and thoughts. The form of questioning and the use of language allows the interview to become participant-led, avoiding any presumption of the presence of change or a diagnostic state. Asking the participant to describe how they feel at that moment, rather than their perception of change, facilitates an exploration of their experience as it appears at the time. Given that all participants would be situated in a clinical context, it was important to invite them to draw on their own experiences rather than their perception of diagnostic categories.

The questioning encourages participants to expand on their experiences by using open terms, such as 'How?' or 'Can you describe?'. This helps establish a rapport between participant and researcher, where the participant feels at ease. The first question is relatively broad and

invites them to discuss how they are now. The subsequent question shifts to a more concrete position inviting participants to describe everyday events or activities. This form of questioning recognises that it can be easier to explain experiences through specific events or activities rather than in general terms. Questions 3-5 orientate the interview around three key areas: self, participant's world and relationships with others.

In the next section (see Figure 2), a temporal shift focuses the interview on the participant's experience of their previous state, whether mania, stability or depression.

*Figure 2. Second section of interview schedule*

6) Can you tell me about the beginning of this episode (\*\*participant's description)?

*Possible prompts: Were there specific signs? Were there particular sensations? Were there particular thoughts? Did anything, in particular, happen at that time?*

7) Can you tell me how you felt, previously, before this episode began (\*\*participant's description)?

*Possible prompts: What words would you use to describe it? What images best describe it? Does it have particular associations for you?*

8) So we've talked about your feelings during this episode at the moment and also how you that you felt before it began. How do you think your experience of these states (\*\*participant's description) relates to the medical view of mania and (\*\*second state already discussed: 'depression' or 'stability')

*Prompts: What seems different? What seems similar?*

Questions 6 and 7 focus on the participant's experience of change, before question 8 asks for a more analytical and comparative response. In IPA interviews, there is often an interplay between descriptive and analytical questions that helps to create depth at different levels of reflection.

The last section (see Figure 3) focuses on the state that the participant has not yet described, as well asking them to reflect on the wider impact of change on their life.

Figure 3. Last section of interview schedule

9) Could you also tell me about a period of your life when you were (\*\*third state not yet discussed: 'depressed' or 'stable')

*Possible prompts: How did you feel? What words would you use to describe it? What images best describe it? Does it have particular associations for you?*

10) So we've talked about your experiences during different states. Can you describe how going through these changes affects your life?

*Possible prompts: How do you manage them over time? Has your management of them changed?*

11) How do you see your future?

*Possible prompts: Is there a particular word that describes it? What images best describe it? Does it have particular associations for you?*

Since the term 'euthymia' is not part of general discourse with service users, I felt that 'stability' would be better understood to refer to the period between episodes. The alternatives, 'recovery' or 'well periods', assumed that the participant would be feeling well which is not necessarily the case. The final questions extend further the temporal dynamics of the interview and explore how change impacts expectations and sense of progression.

Before it was finalised, the schedule was tested during a pilot interview with a friend to see whether any phrases or words felt uncomfortable.

## Interview procedure

### *Setting up the interview*

The first task was to review the terms of the study and invite the participant to sign the consent form (explained above). The form reiterated that confidentiality would be broken if the participant expressed a desire to hurt themselves or other people. For interviews during depression, the participant was asked to fill out a short depression scale (Appendix 2A) and for mania interviews, a mania scale (Appendix 2B).

Subsequently, the participant was asked whether they had any questions about the process. Since participants were generally accustomed to interviews led by a clinician, I explained that the aim of this interview would be to explore their own concerns and would be led by them.

In conducting interviews in research contexts, and specifically with vulnerable populations, a balance of power tends to exist that favours the researcher over the participant (Frith, 2012). This balance of power is likely to be more pronounced when recruiting vulnerable people via clinicians in clinical contexts. I therefore reiterated the terms of consent around their right to refuse to answer any question or terminate the interview at any time, as well as making every effort throughout the interview process to remind participants of their right not to answer and to terminate.

### *Following the participant and pivoting to the schedule*

To encourage participants to talk freely about their concerns and take the lead, it was important to listen attentively, without interruption, and use open questions that encouraged them to expand on their experiences. Rather than rigidly following the interview schedule, I used prompts to coax the participants to delve more deeply and elaborate on their experiences. This seemed to help the participants immerse themselves in their feelings and thoughts which led to further reflection.

While actively following the participant's direction, I also took mental notes of significant experiences they mentioned that might shed light on areas of import in the interview schedule. By pivoting between the schedule and the participant's story, and maintaining an awareness of their relationship, I was able to identify and return to experiences later in the interview rather than interrupting the flow.

### *Forming and maintaining a rapport with the participant*

Rapport with the participant was facilitated not only by listening, but by consciously considering the effect of body language. Participants' accounts often moved into sensitive areas that were immensely important to them. While they needed to be listened to, at times they also required acknowledgement. I would generally say very little, but nonetheless felt that I needed to communicate my acceptance and recognition of their experiences through my embodied response. I consistently maintained eye contact. This seemed particularly important when the participant was speaking about difficult or shameful experiences. While they would often be immersed in recalling those experiences, they nonetheless seemed conscious of my responses and demeanour. Given that they often spoke about experiences that they had never previously disclosed, it was particularly important to recognise that the way I responded would not only impact the quality of the interview but could also influence their ability to

disclose their experiences in other contexts. From this perspective, the researcher has an ethical responsibility to manage their responses and avoid creating any future difficulties for the participant.

#### *Managing sensitivity and emotional breakdown within the researcher role*

Study ethics cover important aspects but, in practice, it is down to the researcher to manage any distress that occurs in the interview, while maintaining ethical boundaries. My understanding of how best to manage the emotional distress improved during the research process. Having interviewed participants before, I appreciated the importance of checking well-being and, if they seemed uncomfortable, reminding them that the interview could be paused or terminated. While at first, I felt anxious if a participant expressed distress, with time, I began to appreciate the importance of acknowledging a participant's emotions. There was a relatively fine line between the participant being comfortably upset and unnecessarily distressed, but this was managed by carefully attending to the reaction of the participant. Over the course of interviews, there was one occasion when the participant asked to terminate the interview before the end.

#### *Managing relationship with participant over time*

In longitudinal studies, a relationship develops between the participant and the researcher that needs to be managed (Calman et al., 2013). The trust I developed with the participants helped them to speak openly and feel comfortable during interviews which became particularly important when interviewing during depression. At those times, trust and familiarity in the relationship were key to conducting a comfortable interview. However, at times I was asked during interview about their clinical care. In my role as a researcher, it was vital that I did not offer advice, however strong the urge to help. To ensure the participant's concerns were recognised, I encouraged them to raise questions with their clinical team.

#### *Finishing the interview*

At the end of each interview, I checked whether the participant was feeling alright. Sometimes, the participant wanted to stay longer and we would spend 15 minutes or so chatting before leaving the room.

The need to maintain a reflexive attitude throughout the research process is well-recognised in qualitative research (Finlay & Gough, 2003). In line with its hermeneutic approach, IPA recognises the significance of the researcher's assumptions and that they can further or obstruct the interpretation of another's experience (Shaw, 2010). It was therefore important to develop an awareness of my own assumptions in relation to the participant and the topic so that it did not negatively affect the interview, analysis or participant. I kept a reflexive diary which I found invaluable for expressing my feelings about the participant and documenting issues that arose during the interview. I also reviewed the interview to check whether the participant had expressed any desire to hurt themselves or other people. In one, the participant mentioned a recent plan to commit suicide and this information was passed to the relevant clinician.

### Transcription

To ensure anonymity, pseudonyms were used and any identifying information was removed or changed. The interviews were transcribed verbatim. All semantic detail was recorded, along with an indication of non-verbal utterances, such as pauses, hesitation or laughter, and any explanatory comments. Since IPA analysis focuses on the experiential content of transcripts rather than detailed prosodic aspects, precise representations of interactions, such as the exact length of pauses, were not required. In this respect, it is recognised that 'transcription is itself a form of interpretative activity' (Smith et al., 2009, p.74). The following transcription notations were included:

Short pauses	...
Clarifying comments	[ ]
Non-verbal utterances	(laughs) (sighs)
Speech emphasised	<i>italicised</i>

A Sony transcription package was used to facilitate the task of moving backwards and forwards through the transcript. The transcripts were imported into Microsoft Word, line numbered and given sufficient spacing on either side for analytical comments.

## Analysis

In this section, I will provide a detailed account of how I carried out my longitudinal analysis. Eighteen months into data collection, none of the participants who had been interviewed during stability and depression had shifted to mania, so I decided to begin longitudinal analysis of the first two interviews for each of the three participants who had been interviewed during both depression and stability. The analysis of mania was drawn from their retrospective experience of mania described during these interviews.

Longitudinal IPA (LIPA) is in its infancy and there is no published guide of how best to conduct its analytic steps. By presenting a detailed illustration of my steps, I aim to inform this area. In longitudinal studies, IPA's inductive and idiographic mode of enquiry reveals change as it occurs through an individual's lifeworld over time. To show idiographic change requires an analytical approach that examines change as it arises for each individual participant before examining the experience of change across participants. In practice, this means conducting the following set of analytic steps:

1. For the first participant, analyse each interview at each time-point and produce a superordinate table of themes for each time-point.
2. For the same participant, analyse longitudinally all theme tables that have been produced and formulate a longitudinal superordinate table of themes for that participant.
3. Repeat the steps identified above for all participants to produce a longitudinal superordinate table of themes for all participants.
4. Conduct a longitudinal analysis of the theme tables for all participants to formulate a master longitudinal table of themes.

To help illustrate how this worked in practice, I will draw on examples from my analysis of Caroline's first interview when she was stable following the first two steps above, then elaborate on steps 3 and 4.

## 1. Analysis of each of the first participant's interviews

### *Entering the participant's world*

The aim of the first step of the analysis is to engage holistically in the participant's experiences and story by reading and rereading the transcript and listening to the interview. Given the time-lag between interview and analysis, it was important to use this process to re-engage with the participant's world. I felt it was necessary to reflect on my own perspective and assumptions which often came to light through my responses to what the participants said. At times, I responded empathically, while at other times, I felt a combination of surprise, curiosity and sympathy. To recognise and manage these feelings, I noted down any that seemed particularly prominent. While my reactions undoubtedly reflected my own preconceptions and experiences, they also provided insight into my initial standpoint in relation to the participant and their story. By writing them down, they could be considered and drawn on as I embarked on closer analytical work.

It was also important to gain a wider view of the shape of the participant's story and get to grips with the temporal and narrative relationship between different sections. This was of particular importance because the participant's focus would be shifting between a sense of their present state and their perspective of other states in the past, as well as being asked to take a more reflective view of themselves and their sense of change over time.

### *Initial noting*

The objective is to create a detailed set of notes on the data that describe the experiences and concerns of the participant, while developing more interpretative comments that capture the significance of those experiences and shed light on how or why they matter (Smith et al., 2009).

My notes were formulated through a line-by-line examination of the participant's words. After underlining phrases or words that were striking, unusual or revealing, I embarked on a detailed examination of the transcript in an attempt to make sense of the patterns of meaning. This focused on the explicit concerns expressed by the participant, as well as a more detailed interrogation of latent meaning and inferences and their possible significance for that participant. To interrogate patterns of meaning, my analysis drew on specific analytical tools and particular interpretative dynamics. Attention was paid to the linguistic and grammatical

features of each sentence or short paragraph, such as choice of words or phrases, linguistic tone, ambiguity, repetition and emphasis, as well as imagery and metaphor. Temporal dynamics were considered, alongside readings of the data at a more conceptual or psychological level. My meaning-seeking reflected a dialectical and iterative movement between different parts and wholes that only progressed as I grappled with their meaning in relation to each other.

When interpreting the participant's sense-making, it was important to reflect on the words of the participant but also my own thoughts. By openly questioning both the patterns of meaning arising from the transcript and my own understanding of them, new possibilities of meaning came to light. This helped me to probe specific meanings and relationships between parts and wholes, and to stay receptive to new or unknown meanings that were only emerging through the analytic process. My openness relied on feeling close to a particular participant and engaging empathically with their story.

Below is a section of Caroline's transcript (see Figure 4) during her first interview when she was stable. In the extract, she talks about how she experiences herself and the world. The exploratory comments in the right-hand column draw on analytic tools that I used to help make sense of the data. They are divided between descriptive (shown in normal type), linguistic (italics) and conceptual (underlined) comments.

Figure 4. Extract from Caroline's annotated transcript (Stable interview)

Transcript extract	Exploratory comments
<p><i>And how would you say you feel about yourself at the moment?</i></p> <ol style="list-style-type: none"> <li>1. More contained. Yeah, more</li> <li>2. like, I will walk down the street</li> <li>3. and I will look at the trees and I</li> <li>4. will like them, before I</li> <li>5. wouldn't even notice there is a</li> <li>6. tree in front of me, so there is a</li> <li>7. sense of connection or</li> <li>8. attachment which at the two</li> <li>9. phases of the bipolar, either the</li> <li>10. manic or the depression, I</li> </ol>	<p><i>Containment? control? self-possession? agency. Use of 'more' suggests this is comparative to depression, return after former loss.</i></p> <p>Perceiving and appreciating her environment as she moves through it (enjoying herself). <u>Interactional connection between self and world.</u></p> <p><i>Acute self-awareness expressed by repeated use of 'I will' rather than 'I'.</i></p> <p>Formerly, unable to see things in relation to self. Use of 'in front of her' attempts to express extent of experiential change. <u>Tree was perceived but she did not notice it. Loss of meaningful world?</u></p>

<p>11. would say, I would feel a 12. sense of detachment, yeah.</p>	<p>No sense of connection or belonging in other two states. <i>'I would say' expresses a more reflective stance as she considers accumulative change over time.</i></p> <p><u>Experience of change as comparative over time</u></p>
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The use of a combination of analytical tools, temporal considerations and iterations between parts and wholes helped make sense of the patterns of meaning around Caroline's experience of being stable. While a detailed account is required to illustrate the interpretative dynamics that formulate initial noting, this is neither a linear nor laborious process, but is often lively and quick.

When first reading this section, Caroline's phrase 'more contained' (line 1) sparked my interest. Not only was this her first depiction of stability, but it seemed an unusual turn of phrase. The linguistic consideration of the word 'contained' highlighted several potential meanings (e.g. restrained; in control; suppressed), but these needed to be evaluated in relation to her wider phrase 'more contained' that suggested that her experience was comparative and framed by her former state. Drawing on my wider understanding of the transcript and my knowledge that she had previously been depressed, I was able to consider other patterns of meaning derived from my understanding of depression. However, Caroline's next sentence more explicitly described her positive experience of walking down the street and responding to her environment (lines 2-4). Taken together, therefore, the different analytical comments and the temporal dynamics suggested that, for Caroline, 'being contained' meant feeling more in control or having more agency. Although the dynamics of this process had helped me get closer to Caroline's experience, the meanings as they presented themselves were not fixed and were further reviewed and developed as I worked through the transcript.

While different forms of analytical commenting can help uncover the meaning of a particular sentence or experience, they also reveal different layers of meaning. For instance, Caroline's description of appreciating her environment as she walked down the street (lines 2-4) appeared relatively clear: she enjoyed it. However, when I examined the sentence in more detail, the experience took on another level of significance. Her repetition of 'I will' suggested that this was not spontaneous but she was acutely aware of her response to her environment. Drawing on a more psychologically-informed interpretation helped me to grasp the existential meaning of her experience. While Caroline enjoyed walking down the street,

there was a sense that she was also experiencing a reconnection between herself and the world that had been lost. This existential significance illuminated the more explicit meaning of the experience: it seemed possible that her enjoyment of the walk was bound up with her revelation. We can see, therefore, how different layers of significance co-existed within Caroline's experiential world.

By shifting my own stance, I was able to grasp other layers of meaning. For instance, Caroline's suggestion that she 'wouldn't even notice there is a tree in front of me' (lines 5-6) was curious. From an empathic stance, it seemed likely that Caroline was trying to emphasise her current change by exaggerating the contrast with her experience of depression. Yet further questioning of these words revealed a more latent significance: although she perceived the tree, she had not noticed it. By considering this distinction at a more conceptual level, I realised that perhaps what Caroline had lost during depression was any sense of a world that had mattered and that made her take notice. This new pattern of meaning in turn shed light on the meaning of stability for her and what she had gained.

### *Generating emergent themes*

Emergent themes are generally "a concise and pithy statement" (Smith et al., 2009, p. 92) that commonly denotes the psychological aspect of the data and strikes a balance between being rooted in idiographic instances and capturing more general concepts. The formation of emergent themes aims to capture portions of the data along with the analytical comments in the initial notes. This process condenses the data into a more manageable form, but the patterns of meaning identified by the notes are retained.

The section of Caroline's transcript already discussed is presented below with emergent themes.

*Figure 5. Extract from Caroline's transcript with emergent themes (Stable interview)*

<b>Emergent themes</b>	<b>Transcript extract</b>	<b>Exploratory comments</b>
Increased awareness instils agency	<p><i>And how would you say you feel about yourself at the moment?</i></p> <p>More contained, yeah, more like, I will walk down the</p>	<p><i>Containment? control? self-possession? agency. Use of 'more' suggests this is comparative to depression, return after loss</i></p> <p>Perceiving and appreciating her environment as she moves through it</p>

Connecting with surroundings instils positive meaning	street and I will look at the trees and I will like them, before I wouldn't even	(awareness - agency). <u>Interactional connection between self and world.</u> <i>Acute self-awareness expressed by repeated use of 'I will' rather than 'I'.</i>
Reflecting on detachment during bipolar extremes	notice there is a tree in front of me, so there is a sense of connection or attachment which at the two phases of the bipolar either the manic or the depression I would say, I would feel a sense of detachment, yeah.	Formerly, unable to see things in relation to self. <i>Use of 'in front of her' attempts to express extent of experiential change.</i> <u>Tree was perceived but she did not notice it. Loss of meaningful world?</u>
		No sense of connection or belonging in other two states. <i>'I would say' expresses a more reflective stance as she considers accumulative change over time.</i> <u>Experience of change as comparative over time</u>

The first emergent theme, 'Increased awareness instils agency', captured Caroline's sense of 'being contained' as she walked through her environment. It highlighted Caroline's increased sense of awareness and pointed to the psychological notion of agency. 'Connecting with surroundings instils positive meaning' brought to the fore the existential significance of her increased awareness. Whereas previously the things in her environment went unnoticed, they now took on new meaning, appearing significant as she felt reconnected with the world. In naming the final theme, 'Reflecting on detachment during bipolar extremes', I stayed close to Caroline's words since they offered an explicit description of her experience. However, the words 'reflecting on' emphasises a shift in Caroline's focus from present feelings towards a more reflective stance where she considered the accumulative impact of change.

In total, 102 emergent themes were formulated. These were transferred to a Word document in list form followed by the relevant page number of the transcript which enabled me to link it to the data.

### *Clustering emergent themes*

The next step was to search for connections between the emergent themes and formulate a structure of superordinate themes that captured the texture and significance of the participant's account. This is a time-consuming activity, involving the negotiation of numerous themes and meanings that emphasise different aspects of the participant's experience. Several strategies are highlighted by Smith et al. (2009), such as putting similar

themes together (abstraction) or examining oppositional relationships between themes (polarization). The analytic process is not linear but characterised by an iterative dynamic of repeatedly returning to the transcript to check the participant's words and meanings. This reflects the circular hermeneutic process of IPA whereby the participant's words and the researcher's interpretations are continually checked to get at the meaning of the participant's experience (Smith, 2007). Key to this process is re-reading quotes and checking that they make sense and are representative in the context of emerging clusters of themes. This dynamic helps ground the researcher's interpretation and the clustering of themes in the data, while also supporting the transparency of the analytic process.

The 102 emergent themes were cut into individual strips and laid on the floor to search for possible connections. Keeping a note of my steps and decisions was important for keeping track of the process and to maintain a reflexive awareness of the basis for my decisions.

The primary focus of this interview was Caroline's experience of stability, but her past experiences of depression and mania were also explored. Initially, therefore, all emergent themes were collated into three domains that followed these three states. Once collated between the three states, I began to look for prominent patterns and relationships between emergent themes within each state.

First, I examined the group of emergent themes relating to Caroline's experience of being in a stable state. Moving the emergent themes strips around physically enabled a visual examination of potential relationships and patterns. During this process, two distinct theme groupings emerged.

In one grouping, clusters of themes illustrated Caroline's awareness of a reconnection with herself, other people and her surroundings. These clusters gave rise to the first superordinate theme 'Reconnecting with self and world' (see Table 2 below). This is a higher order theme that came to light by contrasting clusters of emergent themes illustrating Caroline's distinct experiences of positive connection. Some of these clusters were drawn together by a particular emergent theme. For instance, 'Connecting with surroundings instils positive meaning' drew together themes illustrating her sense of affinity with her environment. In other clusters, similarities between emergent themes combined to reveal new meanings

relating to a sense of resonance with herself. In this respect, the data analysis brought to light meanings that went beyond what was in the transcript.

Table 2. *Superordinate themes and emergent themes for Caroline (Stable interview)*

<b>Superordinate themes</b>	<b>Illustrative extract</b>
Emergent themes	
<b>1 Reconnecting with self and world</b> ( <i>current state of stability</i> )	
Reengaging with activity	'I can take a shower, can do things and then I can go out'
Connecting with surroundings instils positive meaning	'I will walk down the street and I will look at the trees and I will like them'
Emerging hope	'I'm hoping things will change for the better'
Possible self-change	'With a few changes I would be good'
Tentative social interaction	'take me forever to analyse what people have said'
<b>2 Struggling with loss of self, confusion and shame</b> ( <i>current state of stability</i> )	
No sense of self	'Just floating, like on top of the river, nothing is holding me back'
Starting from scratch	'Learn from scratch, you can start life from zero'
Unknown normalcy	'Just like walking on mud, trying different ways'
Shame and punishment	'Punishing myself for that'
<b>3 Energy and disconnection</b> ( <i>state of mania</i> )	
Power and energy	'Like a roller coaster, just full of activities'
Amazing self	'Everything is possible for me to do'
Directionless activities	'Lots of ideas about the future, doing lots of things, going shopping, coming back'
Loss of feeling	It's a behaviour, not a feeling, there wasn't any feeling'
Disinhibited self	'Do just whatever comes and I act with it'

In the other grouping, emergent themes described how Caroline felt about herself as she reflected on changes over time. To ensure accuracy, I checked the temporal dynamics of her reflective statements against the transcript. Clusters of emergent themes illustrated her loss of self, absence of normalcy and sense of shame. These distinct aspects came together to form the second superordinate theme, 'Struggling with loss of self, confusion and shame' (Table 2 above), revealing Caroline's struggle to know who she is and how she should behave.

Having finished stability, I focused on the themes that illustrated her experience of mania. As mentioned, experiences of this state were drawn from participants' accounts during stability

and depression. Caroline's description of mania during stability was closely bound up with her current perspective on herself in that state. Mania evoked strong feelings of shame and her descriptions were often framed by the sense of horror at what she had done. My analysis, therefore, involved several iterations of clustering themes and checking back with the transcript to examine Caroline's experience from different temporal positions. Through this process, I endeavoured to get as close as possible to Caroline's experience. The superordinate theme 3, 'Energy and disconnection' captures her experience of feeling powerful, energetic and disinhibited during mania, which at the same time reflected a form of disconnection with herself and the world.

The aim of the study was to capture and present, wherever possible, the participants' real-time experience of each state rather than their retrospective view. Given that an interview during depression had been conducted with Caroline, the themes focusing on depression (from this stable interview) were therefore not analysed but were set aside and retained in case I needed to return to them during subsequent work.

#### *Moving to the second interview (Depression interview)*

The same steps were followed to complete the analysis of Caroline's second interview, resulting in a table of superordinate themes for depression (Table 3 below). During this interview, Caroline struggled to discuss her experience of mania and this topic was not pursued. The analysis, therefore, examined her experience of depression but not mania.

*Table 3. Superordinate themes and emergent themes for Caroline (Depression interview)*

<b>Superordinate themes</b> Themes	<b>Illustrative extract</b>
<b>1 Fear and isolation</b> ( <i>current state of depression</i> )	
Numbing incarceration	'Emotional numbness, the numbness comes with the same coming of the isolation, into the new world'
Damning monologue	'You don't have a mission in life and there is no hope for you'
Horrifying endings	'I don't see a path...feel life is just finished, the isolation, the death'
Fear of threatening others	'Everything feels scary, couldn't communicate with my parents, not able to make eye contact'
<b>2 Escaping meaningless self</b> ( <i>current state of depression</i> )	
Depleted to nothing	'I feel like nothing, don't exist at all'

Sleep and inertia	‘Woke up at 4’ o’clock, or 6 o’clock in the evening, whatever happened, happened’
Intolerable neglect and self-hate	‘I neglect myself, don’t wanna look at myself’
Fantasising about mania	‘All the time, if it’s possible to become like that again, being manic is comfort zone’
<b>3 Grappling with confusion and shame</b> ( <i>current state of depression</i> )	
Confused sense of self	‘Never know who I am, never had the chance to discover who I was, just go with the flow’
Struggling for normalcy	‘I’m just searching for ways how to become normal’
Malleable directionless self	‘Drifting with the wind, I went with whatever comes along’
Enduring punishment and shame	‘Punish myself, all comes into my head [...] I was a complete shame to them, let a lot of scars’

## 2. Longitudinal analysis of Caroline’s case

In longitudinal studies, the analytical approach harnesses the immediacy and vitality of the participants’ experiences as they occur at different time points and then compares those experiences to identify ways that change has occurred (Neale, 2021). Compared to a cross-sectional analysis, a longitudinal approach therefore has more analytic steps that can shift the focus away from the participant and towards the researcher. Consequently, throughout the longitudinal analysis, I endeavoured to preserve the idiosyncratic richness and complexities of Caroline’s account. Not only does this approach reflect IPA’s idiographic commitment, but it also supports the authenticity and integrity of study findings.

### *Identifying change: comparing similarities and differences*

The longitudinal analysis of Caroline’s case was developed by identifying the differences and similarities across the three states and capturing the nuance of change during each state. Themes were drawn from the superordinate table of themes (Tables 2 and 3 above) and tabled side by side in order to visualise patterns and make comparisons between the three states (see Figure 6 below). Themes illustrating depression and stability were collated in the first and second column respectively, while the third column contained themes relating to mania.

What became apparent when looking across states is that it would be clearer to see Caroline's experience of stability as a reaction to her sense of disconnection during depression by presenting her experience of depression first. Although Caroline's experiences were strikingly different during each state, they were inter-related and shaped by each other, and this configuration would best convey the interrelationship between states. For instance, her interview during stability followed a long period of depression and therefore brought about a shift towards reconnection. Similarly, her second interview during depression expressed a sense of withdrawal that followed on from her reconnection during stability.

Figure 6. Emergent theme clusters capturing Caroline's experience of change across states

Aspect of change	Depression	Stability	Mania
Activity levels	<b>Inertia and sleep</b> 'Whatever happens, happens, I wake up, do nothing, go back to sleep, bed is my friend.'	<b>Reengaging with activity</b> 'I can wake up in the morning and I can take a shower, I can do things, before I was just paralysed.'	<b>Power and energy</b> 'a roller coaster to me, a roller coaster, I didn't need sleep, I was just full of activities'
Connection with feelings	<b>Numbing incarceration</b>	<b>Reawakening sensations</b>	<b>Loss of feeling</b>
View of future	<b>Horrifying endings</b>	<b>Emerging hope</b>	<b>Directionless</b>
Interpersonal world	<b>Fear of threatening others</b>	<b>Tentative social interactions</b>	<b>Disinhibited self</b>
Perceptions of self	<b>Intolerable neglect and self-hate</b>	<b>Possible self-change</b>	<b>Amazing self</b>

Caroline's experience of change across states was characterised by a sense of withdrawal and disconnection during depression which gave rise to a sense of reconnection during stability. While mania featured an immediacy of energy and confidence, it also coincided with a loss of direction and feeling. Five clusters of emergent themes were formulated that each captured a key dimension of Caroline's changing experience of disconnection and connection over time. Each cluster is highlighted in the same colour above: activity levels (Red), sense of the future (Blue), connection with feelings (Green), interpersonal connection (Orange) and self-perceptions (Purple).

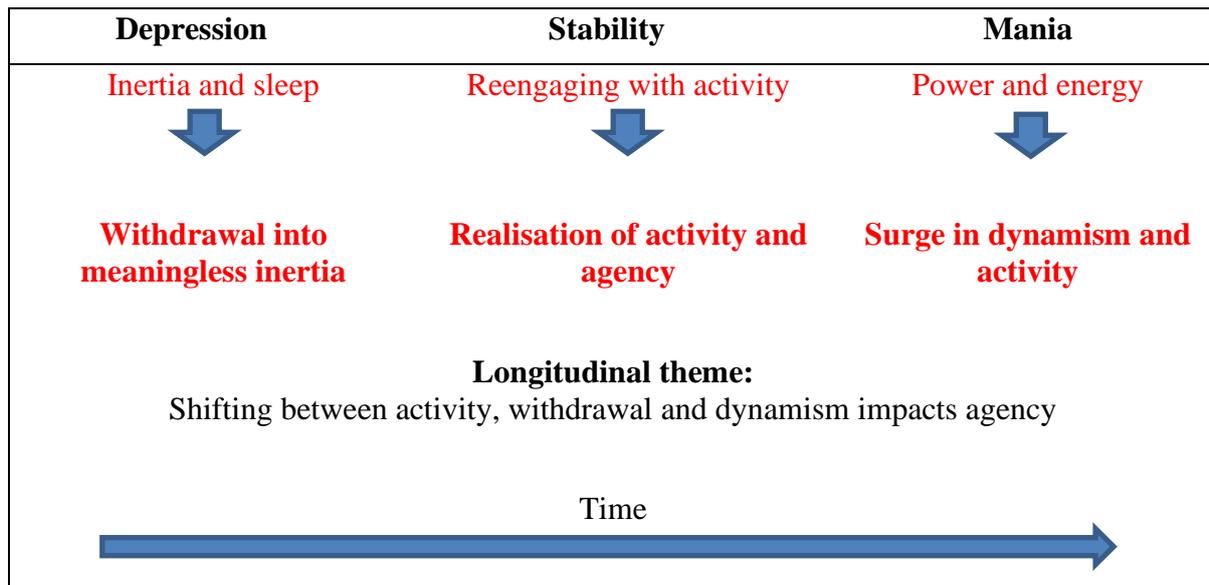
Four emergent themes were not included in the analysis. The process of prioritising themes and retiring others during longitudinal analysis is due to a combination of factors including the volume of data, the focus of the study and the relationships between time-points. In this instance, they were retired because they had no significant connection with themes at other time points.

### *Forming longitudinal themes*

The five clusters orientated around change were examined more closely with a view to elucidating temporal trajectories. To get to grips with transitions within and across the three states, quotes and themes were revisited and checked for temporal meaning. By seeing each theme as a transition, temporal connections came to light that captured Caroline's unfolding trajectory. For instance, it became apparent that the first cluster of themes and quotes (in red, Figure 6. above) described her changing sense of both agency and activity across states. Notice how the quote for the first theme coloured in red, 'Inertia and sleep' (Depression), suggests a collapse in daily routine as well as a loss of practical significance. The subsequent theme, 'Reengaging with activity' (Stability), describes a process of reengagement with her daily routine that also instilled agency, while 'Power and energy' (Mania) expresses a surge of overwhelming energy and agency.

To help convey the momentum of Caroline's transitions in agency and activity during each state, the themes were then relabelled (See Figure 7 below). The new theme names are highlighted in red bold. This iteration is a feature of IPA's inductive longitudinal analysis that brings about a shift in view from the interpretation of an experience at a single time point to one that conceives the same experience as part of an unfolding temporal process.

Figure 7. Relabelling themes to capture the temporal dynamics of a longitudinal theme



A longitudinal theme name was then formulated that encompassed Caroline's trajectory across the three states: Shifting between activity, withdrawal and dynamism impacts agency (see Figure 7 above). While the longitudinal theme captures her trajectory through time, the emergent themes illustrate idiographic transitions during each state.

The process described above was then repeated with the remaining four clusters of themes focusing on Caroline's sense of change across the three states and two clusters illustrating her struggle with confusion and shame during depression and stability. In all, this resulted in seven longitudinal themes for Caroline's case which are presented in Table 4 below.

Table 4. Table of longitudinal themes for Caroline

<b>Longitudinal themes illustrating change across states</b>		
Depression	Stability	Mania
<b>Shifting between activity, withdrawal and dynamism impacts agency</b>		
Withdrawal into meaningless inertia	Realisation of activity and agency	Surge in dynamism and activity
<b>Reconnecting, separating and disinhibition with others</b>		
Separating from others	Striving to reconnect with others	Disinhibited with others
<b>Shifting sense of hope and future</b>		
Loss of future meaning	Emerging possibilities	Instinctive interactions
<b>Changing between positive and horrific sense of self</b>		
Hating self	Possibility of better self	Positivity and action
<b>Extreme shifts in felt connection with self</b>		
Loss of self	Reconnecting with self	Oblivious action
<b>Longitudinal themes illustrating struggle across states</b>		
Depression	Stability	
<b>Struggling with confusion over self and normalcy</b>		
<b>Managing persistent shame</b>		

### 3. Analysis of interviews of other participants

The analytic process described in steps 1 and 2 was then repeated with the remaining two participants, resulting in three tables of longitudinal themes – one for each participant.

### 4. Longitudinal cross-case analysis

The final step was to perform a cross-case analysis of the longitudinal themes from all participants and formulate a master table of longitudinal themes for the group. To this end, I tabled the longitudinal themes for each case together and examined similarities and differences. My approach was to start with one longitudinal theme from one case and then move between cases to see how this aspect was articulated across cases. Through this process, significant relationships between trajectories were brought to light and six clusters of longitudinal themes were identified, presented in Figure 8 below.

Four trajectories of change across states were identified and colour-coded: activity and agency (red); relationships with others (Green); sense of the future (Blue) and changes in feelings (Purple). In addition, two trajectories were identified that illustrated the participants' struggle with confusion (shown in italics) and shame (underlined) that persisted during depression and stability.

*Figure 8: Clustering longitudinal superordinate themes across cases*

<b>Caroline</b>	<b>Julia</b>	<b>Karen</b>
<b>Clusters of longitudinal themes capturing change</b>		
Shifting between activity, withdrawal and dynamism impacts agency	Extreme changes in activity, ability and momentum between states	Changing between shut down, revival and over-activity
Reconnecting, separating and disinhibition with others	Changing from shame to trust and oblivious superiority	Shifting sense of shame, delicate trust and anger
Shifting sense of hope and meaning	Changing sense of fear, certainty and possibility	Shifting from fear of the future to possibility and absolute control
Changes in felt connection with self	From emotional dullness to vitality and kaleidoscopic highs	Changing from emptiness to resurgence of feeling
<b>Clusters of longitudinal themes capturing struggle with confusion and shame</b>		

<i>Struggling with confusion over self and normalcy</i>	<i>Struggling with chaotic self</i>	<i>Grappling confusion and loss</i>
<u>Managing persistent shame</u>	<u>Irreconcilable shameful selves</u>	<u>Conflicting unwanted selves through time</u>

It was also important to flesh out the idiographic texture of participants' trajectories by looking at divergences and convergences between them. Figure 9 below presents the longitudinal themes for each participant focusing on activity and agency and the underlying emergent themes for each state. Examining the themes in this format helps crystallise how the participants' trajectories converged and diverged within and between states.

Figure 9: Comparing longitudinal themes focused on changes in activity and agency

	<b>Caroline</b>	<b>Julia</b>	<b>Karen</b>
	<b>Longitudinal themes</b>		
	Shifting between activity, withdrawal and dynamism impacts agency	Extreme changes in activity, ability and momentum between states	Changing between shut down, revival and over-activity
	<b>Emergent themes</b>		
<b>Depression</b> <i>Collapse in activity assaults agency</i>	Withdrawal into meaningless inertia	Disgust over incapacity and diminishment	Impossible to overcome innate laziness
<b>Stability</b> <i>Regaining control</i>	Realisation of activity and agency	Embracing readiness to act	Anticipating depression despite capacity to act
<b>Mania</b> <i>Escalating activity and illusory control</i>	Surge in dynamism and activity	Wariness of senseless activity	Intensity of activity predicts depression
<p><b>Master longitudinal theme for the group:</b> Extreme changes in activity assault agency</p> <p style="text-align: center;">Time</p> 			

Themes were formulated to convey distinctive similarities between the participants' experiences within each state. For instance, '*Collapse in activity assaults agency*', highlighted in italics under 'Depression' in Figure 9 above, conveys the dramatic reduction in activity and agency experienced by all participants during their depressive phases. This demonstrates the way in which themes can be reconfigured through the evolving analytical process, helping to sustain a dynamic and meaningful account.

The emergent themes also highlight idiographic differences between participants' experiences during specific states. For instance, all participants experienced a revival of activity during stability, but for Julia it was intense while for Karen it was dampened by her fear of depression. A master longitudinal theme was then developed that captured the temporal dynamics of all trajectories from the group: '*Extreme changes in activity assault agency*'.

The process above was repeated for each cluster of longitudinal themes, resulting in six master longitudinal themes for the group (see Table 5 below). The first four capture the changing dimensions of the participants' experiences through time. The themes at each state illustrate the participants' shared sense of change during each state, while the emergent themes convey the idiographic nuance between them.

The last two longitudinal themes convey the participants' ongoing struggle for self-coherency during depression and stability.

Table 5. Master table of longitudinal themes for the group

<i>Depression</i>	<i>Stability</i>	<i>Mania</i>
<b>Extreme changes in activity assault agency</b>		
Theme: Collapse in activity assaults agency <i>Julia: Disgust over incapacity and diminishment</i> <i>Karen: Impossible to overcome innate laziness</i> <i>Caroline: Withdrawal into meaningless inertia</i>	Theme: Regaining control <i>Julia: Embracing readiness to act</i> <i>Karen: Anticipating depression despite capacity</i> <i>Caroline: Realisation of activity and agency</i>	Theme: Escalating activity and illusory control <i>Julia: Wariness over senseless activity</i> <i>Karen: Intense activity, fear of depression</i> <i>Caroline: Surge in dynamism and activity</i>
<b>Changes in feelings impact connection with world</b>		
Theme: Numbing disconnection from self and world <i>Julia: Brutal sadness blunts world</i> <i>Karen: Faced with unresponsive self</i> <i>Caroline: Numbing isolation</i>	Theme: Reawakening of feeling situates self in world <i>Julia: Newfound pleasure and rejuvenation</i> <i>Karen: Relief over responsiveness</i> <i>Caroline: Sensations offer glimpses of meaning</i>	Theme: Engulfed by intensity of non-stop feeling <i>Julia: Freedom from views of others</i> <i>Karen: Venting anger</i> <i>Caroline: Detached self</i>
<b>Shifting perceptions of future disrupt progression</b>		
Theme: Blocked by inaccessible future <i>Julia: Fear of punitive future</i> <i>Karen: Acute anxiety over indecision</i> <i>Caroline: No path whatsoever</i>	Theme: Regaining momentum <i>Julia: Direction enables positive spin on future</i> <i>Karen: Hope springs from new direction</i> <i>Caroline: Glimpse of possibilities despite hopelessness</i>	Theme: Immediacy of possibilities disrupt direction <i>Julia: Super-confidence in illusory possibility</i> <i>Karen: Claiming decisive 'better' self</i> <i>Caroline: Automated and lacking direction</i>
<b>Changing sense of others impacts relatedness</b>		
Theme: Self-isolating against social shame <i>Julia: Social contempt intensifies shame</i> <i>Karen: Avoidance of humiliating relationships</i> <i>Caroline: Acute anxiety over threatening others</i>	Theme: Emerging trust builds relatedness <i>Julia: Newfound trust creates social connection</i> <i>Karen: Uncertain relationships</i> <i>Caroline: Social anxiety limits belonging</i>	Theme: Disinhibited self brings relational detachment <i>Julia: Freedom from views of others</i> <i>Karen: Recognising anger towards others</i> <i>Caroline Indiscriminate relating instils shame</i>
<i>Stability</i>		<i>Depression</i>
<b>Struggling for self-coherency during confusion and chaos</b>		
<b>Feelings of shame threaten self-coherency</b>		

## Writing up the results

The primary aim of writing up results is to present a detailed account that is both systematic and persuasive, and which enables the reader to grasp the full significance of the findings. Writing up results is also, however, an extension of the analytic process and is likely to bring to light new emphases and interpretations.

### Structuring the longitudinal write-up

The first stage of the write-up focused on participants' experience of change. The findings could either be presented case-by-case, which involves exploring each individual participant's case consecutively within the narrative, or state-by-state, where all participants' experiences of each state are presented together.

I initially adopted the former approach. This idiographic approach to writing up longitudinal research helps to flesh out and highlight the relationship between the participant's evolving experience and the way change appears to them over time. Through this process, I was able to extend my analytic interpretation to illustrate the relationship between the different states along with the participant's experience of each.

However, the case-by-case structure struggled to illuminate important aspects of the participants' experience of change. Although change developed through their overall life trajectory, their experience of it was not gradual, but extreme and dislocated. While a case-by-case structure privileges progressive change, a state-by-state approach better conveys the dynamics of discrete change. Therefore, I redrafted the first four themes focused on change to reflect a state-by-state structure.

One key advantage of this approach is that the comparison of participants' experiences of state change is illustrated at the same point in the narrative and is, therefore, easier for the reader to grasp. While some sense of the participant's idiographic journey is inevitably lost in this structure, it complements the key aims of the study. It is worth noting, however, that the initial case-by-case approach meant that I had already conceived the participant's trajectory, putting me

in a stronger position to elucidate aspects of the idiographic relationship between states, which in turn led to a fuller write-up.

## **Chapter 5 – Study One Results: Part A**

### **Extreme change and disconnection with self, others and world**

This chapter presents the first section of longitudinal findings, focusing on the participants' changing experience within and between BD moods and stability. The findings are explored and then discussed in relation to the wider literature with a view to contextualising their contribution to this area of study.

All participants described extreme changes across states that radically altered their experience of themselves, others and their surroundings. Four dimensions of change were identified that together contributed to an unstable trajectory characterised by shifts in connection and disconnection with self, others and the world. The four themes encompass the significant changes that occurred during the three states while also revealing their cumulative significance over time and between states.

Theme one focuses on changes in activity levels and their impact on agency, while theme two examines shifts in emotions and bodily feeling and their implication for connectivity. Theme three explores changes in perceptions of the future and their relationship with progression over time, while theme four focuses on interpersonal instability and disruptions in relatedness.

#### **Theme 1: Extreme changes in activity assault agency**

Participants described dramatic changes in activity during depression, stability and mania and the impact of these changes on their wider sense of control. Activity levels fluctuated during each state and there were striking similarities in the participants' experience of this, but the diverse ways in which each individual perceived and coped with these changes over time was also apparent.

### Depression (Time 1): collapse in activity assaults agency

During depression, the participants described a sharp reduction in activity that gave rise to a significant assault on agency. Though their experiences were defined by a similar pattern of inactivity and loss of daily routine, their individual accounts revealed differences in how they perceived and managed these challenges over time.

When Julia first talks about her experiences she has already been depressed for several weeks and feels frustrated by her inability to execute basic daily tasks:

I'm trying to do things, but I get tired very quickly and crawl back to bed. I'm just doing one-fourth or one-fifth of what I used to do. I kind of live in a mess, I read something, I listen to something, I watch some programmes [pause] basically that's it. Actually, nothing. Nothing!

Julia's efforts to 'do things' are thwarted by lapses in energy that become so oppressive that she is forced to 'crawl back to bed'. Her use of 'crawl' suggests that her exhaustion is not only mentally challenging but also physically crippling, like a burden that weighs so heavily upon her that it restricts her movement. This is a demeaning experience where she feels depleted by doing only 'one-fourth or one-fifth' of what she used to, and what she perhaps feels she ought still to be able to do now.

Her admission that she lives 'in a mess' not only describes her living conditions, but also suggests a deeper sense of chaos that leaves her unable to shape and execute her daily routine. Though she admits that she does 'read something' or 'listen to something', in her eyes these activities are worthless, perhaps because she lacks ownership of them. By the end of the extract, Julia feels increasingly depleted as she is faced, repeatedly, by her own futility and loss of agency which has reduced her to 'nothing'.

Karen's activity has also ground to a halt and she is unable to do anything:

All things just come to a halt... I just don't feel like doing anything. I feel completely lazy, absolutely no interest in doing... I've stopped doing everything, I'm not doing

anything and that just reinforces the fact that I'm lazy and I can't do anything, that I don't want to do anything.

Karen has been drawn into a cycle of inactivity where she feels she has 'stopped doing everything'. Whereas Julia attempted to engage in a daily routine, Karen has 'absolutely no interest in doing' and passively capitulates. She feels helpless yet does not share Julia's sense of depletion and frustration because, in her eyes, her inertia merely 'reinforces' the 'lazy' and incapable person she already is. Notice the shift in tense from 'I feel lazy' to 'I'm lazy', suggesting that she perceives her inertia as bound up in her own intrinsic laziness. Karen's incapacity to act is not a transient symptom of change, but something she perceives as an immovable trait, a 'fact' of her character. Indeed, her use of negatives such as 'can't do' and 'don't want' suggests she expects to be incapable and demotivated as a direct consequence of it.

Like the others, Caroline has withdrawn into inertia:

I wake up at 4 o'clock or 6 o'clock in the evening and I just... whatever happens, happens, order food and the day goes on... I'm very occupied with my thoughts so I don't need TV or anything else... I don't really leave the house at all.

Caroline's daily routine of sleeping and ordering take away food not only curtails activity, but reflects and contributes to her disconnection from her surroundings. Indeed, her physical passivity may be as much a part of her separation from the world as any loss of energy or motivation. Unlike the other participants, who expressed strong concern over their inertia and its implications for their sense of self, Caroline appears largely indifferent. She is immersed in her own 'thoughts' which are so all-consuming that she has no need for activities such as 'TV or anything else'. For Caroline, her 'day goes on' and 'whatever happens, happens' – and it happens to her, without her meaningful participation in it. While having only a limited sense of the relevance or presence of her actions, Caroline has become detached from the world and is consumed by her negative inner reality.

#### Stability (Time 2): regaining control

At the second interview, participants' moods had stabilised and they felt rejuvenated by an increase in activity and an improved degree of control over their daily routine. Two of the

participants, however, felt that their sense of wellness was compromised and struggled with a depleted sense of agency.

During stability, Julia embraces a newfound readiness to get on with daily tasks:

I'm ready to do things, you know, yeah, I'm ready to do things. I kind of make myself breakfast, do the things and then sort things out: cleaning, washing, ironing, probably, as well. I kind of, as a start, take care about myself, basically, yes, take care about myself. Really, I wake up, you know, I have a plan, want to do things I want to go somewhere. This is the biggest change, that I want to do things.

Julia's repetition of 'I'm ready to do things' expresses an eagerness to demonstrate volition over her actions, no matter how straightforward her tasks may be. She enthusiastically reels off a list of daily chores that she spontaneously initiates within her new state of readiness. Breakfast is now possible to 'make myself', words that highlight her sense of independence. During depression, Julia felt she lacked ownership or agency over actions, but now she finds she can shape her life through a regular routine. By planning and executing daily tasks, such as cleaning, washing and ironing, she 'sorts things out' and gains a sense of purpose.

Julia's readiness to engage in activity coincides with a significant increase in self-care. It may be that doing things for herself has given rise to a greater self-awareness. Her remark 'really, I wake up' suggests an emergence into consciousness after her experience of depression, during which she realises she was only half-awake. Not only is she activated and 'ready to do' but she is reconnected with desires that she previously 'forgot'.

When Karen begins to feel better, she is surprised at being able to do things:

'Wow!' Kind of like saying, 'I'm back!' so to speak, so I'm kind of like back to normal kind of thing or whatever. I can actually do things... it's kind of like a novelty. I feel well and it helps me tidy up the house or whatever and then before long I'll be down again, so it's not something I can plan - 'OK, I'm feeling OK, I'll do this, this, this' - because sooner or later, a few days down the line somewhere, I will go back down and then I'll be depressed again and have all those self-doubts and everything.

Karen's exclamation, 'Wow!' expresses the amazement and relief she feels at finally being 'well' and able to 'do things'. For Karen, this revival offers respite from bouts of depression that are so persistent that they make stability feel 'like a novelty', more akin to a break from the norm than a norm itself. Unlike Julia, Karen expresses a growing ambivalence over her present state that she sees as precarious and pervaded by expectation of relapse. Whereas Julia expressed a revived sense of agency when stable, Karen's predictions that 'before long I'll be down again' inhibits her impetus to proceed with a meaningful routine. Being unable to plan activities 'a few days down the line', Karen's agency is hampered and her wellness feels partial. Indeed, Karen's expectation of relapse may undermine her sense of control and impede her from instigating a routine that could prevent it.

Like the others, Caroline recognises an increase in activity during stability:

I can wake up in the morning and I can take a shower. I can do things and then I can go out. Before, I was so scared of going out, dealing with people, doing things on my own, so I was just paralysed. So, there is a difference now. I can take the transport, I can talk to people a little bit, but I think my communication skills have decreased so much, I'm not as communicative as before.

When Caroline 'wakes up in the morning' she is able to engage in her surroundings, 'do things' and shape a daily routine. Whereas before she felt 'just paralysed', she now awakes into an interactive relationship with her environment. Her use of 'just' poignantly expresses the impact of her depressive shut down, something that seems increasingly apparent now she feels well. Like Julia, her account - 'I can take a shower, I can do things and then go out' - expresses a renewed surety in her ability to participate in the world. And yet Caroline recognises 'I'm not as communicative as before' suggesting that her wellness brings into focus her accumulative sense of loss. As with Karen, Caroline's wellness is no magical recovery, but brings enduring difficulties that are inseparable from her shifts in state over time.

#### Mania: escalating activity and illusory control

All participants described a dramatic increase in activity levels during mania that overwhelmed their daily lives for periods of time, significantly altering daily routines and temporal cycles.

In stark contrast to her inactivity during depression, Julia emphasised that in mania she works relentlessly:

I wake up in the morning, go to the gym, work out for 2 hours, then work, you know, but really work so hard, consistently... I'd go to work for 8 hours, after 8 hours I'd take it home and work all weekend, non-stop.

Julia attacks her activities with an energy and drive that enables her to work at a ferocious level 'all weekend'. Changes in her energy levels and drive destabilise her routine, breaking normative temporal cycles and physical limits and, before long, Julia expresses a growing awareness of a widening disconnect between the speed and intensity of her activities and their productivity:

That productivity starts to go... like doing things, but not being productive, agitated, you know, and restless.

Even though her drive for 'doing things' sustains, it fails to result in anything 'productive'. Julia feels 'restless' and 'agitated', physical sensations that reflect an inability to confer meaning or direction on her actions.

Karen is similarly overwhelmed:

You feel like you have the energy to go on forever, kind of thing, and go on and on and on. You feel full of energy and that's why you have the desire to do all of those things and to carry on doing them... then I think I'd end up doing too much, which would end up with me being depressed again.

Karen's boundless energy sparks a strong 'desire' to do 'all those things' and to 'carry on doing them' eliciting dramatic increases in activity and an overbearing sense of agency. Where previously she was relieved at finally being able to do *something*, she now feels exhilarated by an extraordinary urge to do *everything*. Like Julia, her activity possesses a momentum that goes 'on and on and on', driving her forward 'to do all those things and to carry on doing them'. Just as she does during stability, however, Karen fears depressive relapse and anticipates that 'doing too much' will lead to 'being depressed again'. For Karen, her activity is a double-edged sword; on the one hand imbuing enhanced capability and control, while on the other, triggering relapse

and depressive collapse. Despite knowing the pitfalls, she lacks sufficient awareness to de-escalate.

Caroline describes mania as a dramatic rise in affectivity and activity that reaches unfathomable extremes:

It was like a roller coaster to me, a roller coaster... I was very elated, very positive, very aggressive, like everything was possible for me to do, I didn't need to sleep as much as I would normally, I was just full of activities and ideas flowing in my head, doing lots of things.

Caroline feels that mania is fuelled by extremes of elation, positivity and aggression along with a sense that 'everything is possible'. Like the other participants, activities and eventualities that seemed impossible are now open to her and embolden her sense of invincibility. She is 'doing lots of things' and is overflowing with 'activities and ideas' as she anticipates the immensity of her impact on the world. The change that Caroline experiences is all-encompassing and occurs at multiple levels of abstraction, including feelings, physical activities and cognitions. Her 'roller coaster' analogy, however, infers contradictory experiences; on the one hand the invincibility of the powerful machine while, on the other, the fear and vulnerability of the passenger. Her experience, at the time, is of a powerful machine that possesses the dynamism and unpredictability that enables her to 'do... everything possible'. Retrospectively, however, the meaning changes and she begins to realise that her control is illusory and that nothing meaningful is achieved.

### Summary

The analysis suggests a significant relationship between participants' changing activity levels during mood episodes and their sense of agency. What is striking is the way that extreme changes in the participants' actions and routine were imbued with personal meanings that shaped their sense of agency over time. Though all underwent a collapse in activity during depression, each perceived and responded to their inertia in different ways. Whereas Julia struggled to resist inactivity and its surrounding chaos, Karen felt hopeless over her incapacity which she saw as

intrinsic to her laziness. Caroline, in contrast, was severely detached and saw no significance in her inactivity for herself or her world.

Though the escalation in activity levels during elevated moods brought an overwhelming sense of power and self-control, the implications of this experience over time was by no means straightforward. As manic episodes progressed, the easy sense of control felt by some participants shifted into agitation and they began to see their activity as increasingly meaningless. Though all participants regained normal activity levels and routines during well periods, cumulative meanings delimited their sense of self-control: Karen saw no possibility to take control of herself or her depressive relapses and Caroline felt an enduring sense of depletion that limited her ability to interact. Only Julia was able to recover agency during wellness and draw some distinction between her changes in state over time.

## **Theme 2: Changes in feelings impact connection with others and world**

Over time and during different states, the participants described changes in their feelings that impacted their sense of connection with themselves, others and their surroundings. Depression was pervaded by feelings of numbness and loss that receded during wellness as participants began to feel a range of emotions that instilled a newfound connection with others and the world. With elevated moods, however, came an intensity of feelings that possessed an immediacy and focus that was out of kilter with their relational and practical world.

### **Depression (Time 1): numbing disconnection from self and world**

When depressed, participants described a sense of numbness that reflected and expressed a change in their emotional state and bodily feeling. Though each participant attributed different meanings to their numbness, for all it was severely disruptive to their sense of connection with themselves, others and their environment.

Julia's sadness arises bodily and blunts her sense of connection:

It's painful kind of, you know, it's so sad a word, it's painful, yeah, I feel really kind of... that sadness and everything, it makes you like numb, you know, everything, you know paralysing you, yes, paralysing...emotionally painful, very much painful for me.

Initially, Julia describes depression as ‘painful’, a word that is ‘so sad’ that it captures the emotional suffering that she is struggling to express. For Julia, the pain of ‘sadness’ is so overwhelming that it ‘makes you like numb’. Notice her use of ‘makes you’ here; the intensity of her emotional pain forces her into a state of numbness and is ‘paralysing you, yes paralysing’. Her repeated use of the word ‘paralysing’ highlights the physicality of her emotional suffering arising bodily and disconnecting her from any sense of a shared affective space. This disconnection is also ‘paralysing’ emotionally as it leaves her feeling inert and stunted.

Similarly, at T1, Karen, describes a loss of feeling:

I’m completely numb, so I’ve lost kind of all emotion... I don’t see myself crying now coz, I don’t think I have it in me. And then on the other side of things, I don’t get happy either, or I don’t experience any actual happiness so it’s kind of like I don’t have much emotion in me... I don’t have much emotion left.

Karen reflects on a loss ‘of all emotion’, a sensation that leaves her empty. Whereas Julia felt numbed by the force of her painful sadness, Karen’s numbness reflects and expresses a loss of all feeling and emotional vitality. The ensuing emptiness prevents her from being able to express emotion – ‘I can’t see myself crying now’ or to ‘get happy either’. Karen is acutely aware that her emotional world is depleted, intensifying her suffering as she reflects upon the lack of any ‘emotion in me’. Moreover, she sees this as a personal defect where she doesn’t ‘have it in me’ to generate what, in her eyes, would be an acceptable range of emotions. This is different to the numbing paralysis which Julia experiences but sees as part of her depressive pain and sadness rather than a character flaw. Karen’s closing words, ‘I don’t have much emotion left’, are tinged with foreboding, expressing a sense that she has little more to give.

When Caroline falls into depression, the numbness transports her to another world:

Numbness, numbness, emotional numbness. With emotional numbness, the numbness comes with the same coming of the isolation into the new world, the fear comes in because you know you’re going into that hole again, diving in, like diving into a big sea, and you feel like, you fear it and then you don’t wanna talk to anybody.

Like the other participants, Caroline sees her ‘emotional numbness’ as severely compromising her affective world, but in contrast, she views it as intrinsic part of her world. Numbness is inseparable from ‘the isolation’ she feels when entering the ‘new world’ of depression. It envelops her and is like ‘going into that hole again’, where she feels trapped and alone. For Caroline, it is synonymous with the fear that comes with ‘diving into a big sea’: huge, overwhelming, with no way out. Her use of metaphor emphasises the physicality of her changes in feeling that are both sensual and spatial. Unlike the other participants, Caroline is not only shut off from any shared affective space, but the world that she felt part of when she was well no longer even exists to her. The crux of her disconnection is expressed as the ‘coming of the isolation’ that arises along with her ‘emotional numbness’ and fills her with dread. Like the others, her depressive world elicits feelings of fear that only intensify her exclusion, precluding any sense of a shared affectivity that could reintegrate her.

#### Stability (Time 2): reawakening of feeling situates self in world

By the second interview, all participants described a revival of positive feelings that for most evoked a sense of vitality and created a welcome affinity with their surroundings and other people.

When Julia begins to feel well, she describes the reawakening of her feelings in evocative terms:

It’s like spring, you know, everything is alive, you know, fresh, you know that freshness! I feel good about things that are happening, I’m excited about my trip, it’s like beautiful weather, beautiful people.

Julia’s bodily feeling is irrevocably changed from paralysing numbness to feeling ‘alive’ with a vitality and ‘freshness’ that is in harmony with her environment. It is ‘like spring’, a felt reawakening in a world where she is ‘alive’ and can develop again. She is no longer aware of her body as a numb barrier to the world; instead it possesses a ‘fresh’ lightness that is barely noticeable at all. This reawakening activates a range of positive feelings – ‘I feel good about things that are happening, I’m excited’ – and the world offers the possibility of being ‘beautiful’ again.

Julia’s exuberance, however, is tinged with a wariness that she must remain on an even keel:

The most important thing is not to get too excited! Sometimes I don't notice those moments. Sometimes, you know, I ask him [her boyfriend], you know, just poke me if I'm too over-active.

Though the influx of feeling has released her from her depressive paralysis, it now poses a potential threat to stability. Acutely aware that she does not necessarily 'notice those moments' when her feelings escalate, she relies on others to monitor her behaviour.

Though Karen's well periods are short-lived, at T2 she is also relieved to feel responsive again:

I feel happy, whereas when I'm depressed I feel very, very, numb so I feel that I can't really feel anything. We had a passing away in the family; my aunt died in March and I couldn't cry coz I didn't think I could. So now I just feel happy, feeling content with life and feeling like I'm coping with everything and I know what I want to do and I know what I want in life, yeah all of those feelings.

Karen's emotional world is transformed from being 'very, very numb' to feeling 'happy' and 'content with life'. Where Julia's rejuvenated feelings instilled a sense of vitality and growth, Karen's bring a sense of relief at being able to express a normal range of emotions. When she highlights that she 'couldn't cry, coz I didn't think I could' after her aunt died, we realise how the ability to feel not only brings a sense of connection with others but also control and normalcy. Karen is reassured by 'all those feelings' that reveal 'what I want in life', reconnecting with herself and enabling her to 'cope with everything'.

Yet when Caroline becomes well, at T2, she struggles to reconnect:

I feel now there is a sense, like the sensations, the sense of smell and the sense of... there was moments in my life where I was happy and I can sometimes, during the day, touch that point and come back from it but, at least, there is a sense where I can relate to myself.

Caroline's reconnection is tentative, intermittent 'like the sensations, the sense of smell' but confined to 'moments' that she can recognise from when she felt happy in the past. She does not experience the immediacy of feelings that created a positive and grounded sense of self in Julia and Karen. And her phrase – 'I touch that point and come back from it' – suggests the fleeting

nature of feelings that are not fully embodied in the present and only accessed through memory. Her use of ‘touch’ suggests that her contact with former happiness manifests as a somatic feeling that cannot be sustained. Moreover, her words suggest some distance between the weakness of her sensations in the present and their former affective vitality. Nonetheless, these ‘moments in my life when I was happy’, however precarious, provide at least some ‘sense of where I can relate to myself’.

#### Mania: engulfed by intensity of non-stop feeling

During mania, participants described being overwhelmed by an intensity of feeling that, despite having no apparent cause or source, sustained for significant periods of time. At the height of episodes, participants were captivated by a force of feeling that brought a palpable sense of purpose, but retrospectively was seen as meaningless and incoherent.

When manic, Julia is propelled by an enduring high:

You feel so good, you know, kind of I would say the same, like you would on drugs, you know, like cocaine, like cocaine, but all day long, every day, non-stop.

Julia feels ‘so good’ and likens this feeling to an ongoing drug-fuelled high. Her words express not only the intensity of the high, but its continuous and overwhelming character, in persisting ‘all day, every day, non-stop’. For Julia, this euphoria is without source, direction or interaction and is seemingly self-supporting. In contrast to the harmonising positive feelings during stability, her manic high possesses an artificiality that, ‘like cocaine’, struggles to provide any tangible connection between herself and her environment.

Contrast this with Karen who confronts others with an anger that she is usually too inhibited to reveal.

I started shouting and crying and screaming or whatever – “This person’s done this to me!”, whatever... I go out actually looking for places where I can confront people cos I have the confidence to do it, so that’s something I was lacking before, so I felt that I didn’t have the confidence to confront people or to argue... I wasn’t scared of speaking my mind anymore, whereas generally [when well] I’d be like a bit hesitant.

Karen recalls being filled with an anger that sends her ‘looking for places where I can confront people’ and release her inner rage. No longer inhibited by others, she feels emboldened and starts ‘shouting and crying and screaming’ in an explosion of self-righteous fury. This is not the artificial high that Julia experienced, but an outpouring of indignation - ‘This person’s done this to me!’ - and a desire to put things right. And yet Karen’s newfound ability to ‘speak her mind’ empowers her and she no longer feels ‘hesitant’ or ‘scared’ but instead enjoys having the ‘confidence’ to express her feelings.

When manic, Caroline struggles to express how she feels and is far more conscious of her actions than her emotions. When asked about her feelings she admits being;

Happy, I’m really happy! (Pause) To be honest, it’s not a feeling, it’s a behaviour rather than a feeling, there wasn’t any feeling to it, no, I wouldn’t understand how I felt. [When well], I can feel things, but when I’m at the manic episode I don’t feel because I’m just following my instincts it’s just actions, yeah, I’m very detached, distorted, damaged.

Caroline admits that she is ‘really happy’ during mania but sees her experience as predominantly a ‘behaviour’, during which ‘there wasn’t any feeling to it’. As she continues, she realises that ‘she wouldn’t understand’ how she feels ‘because I’m just following my instincts’, something that appears to be propelled by the confidence of ‘just actions’. Whereas during depression, Caroline felt a sense of isolation that was embodied, during mania she is disconnected, acting in a way that retrospectively is bereft of valid feeling or meaning. Her words suggest a lack of awareness or understanding of ‘how I felt’ or of even having ‘a feeling’. Like Julia, mania for Caroline brings a ‘happy’ high but it is disengaged: ‘It’s just actions, yeah, I’m very detached, distorted, damaged’. Whereas Julia stressed the artificiality of mania, Caroline points out the absence of conscious feeling which is a significant part of her sense of humanity. This detachment from herself and her environment leaves her feeling distorted and damaged.

#### Summary:

The accounts suggest a significant relationship between the participants’ changes in feeling during different states and their sense of connection with themselves and others. Indeed, a

defining feature of episodes was the way that participants' bodily feelings and emotions were born out of and reflective of their relationship with the wider world.

Notably, their changing sense of connection arose not only through the range of emotions that were experienced, but also through their bodily sense. During depression, the body was experienced as a numbing obstacle to self-world fluidity, while during mania bodily sense was alive with super-charged feelings of energy that was out of tune with others and environment. Yet the numbness that the participants all described during depression was imbued with distinct personal meaning. While Julia saw it as a reflection of her paralysing sadness, it constituted detachment for Caroline and Karen saw it as emotional loss.

Episodes were associated with different emotions, such as sadness during depression and ecstasy during mania, but the relationship was not necessarily clear-cut or consistent. Elevated moods brought an intensity of feeling that filled all participants with a sense of immediacy and purpose. Retrospectively, however, Julia felt artificial, while for Caroline, it precipitated a loss of meaningful feeling. Karen, though, found the confidence to vent her inner-most anger, bringing positive feelings and an improved sense of self. What was universally true was that during both depression and mania, participants were only able to access a limited range of emotions and these states were characterised by an inflexibility in emotional experience that impacted their ability to respond to others and to experience connection.

Responsiveness returned during stability when participants' enjoyed feelings that were not only more positive but also introduced a sense of affinity with others that was expressed bodily and emotionally. Caroline accessed only fleeting moments of contentment that lacked bodily immediacy and could not be sustained. For the others, however, their feelings no longer instilled disconnection and difference, but instead precipitated a sense of shared affectivity and belonging which led to a more positive sense of themselves in the world.

### **Theme 3: Shifting perceptions of future disrupt progression**

Participants' shifting expectations of the future significantly influenced their sense of progression and opportunity. Though similarities between the participants' relationship with the future over time were evident, there were striking differences. During depression, participants

felt blocked by the expectation of a future that was horrific or inaccessible, while during mania, they were propelled towards an array of seemingly immediate possibilities.

#### Depression (Time 1): blocked by inaccessible future

When participants talked about depression at T1, they all described a disconnection with the future and the sense that their way forward was blocked. Yet this manifested itself in markedly different ways.

Julia's sense of futility over her inactivity during depression is foreshadowed by acute feelings of dread:

I'm so scared of what's happening tomorrow and actually, oh, I think a lot of bad things could happen to me. I'm, you know, really stressed and anxious, extremely anxious, all the time, all the time... I'm just generally [when well], a bit, always a bit scared of the future, but when I'm depressed then I think I'm gonna be one of those people who lives in a horrible place... in social housing with, you know, all those crazies... when I'm depressed I don't have any option.

Julia is faced by a horrifying future that, in her eyes, is laid out with such certainty that she feels 'really stressed and anxious'. To her, impending ruination is not one of a range of possible outcomes but is set in stone. What exacerbates her anxiety is the proximity to suffering that is forever 'happening tomorrow' and fuels her stress 'all the time'. Her sense of vulnerability is intensified by multiple dangers that she envisages - 'I think a lot of bad things could happen to me' - and the feeling that, even if she could evade the 'bad things', more would automatically take their place.

As she describes living 'in a horrible place, in social housing, with all those crazies', her vision of destitution and shame has a clarity that brings it into the present. As the extract unfolds, we realise how the immediacy of Julia's fate robs her of any choice over how to progress or define herself. She is 'gonna be one of those people... with all those crazies' who are at the bottom of the social pile with no option but to suffer and she is acutely aware that she has changed from being 'just a bit scared of the future' to feeling terrified of an inexorable fate over which she has no control. The future has lost all sense of possibility: the openness and flexibility that comes

with the momentum of action and a regular routine has been replaced by a fixed sense of foreboding.

Like Julia, Karen is plagued by a sense of the future that weighs heavily and fills her with anxiety:

Negative thoughts completely weigh you down... I just feel I'm not coping – 'Ah no! I've got to do this! I don't know how I'm gonna do it.' The natural thing is just going to sleep or lying in bed, because I don't know what needs to be done... I go to sleep hoping that I won't be here tomorrow and that I won't have to wake up and address the school [problem]... somebody else can take over and I won't have to address that, yeah, hoping that there is no future, hoping that there isn't anything I have to address, cos it's just so scary.

Karen is oppressed by the uncertainty that pervades her projects and frustrates her ability to proceed. Unlike Julia, she is not fixated by negative certainties, but weighed down by a fear that not only scuppers her plans but instils enduring hesitancy. Being in a constant state of panic, her anxiety inhibits actions - 'I've got to do this!' - leaving her feeling incapable - 'I don't know how I'm gonna do it.' Whereas Julia was obstructed by the clarity of her predictions, Karen is impaired by an anxiety that blocks any route forward.

As the extract unfolds, we realise that Karen's inaccessible future shapes her purposeless and inactive present. Disconnected from her plans and fearful of them, Karen feels like 'just going to sleep' in the hope that 'I won't be here tomorrow' so 'somebody else can take over'. Like Julia, Karen's loss of future and practical significance leaves her helplessly inert and unable to muster the momentum to cope with daily problems or foresee possible change. She wants the future to disappear: she craves an escape from the daily onslaught and welcomes the possibility of an endless sleep where 'there is no future' and she has nothing more 'to address'.

Like the others, Caroline cannot see a way forward:

I don't see a path, I don't see a path at all... I don't want to end my life because as I said nothing matters to me... the days pass and it's going on, mostly it's a comfort for me to

be honest (laughs)... I never thought that I would be able to speak again, something like... I just felt life is all finished, the isolation, the death.

Caroline's repeated assertion that she can't 'see a path' emphasises her sense of disorientation. Her words also hint at her ongoing detachment from the passing of time. Caroline is stuck in a cyclical present, yet this is not something that manifests in fearful negative predictions or anxious indecision. Instead, it feels like an inevitable part of her deeper temporal detachment. Unlike the others, Caroline feels 'nothing matters' and that her 'days pass and it's going on' without being meaningfully engaged or connected. Without a grasp of what 'matters', she has no framework from which to anticipate, act or reflect and has little basis on which to differentiate one day from another. She possesses limited grasp of time passing and without this, her life feels static. Time no longer shapes Caroline's experience, but has become an explicit object of her experience and she watches it 'going on', a persistent reminder of her irrelevance.

Strikingly, Caroline admits that her inaccessible future is 'mostly a comfort', a temporal void perhaps, where she feels protected from the horrors of the past when 'life is all finished' and from a fearful future when she 'would not speak again'. With bitter irony, she laughingly admits the cold 'comfort' of her detachment where she doesn't 'want to end my life because... nothing matters to me'.

#### Stability (Time 2): regaining momentum

By the time the participants have stabilised at T2, they notice a change in their sense of momentum and their ability to conceive a way forward. As Julia's depression lifts, she discovers a new sense of possibility:

I felt really dark [during depression], I felt, that's it, I'd lost all opportunities and I'm gonna live like a vegetable. So now I do believe that things are gonna get better, you know, sort it all out... What can I do? I have to move forward, move forward, you know, do something, do, there's always ways.

Now Julia believes 'that things are gonna get better' and no longer sees herself as someone who is 'gonna live like a vegetable'. Notice her use of tense - 'I'm gonna live' - suggesting that her perception of her state is future-orientated. Relieved to be released from her dark vision of the

future - 'I felt, that's it' - she now perceives scope for change, but remains unsure over how 'things' may change or what her objectives should be. She senses an opportunity to 'sort it all out', yet this is contingent on her ability to 'move forward' and 'do something' to activate change. Her path remains precarious and it is with a hint of desperation that she says, 'I have to move forward' and 'do something'. Her plaintive, 'What can I do?', more an exclamation than a question, expresses where she feels she is, compelled to 'move forward, move forward' and 'do something' to change things for the 'better'.

Like Julia, Karen's sense of the future and her movement towards it is transformed:

It feels like you're going somewhere, you're able to see some kind of future... you feel a lot more capable and it makes you feel positive as well that things are moving in the right direction so you remind yourself you're getting better.

What is striking is the degree to which her recovery is expressed as a physical, temporal and perceptual reconnection, during which she is 'moving in the right direction' and can 'see some kind of future'. Like Julia, she has no specific objectives or plans, but finds that she can now perceive 'some kind of future' that is imbued with an openness and possibility that draws her forward, making her feel 'capable' and 'positive'. Yet her awareness of 'moving in the right direction' also carries a wider significance for her recovery: 'you remind yourself you're getting better'. Karen appreciates that momentum will help her get better but, unlike Julia, she is less aware of her role in activating future change.

Like the others, Caroline sees a future with hope:

I'm hoping things will change for the better, it needs to for me. The more I put into it the more result I find so I feel there is... I'm not as hopeless even though nothing excites me anymore or hurts me anymore but I'm not hopeless and I wanna learn, I'm open to learning.

Caroline feels reconnected with her daily cares and concerns and expresses hope 'that things will change for the better'. This springs from a new sense of possibility and 'change' born out of her reconnection with temporality. Time is no longer an external object, but something that shapes life and confers meaning and direction upon it. Caroline's sense that 'the more I put into it, the

more I will find' suggests her experience is imbued with the coherency of anticipation and fulfilment. Like Julia, she has a newfound awareness of her part in activating future change, something that brings a sense of impetus; 'I'm not hopeless and I wanna learn'. But while her condition has improved and she can see a future with possibilities, she cannot muster enthusiasm for it; 'nothing excites me anymore or hurts me anymore'.

#### Mania: immediacy of possibilities disrupt direction

During elevated moods, the participants experience a future where everything is possible and vividly within their reach. Future possibilities envisaged during mania possess such immediacy that they neither require anticipation nor specific actions that could realistically achieve them.

Julia's mania introduces widens her possibilities beyond what she previously experienced:

You're so confident, you're really confident, over-confident... A guy came and said, "Can you do a [building] project?" I say, "Of course." It was like a five-storey building! I took it and really believed it, like I will easily do it, like one, two, three, four [snaps her fingers]. I never did it myself, of course.

In mania, the future is Julia's for the taking and she is driven by a confidence and directedness that keeps her constantly on the move. Her future is no longer a solid obstacle, as it was during depression, but is open-ended and detached from obligations or limitations. Though her projects are pursued with confidence, she is unrealistic. Every project she conceives, no matter how time-consuming or ambitious, appears instantly achievable, 'like one, two, three', and she is locked within an ever-active present, without any system of anticipation or reflection to guide it. Julia's admission that she 'never did it myself, of course' expresses a sense of resignation over her foolhardy manic self that, in retrospect, feels disconnected from who she is or wants to be. Her words, 'of course' convey the inevitability of her failure that perhaps also has come to influence her view of recovery.

In contrast to Julia, Karen feels that she finally can be who she wants to be:

I think it feels like a better version of me... I feel very capable and I know what I want to do and I know what I want out of life and then, on the other hand [when depressed], you feel completely lost and you feel hopeless and you don't make any decisions.

Karen feels released from the 'hopeless' indecision of depression and accompanying sense that nothing is possible. She feels that her decisive manic self is a 'better version of me' who knows 'what I want to do' and 'what I want out of life'. Contrast this with Julia, whose manic behaviour is inconsistent with her objectives and frustrates any prospect of a meaningful future.

Like the others, Caroline becomes engaged with a future that appears instantly clear and accessible:

I'm having lots of ideas about the future: energetic, doing lots of things, going shopping, coming back, not, not useful things... working like a machine, you just set the machine on and the machine just works, you give it instructions and it just follows the instructions, without having a sense of, oh wait this might be dangerous for you, I lose my direction so when I have to start from the beginning I have to find ways of where to direct myself again.

Caroline feels energised by the myriad of possibilities. She has 'lots of ideas about the future' that drive her activities where she is 'doing lots of things, going shopping, coming back'. In retrospect, however, Caroline is troubled by her direction-less activity where she is 'working like a machine' and blindly following 'the instructions'. Like Julia, Caroline perceives this automated manic self as detached from her values, cares and experiences that ordinarily inform her choices and provide a framework through which to anticipate, act and move forward.

As the extract unfolds, she acknowledges 'I lose my direction', a telling admission that not only expresses the chaos of mania, but also suggests a deeper disruption in Caroline's intentionality and sense of self that endures during recovery. It may be that the framework that would normally direct her is disrupted so she 'must start from the beginning' and 'find ways of where to direct myself again'.

## Summary

The analysis suggests that the participants' ability to progress and to foresee opportunities was shaped by a sense of the future that changed during different states. Notably, the way that the future appeared to participants informed both their sense of direction and momentum. Indeed, changes in their experience of temporality during different states brought about transformations in their perception of present and future possibilities.

Depression precipitated an inaccessible future that trapped participants in a cyclical present and precluded any possibility of progression. Two participants faced an impossible future defined by horrific prediction and anxious uncertainty while one, Caroline, lost any sense of time and her relevance to it. In contrast, during stability the participants' sense of momentum was regained and the future offered glimpses of opportunity and change. Though some felt invigorated by a hopeful future, Caroline felt an enduring sense of fear that prevented her from investing emotionally in it.

Striking differences were revealed in how participants experienced the future during elevated moods. Mania brought an expectation of the future where every desire imagined by participants seemed immediately accessible to them. And yet Caroline and Julia's plans during mania had no practical significance and were never fully realised. Though the participants shared similar experiences of increased confidence and possibility, their impact on progress was distinct: Karen's ability to realise her aspirations was facilitated during high moods, while Caroline and Julia felt that their expectations and associated actions lost any meaningful direction.

## **Theme 4: Changing sense of others impacts relatedness**

The participants' experience of other people altered during the three states, creating a shifting interpersonal landscape where relational trust and social interactions changed and the meaning of even the closest relationships became redefined. Disruptions in some participants' relatedness during discrete episodes also impacted their relationships with others even when well.

### Depression (Time 1): self-isolating against social shame

During depression, participants were overwhelmed by acute feelings of social worthlessness, a strong sense of shame and, to varying degrees, struggled to interact with close others. Though they shared a need to isolate, they also perceived their seclusion in markedly different ways.

For Julia, feelings of fear and worthlessness intensified in the presence of close others:

Close people are judging you, you just want to disappear, you feel like you've lost the people who care about you (she cries)... I think I'm afraid to lose them, that they won't be able to stay any longer. That feels quite possible, it makes you feel bad, like stressed, scared.

Julia is afflicted by the presence of close others, whose purpose, in her eyes, is to expose her worthlessness. She feels 'close people are judging you, you just want to disappear', expressing an anxious awareness of the critical gaze of others and an unbearable sense of inadequacy in their presence. The condemnation she feels possesses an immediacy that is physically felt, instilling a strong desire to 'disappear' and escape physical proximity.

As the extract unfolds, Julia breaks down, overwhelmed by the pain of feeling she has 'lost the people that care about you'. What is unbearable for Julia is that the people who matter to her appear inexplicably and immutably altered, imbuing her relationships with a pervasive sense of estrangement and loss. Despite her alienation, she remains fearful that they 'might not be able to stay any longer' and that she could 'lose them' from her life completely. Notice her unusual turn of phrase - 'won't be able to stay' – perhaps reflecting a reluctance to verbalise her deepest fear that close others will abandon her, leaving her feeling vulnerable and unlovable in a hostile world.

Julia's feelings of worthlessness with others also structure her wider social world that now appears superior and inaccessible:

I feel worse than everybody else probably. When I compare with other people, I think, you know, yes, I'm like a way worse person than they are or anybody else probably is.

Julia's social world is bereft of particularity and only serves as proof of her inadequacy. Her words suggest that by being 'worse than everybody else' she lacks the normative attributes of social comparison, so that she feels not only alienated but dehumanised and excluded. An acute sense of shame means Julia is desperate to avoid her friends and associates and withdraws into the relative comfort of isolation:

'I don't want them (other people) to see me like this. Probably I feel ashamed of me, that why I don't want to see them'

When Karen talks about being with others during depression, she expresses a strong sense of failure:

I just feel I can't face them, yeah, I can't face them, I don't know how to talk with them, I feel really bad in my relationships, I feel like a terrible wife, with the kids like a terrible mother cos I'm not taking care of their needs.

Being with her immediate family brings the fear of being perceived negatively by them. Like Julia, she sees herself as the passive object of their critical judgements and lacks the ability to change or redeem herself. Her repetition of 'can't face' suggests she senses her inadequacy through the perceptions of others and it is this reflected sense of self that instils feelings of shame and hopelessness.

Her sense of failure in their presence is intensified by an inability to 'know how to talk with them'. Like Julia, Karen feels estranged by her inability to fulfil the relational roles that she feels she is expected to adopt. Whereas Julia could not tolerate changes in others, Karen struggles with her sense of herself as a 'terrible wife' and 'terrible mother', something that makes her 'feel really bad'. Like Julia, Karen's impulse is to hide, to withdraw into protective seclusion:

I'll kind of give my bubble wrap, kind of trying to remove myself from reality or having to face reality. Yeah, I can just hide myself away and hopefully they're gonna move on without me.

To some degree, Karen's self-inflicted isolation acts as 'my bubble wrap', protecting her from 'having to face reality' and become the wife and mother that she feels she cannot be. Far better,

in Karen's eyes, that she 'remove herself' from the expectations of 'reality' in the hope 'they're gonna move on without me'. Notice Karen's words, 'hide myself' that once again express a physical urge to disengage from others by concealing herself bodily.

Like the other participants, Caroline cannot endure being with others during depression:

You don't want to talk to anybody and you don't wanna communicate and you just wanna run away whenever you came, I just wanna go and be inside that cage.

For Caroline, her separation from others is a 'cage' suggesting a particularly restrictive incarceration. This is no protective 'bubble wrap' but an enforced solitary confinement where she is imprisoned by fear and persistent self-critical thoughts:

Everything feels scary, fearful, the fear is just lessening now, but the first couple of days, or even the whole week, I couldn't even communicate with my parents... the closest person to me, which is my mum, I felt the same, it felt lonely... I cannot say anything because it is all internal, internal dialogue, it is just monologue, just telling myself this how it is... you're not able.

Caroline describes an 'internal monologue' that has such intensity that it suffocates her speech. Whereas the other participants felt incapacitated by the judgmental perceptions of others, Caroline seems paralysed by a persistent persecutory voice, 'just telling myself this is how it is... you're not able'. Notice how Caroline corrects herself from, 'it is all internal dialogue' to 'it is just monologue', suggesting the persistence of critical thoughts over which she has no control.

Her closest relationships have altered and people who previously offered support and companionship now appear distant, even threatening. Like Karen, Caroline's separation from close others manifests in a sense of threat – 'everything feels scary' - that coincides with her inability to communicate with them. Despite her detachment, Caroline retains an acute sense of what is missing and what she has lost. As she exclaims, 'I couldn't even communicate with my parents', we begin to appreciate her loss of the person she is closest to – 'my mum' – something that feels deeply lonely.

### Stability (Time 2): emerging trust builds relatedness

By the second interview, participants described a change in their experience of being with others, who they now perceived in a more welcoming light. Important differences, however, emerged between the idiographic accounts, emphasising the enduring struggle for some participants in cementing a sense of relational trust.

Julia is no longer surrounded by the crushing judgment of others:

You feel more positive about other people. You have a good opinion of other people, whereas before I probably have a bad one, I can forgive more... so it's about other people and you can see the beauty... I now have that positive-ness, I think now other people are good, they're nice.

Julia is drawn towards the possibility of a secure interpersonal world where she feels 'positive about other people' and 'has a 'good opinion' of them. Other people seem 'good, they're nice' and she recognises their 'beauty' and 'positivity', something that not only rekindles a sense of safety and shared belonging but also brings self-transformation - 'I can forgive more.'

Interpersonal trust has been restored so that those others who previously appeared superior and estranged now feel safe, familiar and self-affirming. Interestingly, Julia seems aware of the change in her perceptions from 'probably a bad one' to 'a good opinion of other people' and attributes this to the 'positivity' of her transformed perceptions where the world is revealed in a trusting and welcoming light. This newfound trust precipitates a reconnection with others where and she feels sufficiently safe to initiate social interaction:

I'm kind of interested. I do not ignore messages, I can answer it finally. Finally, you kind of show initiative.

Like Julia, Karen is relieved to be able to communicate easily with others:

I feel good about others, I'm fairly relaxed and don't feel agitated... When I'm depressed I just wouldn't be able to talk at all, so just having a decent conversation with somebody and feeling the different emotions... but I think every now and again I feel this person did this, this, this, this kind of thing, and I think, 'OK can I move on? Am I gonna hold that

thing against them forever?'. So I'm trying to kind of figure out what I should be doing, the way that I should be acting.

Like Julia, Karen feels 'good about others', suggesting a similar restoration of trust where she no longer 'feels agitated' and anxious around them. For Karen, her relational reconnection is brought to life through 'feeling the different emotions' during interactions, that also offers the possibility of self-transformation. In contrast to Julia, however, Karen still faces anxiety over 'what I should be doing' and 'the way I should be acting'. At times, she is reminded of the wrong-doings of others when 'this person did this, this, this, this', and the positivity that sustained the fluidity of her interactions falters. As Karen exclaims, 'can I move on?', she grapples with the possibility that her resentment will endure - 'Am I gonna hold that thing against them, forever?' - and perhaps considers the implications for her recovery. Karen is trying to 'figure out what I should be doing, the way that I should be acting' in an effort to establish a way of being with others where she feels sufficiently safe to 'move on' and recover.

While Karen suffers bouts of anxiety over the intentions of others, Caroline is overwhelmed by a persistent self-consciousness that severely limits the fluidity of her relationships:

Very sensitive, very sensitive, I just want like a miracle to happen and to make me not think all the time before I talk or before, or think after I talk of what conversation that has taken place, how it was and how I've come across or how people have judged me, it's keeping me quiet.

While the other participants' return to wellness gave rise to a sense of trust, Caroline remains anxious, feeling 'very sensitive' during day-to-day interactions and preoccupied with 'how I've come across or how people have judged me', something that is 'keeping me quiet'. Her anxiety seems to arise not only from a lack of trust but also a loss of surety of how to behave in an acceptable way. She is engaged in constant self-analysis where she strives to predict 'before I talk' and revisits afterwards 'how it was and how I've come across'. Caroline's self-scrutiny prevents her from engaging comfortably in interactions with others, but she is nonetheless fighting to reconceive and develop a socially acceptable way of being with them.

### Mania: disinhibited self brings relational detachment

All social inhibitions dissolve during mania, bringing a sense of release from social connection as well as a detachment from others. In stability, they needed to interact with others but now they feel that others are somehow beholden to them.

When Julia shifts into mania, she revels in her sense of superiority:

When I'm high, I don't care what they [others] think, I think about myself well, and they're all wrong and it's only me who is right. I'm a Princess, Empress!

Julia feels she possesses the superiority of an untouchable 'Princess' and the control of an all-powerful 'Empress'. Whereas during depression she felt depleted and imprisoned by people's perceptions, during mania she does not 'care what they think' and is liberated from any desire for social validation. In fact, Julia seems so self-consumed and preoccupied with thinking 'about myself' that other people barely exist. In Julia's eyes, she is set apart from other people who are 'all wrong and it's only me who is right'. Others no longer offer the enticing possibilities that were apparent during wellness and seem largely irrelevant. Though Julia's sense of liberating detachment is markedly different to the social estrangement of depression, it also reveals notable similarities in interpersonal structure. In both states, other people appear devoid of individuality or flexibility, congregating as an unchanging and anonymous 'other' that acts as a fixed wall between 'they' and 'I'.

Karen's anxiety dissolves during elevated moods and she is engulfed with fury over the perceived offences of others:

I've been very, very angry, at times, I used to blame people for things, maybe they did years ago, so there was that side of things when I used to get angry very, very quickly... It was almost like I perceived a completely different side to them and that was when all the anger and resentment came from, kind of stemmed from, I had a lot of anger inside me so I was venting out the anger.

Unlike Julia, Karen does not detach from others or revel in their irrelevance, but seems vividly alive to their pertinence. Her long-held anger, previously kept in abeyance, is released when

faced by ‘a completely different side’ to others and flares up with such startling ferocity that she becomes angry ‘very, very quickly’. Her perception of others dramatically switches to ‘a different side of them’, not only igniting her fury but exposing the source of her feelings where ‘all the anger and resentment kind of stemmed from’. Despite striking differences in their affective experience during this phase, Julia and Karen are both empowered by elevated moods and, rather than feeling accountable to others, presume that others are answerable to them.

Like the others, Caroline’s mania releases her from her struggle with anxiety during stability. She is no longer focused on the acceptability of her interactions and freely befriends and speaks with anyone:

Whatever comes, just comes... start talking to people, maybe become over friendly... so I start to talk and talk and talk... like I would feel very sexually active, so I became very friendly with men on the street or wherever.

Caroline is no longer paralysed by self-consciousness. She feels relaxed with others and has an overwhelming physical desire to be with them. ‘Whatever comes just comes’ and she freely begins ‘to talk and talk and talk’ with others in a way of being that is guided more by instinct than anticipation or consequence. She feels ‘very sexually active’ and becomes ‘very friendly with men on the street or whatever’ viewing them as a source of pleasure. Like Julia, Caroline is released from the significance of interpersonal ties and ‘people’ no longer confer the pressure of personal meaning and expectation. From this perspective, ‘people’ are imbued with a generality and detachment that is reminiscent of her experience of other people during depression. However, whereas during depression, she perceived others as an impassable threat or punitive force, during the highs of mania they are viewed as being subject to their own needs and desires.

#### Summary:

The accounts suggest a significant relationship between the interpersonal world of participants and their changes in mood over time. Extreme episodes created an unstable interpersonal world that transcended the participants’ closest familial relationships as well as their wider social world. What is striking is not only how the participants’ perceptions of others changed during episodes, but how the balance of relational power shifted accordingly. At one extreme, during

depression, the participants felt persecuted and alienated, a dynamic that drove them into seclusion and even deeper isolation, yet during elevated moods the balance shifted dramatically and other people no longer held a position of judgement but were seen instead as subservient facilitators of their own desires. Released from social inhibitions, the participants pursued a diverse range of interpersonal needs, from Julia's feelings of superiority to Karen's need to express anger and Caroline's desire for sexual pleasure.

Mood episodes created a stark interpersonal imbalance during which perceptions of self and others became depersonalised, inflexible and devoid of individuality. Within this, relatedness was disrupted: during depression, social interactions appeared insurmountable and during high states behaviours and activities became disconnected from others. The analysis suggests, however, that the relational imbalance diminished during wellness and relatedness was regained through a sense of interpersonal trust and positive feeling. For two of the participants, this experience was only partial and they continued to struggle with social interactions, feeling an enduring uncertainty over how to fit in or measure up.

## Discussion

This study set out to provide new insight into the lives of people with BD and their experience of change during different states and over time. No work has previously examined change as it occurs within and between BD moods and yet understanding this aspect and its cumulative impact is likely to facilitate better understanding and the development of strategies that promote stability and self-management.

A longitudinal qualitative approach provides a real-time structure within which complex processes underpinning a person's trajectory through time become visible. This approach is less concerned with capturing change as a unitary, unfolding progression and more with understanding the temporal threads that make manifest that process (Neale, 2021). By bringing a longitudinal perspective to this area of enquiry, this study helps to demystify the sense of chaos that is widely reported in the qualitative literature, providing new insights on the experience of living with BD.

Four themes were identified that encompass the participants' experiences of depression, mania and stability, revealing core dimensions of their changing experience through time. These include changes in their activity and sense of agency, feelings and sense of connection, perceptions of the future and momentum, and relatedness with others. These trajectories both shine a light on and better explain an unstable experience that is characterised by significant fluctuations in the participants' sense of connection with themselves, others and the world.

#### *Extreme changes in activity assault agency*

The participants experienced extreme changes in activity levels during periods of depression, stability and mania that were interrelated and profoundly impacted their changing sense of agency over time. Agency is commonly understood to reflect a person's capacity to act independently and is closely related to feelings of autonomy and control (Moore, 2016). While agency is not highlighted per se in the qualitative literature on BD, several studies have found that living with BD creates feelings of being out of control (Crowe et al., 2012; Fernandez et al., 2014; Folstad & Mansell, 2018; Hormazábal-Salgado & Poblete-Troncoso, 2020; Lim et al., 2004). This is linked to living with instability and, more specifically, with an inability to predict or control behaviours and mood symptoms (Crowe et al., 2012; Hormazábal-Salgado & Poblete-Troncoso, 2020; Lim et al., 2004). Loss of control also diminishes self-esteem, destabilises future goals and is the primary reason for wanting to escape the condition (Folstad & Mansell, 2018; Inder et al., 2008).

By taking a longitudinal approach that accesses experiences at different time points, this study demonstrates in greater detail the way that changes in a person's experience of activity during different states can undermine their sense of agency. From this perspective, feeling out of control is not a static event, but instead is a fluid and cumulative process that involves a person's shifting relationship with activity during different mood episodes.

In defining the relationship between action and agency, Gallagher and Zahavi (2012) differentiate the agency of action from the ownership of action: in the former, a person experiences being the source of that action, whereas in the latter they experience it as having

occurred to them or being the subject of it <sup>1</sup>. Agency in action is therefore bound up in both the embodied experience of action and the intention to act. Together these instil the experience of being an author of an action and being in control of it.

This study indicates that the inability to act during depression leads to a collapse in routine that undermines agency. Participants were acutely aware of a reduction in their activity and also expressed a loss of volition over themselves and their world. Julia felt chaotic due to her inability to initiate desired activities, Karen saw herself as incapable of doing anything and Caroline expressed only a limited awareness of her actions, activities, or their meaning. These findings reveal that for people with BD there is a shift between agency and ownership of action over time, bringing about acute instability. Experiential studies examining depression in BD are scarce. One such study suggests that depressive inactivity is precipitated by negative thought cycles (Fletcher et al., 2013) but the current study reveals depressive inactivity as part of a wider process within which activity change interrelates with agency at specific times and in different ways.

This study also suggests that the participants' experience of depleted agency during depression varied and was shaped by meaning and possibilities. Although Julia felt daily tasks were physically crippling, her keen awareness of her former capabilities sustained her efforts to act. In contrast, Karen perceived her collapse in activity as inevitable because of her ongoing fear and expectation of depression. Meanwhile, Caroline's loss of activity reflected an acute sense of inertia where she had limited awareness of her actions of their relevance. Ratcliffe (2015) argues that during clinical depression a person's experience of action, which is normally accompanied by a sense of freedom, undergoes a change in possibilities that affects agency. In some forms of depression, although a project may seem impossible to a person, they retain a sense of it being achievable to someone else, while in others, a person feels that nothing is significant to anyone, bringing about a collapse in activity and an erosion of meaning<sup>2</sup>. While this study complements

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<sup>1</sup> See Gallagher & Zahavi (2012, chapter eight, p179) for a wider discussion of experiential sense of agency and the relationship between sense of ownership (or mineness) for movement and sense of agency for action. Later in the chapter, the authors discuss the connection between agency and temporal experience (retention and protention) which is also the focus of the discussion of theme 3 (Shifting sense of the future disrupts momentum).

<sup>2</sup> See Ratcliffe (2015, p170) for other types of experiences of diminished agency that feature in depression. In addition, he suggests that the world might still include meaningful projects for a person but the allure is gone and no longer solicits action and also an overwhelming feeling of passivity before some threat which can contribute to other types. This sense of threat is expanded upon in theme three of this study.

this view, it also reveals that the loss of possibilities during depression are part of a trajectory of changing possibilities and meaning during different states and that this is expressed during both mania and stability.

During mania, participants described a sharp increase in activity that was in direct contrast to their experience of depression. This was accompanied by a feeling of being able to do anything and of endless possibilities. Findings in the wider qualitative literature indicate that mania coincides with an intensity of energy, activity and productivity that gives rise to a sense of control (Crowe et al., 2012; Folstad & Mansell, 2018; Mandla et al., 2017; Rusner et al., 2009; Russell & Moss, 2013). Although the surge in activity and energy instils a sense of empowerment, it is also viewed as chaotic and disrupting self-control (Folstad & Mansell, 2018; Russell & Moss, 2013).

Phenomenologists contrast the loss of practical significance during depression from the excess of significance experienced during mania (Bowden, 2013). Although mania activates a surge in energetic action, there is no discrimination between the relevance of activities, leaving a person engaged in multiple projects that are decontextualised from their temporal or practical significance (Bowden, 2013). While agency arises through first-order intentions and bodily movements, it also derives from second order retrospective attributions<sup>3</sup> (Gallagher & Zahavi, 2012). In the current study, participants often viewed themselves retrospectively as unthinking machines during mania who, unable to interpret themselves in terms of longer-term cares, had lost the sense agency that was pivotal to their humanity. This reveals the way in which extreme changes in activity create distinct and varied challenges to agency during depression, mania and its aftermath. Depression prevented the participants' from acting on their intentions and mania imbued absolute control over them while during its aftermath, they experienced an acute discordance between their intentions and actions.

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<sup>3</sup> Graham and Stephens (1994, p.3) define second order retrospective attributions as “whether I take myself to be the agent of a mental episode depends on whether I take the occurrence of this episode to be explicable in terms of my underlying intentional states”.

Moreover, this study suggests that agency is not necessarily restored during stability because of the cumulative impact of experiences during BD moods. (Crowe et al., 2012; Inder et al., 2008; Lim et al., 2004). While all participants described a return to former activity levels during stability, two of the group struggled to regain agency: Karen saw depressive relapse as inevitable and Caroline struggled to interact with others. An inability to take control of behaviours during BD euthymia has been linked to low self-efficacy beliefs that reinforce existing difficulties (Bandura, 1977; Smith et al., 2020). Moreover, a lack of self-efficacy in BD has been found to predict low physical activity (Vancampfort, Correll, et al., 2013). Current study findings, however, emphasise an alternative view where the relationship between self-efficacy and behaviour reflects a trajectory of changing activity and agency that is cumulative and thus can diminish agency during well periods.

#### Changes in feelings impact connection with others and the world

A further dimension revealed by the longitudinal analysis was the change in participants' feelings and their connection with others and the world. During depression, all participants described a sense of numbness that blunted their affinity with themselves and their world. While Julia described a paralysing sadness that was so intense it 'makes you numb', Karen felt a loss of emotion that left her unable to react, and Caroline experienced the horror of physical numbness and emotional isolation.

Although no in-depth investigation of bipolar depression exists in the wider literature, work focusing on different diagnoses of depression offers illuminating insights (Rhodes & Smith, 2010; Rhodes et al., 2019; Smith & Rhodes, 2015). In one study, chronic depression was illustrated as a profound sense of emptiness that encompassed a loss of emotions and thoughts and a numbing of the self (Rhodes et al., 2019). A feeling of emptiness is commonly described across several disorders and during depression is associated with bodily numbness and profound loss of purpose (D'Agostino et al., 2020). While some cross-sectional studies explore the progressive experience of depression (e.g. Karp, 1994), their retrospective view offers limited insights into its processual nature. This study, however, suggests that the participants' numbness, disconnection and loss was comparative and linked to the past. Participants described being paralysed by the pain of sadness and numbed by the fear of 'going into that hole again'. In some

contexts, the numbness of depression is considered a bodily defence from painful emotions and loss (Didonna & Gonzalez, 2009). Current study findings suggest that it was related to past the experience of depression, which was imbued with fearful meanings.

Fuchs (2013a) argues that during depression, the lived body loses its fluidity and becomes inert which disrupts the emotional feeling that normally shapes a person's interactions with the world<sup>4</sup>. A loss of social connection during bipolar depression is reported in other studies and has been identified as one of the most distressing aspects of living with the BD (Inder et al., 2008; Warwick, Mansell, et al., 2019). In one study, for example, parents describe inhabiting a separate world where they feel disconnected from their children, despite being physically together (Tjoflåt & Ramvi, 2013). This resonates with the experiences of this study's participants, whose bodily numbness not only blocked their actions, but created a barrier to their sense of themselves and others. Their idiographic trajectories also bring novel insights. For example, although all participants described a numbed self, Caroline's disconnection was also spatial as she came to inhabit a world of numbing isolation.

Elevated expansive or irritable mood have long been identified in diagnostic criteria as defining characteristics of mania. While some studies indicate that elevated mood is a core feature of mania, others suggest that mania is better understood as an overall increase in the intensity of all emotions (Henry et al., 2003) with increased mood reactivity (Martino et al., 2020). In the current study, participants described being overwhelmed by emotions during mania that ranged from feeling happy to being angry. Despite expressing distinct emotions, all participants were freed from social constraints and felt emboldened to express their feelings. Consistent with this, other studies suggest that the feeling of ecstasy during mania is inseparable from being disinhibited, self-confident and open with others (Lobban et al., 2012; Mandla et al., 2017; Russell & Moss, 2013). Current study findings support this but also point to an inflexibility of feeling and unresponsiveness to others that has not been highlighted in the qualitative literature. Positive emotions in BD have been found to be driven by biases towards positive stimuli and emotional goals and are maintained by the tendency to ruminate on, and enhance, positive

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<sup>4</sup> In Fuchs (2013a) this is referred to a corporealization of the lived body and leads to psychomotor inhibition as well as changes in sensorimotor space that becomes limited to the close environment.

emotions (Gruber, 2011). For instance, models suggest a persistence of positive emotion during mania that reflects a lack of flexibility in shifting emotional response to context (Urosević et al., 2008). This study extends this view by indicating that an inflexibility of emotional range is experienced during both depression and mania and is underpinned by consistent difficulties with emotional resonance and connectivity with others over time.

The value of accessing the idiographic trajectories of participants was particularly apparent when considering the changes during stability which heralded a newfound affective connectivity after depression. Julia experienced a sense of bodily vitality in her environment and Karen felt emotionally responsive to others, instilling a greater sense of belonging. Caroline's struggle to reconnect reflected a weakness of bodily sensation, whereby her felt sense was fleeting rather than fully embodied in the present. The primacy of the body in connecting with feelings and conveying meaning to others is illustrated in Eatough & Smith's (2006) exploration of one woman's experience of anger, whereby bodily change is a key aspect of what anger feels like and being angry is lived through the body. The meaning of emotional connection is experienced as a felt meaning rather than as thoughts or words, reflecting a pre-reflective engagement with the world. This resonates with the participants' experience of reconnecting with feelings during stable periods, whereby their felt sense seemed inseparable from their sense of vitality and reconnection with their environment and themselves.

### Shifting perceptions of the future disrupt momentum

The participants experienced a sense of the future that dramatically changed between different states and coincided with a shifting sense of momentum. Qualitative accounts in the wider literature suggest that people living with BD see a future that is imbued with a strong sense of uncertainty (Maassen et al., 2018; Michalak et al., 2006; Proudfoot et al., 2009). This is compounded by a disrupted sense of momentum and difficulty achieving goals (Inder et al., 2011; Inder et al., 2008; Lim et al., 2004; Tse et al., 2014). Although cross-sectional psychological work has highlighted the negative impact of changes in tempo on people's certainty and aspirations, no work has explored how a person's experiences change through time. By taking a longitudinal approach, this study introduces a novel shift in ontological focus

whereby time is no longer external but part of the very nature of being (Neale, 2021). The participants' experience of temporality shifted from being trapped by an inaccessible future during depression to an overwhelming sense of possibilities and accelerated momentum during mania.

Phenomenologically, the way time is subjectively experienced is distinct from the objective measurement of clock-time (Fuchs, 2013b). One dimension of subjective temporality involves the speed of time which, according to quantitative measurement, slows down during depression (Thönes & Oberfeld, 2015) and accelerates during mania (Bschor et al., 2004). However, a quantitative paradigm is unable to fully capture the experience of lived time since it is not only embodied, enacted and socially embedded, but also unfolds within a structure that stretches into both the past and the future (Cavaletti & Heimann, 2020). By drawing on the strengths of a longitudinal qualitative approach, this study reveals temporality as it is lived for people living with BD and sheds light on its psychological significance which has been largely overlooked.

Clinical phenomenologists have long argued that episodes of mania and depression involve a disturbance in the formal structure of temporal experience (Binswanger, 1964; Minkowski, 1970). For instance, Minkowski (1970) observed that temporality during mania could not be fully explained by the existence of acceleration, but also involved a disruption in the way his patients experienced the unfolding of time. Developing this work, Binswanger (1964) argued that mania coincides with a shift towards an overly optimistic future orientation that is not only disconnected from the past but also reflects a momentary present that is discontinuous and lacks continuity. Similarly, a recent study that examined the temporal experiences of people during mania, found that the most prominent theme was a positive, yet unspecific, orientation towards the future that altered their activities in the present and affected their relationship with risk (Martin et al., 2019). The liberation of mania, therefore, may be bound up with a sense of freedom over the future that, according to writers in this area, coincides with grandiose delusions and unattainable goals (Gruber et al., 2012; Sass & Pienkos, 2013).

This work resonates with the manic experiences of the participants in the current study, whose future projects were immediately accessible and no longer limited by events in the past.

However, this study extends current understanding by revealing the experience of temporality, and specifically the future, during mania and depression as interrelated within a person's trajectory. While the participants were propelled into an endless array of possibilities during mania, which were seen to be discordant retrospectively, during depression they then experienced a sense of foreboding that stalled their ability to move forward.

Ratcliffe (2015) argues that depression is characterised by a profound change in temporal experience, whereby the interplay between the anticipated possibilities and their fulfilment is disrupted, amounting to a loss of practical significance. While some notions of temporality in major depression in the wider literature highlight a fixation with the past (eg. Tellenbach, 1980), others highlight an inhibition in people's ability to self-realise (Straus, 1947). In a recent large-scale study, the temporal narratives of participants during depression included an inhibition of becoming, a gloomy future and a blocking of the flow of time (Stanghellini et al., 2017).

This study suggests that the experience of a blocked future is apparent during BD depression, but the idiographic accounts indicate key differences. Although Julia and Karen were plagued by a horrific future that blocked progress, Caroline experienced a detachment from the passing of time. As Ratcliffe suggests, depressive experiences can involve an overwhelming loss of practical significance during which the passing of time no longer acts as a 'a meaningful transition from one state of affairs to another' (Ratcliffe, 2015, p. 185). By revealing the participants' trajectories and way they diverge and converge through time, we can also see how these experiences both reflect and shape an ongoing process that encompasses stability.

The participants' stability was also characterised by a sense of the future that instilled momentum and the possibility of positive change. Having been depressed, the participants expressed an acute awareness of a significant change in their experience of temporality that might otherwise would have gone unnoticed. While all participants were able to envisage a future, they varied in terms of their capacity to engage with it. Julia felt motivated to direct herself forward, but Caroline experienced an enduring sense of emotional detachment. It may be that the loss of meaning experienced by Caroline during depression was so profound that her relationship with time was more permanently undermined.

### Changing sense of others impacts relatedness

The participants in this study experienced an unstable interpersonal world during mood episodes which were characterised by dramatic changes in their perceptions of others and a shifting relational connection. While there is growing recognition of the importance of interpersonal experience in BD, this study highlights an alternative perspective. To this point, the primary focus of qualitative literature has been the impact of episode volatility and challenging behaviours during mania on interpersonal lives, such as emotional loss and marital break-up (Granek et al., 2016; Inder et al., 2008; Michalak et al., 2006; Owen et al., 2017). This study, however, illustrates the way in which a person's interpersonal world shapes relatedness, encompassing shifts in connection and disconnection with others during different moods. From this perspective, the interpersonal difficulties associated with behaviours during moods arise as part of a changing relational connection during different states characterised by disrupted relatedness. These insights are likely to help those people affected to both anticipate and understand, as well as manage, interpersonal change.

During depression, participants struggled with feelings of worthlessness in relation to others that drove them further into isolation. Qualitative work in this area suggests that people's experience of BD depression is bound up with their shifting perceptions of others and how they feel they are perceived (Crowe et al., 2012; Owen et al., 2017). In one study, participants' perceptions of minor social events and innocuous responses reinforced a sense of worthlessness during BD depression, creating feelings of being trapped (Owen et al., 2015). In other studies, perceptions of others' responses prompted a need to hide (Fernandez et al., 2014; Fletcher et al., 2013). Consistent with this, the participants in the current study felt trapped by the gaze of others which they perceived to be persecutory, causing them to withdraw. This dynamic has been conceived within the integrative cognitive model of BD (Mansell et al., 2007) where, during BD depression, a person's extreme appraisal of other people's responses lead to behaviours, such as social withdrawal, that exacerbate low mood (Fletcher et al., 2013). However, this model cannot fully explain the experiences of the participants in the current study, whose withdrawal was experienced both emotionally and physically and seemed to arise primarily from being looked at, rather than through verbal interactions.

Sartre (2003) suggests that being looked at by another involves a change in embodied experience from the body being something that perceives the world to it being something that is perceived<sup>5</sup>. In resisting this process, people with schizophrenia struggle to shift self-positions and are at risk of becoming locked within a negative projection (Lysaker et al., 2005). Experiential work in the area of BD similarly suggests that in social situations people feel vulnerable to the external influence of others and a diminished sense of self (Inder et al., 2008). This body of work echoes the participants' experiences in this study, where their sense of submission to others and persecution by them created disconnection and disrupted relatedness. However, this disruption was also bound up with their trajectory across states, including mania. Although participants felt a sense of release from the constraints of other's perceptions during mania, which enabled them to pursue their own needs, this also heralded a disconnection from others' concerns that were seen to be insignificant. While mania promotes disinhibition, self-esteem and social interaction (Lobban et al., 2012; Owen et al., 2017; Russell & Moss, 2013), it can also lead to the loss of relationships and trust (eg. Granek et al., 2016; Hormazábal-Salgado & Poblete-Troncoso, 2020; Russell & Moss, 2013). This study brings to light a stark switch in relational power between depression and mania within which perceptions of self and others are often inflexible and depersonalised.

The participants' awareness of an interpersonal disconnection during mania and depression was further emphasised by their relief over the return of a positive relational feelings during stability. This is echoed by other work in this area where recovery is associated with gaining control over social environment (Owen et al., 2017) as well as the development of interpersonal trust in the longer term (Granek et al., 2016; Rusner et al., 2010). However, while all participants experienced improved relationship with others, two of the group continued to struggle with anxiety over their interactions. Considered within the context of each participant's idiographic trajectory, connections are revealed between the struggle with agency during stability and the

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<sup>5</sup> Sartre illustrates this experience with the example of a person spying on someone who is absorbed in listening to a conversation and looking through keyhole. While they are absorbed in their practical activity their body is inconspicuous, but on realising they are being watched, the focus shifts onto their physical body as an object of the perception of others (Sartre, 2003, p282). In instances of shame, the judgemental eyes of others are felt bodily and in an increased awareness of bodily discomfort or awkwardness.

difficulty in regaining interpersonal trust. This emphasises the need to consider the process of change through time and its cumulative impact on stable periods.

## **Chapter 6 – Study One Results: Part B**

### **Searching for self-coherence: confusion, disruption and shame prevail**

This chapter presents the second section of longitudinal results, revealing the participants' search for self-coherency while experiencing significant feelings of confusion, disruption and shame.

Where the last chapter examined the participants' awareness of change during distinct moods, this chapter explores their ongoing attempts to take stock and make sense of who they are, despite their shifting state. This involves a shift in focus from exploring the participants' sense of immediate change to a wider examination of their reflections on their changing sense of self. The findings are explored and then discussed in relation to the wider literature with a view to contextualising their contribution to this area of study.

Two themes illustrate the participants' search for self-coherency. The first reveals their struggle to pin down a 'normal' self and the sense of confusion, frustration and disorder this creates. The second explores how their feelings of shame and humiliation over extreme behaviour creates a threat to their sense of self. Across both themes, the findings show that the search for self-coherency becomes ever-more precarious as they grapple with mounting confusion, loss of control and shame.

The themes are presented in case-by-case format rather than state-by-state, as used previously. Whereas the last chapter illuminated extreme change during each state, a case-by-case approach helps elucidate the evolving meaning of each participant's struggle and how this unfolds.

#### **Theme 1: Struggling for self-coherency during confusion and disruption**

The participants described an ongoing struggle to identify a normal self that could bring coherency to their lives. This led to an acute sense of confusion and inconsistency, intensifying depression and diminishing wellness, and was compounded by their inability to envisage a clear

future. As a result, they all felt out of control and, in one case, this created an overwhelming sense of chaos.

Looking first at Julia's case, we see how her search for normalcy is ever present and creates feelings of confusion and frustration. During depression, she is beset by uncertainty over who she is and how to find herself:

‘Where is real me? Where, you know, is my bipolar? Where is my depression? Where is my mania?’... I’ve been thinking about it a lot actually, you know. I’m kind of, I’m not sure which one is normal me. Will I ever be normal?

Julia feels disorientated by persistent changes in state that prevent her from locating a ‘real’ self: ‘Where is real me?’. The issue preoccupies her and she battles to make sense of it; ‘I’ve been thinking about it a lot’. The problem is compounded by the need to disentangle a ‘real’ self from her changing bipolar states. Her persistent self-questioning - ‘Where is real me? Where is my bipolar? Where is my depression? Where is my mania?’ - expresses an inability to pin down and control her shifting states. She is engaged in a search to locate her real self, asking not ‘Who?’ but ‘Where?’. Though she recognises that these different selves belong to her – ‘my mania’, ‘my depression’ – over time, they leave her feeling lost. Her inability to find her real self exacerbates her sense of hopelessness during depression: ‘I’m not sure which one is normal me. Will I ever be normal?’

Julia's battle for authenticity persists even when she is well:

I feel, you know, like a kind of person who doesn't know who, who, who she is, kind of feeling like losing sometimes yourself, which one [state], yeah, is true me... When it's like a bit up or a bit low, so sometimes I think to myself, you know: ‘Where am I? Where are you? Where you gonna end up? What should I do?’... Stressing, because you kind of think, it makes you feel and think, you know: ‘Where am I gonna be tomorrow?’

The sense that Julia is ‘losing herself’ remains during stability. Indeed, it has added import. Without a grasp of her normal self, she has no basis from which to monitor moods and prevent relapse. When she feels ‘a bit up or a bit low’, anxiety pervades: ‘Where am I?, Where are you?’ This results in her ‘stressing’ as she fears the destabilising impact of her confusion on her ability

to stay well and that she might tip into mania or depression: ‘Where you gonna end up?... Where am I gonna be tomorrow?’

Her inability to find normalcy also becomes an affront to self-respect. Whereas during depression she felt helpless, she now feels like the kind of person who ‘doesn’t know who she is’, despite being objectively better. Without an identifiable sense of herself, she has become a person who is deficient in both character and direction.

As Julia reflects further on her inconsistency, she is struck by the disruption to her wider life:

It makes a mess, you know, it makes a total mess! Cos you’re not consistent, there’s no adequate consistency...If you have a goal like, you know, it kind of really like, it distracts a lot, yeah, it really distracts. Cos when you start it, you know, then you go all manic, or, you decide not to do it anymore, or you’re depressed or you’re really bad at whatever you’re doing, so yeah, it effects. I still don’t, I don’t know how to manage.

Julia is frustrated by her changeable self that she now realises ‘makes a total mess’ of her life, preventing her from progressing with her plans. The crux of the problem is that her changing mood ‘really distracts’, destabilising projects and preventing her from achieving ‘a goal’ that might bring consistency. Despite her desire to kick-start projects, she cannot rely on herself, expecting to ‘go all manic’ or ‘decide not to do it anymore’, get ‘depressed’ or be ‘really bad at whatever you’re doing’. Julia blames the ‘total mess’ of her life on her inability to realise consistency. She admits ‘I don’t know how to manage’ despite her significant efforts to take control, leaving her feeling diminished.

In Karen’s case, self-coherency has become an ideal that she feels is beyond her. Her sense of inconsistency feels insurmountable during depression:

I can’t relate to any normality at all, I’m completely different all the time and have no idea where I really am... I think the duration of time that I have been fully functioning, or what you would call normal, has been very limited and it doesn’t last for that long. It only lasts for maybe a week or couple of weeks and then that’s probably it and then I fall back into the depression.

Karen feels ‘completely different all the time’. Normality is fleeting and hard to pin down. Like Julia, her changes in state are cumulative, leaving her unable to ‘relate to any normality at all’ and instilling feelings of helplessness. However, whereas Julia searched for coherence between past and present selves, Karen feels consistency is beyond her. In her eyes, any possibility of normalcy has already been taken, leaving her with ‘no idea where I really am’. Given her ‘limited’ periods of ‘fully functioning’ in the past, Karen sees no possibility for normalcy in the future. Her turn of phrase, ‘what you would call normal’, reveals her dissatisfaction with a version of ‘fully functioning’ that only ‘lasts a week or couple of weeks’ before she falls ‘back into depression’.

As Karen recovers, her sense of how she should be when well makes her unstable reality even harder to tolerate:

I just like kind of struggle with it [stability], cos I’m changing and that kind of puts me off kilter, like all the time, so there’s no normal really, even though I kind of know what it should be, when I’m well, I just kind of don’t get there.

Karen sees herself as insubstantial: ‘I’m changing... there’s no normal really’. Like Julia, her changing self is a constant ‘struggle’, impeding her ability to self-align and undermining her ability to feel well. Though both participants struggle with incoherency, its impact on their experience of wellness differs. Julia had little sense of normality which made her stressed. Karen knows who she ‘should be’, but cannot stay well long enough to ‘get there’. Karen’s potential to integrate a coherent self is undermined by the brevity of stable periods, leaving her ‘off kilter’ all the time.

As she contemplates her future, Karen’s sense of uncertainty becomes overwhelming:

There’s no consistency! Stop, start, stop, start, kind of thing, so that feels like I don’t know how I’m going to be feeling next week or the next few days or the few months, and I’m already worried about the months that I’m off from work [...] So, I’d hope there would be a lot more consistency and I could generally pick up, so I could be in control of things, so I could be well for most of the time rather than the other way around.

Like Julia, Karen becomes exasperated by her life. The ‘Stop, start, stop start’ prevents any continuity of self from which to predict how she will be feeling ‘next week’ or in a ‘few months’. This is deeply worrying and she fears the chaos that her variability will create, forcing her to be ‘off from work’ for prolonged periods. She feels ‘things are unpredictable’ with the only certainty that she’s ‘not sure where they’re going’, making it impossible to bring coherency to her life. Though she hopes that well periods could provide ‘a lot more consistency’, allowing her to ‘be in control of things’, the reality is ‘the other way around’.

Compared to Julia and Karen, Caroline’s search for self-coherency goes deeper, necessitating the creation of an identity from scratch. This burden proves insurmountable and she becomes passive and disconnected.

During depression, Caroline sees the formation of an identity as a matter of survival:

I’m just searching for ways how to become normal, I’m very confused in what I’m going through... I’m trying to build an identity for myself that can survive out of the change, to be well. But how can I survive? I don’t know the right way for me?

Caroline is ‘searching for ways to become normal’, prompted by a need to orientate herself through the confusion of ‘what I’m going through’. Where Julia looks for coherency among the different selves she experiences in different states, Caroline’s sense of normalcy cannot be found from experience but is something she must ‘build’. Notice she says ‘become normal’, suggesting that normalcy must be developed from scratch. Caroline’s need for an identity seems more delicate than the other participants, involving higher stakes. A coherent sense of self would not only create consistency, but would safeguard her, enabling her to ‘survive out of the change’. However, ‘the right way’ eludes her, creating an acute sense of vulnerability: ‘But how can I survive?’

Caroline remains dogged by confusion even when she becomes stable and struggles to know how to behave:

I don’t understand if it’s normal or not normal, I have to be told you’re acting in a strange way, I don’t know what’s the normal way and that’s what I am, just like walking through

mud, trying different ways out, like maybe there's the right way, maybe there's not so, through hearing what people are telling me.

Caroline has lost any notion of social normalcy or how to achieve it: 'I don't understand if it's normal or not normal, I have to be told you're acting in a strange way'. Julia and Karen both struggled to pin down a coherent sense of who they are, but Caroline's sense of confusion runs deeper, leaving her unable to guide her behaviour from one moment to the next. She feels impaired, as if she is 'walking through mud', a comparison that vividly conveys the slow effort involved in trying to find her way in a confused and unclear world. Unable to differentiate between 'normal or not normal', her efforts become indiscriminate. In contrast to the others, Caroline is wholly reliant on 'hearing what people are telling me', to shape who she can become.

As Caroline reflects on the direction of her life, she describes herself as aimlessly meandering from one day to the next:

I'm just floating like on top of the river, I'm just floating, nothing holding me back, that sense of identity, who I am, I am just floating from depression one day to mania one day and that's it going around.

Caroline sees herself as 'just floating on top of the river' as if suspended in time, with no control over her course or destination. Notice her surprising turn of phrase – 'on top of' – emphasising that she is not actively engaged with the water but just 'floating' with its flow. Where the others expressed an urgent need to impose order and direction to their disrupted lives, Caroline seems disconnected from temporality and remains passive. Without a 'sense of identity', she feels unbounded, with 'nothing holding me back'. Unlike Julia and Karen, who retained a keen awareness of plans and desired direction, Caroline has no sense of self, either now or in the future. She is listlessly disconnected, in a place where nothing changes and she is 'just floating from depression one day to mania one day' and repeatedly 'going around'.

#### Summary:

The participants engaged in an ongoing search for a coherent sense of themselves that could confer consistency and help them to navigate change and realise a future. This created a

significant struggle, eliciting feelings of confusion, exasperation and frustration that compounded their sense of instability.

During depression, their struggle with incoherency exacerbated confusion and hopelessness, but the way this unfolded for each participant varied: Julia was lost among disparate selves, Karen felt self-coherency was beyond her reach and Caroline felt she was starting from scratch.

Even during stability, when the participants believed that they should be well, they were unable to realise normalcy and this only intensified their sense of inadequacy. It also created barriers to staying well. Julia struggled to monitor normal moods and Karen was never well long enough to establish normalcy while Caroline lost all sense of how to be from one moment to the next, relying on others to guide her behaviour.

An inability to envisage or realise future plans exacerbated their sense of incoherency and loss of control. Julia and Karen struggled with their inability to control their own future, while Caroline became passively disconnected from it.

## **Theme 2: Feelings of shame threaten self-coherency**

As part of their search for self-coherency, participants were also forced to reflect on extreme and unacceptable behaviours during mania and depression. This created feelings of humiliation and a sense of shame arose that led to an assault on self-concept.

In Julia's case, the reality of her manic actions first hits home during depression:

You feel ashamed [sighs] because after you did all those things, you know, which, you know, Ahh! I cannot say... you know, you feel awful, really awful, especially if people remember and they ask you 'Do you remember you were doing that?' 'Please no, don't remind me! Please don't!'

After the highs of mania, Julia struggles to reconcile her behaviour with who she feels she should be. She is left with the guilt of having done 'all those things' which are so 'awful' she cannot bring herself to disclose them: 'Ahh! I cannot say'. Any mention of 'those things' elicits 'really awful' feelings that weigh heavily upon her and threaten her self-concept. Her sense of shame

becomes particularly hard to bear in the presence of others who remind her of her lapses. When questioned – ‘Do you remember doing that?’ – she resists, begging them to keep quiet: ‘Please no, don’t remind me! Please don’t!’ Julia’s humiliation is kept alive through the memory and interactions of others, despite her efforts to forget and avoid it.

As Julia begins to feel better, the shame develops into a sense of disbelief:

Sometimes you ask: ‘Was it me?’ You know, ‘I don’t believe!’ You know, that’s the kind of feeling, I don’t believe it’s me, you know, I have that feeling and when I take the dress [a particularly flamboyant dress], for example, no, I really was now looking through my wardrobe, I thought how the hell could I wear this dress?

Julia is confronted by a self that is incongruous and unwanted. She cannot reconcile her outlandish actions with who she feels she is. Her disbelief manifests as a ‘kind of feeling’, suggesting an affective rejection of her mania which is such an affront to self that ‘I don’t believe it’s me’. Despite tangible evidence of her change during mania, such as the dress she wore during her episode, she still cannot accept it: ‘How the hell could I wear this dress?’ She has little choice but to suffer the social shame of her actions, but she strives to disassociate herself from it. There is a sense that Julia is protecting herself from her manic self which poses a threat to self-concept.

Karen does not attempt to resist or disassociate from unwanted behaviours and her sense of self during depression is therefore crippling:

I can’t cook, I can’t do this, I can’t look after the house, I can’t look after the needs of the kids properly, I can’t do this, all those things I can’t do properly because I’m lazy, that’s who I am, so I keep thinking to myself I’m lazy, that’s who I am, but actually it’s the illness that makes me lazy... but there’s a long list of things that needs to be done, anyone can see that, but I’m just too, yeah, lazy to get up and do anything.

Karen’s shame stems from seeing her depressed self as useless. Her repetition of ‘I can’t’ expresses frustration at her incapacity which she sees as unacceptable and a direct consequence of her ‘lazy’ character. Rather than find ways to avoid integrating this version of herself, as Julia does, Karen submits to it, reinforcing its validity: ‘I’m lazy, that’s who I am’. We see a flicker of

doubt, as she considers the impact of her condition - 'but actually it's the illness that makes me lazy'- yet it is fleeting and Karen gives it little credence, focusing instead on 'the long list of things to be done' which she knows she is 'too lazy' to do. By validating it as a character flaw, Karen punishes herself, actively intensifying her depressive state. It may be that, compared to Julia, it is harder for Karen to find ways to escape the impact of her unwanted state on her sense of self.

When stable, Karen struggles to make sense of unacceptable extremes of behaviour and their implications for her self-coherence:

It's me, part of the illness. But how is it possible to be so useless, to stay in bed until the afternoon one day and then, the other day, I get up and all of a sudden, I know what I need to do and I go off the scale... so, it's like you're nothing, you're like completely different polar opposites, you've got one extreme and then you've got the other extreme with no in-between whatsoever.

Karen is struck by her discordant states and struggles to reconcile her contrasting behaviours when depressed and manic. The switch between them is so 'sudden' that she finds it inconceivable that it can all be the same person: 'How is it possible?' Moreover, the changes Karen undergoes seem random, happening from 'one day' to 'the other day' without perceivable cause or order. Critically, unlike Julia, Karen recognises her extremes as part of herself - 'it's me, part of the illness' - but struggles to make sense of them. As a result, she is caught between two shameful 'polar opposites', leaving her feeling like 'nothing' and with 'no in-between whatsoever'.

Caroline's trajectory has echoes of both Julia and Karen's. Like Julia, she has to confront her shameful behaviour during mania. But where Julia resists and disassociates, Caroline has more in common with Karen in both accepting that this is part of her self and struggling to reconcile it with who she feels she should be.

The shame that Caroline feels about herself intensifies during depression:

[During mania] I feel I've exposed my body and my like...with men on the street, or, anywhere... so that makes me punish myself, feeling dirty, feeling guilty. I realise what I

have done, so I start punishing myself for that and start isolating for it, about those things, yeah, which all comes when I've just come down from the episode, all comes into my head to analyse it, to realise it, it takes me into the deepest depression, so having to cope with these episodes, makes worse episodes.

Caroline recoils in shame over her actions during mania. The process of realisation is sudden - it 'all comes...all comes into my head' - bringing with it an intensity that is difficult to bear. It is a cruel awakening to a shocking reality: 'I've exposed my body'. Humiliated by the flagrancy of public exposure, Caroline is 'feeling dirty, feeling guilty' and takes steps to chastise herself for what is an acutely personal transgression. It requires significant mental effort 'to analyse it' and 'realise it', taking her 'into the deepest depression'. As she realises the extent of 'what she has done', she starts 'punishing myself for that' and starts 'isolating for it'. Julia finds ways to avoid the humiliation of mania but, like Karen, Caroline's struggle to make sense of and 'cope with these episodes' brings a sudden exposure to unwanted self-meanings that cannot be reconciled.

Even as Caroline stabilises, she still feels acutely compromised:

I've lost my contacts because I've messed them up, I've lost my dignity, I've lost my direction, so, when I have to start from the beginning I must find ways of where to direct myself - 'am I gonna stay with the same people whom have seen me in this particular episode [of mania] or change into a different direction again? - so that is the main thing for me, being exposed.

Unlike Julia, Caroline accepts culpability for her manic self, something that leaves her depleted: 'I've lost my dignity, I've lost my direction.' For Caroline, she is back to ground zero, reduced to nothing and must 'start from the beginning' and rebuild a new identity from scratch. Caroline feels that she must change, perhaps in order to protect herself from the debilitating shame of 'being exposed'. Like Julia, Caroline's shame has a strong social dimension that influences the direction she will take. She must choose whether to stay 'with the same people whom have seen me in this particular episode' or 'change into a different direction again'. Notice her use of 'again', suggesting that this is not novel, but an unremitting process where time and again, she must redirect herself out of her shameful self-depletion.

### Summary:

The participants' persistent feelings of shame created an assault on self and self-coherency. Their behaviours during episodes carried humiliating meanings that were discordant with their values and who they felt they were or should be. Both Julia and Caroline felt humiliated by their actions during mania while Karen was sickened by her failure to fulfil the social roles expected of her.

The participants were also acutely aware that these states had also been witnessed by others, intensifying their shameful impact and perpetuating their negative meanings.

The impact of shame on the participants' self-concept was mediated, in part, by their ability to resist or disassociate themselves from it. The way that participants responded to their sense of shame had distinct implications for their experience of depression and stability. Julia pushed away reminders of mania during depression, but the others ruminated on their behaviour which intensified their depressive self-punishment. As the participants stabilised, Julia continued to resist the implications of mania on her sense of self and refused to give credence. Conversely, Karen and Caroline felt an enduring sense of depletion.

Findings highlight a complex and delicate dynamic whereby the participants' ability to resist discordant selves could protect their sense of self, but also contributed to their ongoing struggle to reconcile themselves and realise a coherent self-concept.

### Discussion

This study highlights the participants' ongoing struggle for self-coherency as they attempted to reconcile disparate selves and formulate a sense of normalcy and consistency over time.

Reflecting on their changing sense of self and wider life was a precarious process that created feelings of confusion, loss of control and shame.

Whereas the last chapter revealed key dimensions of change for participants during different states, these findings go to the heart of each participant's need to gain a unified sense of who they are across different time periods. In taking a longitudinal approach, this study provides new insight into people with BD and their perpetual struggle with an incoherent sense of self. The

way in which it develops during depression and well periods is brought to light, illustrating how this creates further instability which, in turn, questions self-coherence.

The first theme illustrates each participant's struggle to realise a sense of coherency and the confusion this created, intensifying instability and undermining self-control. The struggle for self-coherency is an ongoing individual process that is informed by past and present meanings along with the ability to realise future plans. Findings indicate that this process compounds experiences of depression and well periods.

The second theme then examines the sense of shame instilled by extreme behaviours and the threat this poses to self. While the struggle with coherency forces participants to attempt to make sense of themselves through time, this process also creates difficult feelings of humiliation. Indeed, findings point to the fundamental role of shameful feelings in preventing the integration of a more coherent self. The ability of participants to disassociate themselves from shameful experiences mediated its impact on their self-concept.

#### Struggling for self-coherency during confusion and disruption

Qualitative findings on BD highlight the contradictory experiences of self during different states and the way in which these give rise to a confused sense of self (Inder et al., 2011; Inder et al., 2008; Jönsson et al., 2008; Lim et al., 2004). For instance, one study of young people indicated feelings of bewilderment and contradiction that together challenged the development of stability and coherency (Inder et al., 2008). While this highlights the significance of identity confusion for people diagnosed with BD, it offers limited insight into the ongoing struggle for self-coherency over time. One study did draw data from different time points during therapy, but the data was merged thus preventing the formulation of longitudinal insights (Inder et al., 2011; Inder et al., 2010).

The current study goes further by revealing that the participants' struggle with incoherent selves and disruption is ongoing and pervasive, exacerbating confusion and instability. Findings are consonant with the notion of the self as a continuous reflexive project whereby the individual is

compelled at regular intervals to self-scrutinise and build a coherent identity (Giddens, 2008)<sup>6</sup>. The current participants perpetually grappled with their sense of coherence, constantly looking for ways to formulate a sense of who they were: while Julia rejected irreconcilable selves, Karen felt normalcy was unachievable and Caroline attempted to build coherency from scratch. The longitudinal perspective brings novel insights into the evolving meaning of this process for participants during depression and stability. During depression, confusion compounded feelings of helplessness, whereas their inability to find normalcy when stable only intensified their sense of inconsistency and inadequacy. Findings therefore illustrate how the search for self-coherency over time caused greater confusion, disruption and distress, exacerbating their condition.

The struggle for normalcy has been viewed by some as a deep existential issue that not only creates feelings of inauthenticity, but also initiates a daily battle to decipher normal actions and feelings from the illness (Goldberg, 2019; Rusner et al., 2009). People diagnosed with BD preserve an awareness of their contradictory behaviours and emotions during different states, driving a constant struggle to synthesise and connect with a normal self that can establish coherency for the future (Borda, 2016). Psychiatric diagnoses serve to reinforce social norms, such as moderation and self-consistency, that then demand self-surveillance and presume that failure to achieve this is a flaw (Wilson et al., 2018). The present study supports this view. In fact, the participants' inability to realise, or connect with, a normal sense of self not only led to intense self-scrutiny and feelings of inadequacy but for one participant, Caroline, amounted to a loss of self and a threat to survival. Findings thus point to the need for therapeutic interventions to focus more on identity coherence for people with BD, as well as the potential value of self-acceptance and shared responsibility in ameliorating the burden of this process.

Prominent perspectives position identity as a life-long developmental process where self-sameness and the sharing of essential characteristics with others instils identity coherence (Erikson, 1959). BD studies suggest that the onset of symptoms during adolescence or early adulthood may lead to disrupted coherence (Inder et al., 2008). This study further points to

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<sup>6</sup> Giddens argues that the individual is wholly responsible for reconstructing and rebuilding a coherent and rewarding identity and that this process persists indefinitely. During this process, a person appropriates their past by selecting aspects based on their anticipated future (see Giddens, 2008 p80-81).

identity incoherence for people with BD, but in middle adulthood. Overall, study findings extend understanding of the nuanced relationship between the struggle with incoherency and the experience of change. Findings from Part A, presented in the last chapter, together with present findings help illuminate this aspect. For instance, the profundity of Caroline's self-confusion in this chapter reflects and interrelates with her inability to reconnect during stability in the previous one. This aspect, that sets Caroline apart from the others, points to the importance of establishing a sense of reconnection during stability, including feelings, the future and other people.

Qualitative studies highlight the experience of being out of control and the way that this reflects and shapes a person's chaotic and inadequate sense of self (Chapman, 2002; Fernandez et al., 2014; Folstad & Mansell, 2018; Hormazábal-Salgado & Poblete-Troncoso, 2020; Mandla et al., 2017). The sense of chaos for people with BD reflects a person's experience of their current life and also their overall trajectory that is characterised by unmanageable disruption (Crowe et al., 2012). Losing control of one's life is often equated with an inconsistent or insubstantial sense of self (Inder et al., 2011; Inder et al., 2008; Jönsson et al., 2008; Tse et al., 2014).

Similarly, this study illustrates the disruptive impact of mood change on the participants' lives and their sense of self, but it also highlights the significance of temporality and the future in this process. Julia and Karen's struggle with disruption to their plans and goals not only created uncertainty but also exacerbated their incoherent sense of self.

In Giddens' (2008) trajectory of the self, the reflexive construction of self-identity not only relies on reinterpreting past events, but also on preparing a future that reflects and actualises the self's ongoing biography. Future plans may be constantly revised and reconstructed, but the coherency of self relies on an awareness of an ongoing connection between past, present and future. While Julia and Karen were aware of their future selves and this motivated their struggle to restore order, the sense of change brought into question their ability to realise it. In contrast, Caroline had not sense of identity to direct her path and remained temporally disconnected.

### Feelings of shame threaten self-coherency

Shame negatively impacts a person's sense of self by forcing the individual to contemplate the possibility of a defective or worthless identity (Lewis, 1971). One study that compared shame in BD and unipolar depression, found that BD I is correlated with trait shame and shame-proneness (Highfield et al., 2010). Findings in the qualitative BD literature point to the significance of self-stigma, whereby the negative attitudes of others are internalised, manifesting in feelings of shame, a negative view of self and an absence of belonging (Hormazábal-Salgado & Poblete-Troncoso, 2020; Inder et al., 2008; Michalak et al., 2011; Richard-Lepouriel et al., 2020; Suto et al., 2012). Evidence suggests that shame is a social emotion arising from situations where a person's failings are put on display for evaluation by others (Gilbert & McGuire, 1998).

In the current study, the participants' sense of shame was precipitated by their realisation and awareness of how their behaviours were perceived by others during mood states. However, findings add insight to this area by revealing the persistence of shame during both depression and stability, as well as differences in how it is managed between the two states. During depression, the participants' realisation that their shameful interactions had been witnessed by others undermined their sense of self and exacerbated depressive rumination and withdrawal. Julia and Caroline expressed self-loathing over the exposure of manic actions, and Karen was horrified by her incapacity to perform social roles. Studies suggest that high levels of shame are associated with the development of depressive symptoms (Pinto-Gouveia & Matos, 2011). Indeed, shame is understood to instil a sense of inferiority and helplessness, driving the tendency to hide or withdraw, and can be accompanied by anger and self-disgust (Frijda et al., 1989; Gilbert, 2000; Tangney, 2002).

During stability, the participants' ability to manage shame was mediated by the way they responded to identity challenges. Julia expressed disbelief over her outlandish behaviours, but others struggled with a sense of diminishment that prompted a search for a new identity. The denial of episode impact can prove problematic for managing moods and adherence, yet in this study it seemed to protect valued aspects of Julia's identity from the threat of humiliation. This is echoed in other work in this area that illustrates the strategies of people with BD to deny, reinterpret or ignore shameful information that would otherwise diminish identity (Chapman,

2002; Charmaz, 1991). When considering the wider findings of this study, Julia's particular ability to resist identity threat may be related to the fact that her sense of agency had recovered during stability. Indeed, in the last chapter, Julia was the only participant who felt she had fully regained agency on becoming well.

Overall, findings highlight the pivotal role of shameful feelings in preventing the reconciliation of selves and experiences and forming a more coherent sense of self through time. As Potter (2013) suggests, BD behaviours that conflict with personal values and are inexplicable to others both undermine agency and prevent the formation of a coherent narrative. Findings pointing to the need for therapeutic interventions to focus on this aspect as well as consider the complex dynamic between resisting undesirable selves, accepting contradictory experiences and reconciling self-coherence.

**Part Two: An experiential investigation of first episode  
psychotic mania and early intervention services**

## Chapter 7 – Literature Review and Method: Study Two

### Introduction

The first study revealed that the participants' trajectories were bound up with extreme changes to themselves, other people and their environment, creating an ongoing struggle for self-coherency that intensified feelings of confusion, disruption and shame.

The participants had been living with BD for several years and had experienced multiple episodes that prevented them from realising a coherent sense of self. While successive episodes brought extreme changes to key aspects of themselves and their lives, this inconsistency precipitated an unremitting struggle for self-coherency that compounded feelings of instability, even during well periods. Therefore, I became increasingly aware of the need to alleviate suffering during episodes and well periods by preventing relapse and supporting self-coherency and stability. The participants' sense of confusion, chaos and shame made it increasingly difficult for them to reconnect during periods of stability and engage in activities that might help them to stay well. The loss of agency experienced during well periods is also recognised to intensify over time, limiting a person's ability to engage with therapeutic techniques and adhere to medication regimens (Reinares et al., 2010; Scott et al., 2006; Tohen et al., 2010).

These findings indicated the importance of finding ways to prevent relapse early in the illness and before successive episode changes have already destabilised a person's trajectory, eroded their experience of well periods and precipitated a struggle with incoherency. This led me to look more closely at the potential for early intervention to improve the lives of people diagnosed with BD.

Over the last 20 years, NHS early intervention (EI) psychosis services have offered treatment to people with first episode psychosis. The majority treated within EI services meet the diagnostic criteria for schizophrenia, but the entry criterion of first episode psychosis is relatively wide and includes people with first episode BD and manic psychosis. The key aims of EI psychosis services are to improve illness management, reduce the risk of recurrent episodes and hospitalisation (NICE, 2014). Study one findings and the wider literature both highlight the need

for, and potential benefit of, early intervention for people diagnosed with BD. However, current knowledge around first episode BD and early intervention for this specific group is lacking. Part Two will therefore extend the investigation of mood change to explore the experience of first episode psychotic mania and early intervention for people diagnosed with BD. IPA will be used to illuminate the personal experiences of participants and provide idiographic insights.

This chapter will provide an overview of the quantitative knowledge around first episode BD, first episode psychosis and EI psychosis services, review the relevant qualitative findings in these areas and clarify the rationale for prioritising early intervention for BD. The method used for the second study will be outlined and will only include additional and specific information.

## Literature review

### Psychosis in BD: first episode psychotic mania

Psychosis commonly occurs during episodes of both depression and mania for people diagnosed with BD (van Bergen et al., 2019). Of this group, 70-88% experience psychotic symptoms during their first episode of mania (Tohen et al., 2003; Yatham et al., 2009). In BD, a first episode of mania, with or without psychosis, has key diagnostic significance in the prevailing criteria: in DSM-5, it signifies a diagnosis of BD I and in ICD-10 it is a key determinant of BD (APA, 2013; WHO, 1993). According to ICD-10 criteria, mania with psychotic symptoms is characterised by classic symptoms of mania (see Chapter 2, p.16 for criteria) with the addition of psychotic symptoms, such as delusions or hallucinations, extreme excitement, excessive motor activity, flight of ideas and incomprehensible communication. A diagnosis of BD - current episode mania with psychotic symptoms - rests on the presentation of a manic episode with psychotic symptoms, in addition to one other affective episode in the past (WHO, 1993). In DSM-5, BD mood episodes with psychotic features include the presence of delusions or hallucinations that can be mood congruent or mood incongruent (APA, 2013).

According to DSM-5, delusions are fixed beliefs that an individual holds despite contradictory evidence, whereas hallucinations are perceptual experiences that occur in the absence of true external stimuli (APA, 2013). Psychotic experiences, however, are not uncommon in non-clinical populations and recognition of this has recently challenged the more conventional

medicalised view of psychosis, where holding such beliefs or hearing voices are indicative of psychopathology (Read et al., 2009).

Compared to the wealth of research on psychosis in schizophrenia, empirical knowledge on psychotic symptoms in BD is scarce (Raballo et al., 2018). The most prominent delusional or hallucinatory symptoms during psychotic mania include grandiosity, lack of insight and sense of suspicion or persecution (Canuso et al., 2008; Nehme et al., 2018). Although it is commonly argued that delusions and hallucinations in BD tend to be mood congruent, meaning that they are in accordance with the person's current mood (Raballo et al., 2018), some studies indicate that one third of psychotic symptoms in BD are mood incongruent (Black & Nasrallah, 1989).

Somewhere between 48-93% of people with current or past experiences of psychotic mania report at least one type of delusional belief, the most of common of which is grandiose ideation (Burton et al., 2018; Smith et al., 2017). Grandiose delusions are defined as false beliefs about inflated worth, power, knowledge, identity, or religiosity and are held with the greatest conviction (APA, 2013; Appelbaum et al., 1999). They are most frequently reported by individuals during mania, whereas persecution and paranoid delusions are more commonly reported during psychotic depressive episodes (Smith et al., 2017). The content of delusions does not appear to differentiate BD from other psychotic disorders, but some studies indicate that the frequency of delusions of grandeur are higher in BD mania than schizophrenia and may differentiate the two (Pini et al., 2004). Recent approaches to psychopathology, however, advocate a focus on transdiagnostic efforts to understand symptoms and mechanisms (Bentall, 2006).

Around two thirds of people with BD with a history of psychosis present with hallucinations along the course of the illness (Raballo et al., 2018). Evidence suggests that across diagnostic groups of BD, schizophrenia and schizoaffective disorder, auditory hallucinations are more common than visual hallucinations and symptoms are higher during the early illness course (Goghari & Harrow, 2016). The exact proportion of individuals with BD who experience auditory hallucinations varies considerably across studies, yet in a recent review it is estimated to be approximately 57% (Toh et al., 2015; Waters & Fernyhough, 2016). Three types of auditory hallucinations have been identified in BD: voices with negative content, others conversing in the

third person and those providing a running commentary (Toh et al., 2015). The second type – conversing in the third person - is most common during manic episodes (Kumari et al., 2013). While hallucinations and delusions are common aspects of manic episodes, they tend to be brief and often have grandiose, religious or paranoid components that generally dissipate during early recovery (Carlson & Goodwin, 1973; Lowe, 1973).

The degree to which the clinical course differs between BD patients with and without psychotic symptoms is not clear, but some studies have found an association between psychosis and earlier illness onset, more frequent hospitalisations (van Bergen et al., 2019), increased frequency of mood episodes, symptom severity (Canuso et al., 2008; Levy et al., 2013; Nehme et al., 2018) and poorer functional outcomes (Coryell et al., 2001). However, some studies have also found no differences between morbidity, psychosocial or vocational outcomes between groups (Keck et al., 2003). Substantial differences between BD patients with and without psychosis have been reported at the neural level (Ekman et al., 2017). For instance, BD patients with a history of hallucination report reductions of gray matter volume in the right posterior insular cortex compared to those without a history of hallucinations (Raballo et al., 2018).

#### Qualitative experiential literature: first episode psychosis

A search of empirical research in this area revealed that no qualitative work has focused on the experience of first episode psychotic mania in BD. In keeping with the wider quantitative literature, the predominant focus of work has been on experience of first episode psychosis for young people with a diagnosis of schizophrenia or schizoaffective disorder (Boydell et al., 2010; Griffiths et al., 2018). This work, however, is likely to offer insight into how psychosis is experienced for people during their first episode despite the recognised differences between first episode for BD and schizophrenia (Jauhar et al., 2019).

Some studies explored all aspects of psychosis including the period following first episode (e.g. McCarthy-Jones et al., 2013), but I will limit this review to work that focused on adults' experience of first episode psychosis itself. Since a significant proportion of these studies adopted phenomenological approaches, such as IPA, that are closely aligned to the approach used for my study, these findings will be presented.

The emotional lived experience of first episode psychosis is vividly illustrated in several phenomenological studies. One study by Vodušek et al. (2014) aimed to examine the emotional experience of first episode psychosis for people with schizophrenia. Twenty participants (12 male, 8 female) with an average age of 22 were interviewed at two time points, first at admission to services and then six months later. The themes revealed participants' emotional experience prior to, during and after their psychotic episode. When well, their emotions felt inaccessible, unstable or suppressed by anxiety, but as their episode began, they experienced a reconnection with their feelings and a newfound authenticity of self. This initially gave rise to a sense of control, but over time changed to a feeling of being haunted and threatened.

Similarly, Hutchins et al. (2016) used IPA to examine the experiences of 8 people (6 male, 2 female), aged 19-35, in an EI service who had experienced onset of psychosis within the past 5 years. The authors found that psychosis coincided with intense feelings, including guilt, anger and fear, that was expressed through auditory and visual hallucinations. Other people were perceived to act strangely, creating a sense of threat. All participants had struggled with distressing life events prior to their episode and had attempted to cope emotionally by either blocking out feelings or ruminating on them.

IPA was also used by Milligan et al. (2013) to explore the experience of auditory verbal hallucinations for 6 people (5 male, 1 female), aged 17-30, with recent experience of psychosis. Findings pointed to the relationship between the type of voices heard and the participants' experiences of events. Feelings of paranoia, isolation and suicidality escalated when hearing negative voices, but life events exacerbated the critical tone of these voices. They attempted to reject the voices, but their persistence, and the distress it caused, often precipitated crises. These crises could intensify negative voices or shift positive voices to becoming abusive, but they also prompted the participants to disclose their hallucinations to others, enabling improved social support.

One other study (Bögle & Boden, 2019), that examined first experience of psychosis in a more mature sample of 7 participants, also conveyed vivid emotional experiences during psychosis that amounted to perceptual experiences of being under attack and feeling trapped or powerless. Participants described a theatrical sense of unreality as well as a constant threat of harm and

disconnection from others. Some participants associated unusual perceptual experiences of being bullied and attacked with historical or contemporary experiences of abuse.

The relationship between trauma and first episode psychosis was explored more fully by Dunkley et al. (2015) who examined the experience of 10 participants (7 male, 3 female), aged 22-28, with recent first episode and hospitalisation. During the acute phase of the episode, participants struggled with a lack of control over themselves and interactions with others, along with a sense of disconnection from their normal world and sense of self. Feelings of estrangement, stigma and loss during their episode endured and intensified during the recovery phase. An altered sense of self during first episode psychosis is also highlighted in the findings of Connell and colleagues (2015a), who used IPA to examine the experiences of 26 young people (6 females, 20 males), aged 18-25. These participants experienced a disturbed sense of self, a depletion of trust and they struggled with the early days of hospitalisation.

Fenton et al. (2014) focused on the impact of hospitalisation on the experience of early psychosis, using IPA to examine the experiences of 6 people (5 male, 1 female), aged 20-33. Findings illustrated the sense of disempowerment and confusion that arose from being sectioned. While participants described feeling safe and cared for by some staff, they found being hospitalised a traumatic experience, characterised by a prison-like environment that felt fearful, restrictive and chaotic. Hospitalisation also precipitated a challenge to the participants' identity, creating a need to make sense of their situation by differentiating themselves from other service users.

Two IPA studies, that focused on the experience following first episode psychosis, highlighted overwhelming feelings of confusion, the sense that everything they thought they knew had been brought into question and difficulty identifying reality (Attard et al., 2017; Perry et al., 2007). The findings of Attard et al. (2017) suggested that while participants felt powerless and fearful during psychosis, they were resolved to avoid relapse by getting back to a normal routine. Perry et al. (2007) also emphasised the need for normalcy, friendship and routine following the confusion and perceived injustice of hospitalisation. A further IPA study by Connell (2015b) found that participants either experienced a loss or strengthening of self after first episode

psychosis. Those that experienced loss were preoccupied with their experience of the episode, while others took control of agency which strengthened their sense of self.

The experiences of people with BD are not represented in these studies, yet in one recent study that used a combination of thematic analysis and grounded theory to examine whether grandiose delusions were harmful, nearly half the sample (6 of 15 participants) were diagnosed with BD (Isham et al., 2021). Nevertheless, the age range of participants was wide and it did not focus specifically on first episode. Findings suggested that grandiose delusions held significant meaning and provided a sense of purpose, belonging and identity that drove the persistence of beliefs. Grandiose delusions, however, were also associated with a range of harmful experiences in different areas of life.

#### Early intervention psychosis services and BD

In the UK, people with first episode psychotic mania and a diagnosis of BD are likely to be managed within early intervention (EI) psychosis services (Marwaha et al., 2016). Estimates suggest that people with first episode BD make up 5-20% of service caseloads (Henry et al., 2007; Macneil et al., 2011). Over the last 20 years, the development of EI psychosis services has been motivated by studies showing improved outcomes in people with first-episode schizophrenia when treatment is initiated earlier (Jauhar et al., 2019). The focus of research on schizophrenia reflects the predominance of this group in EI services, whereby 70% of patients seen by services meet the diagnostic criteria for this group (Henry et al., 2007).

EI services aim to reduce the duration of untreated psychosis, prevent relapse and hospitalisation (NICE, 2014). Psychosis is the first mental disorder in England to have an NHS access and waiting time target of commencing treatment within two weeks of referral to EI services (Department of Health, 2014). Engagement with EI psychosis services typically lasts three years, is more intensive than secondary care and includes a combination of pharmacological and psychological interventions along with the provision of information and support with social, employment, education, housing and financial issues (McGorry, 2015).

A recent review found that across 10 randomised controlled trials (RCTs), 2 based in England, EI services were associated with better outcomes, including reduced treatment discontinuation

and hospitalisations, improved involvement in school or work, reduced symptom severity and better quality of life (Correll et al., 2018). The findings of a recent Cochrane review similarly found improved outcomes associated with specialised EI treatment, but were inconclusive over whether benefits are maintained after treatment (Puntis et al., 2020). Evidence from England and elsewhere indicates the cost-effectiveness of EI services compared to standard care (McCrone et al., 2010).

EI services, however, were developed in line with evidence from studies focusing on first-episode schizophrenia and are not tailored to BD (Jauhar et al., 2019). As a result, little is known about what service structures or treatment programmes constitute optimal care for this specific age and diagnostic group (Marshall & Rathbone, 2011; Marwaha et al., 2016). Current UK guidelines suggest that while early intervention for the management of BD in young people is a priority, NHS services for BD have not been prioritised and are often variable or poor (Goodwin et al., 2016). Compared to schizophreniform psychosis, BD reflects a distinct clinical presentation and response to treatment, underlining the need for more understanding of early intervention for this group (Jauhar et al., 2019). Consequently, intervention for BD early in the illness course has been identified as a key priority area in psychiatry, leading to recent calls for further research in this area (Jauhar et al., 2019; Marwaha et al., 2016).

### The rationale for early intervention for BD

The rationale for prioritising early intervention for people with first episode BD is strong. The interval between BD onset and illness management is estimated to be 5.8 years: the median age of mania onset is 24 years and initiation of treatment occurs at the age of 30 (Berk et al., 2007; Dagani et al., 2017). Accumulating evidence suggests that longer duration of untreated BD may lead to increased risk of episode recurrence and shorter intervals between episodes that are linked to poorer outcomes (Berk, Brnabic, et al., 2011; Berk et al., 2009). Moreover, in BD there is a step-wise decline in cognition, functioning and employment outcomes with increasing episode number (American Psychiatric Association, 2013; Marwaha et al., 2013; Vieta et al., 2013). Quality of life is known to deteriorate in BD which is likely to be a function of the illness progression (IsHak et al., 2012; Michalak et al., 2013). As more episodes occur and the condition progresses, the impacts on functioning and lifestyle are compounded. Neuroimaging and cognitive evidence suggest that there may also be a neuro-progressive aspect to BD (e.g.

Kozicky et al., 2016). Although studies in this area are mixed, neuroimaging and neuropsychological evidence suggests that BD may have a staged nature which could be ameliorated by early intervention (Singh et al., 2017).

A recent meta-analytic review revealed a high risk of episode recurrence within the first year of first-episode mania which decreases by four years post onset (Gignac et al., 2015b). A subsequent study suggested that despite high rates of remission and recovery at six months following first-episode mania, 58% of patients experienced another episode within one year and 74% by four years. Moreover, recurrence within one year was associated with a higher rate of recurrence in later years (Gignac et al., 2015a). Taken together, this evidence highlights the potential role of early intervention during the first 12 months following first-episode mania in reducing treatment delay, risk of recurrence and promoting early remission and functional recovery (Conus et al., 2014).

Compared to the wealth of research on first episode schizophrenia, first episode psychotic mania has been largely neglected. One study that compared the clinical and functional outcomes of young people presenting with first episode psychotic mania and first episode schizophrenia in an early intervention service in Hong Kong found that at baseline, first episode psychotic mania patients were younger, more likely to be hospitalised, had shorter periods of untreated psychosis and more severe positive symptoms (Chang et al., 2016). Although first episode psychotic mania patients had better functional and clinical outcomes in the initial 3 years of treatment, only 37% attained functional remission at 3 years. This raises the question whether services, initially designed for those with first episode schizophrenia, is the optimal approach for people with BD.

#### Treatment and early intervention for BD

The majority of evidence on the efficacy of psychological treatments for BD derives from RCTs, meta-analyses and systematic reviews dominated by samples of middle-aged adults with established BD (Vallarino et al., 2015). The latest National Institute for Health and Care Excellence (NICE) guidelines for established BD recommend a combination of pharmacological and psychological intervention (NICE, 2014). However, clinical guidelines in the UK and elsewhere offer limited advice on the treatment of first or early episodes of mania (Chia et al., 2019).

The British Association of Psychopharmacology (BAP) (2016) suggests that patients with acute mania should be offered access to a specially-trained psychiatrist, as well as prompt and assertive interventions including hospitalisation if necessary. Other guidelines from Canada and Australia, where early intervention is more developed, recommend starting comprehensive treatment, including mood stabilisers and psychosocial interventions, from first presentation along with support with coming to terms with illness and acceptance (Malhi et al., 2015; Yatham et al., 2018). Maintenance treatment following first episode mania is recommended by five guidelines worldwide, with BAP recommending enhanced psychoeducation along with motivation and family support (Goodwin et al., 2016).

Accumulating evidence suggests that earlier pharmacological and psychological treatment for BD results in improved outcomes in treatment response, relapse rate, time to recurrence, symptomatic recovery, remission, psychosocial functioning and employment (Joyce, 2016). Post-hoc analyses suggest that cognitive behavioural therapy (CBT), group psychoeducation and family education could be more effective for individuals who have had fewer BD episodes (Colom et al., 2010; Reinares et al., 2010; Scott et al., 2006). Similarly, some studies indicate an improved response to pharmacological interventions at first episode compared to multi-episode mania (Tohen et al., 2010). Equally, treatment response may be related to age: one study suggests that early intervention at a mood disorder clinic led to a reduction in hospitalisation admission rates that was most marked in the younger age group (18-25) (Kessing et al., 2014).

Research on interventions for young people at the early stage of BD is limited (Vallarino et al., 2015). However, three interventions have been tested, originating from therapy models employed in EI psychosis services (Alvarez-Jimenez et al., 2013; Early Psychosis Prevention and Intervention Centre, 2001; Macneil et al., 2009). One programme in Australia, known as EPICC, recognises the various challenges of treating young people with psychosis, such as engagement, family and developmental factors (Early Psychosis Prevention and Intervention Centre, 2001). Conus et al. (2010) reported on a 12-month follow up of 108 individuals with a mean age of 22, presenting with psychotic mania who had entered the EPICC programme. Participants were offered 18 months of individualised case management along with various psychosocial and

psychological treatments. Findings suggested that 12 months after treatment, clinical and functional outcomes were better in patients with BD than in patients with schizoaffective disorder.

Macneil and colleagues (2009) developed an intervention, evolved from the EPICC programme, that was tailored to first episode BD or affective psychosis. While it mainly focused on CBT, it included modules on key recovery concepts, such as psychoeducation and engagement, social rhythm regulation, family work, managing alcohol, co-morbidities and stigma. Findings from one clinical controlled trial of this model offered to individuals with first-episode mania aged 15-25 suggested improvements in depressive symptoms, illness severity and functioning in the intervention group, but no difference in manic symptoms or relapse rates (Macneil et al., 2012).

In an Australian feasibility study, an online series of behavioural interventions were offered to young people aged 15-25 with first episode psychotic disorder or mood disorder with psychotic features (Alvarez-Jimenez et al., 2013). The findings pointed to improvements in social connectedness and programme uptake and although the intervention was developed for non-affective psychosis and only two cases out of the sample had an affective psychosis, the individually-tailored elements and the CBT make this appropriate for BD.

When considering the optimal early intervention service model for BD, the single most relevant study, conducted in Denmark, compared the outcomes of specialised and standard care (Kessing et al., 2013). Participants entered the study following discharge from inpatient care for their first, second or third episode of BD. Specialised care led to reduced relapses during the 2 years of treatment, but also for the next four years when patients returned to treatment as usual. Specialised treatment included counselling about transition to hospital, psychoeducation, pharmacotherapy and psychotherapy. Additionally, for those who received specialist treatment, hospital re-admission over the subsequent 6 years was reduced by 20%, translating into substantial cost savings. This is significant given that the economic burden of hospitalisation for BD in the UK is estimated to be £190 million annually (Young et al., 2011).

### Qualitative experiential literature: early intervention for first episode psychosis

In line with the wider quantitative research in this area, qualitative research on the experience of EI services for first episode psychosis does not focus on people diagnosed with BD (Loughlin, 2020). One qualitative study has examined staff perspectives of managing BD in EI psychosis services (Marwaha et al., 2018). The majority of EI staff reported no clear care packages for BD, a lack of understanding of specific treatments and a need for more training to meet the needs of this group. The experience of EI services for people diagnosed with BD and following first psychotic mania is, however, not yet known. Studies on early intervention services for first episode psychosis have been conducted in the UK, Denmark, Norway, Australia, parts of Asia and the North America (McGorry, 2015). Work on BD specifically is lacking, but these studies provide insights into how early intervention is experienced by young people following first episode psychosis.

A proportion of studies have examined young people's experience of engagement with services (Lal & Malla, 2015). Stewart (2012) used a grounded theory approach to explore the views of 30 people (15 female, 15 male), aged 18-20 years in Australia. Engagement with early intervention was impeded by poor relationships with care providers during hospitalisation, but this was overcome by the provision of empathic, accepting, flexible and optimistic relationships of staff within EI services. Additionally, peer group engagement was seen as helping to solidify engagement by normalising experiences. Relational experiences were highlighted in a study by Tindall et al. (2018), whose thematic analysis of the experience of 9 young people indicates the importance of trust building for long-term engagement. An IPA study by the same authors suggests the motivating role of normalisation in attending the service, as well as the importance of caring relationships with case managers in sustaining service engagement (Tindall et al., 2015).

A further study in the US found that participants saw their relationship with their therapist as pivotal. They valued being listened to and saw benefit in addressing the practicalities of getting back to a normal life (van Schalkwyk et al., 2015). A UK-based study that interviewed 16 people within 6 months of entering EI services suggested that during the early stage, participants were absorbed in attempting to understand and normalise their experiences of first episode and relied

on relationships with key workers to talk them through and gain insight from their knowledge in this area (Allard et al., 2018).

Harris et al. (2012)'s IPA study examined the longer-term experience of 8 young people (3 females, 5 males), aged 21-37, who had been in EI services in the UK for 2-3 years. While participants struggled with feelings of stigma and shame, and had difficulty disclosing psychotic experiences to others, positive relationships within the service, with their care coordinator or peer support groups, helped them to engage in wider interventions. Being in the EIS enabled them to make sense of and normalise their experiences, as well as promote a more positive sense of self. While some talked of improved agency, promoted by acceptance and control, others felt they had limited choice over the interventions offered and felt powerless.

The value of a person-centred relationship with key workers within early intervention services is echoed in a study by O'Toole et al., (2004) that explored the experience of 12 young people in the UK. A grounded theory longitudinal study by Lester and colleagues (2011) also highlighted the benefit of long-term and genuine relationships with key workers along with youth-friendly activities. The pivotal role of family members in facilitating contact with the team was highlighted, as was benefit of key workers in supporting the recovery of a positive sense of self. An extension of the same study that interviewed participants within 6 months of discharge suggests that participants saw EI as a gold standard service that was valued for its provision of continuity of care, along with hope for future opportunities, relapse prevention planning and discussion of identity change (Lester et al., 2012). Findings suggested that some participants felt ready to manage without the service but had unrealistic expectations of primary care once discharged. One phenomenological study of 16 young people (12 male, 4 female) in Brazil who had entered a specialist outpatient service found medication, relationships with professionals, family support, personal effort and hope as well as future prospects to be key to recovery (Eisenstadt et al., 2012).

A recent meta-synthesis of studies examined carers and young people's experiences of early intervention services. It highlighted the central importance of a personal relationship with EI staff, informed by a person-centred approach that was genuine, caring, equitable and flexible

(Loughlin et al., 2020). Results indicated that these positive relationships also formed the basis for progress during recovery, including the level of agency experienced by participants, providing a positive framework for future relationships and facilitating a more positive identity through acceptance and self-compassion. The priority of participants to live a normal life was also identified and was seen as more important than more measurable goals, such as symptom reduction.

## Conclusions and research question

Despite evidence that points to the potentially critical role of early intervention in improving the experience and outcomes for people diagnosed with BD, knowledge in this area remains scarce. Quantitative work highlights a window of opportunity during the first year following first episode mania to intervene and reduce the risk of relapse. Meanwhile, study one of this thesis points to the priority of preventing successive episodes before extreme changes erode well periods and create ongoing suffering.

However, it is not yet known how young people diagnosed with BD experience first episode psychotic mania or how they perceive their treatment journey within existing EI psychosis services. Phenomenological literature on first episode psychosis points to the emotional intensity of this experience, along with the challenges of hospitalisation, that together alter a person's sense of normalcy, connection with reality and identity. The key construct identified is the quality of relationships with EI staff and the value of person-centred and long-term relationships in facilitating understanding, acceptance and the recovery of normalcy and identity. Yet qualitative literature on first episode psychosis and EI services focuses predominantly on people with schizophrenia, reflecting the predominance of this diagnostic group.

The main aim of this study, therefore, is to capture idiographic insights into young people's experience of psychotic mania and their subsequent involvement in EI services. The study aims to answer the following research question:

**How do young people diagnosed with bipolar disorder experience first episode psychotic mania and the support and treatment offered by NHS early intervention psychosis services?**

While the focus of previous studies on EI for first episode psychosis has often concerned matters of engagement or aspects of the recovery process, this study will use IPA to elucidate the personal meaning of this journey for participants with a view to shedding light on the fundamental experience of change and how this is managed within NHS EI services.

## Method

### Early intervention services for psychosis: study setting

The study was developed at EI psychosis services hosted by East London Foundation Trust where 10-15% of service caseloads met the criteria of BD diagnosis following first episode psychotic mania, equating to around 20 people at each service. To achieve recruitment targets, the study was implemented at two services and initial contact with service leads was facilitated by the clinical supervisor.

The EI services provided treatment and support to people aged 18-65 experiencing or recovering from a first episode of psychosis for a period of up to three years. They were multidisciplinary services, with a strong ethos of hope and an emphasis on promoting recovery through evidence-based interventions. Professionals within the teams included occupational therapists, nurses, doctors, social workers, psychologists and support workers. Services aimed to commence treatment within two weeks of referral, in accordance with the EI access and waiting time standard (NICE,2016). Service users were referred to the service from GPs in the community or from hospital. They were allocated a care coordinator from a nursing or social work background who supported them to achieve individual recovery goals and with a range of health and social care needs. Continuity of care and clinical responsibility was provided via the care coordinator and the consultant psychiatrist from first contact to service discharge. Care coordinators also worked with ward staff and were involved with inpatient care.

Service provision was delivered in accordance with National Institute for Health and Care (NICE) guidelines for schizophrenia and psychosis in adults (NICE, 2014) and was not tailored to people with BD. All service-users were offered anti-psychotic medication and ongoing psychiatric input, CBT for psychosis and Behavioural Family Intervention. Service users were

also offered other individual or group psychological interventions, depending on their need and preference. Employment and education support was provided along with physical health checks and psychosocial recovery groups. Support and information were also extended to family members.

### Study design

Like study one, IPA was used to explore the meaning of experiences for participants (Smith, 2009). A cross-sectional approach was employed that aimed to interview participants on one occasion within the first two years of entering the service. Unlike study one, participants were only interviewed when stable.

### Participants

11 participants (8 men, 3 women) aged 21-35 (average age 26 years) were recruited and interviewed. Ten were interviewed within 18-24 months of being in the service following first episode psychotic mania and one was interviewed within 3 months of entering the service (See Table 6 Below).

*Table 6. Table of participants for study two*

<b>No.</b>	<b>Name</b> Pseudonym	<b>Gender</b>	<b>Age</b>	<b>Diagnosis</b>	<b>Stage in service</b>
1	Edward	Male	22	BAD F312	Close discharge
2	Alex	Male	27	BAD F312	Close discharge
3	Jane	Female	25	BAD F312	Close discharge
4	Dave	Male	26	BAD F312	Still in service
5	Karen	Female	32	BAD F312	Still in service

6	Steve	Male	30	BAD F312	Still in service
7	Jenna	Female	24	BAD F312	Still in service
8	Joel	Male	26	BAD F312	Still in service
9	Craig	Male	35	BAD F312	Close discharge
10	Eric	Male	21	BAD F312	Still in service
11	Liam	Male	24	BAD F312	Still in service

*\*BAD F312 = Bipolar Affective Disorder, current episode manic severe with psychotic features*

All participants had received a diagnosis of bipolar disorder, signified by a first episode of mania with psychotic features, either on entering the EI psychosis service or shortly before. All participants were hospitalised for a period ranging from between one and four months prior to entering the EI service. Ten were sectioned involuntarily during their first episode of psychotic mania, and one was sectioned voluntarily following a suicide attempt during depression. First contact with the EI service generally occurred shortly before discharge from hospital during visits from their care coordinator. Most participants had struggled with low mood or depression after their first episode, the duration of which varied from a few weeks to several months. A table providing details of each participant's hospitalisation, depression following first episode, interventions at the EI service and relapse is provided in appendix 3A.

### Recruitment

The recruitment strategy was mostly the same as study one (see Chapter 4, p. 59-60), the only difference being that a mood assessment was not required. Participants were recruited purposively through consultation with their clinical team at the service. While potential participants were usually asked by their care coordinator whether they were interested in participating, some were approached by their psychologist or psychiatrist. As participants would

only be interviewed once during stability, there was no requirement to assess their capacity to consent or to maintain contact for extended periods during the study.

### Participant and researcher safety

The same procedures as study one were used to ensure participant wellbeing during the interview and in the event of disclosure of risk (see Chapter 4, p. 60-61). Interviews were conducted in a private room at the service where clinical support was available should any difficulties arise.

### Ethics

During autumn 2017, I made the necessary amendments to the study protocol and submitted a substantial amendment on the IRAS system. The application was submitted in December 2017 to Camden & Kings Cross REC and approval was given in January 2018 (see Appendix 3B). A research passport was subsequently sought for East London NHS Trust and was granted in April 2018 (See Appendix 3C). HRA approval was granted in April 2018 (see Appendix 3D).

### The interview

Like Study One, an IPA semi-structured interview format was employed (See Chapter 4, p. 63-66). The interview schedule was orientated around key topic areas, including the experience of first episode psychotic mania and the EI service and is presented below.

### *Figure 10. Study two interview schedule*

- 1) Can you describe how you felt during your first manic episode?  
*Prompts: How did it feel? What images best describe it? What words would you use to describe it? What associations does it have for you?*
- 2) Can you describe any particular ideas or activities that preoccupied you during the episode?  
*Prompts: Anything unusual? Anything difficult? What images would you use to describe it?*
- 3) How did you feel?  
*Prompts: About X (hallucinations or delusions mentioned)? How did this make you feel about yourself? How did you feel about the world at that time?*
- 4) How did you feel about other people during this time?  
*Prompts: People close to you? People you know less well? How did you think they saw you? Is this normal for you?*
- 5) Once you came down from mania, can you describe to me how you felt?

*Prompts: How did you feel? What word would you use to describe it? What image? What association does it have for you?*

6) How did you feel about yourself at that time? *What word would you use to describe it? Prompts: What image would best describe it? How did you feel people saw you?*

7) Can you describe how you felt when you started seeing people from the early intervention service?

*How was your mood at that time? What word would you use to describe it? What interventions have helped you to manage to this point? How do you feel about the service now? How could the service have better met your needs? What do you want from it now*

8) How did you feel about the service at that point?

*Like it? Resent it? In what way did you feel that you needed it? What mattered to you then? How did it help you to cope?*

9) How do you feel you have managed within the service since that time?

*How have you coped with your moods? How has the service supported you since that time? What has mattered about the help they have offered?*

10) How do you feel about yourself at the moment?

*Prompts: Is there a word that describes it? An image? How has this changed during your time at the service?*

11) Can you describe how you see your future?

*Prompts: What word would you use to describe it? How has this changed?*

### Interview procedure

The same interview procedure as Study One was adopted (see Chapter 4). No participant asked to terminate the interview before the end or expressed any desire to hurt themselves or other people. I continued to use my reflexive diary to express my feelings in relation to the participants so that it did not negatively affect the interview. The main challenge during the interview process was to recognise and manage my own feelings around the participants' progress. My diary entries helped me to reflect on my desire that the participants would progress and benefit from their time in the EI service and avoid relapse. Recognising this helped me to manage these feelings and avoid expressing them during interviews where it was important that participants could talk candidly and without any sense of pressure to make progress or feel better. Each interview lasted between 52 and 88 minutes.

## Transcription

The process of transcription used in Study 1 was adopted (see Chapter 4, p.69).

## Analysis

A cross-sectional IPA analysis of the 11 participants was conducted.

### *Analysis of each case*

The first step was to conduct an analysis of each participant's interview following the same analytic steps illustrated in Chapter 4 (See p.70-78). This process resulted in a table of superordinate themes for each case.

### *Cross-case analysis*

The next task was to examine the themes for patterns across cases. This process involved clustering the superordinate themes and their constituent themes from all the participants into master themes that represented the group.

To help identify connections, all superordinate themes and their underlying themes were cut up into strips of paper and laid on the floor. Colour coding linked the themes to participants which enabled me to move the strips around and gain a visual representation of the patterns of relationships. First, the prominent relationships between superordinate themes were considered and grouped into key domains. The emerging structure of superordinate themes was then examined in relation to the underlying themes. Afterwards, the underlying themes were also cut up and moved around. As new relationships became apparent, some themes were kept with their original superordinate themes, while others were moved to alternative groupings that better expressed their significance. Some themes were also clustered together to form new higher order themes. As with the longitudinal analysis, crystallising the different types of connections between themes and higher order themes required a close examination of underlying themes, quotes and transcripts.

Although most themes were integrated into the evolving structure, a small number did not contribute to the developing analysis and were set aside. By periodically checking their significance, however, some were reincorporated and by the end only a small number were

omitted. Once clustered themes were formulated that captured the texture and significance of the participants' data and contributed to a coherent story, they became master themes. As with the longitudinal analysis, theme names were chosen that best encompassed the underlying themes, resulting in a master table of themes for the group (See Table 7 below). A full version of the master table of themes with exemplar quotes is included in Appendix 3E.

A core consideration during cross-case analysis is the degree of representativeness of participants for each theme. According to IPA quality criteria (Smith, 2011a), for samples of between 4-8 participants, a minimum of three participants for each theme is adequate, while for larger samples, extracts from either half of participants or from three or more participants, with measures of prevalence should be presented. The four higher order themes represented all 11 participants. In all themes, except for the last, 'Pressure, change and proving self', a minimum of six of participants were included. When developing master themes, the significance of a theme can be related to its pertinence and particular insight rather than its prevalence. As the last theme provided compelling insight into manic relapse for three of the participants, it was included.

*Table 7. Master table of themes for the group*

<b>First episode psychotic mania: control, persecution and imprisonment</b>
Conjuring powerful and persecuted selves
Imprisoned, restricted and depersonalised
<b>Struggling with loss of self during aftermath</b>
<b>Rebuilding within early intervention service</b>
Piecing together the past
Reassessing subjective view
Feeling empowered
Seeing a future
Having a safety net
<b>Managing wellness and relapse</b>
Balancing self-renewal and staying well
Coping with compromise
Pressure, change and proving self

## Chapter 8 – Study Two Results: Part A

### Changing sense of power and persecution instils loss of self

This study examined the experience of first episode psychotic mania and early intervention for young people diagnosed with BD. In this chapter, the first two themes of the results are presented, illustrating the participants' experience of first episode psychotic mania and hospitalisation, along with their struggle with depressive feelings and loss.

Two themes will be explored. The first captures the participants' experiences during their episode and the way in which it altered their sense of control over others and the world. Some participants believed they had been transformed into supernatural beings possessing absolute control, while others described being under attack and crippled by persecutory forces. Between these opposing extremes, there were participants who exploded into angry retaliation. Extreme changes in the participants' sense of control were compounded by their experience of involuntary hospitalisation, which involved restrictive conditions and practices that led to feelings of humiliation and challenges to personhood. The sense of loss and confusion expressed by participants after their episode is explored in theme two which elucidates the enduring impact of first episode on their sense of self.

#### Theme 1: Control, persecution and imprisonment

##### 1.1 Conjuring powerful and persecuted states of self

For some participants, psychotic mania conjured up a magical self, emanating mystical qualities and powers. Though each participant experienced different personas and potencies, they were all imbued with the ability to take control of the world around them. When we hear Eric's experience of psychotic mania, we realise that the power he covets requires a particular form of transformation:

The sun was a recognition of this kind of divine, or, or ordainment or whatever and I remember, I would walk in and literally like, I would spread my arms sometimes and I would feel like thank you literally thank, um, this supposed

god that was being represented by the sun, for everything that I was being given cos, again it felt like a gift, felt amazing having all these thoughts [...] perceive myself not just an object of desire, but as someone who should be turning himself into an object of desire because that inherently would mean that you have control over other people.

Eric sees his elevation to god-like status as a ‘kind of divine’ ‘ordination’ that sets him apart. His consecration is no earthly procedure, but a metaphysical transformation triggered by the burning heat and light of an ultimate deity ‘represented by the sun’. As he ‘spreads out his arms’, Eric embraces the possibility for change and the influx of ‘amazing’ thoughts, which he sees as a ‘gift’ and is thankful for. Notice how Eric’s transformation appears to be both cerebral, involving his ‘thoughts’, and physical, as he exposes his body to change. As the passage unfolds, we realise that what matters to Eric is that he becomes an ‘object of desire’. In Eric’s eyes, this means not only becoming the ‘object’ of his own ‘desire’ but also ‘turning himself’ into the ‘object’ of other people’s. Through this process, he feels able to ‘inherently’ control other people by arousing their desire for him but, by implication, refusing to give himself to them. As such, we begin to appreciate the degree to which Eric’s experience of psychotic mania reflects his own transformation, driven by the need to control his world.

Similarly, Craig was elevated to a position where he possessed world control, that he defined as an:

Epitome... Cos it was the highest point of being alive [...] in control felt really like, um, not nothing is real, but seeing past the whole, the, like the police and all these sort of things, I was looking beyond that, I was thinking more like, from a soul perspective, that there's nothing that can harm you.

Craig experiences an all-powerful state that he sees as ‘the highest point of being alive’ and is encapsulated by the word ‘epitome’. While Eric felt sexual and intellectual potency, Craig realises a superior perspective where he can ‘see past’ the ‘real’ appearance of ‘things’ and into the inner ‘soul’ of things. His newfound ‘soul perspective’ brings him closer to the essence of the world around him and makes him indestructible. Notice the shift in the passage from feeling ‘in control’ to ‘there’s nothing can harm you’ that reveals the fragility at the heart of Craig’s

experience. By becoming an ‘epitome’, Craig crystallises a superior form of understanding and perception, but also finds protection from others and the world around him.

While Craig and Eric were elevated to abstract metaphysical states, Jenna’s supernatural persona was more familiar:

I was some sort of a, witch, or a good witch or whatever was going through my head [...] I was imagining that I'm some sort of person with special powers. Um, and I thought that everybody, I don't know how to say it in English, umm, you know, like wizard [...] So, I was pretty much in my head, err, just doing a spell for everything I was seeing around me.

Compared to Eric and Craig, Jenna’s change to ‘some sort of witch’ is expressed in more grounded terms. She is quick to stress that her persona arose internally, as something she ‘imagined’ or ‘going through her head’, rather than part of her experienced reality. Unlike the others, there is little suggestion that her witch-like powers reflect her own transformation but are merely a consequence of her imagination. Nonetheless, she is also engaged in conferring change upon the world around her and describes ‘doing a spell for everything I was seeing around me’.

At the other extreme, some participants described psychotic mania as being under attack, either by other people or metaphysical forces, and being crippled by fear. While Eric, Craig and Jenna were empowered by their transformation, these participants were rendered helpless by threat, fear and a loss of power. Take Liam, who describes his experience of relentless persecution:

There was like this terrifying face painted on my TV, that was like watching me and I wasn't sleeping at all. I thought I was in a television show, I thought I was in like a video game. I thought that, umm, like the, the, president of something like of America was trying to like kill me, kill my family [...] I was pretty paranoid, just feeling like things were out to get me, terrified, and I just couldn't escape. So, I don't know, um, a picture, I guess my own personal hell that I was just not in control of at all.

When he enters a world where he is being constantly watched and hunted, Liam is in a high state of alert. At one moment, he is being watched by a ‘terrifying face’ on his TV that appears fixed,

as if ‘painted’, and that prevents him from ‘sleeping at all’. At others, he is trapped within a ‘video game’ or ‘television show’ and the ‘president of America is trying to like kill me, kill my family’. We realise that Liam is living a relentless stream of scenarios where he feels that he is constantly under threat. Notice how the crux of his entrapment arises from his feelings of fear and paranoia. While the source of threat changes from powerful presidents to supernatural forces, what stays constant is his belief that ‘things were out to get me’ and the feeling of being ‘terrified’. Indeed, his phrase ‘my own personal hell’ seems to take on dual meaning: not only is he trapped by hallucinations that he cannot control, but he is paralysed by his own fear and inability to change them.

Steve also found himself in his own personal hell:

My neighbours are peering through, through the windows and they're laughing at me with like, demonic faces. And it's like, and I'm walking through, like this my own version of hell [...] If I stood still under an open sky, they wouldn't be able to see me, like, if I stop, if I stopped with my cloak and I hunched down then they wouldn't be able to catch me [...] So, I mean, after I lived, I lived that and survived that, I have no fear because I've lived all my worst nightmares I'm fearless.

Like Liam, Steve sees his psychotic mania as being devised to evoke all of his ‘worst nightmares’. Although certain aspects of his ‘demonic’ hallucinations appear generic, they take on a highly personal quality because it is his ‘neighbours’ who are ‘peering’ and ‘laughing’ at him. As the passage unfolds, we realise that, like Liam, Steve is persistently hunted, forced to use his ‘cloak’ so ‘they wouldn’t be able to catch me’. In contrast to Liam, however, Steve retains some measure of agency. Although he is unable to stop the threat he faces, he is not incapacitated and finds himself ‘walking through’ his nightmares and hiding from the danger of an ‘open sky’. A similar self-possession is expressed when Liam considers how he has changed after his episode: through ‘all his worst nightmares’ he has ‘survived’ and is now ‘fearless’.

While some participants’ experience of persecution was the stuff of nightmares, for others it arose in more familiar contexts. Dave described similar feelings of fear, but arising from his work environment:

People were coughing at me at work and stuff like that. So, there were like, sorts of audio triggers, like I felt that people were talking [...] everybody's after you, don't know who you can trust. You think that almost everybody's in on it... just so intense, fearing they'll come down on you.

Dave feels attacked by people 'coughing at me' or 'talking' at work, incidents that confirm that 'everybody's after you' and that, 'you don't know who you can trust'. Dave's perception of work colleagues represents the threat of an overwhelming other that 'everybody's in on' and that he fears will 'come down on' him. Notice his choice of words - 'come down on you' - suggesting that others will crush him, both physically and mentally, and perhaps even destroy him altogether. As the passage unfolds, we begin to appreciate the precariousness of his relationship with others, who he feels he cannot trust and who, at any moment, might destroy him. Like Liam and Steve, Dave is trapped by his fear that is manifest in his delusions and yet remains a crippling part of his lived reality.

The persecution experienced by participants during psychotic mania sometimes shifted from being attacked to being destroyed. Liam's sense of foreboding merged with his own death:

I thought I was going to die. I thought I had died, um, I had an experience when I was in my garden, and then I thought I was like, I thought I was in Skegness and I thought that I couldn't leave the house because we're all, that we're all dead and that we couldn't leave.

As Liam shifts from believing 'I was going to die' to 'I thought I had died', he struggles to articulate any temporal difference between life and death. As far as he's concerned, the primary consequence of his death, and that of other people, is that it has prolonged his entrapment and renders him unable 'to leave the house' because 'we're all dead' and 'we couldn't leave'. In this we begin to appreciate, Liam's sense of fearful entrapment, from which he cannot be released, not even in death.

While some participants were under attack during psychotic mania, others described a sense of anger that was so overwhelming that they went on the offensive.

When Karen shifts into psychotic mania, she experiences an explosion of fury:

My anger, it just felt like ‘the scream’ [a painting], you know a furious scream at like everyone... it's like not being understood, it's like I was in a different world from the other people [...] started smashing up plates, like throwing, throwing them out, out, of the window, err [...] my mum came over from Malaysia, all that way and, and I was even angry seeing her [...] I, umm, grabbed her hair and I told my mum just to leave [...] It was a feeling of being betrayed, but not sure by whom?

Karen feels an overwhelming anger that is best reflected by the howling sense of despair captured by Edvard Munch's famous painting ‘The Scream’. This comparison suggests a dramatic outpouring of inner fury that is not directed at one event or person, but ‘at like everyone’ who makes her feel misunderstood and excluded. Like the figure in the painting, however, Karen's scream of anger is also a hollow expression of desperation and despair. When she describes her experience of being ‘misunderstood’ and ‘in a different world from the other people’, it seems that she is not only referring to her episode, but the wider world where she has a ‘feeling of being betrayed’.

Karen's fury is also directed at objects and she is ‘smashing plates’ and ‘throwing them out of the window’. We sense that she is angry at the entire fabric of her world that she feels has let her down. Karen has reached the point where not even her mother, who visits from Malaysia, can redeem herself and so she ‘grabs her hair’ telling her to leave. However, Karen is at a loss to make sense of these feelings of betrayal that have no clear source, -‘not sure by whom?’- but have nonetheless put her at war with the world. It may be that this inability to make sense of her feelings fuels her fury and leaves her helpless, as if possessed by its relentless power.

While all participants transformed into supernatural, persecuted or attacking states of being, their experience of opposing states was not necessarily stable. Take Joel, who at one moment was God's chosen spiritual missionary and the next was possessed by the Devil. As he attempted to express the nature of change, he drew on the following analogy:

When I feel like I am powerful and happy somehow, I feel extreme happiness, there were periods of extreme happiness, it's as if my mind is a big house, very organised, beautiful garden, books on shelves, very organised, and there's a

host inside there that is very happy, very extroverted. But this house has a secret. It's got a chamber, it's got a basement, and inside this basement, there's a very, very dark person, beast, it's a beast, the beast comes out, and when the beast comes out, it's unexpected, it doesn't announce that it's coming out, it just pops out. It closes the windows, closes the doors. It rips all the books apart and it kills the host. The host disappears absolutely, and this house is being ravaged by this beast. The beast is angry it's sad, it's depressed, it's anxious. It doesn't allow happiness to come out. It rips me apart completely.

Joel's 'periods of extreme happiness' during his episode are pervaded by a sense of beauty and harmony. He compares this state of being to living in 'a big house' which he describes as 'very organised, beautiful garden, books on shelves, very organised'. Notice his repetition of the word 'organised' that expresses the sense of order he feels, an idyllic perfection epitomised by the 'beautiful garden'. As he continues, he explains that the house 'has a host inside' who feels 'very extroverted' and 'happy', but is blissfully unaware that the house has a 'dark, dark' 'secret' below.

While 'the host' and his 'happiness' is above ground, on the underside, 'it has a basement' with 'a very, very dark person, beast, it's a beast'. Joel illustrates an opposing state of being – 'a beast' – who comes unannounced and 'just pops' out without warning. His choice of the words 'chamber' and 'basement' not only reflects the dormant nature of this being, but also its debased morality. As his words slip from 'person' to 'beast', we see the full meaning of this hidden being who, in Joel's eyes, manifests a violent satanic power.

Joel expresses the terror of being both entrapped and ravaged by this dark persona: all 'windows' and 'doors' close and all the order and knowledge of his joyful state of being is annihilated: 'it rips all the books apart and it kills the host'. We begin to realise that not only does Joel experience extreme fury but he also suffers the loss of 'happiness' and the world it creates: 'the house is being ravaged by this beast'. Towards the end, Joel's words intimate a sense of empathy with this violent 'beast' who he recognises is 'angry, sad' 'depressed and 'anxious', but nonetheless 'rips' him 'apart completely'.

## 1.2. Imprisoned, restricted and depersonalised

During psychotic mania, 10 of the 11 participants were sectioned for between one and six months. Seven of those participants described feeling imprisoned, with no control, eliciting feelings of diminishment and fear. This was compounded by the restrictive practices they experienced during interactions with the police and in hospital, which included physical restraint, enforced medication and removal of possessions. Together, these created challenges to agency and personhood.

As Dave was put under section, he described a rising sense of fear and anxiety over when, or if, he would be released:

I just felt like it's a bit like, um, I'm in prison, but it's a bit, I was scared of, I thought that once they section me, I was thinking that they're not gonna let me out [...] you're stuck essentially, you are still stuck [...] your freedom's gone basically um, you're being told like what to do in terms of medication and everything.

Although Dave knows that his hospitalisation is part of a medicalised procedure, he admits that it feels like 'I'm in prison'. From his perspective, he has relinquished control over 'everything' in terms of what he can do or the 'medication' and his 'freedom's gone basically'. The use of 'basically' suggests that his loss of liberty undermines his personhood at a fundamental level. This gives rise to fears that 'once they section me' they are 'not gonna let me out'. Not only do his words express his mistrust in the system, but his lack of agency within it. His repetition of the word 'stuck' stresses that being sectioned has left him glued to the spot, without agency, unable to do anything.

Like Dave, Karen was trapped in an environment where she had no control:

People around me were all a bit weird. You know, or, sick people, it is like, err, 'One fly over Cuckoo's Nest' - you know, you, once you're there, you have to demonstrate you're not mad and all that, and it's just, you know, it's horrible. It's the sane person's worst nightmare, is like that.

Karen describes the horror of being surrounded by ‘sick people’ which she compares to being in the film, ‘One Flew Over The Cuckoo’s Nest’, set in a psychiatric institution. In her eyes, being ‘around’ people in this context renders her immediately insane. Whereas Dave was hamstrung by a loss of control over what he does, Karen has lost control of how she is perceived and is imprisoned by a label. This is her ‘worst nightmare’, a place where her personhood is contingent on the decisions of others who have control over her sectioning and whether she is seen as ‘sane’. What she finds ‘horrible’ is that she must ‘demonstrate’ to others that ‘she’s not mad’ as it is the only way she can secure release and recover who she is.

Participants also described the debilitating impact of restrictive practices on agency and self-respect. Although the use of physical restraint was generally short-lived, even momentary, it created an enduring negative impact. Alex, who was taken by police to the secure ward, felt criminalised and demeaned:

About five or six of them [police officers], super aggressive, pulled me to the ground, tried to turn like my face forward you know, like, you know, like I’m a piece of nothing... okay, what is, what is the reason for this kind of attitude? And they did that twice and then they just scurried out the room.

Alex vividly expresses the humiliation of being forced ‘to the ground’ by ‘five or six’ police officers in a way that was ‘super aggressive’ and made him feel ‘like a piece of nothing’. The simile not only evokes feelings of worthlessness at being ‘nothing’, but also a sense of being objectified as one ‘piece’. The indication that this was done ‘twice’ to him, and without explanation or discussion, only reinforces the sense that his body no longer belongs to him. While the physical violation is demeaning, it is also the sense of disgust as they ‘turn’ his ‘face forward’ and refuse to look him in the eye. As the passage unfolds, we realise that it is the ‘attitude’ underlying the use of restraint that leaves Alex feeling not only physically dispossessed, but reduced by inexplicable contempt; ‘what is the reason for this kind of attitude?’

Similarly, Edward stressed the shock of physical restraint:

Restraining very physically, umm, I mean, painfully and that's something I've never really experienced before. I mean, I don't even remember very much of it

because I was put under a lot of sedatives, umm, you know, the experience of when they like hold you down and sometimes they put like a depo or injection or something that, that was (pause) like a...a very humbling like.

Edward cannot 'remember very much' of his experience of being restrained when sectioned, though he can recall that it was 'physically' and 'painfully' 'very humbling'. Compared to Alex, Edward expresses little sense of injustice, but expresses a similar sense of humiliation from being held down and having them 'put like a depo or something'. This is something that he had 'never experienced', or thought possible for someone like him, and it feels like an affront to self-respect. His struggle to articulate enforced medication, 'put like a depo', suggests the emotional difficulty of reflecting on this event. Like Alex, he admits that the physical restraint, though momentary, has left him diminished and has stayed with him long after discharge.

Another aspect of sectioning, described by Edward and other participants, was the removal of personal belongings:

Straight away you're, you're just stripped of all your like, umm, like your phone your, err, like, all your independence and just, umm, I wouldn't say dumped onto a ward, but just left, left alone with, umm, yeah, no, no independence, umm, yeah, (sigh).

Edward is horrified as he feels 'stripped' of his possessions and 'left alone'. His use of the word 'stripped' suggests that the removal of belongings is painful and depersonalising. Like Alex, Edward is shocked by the suddenness, the way it is imposed 'straight away' and seemingly without explanation. His use of the negative in the phrase 'I wouldn't say dumped' is telling as he struggles to admit his feeling of being discarded. Like physical restraint, the loss of personal belongings erodes his sense of personhood and leaves him feeling objectified and unworthy. Without belongings, 'like your phone', he has lost the practical possibility of contacting others, resulting in isolation; 'just left alone, with, umm, yeah, no, no independence'.

Jane offered vivid insight into the significant impact of containment and treatment on what she felt able to be:

There was a point where I felt like I was being treated like a, treated like a caged animal at some point, so I actually felt um, like I was as worthy or unworthy as a dog, so much so that I kind of ate my food on my hands and knees.

Being ‘treated like a caged animal’ is an experience that makes Jane feel ‘unworthy as a dog’ and compelled to eat food on her ‘hands and knees’. Like the others, her confinement undermines her sense personhood, leaving her feeling degraded and depersonalised, as if she is a ‘dog’. Not only does this make her feel ‘unworthy’ but it shapes her behaviour and dictates the way she interacts. Jane’s experience not only questions her right to be treated as a person, but also robs her of her identity as a human being and replaces it with something sub-human.

## **Theme 2: Struggling with loss of self during aftermath**

In the aftermath of first episode, participants experienced a loss of self that left them feeling diminished and inadequate as well as hindering their ability to move forward. While some mourned the loss of their superior manic self, others struggled to regain who they were, or what their sense of normal should be. The participants saw themselves as diminished and inadequate during this period and tried, with varied levels of success, to get back to who they felt they should be.

As Eric reflected on how he felt during the aftermath of his episode, he expressed the sadness he felt at being a shadow of his former manic self:

I just felt sapped (laughs). I felt like, I literally felt like someone had come in and just cut off a part of my body and taken it and said - 'No, this isn't you anymore!' [...] I was kind of grieving that version of myself that had just disappeared [...] I was angry at myself, you know, I tried bargaining with, or trying to trick my way through, hoping that it would come back by just drinking some alcohol, um, and I think I just went through those, but mostly it was just anger and a lot of sadness.

Eric’s initial declaration that he felt ‘sapped’ suggests a sense of being drained after the high energy of mania. As he elaborates, however, we see that this deterioration also

reflects an assault on his sense of self that is best expressed as a physical violation; ‘someone had come in and just cut off a part of my body and taken it’. Notice his use of metaphor to express his feelings of victimisation at the hands of a vicious other who has ‘come in’, ‘cut off’ part of himself and dictated who he cannot be; ‘No, this isn’t you anymore!’. In this description, Eric evokes the painful violation of his selfhood, that is suddenly and ruthlessly removed, without any consideration for his wishes. For Eric, this violation of his selfhood manifests bodily, revealing the pivotal position of mania in his self-concept.

As the passage unfolds, we realise that he is ‘grieving that version’ of himself, something made all the harder by having it inexplicably ‘just disappear’. Lacking any identifiable cause, the only person he can blame is himself and so he is ‘angry at myself’ for letting it go. Nonetheless, in Eric’s eyes, mania can be re-awakened and he tries ‘using alcohol’, ‘bargaining’ or ‘tricking my way through’ in a desperate attempt to resurrect it.

Like Eric, Karen felt that she was no longer the person she wanted to be:

I burnt everything I have, as a candle, like, that calm (laughs) and it's -whooff - and it's gone [...] It's like the pure self [...] so, like you've suddenly figured out you've got an evil twin, my chaotic twin and highly functioning brain for not doing anything good (laughs), and this is the me, like the, the more calm, the boring other person (laughs), because that other one is amazing.

Karen’s experience of mania brings into focus the ‘boring other person’ she now sees herself to be. Like Eric, she is spent, ‘whooff’, and in the cold light of ‘calm’ feels debilitated as she recalls her ‘amazing’ other self that has vanished. While Eric felt violated by the loss of his better self, Karen’s experience is not clear cut. She admires her ‘amazing’ manic self, but also sees her as an ‘evil twin’ that is ‘chaotic’ and ‘not doing anything good’. In contrast to Eric, Karen feels that her mania has ‘burnt everything I have’. Though captivating, she has had an enduring destructive impact on her world. For this reason, Karen cannot see herself in purely manic terms, but rather as two selves, ‘the boring’ and the ‘amazing’. While her episode has laid bare a ‘boring’ self that she struggles to accept, she recognises that ‘this is the me’ she must live with.

Some participants felt intense confusion over who they now were and struggled to find continuity between past and present selves. Although Jenna felt relatively well in the aftermath of her episode, she was distressed by her loss of normalcy:

I couldn't understand what's real and what's not. Where is me? Am I the real me now? The one which is quiet, the one more calm? Or is it me the chatty, bubbly person that I was? [before episode]. It was really hard because I was telling Jack [care coordinator] all the time or saying - 'I want my self back, I've lost myself and I'm not the same, no, no matter how much I try, it just doesn't come, it just doesn't feel the same' - So, you just keep yourself to yourself, but you feel so awkwardly horrible about it cause you feel, 'No, no, that's not me. It's not me.'

As Jenna reflects on the period following her episode, she admits that she cannot 'understand what's real and what's not'. Her confused questioning, 'Where is me?' suggests that, although she knows who she should be, the problem lies in how to locate herself. Her sense of reality has been undermined, instilling feelings of uncertainty over authenticity; 'Am I real me?'. Jenna is faced by two possible selves, the 'quiet' and 'calm' one she is now and the 'chatty, bubbly person' prior to her episode.

Like Eric and Karen, Jenna has 'lost' herself and finds her current state of 'quiet' insufferable. However, it is not the superiority of mania that she covets, but the sense of continuity and authenticity that she would gain from having her 'old self back'. Like Eric, she strives to resurrect her past self, but no matter how hard she tries 'it doesn't come'. Indeed, her words express a degree of resignation as she admits, 'you just keep yourself to yourself', though it feels 'awkwardly horrible'. Jenna must cope with compromise, but she can at least reject this unwanted self because she knows who she is; 'No, this is not me. It's not me!'

Like Jenna, Alex described the impact of extreme moods on his sense of normalcy and ability to move forward:

There was a period where I kind of lost the sense of what my normal self is. So, I've gone through just living in extremes, like there was the mania, then

there was the low mood, what is normal - for you - so it kind of skewed that for me.

Alex is acutely aware of the impact of extreme moods on his understanding of self. In contrast to Jenna, however, he focuses on 'what my normal self is' rather than 'where'. Whereas Jenna had a distinct notion of what she wanted her normal self to be, Alex is far less certain, as 'what is normal' became 'skewed'. His choice of the word 'skewed' suggests that 'living in extremes' meant his sense of normalcy became distorted. Indeed, what both participants share is a need for some form of normalcy of self that can provide them with the stability and continuity to progress. Notably, Alex's use of the past tense is different, indicating that he has gone some way to resolving his confusion and, perhaps more than Jenna, has established a new sense of normalcy.

Although participants struggled in their different ways with a loss of self after their episode, for the most part they recognised the potential to get it back, by triggering mania or awaiting normalcy. However, for a small number mania had left them irrevocably compromised. Steve's experience of psychotic mania forced him to start again:

It was so important to me, like being a master of myself, being a master of the mind, like being a master of the mind...and all of a sudden, I've lost my mind. I was like - 'Huh? Where did that come from? So, that's how it feels to be like knocked down, yeah, I was knocked down... yeah, yeah, I was knocked down I was broke back to earth, I was grounded [...] to lose my consciousness, because I lost it. I was in there, but I wasn't in control, was full on an unconscious experience, but I was widely awake to it.

Like Jenna and Alex, Steve's mania has created a severe challenge to his self-concept - 'all of a sudden' he has 'lost my mind'. Whereas Jenna and Alex aim for normalcy, Steve's sense of being 'knocked down' and 'broke back to earth' possesses a far more permanent ring. He evokes the sudden sense of not only falling, but going back to nothing, from where he must start anew. Steve, it seems, has undergone an irreversible transformation from being 'master of myself' prior to mania, to someone who 'lost my mind'. What appears to be the crux of this experience is that although he was 'in there' and 'widely awake' and aware of his delusions, he 'wasn't in control'

of them. From his perspective, he has lost his 'consciousness' and feels unable to resurrect his previous self. He is 'grounded' and must go back to 'earth' in order to become something new.

### Summary

In first episode psychotic mania, the participants described diametrically opposing states of being that each dramatically altered their sense of control over the world and precipitated an intensity of feelings. Some believed they had been transformed into supreme beings with absolute control, while others were the victim of attacks and persecution or turned on the offensive. Although their experiences were strikingly distinct, they expressed a similar struggle with control, trust and uncertainty. The sense of persecution that was felt by some participants during psychotic experiences also reflected, and was prolonged by, their experience of hospitalisation. Not only were participants hard hit by the loss of independence during involuntary section, but some saw it as synonymous with imprisonment and punishment. Restrictive practices and removal of belongings during sectioning were traumatic and an affront to self-respect and personhood. For all participants, episode aftermath coincided with a loss of self that, for some, contributed to low mood, anxiety and uncertainty.

### Discussion

#### Control, persecution and imprisonment

The balance of power between self and others was at the heart of the participants' experience during first episode psychotic mania, indicating the importance of interpersonal relations and identity in constituting experiences of self (Ratcliffe, 2017). While some participants were transformed into an omnipotent self that overpowered other people, others became victimised by them.

Grandiose delusions during psychotic experiences are commonly characterised by the experience of special powers, a mission or a significant identity (Picardi et al., 2018). Despite being experienced by two-thirds of people with BD, they are the most neglected psychotic aspect in research (Knowles et al., 2011). Emerging work suggests that they are meaning-making experiences that confer a sense of purpose, belonging and self-identity (Isham et al., 2021). In one study that focused on spiritual and religious experiences during mania, mystical experiences

provided elevated insights into the human condition that were seen to imbue enduring meaning to the participants' lives (Ouwehand et al., 2018).

This study extends understanding of this area by providing insight into the experience of grandiose delusions during first episode psychotic mania for people diagnosed with BD. Four participants experienced a superior persona during psychotic mania, that was endowed with elevated abilities and a higher sense of purpose. Eric felt transformed through his ordainment into a higher order, Craig held exalted insight that was above that of others, Jenna possessed supernatural power and Joel was an adorned spiritual leader. Rather than conferring belonging, their exalted state distinguished themselves from others. Theories posit that grandiose delusions may either develop to compensate for an underlying sense of isolation, lack of self-worth or powerlessness (Beck & Rector, 2005), or to prevent distressing thoughts (Neale, 1988). Other writers propose that they may play a role in protecting social self-esteem or social rank (Knowles et al., 2011). This study brings empirical support to this suggestion. Findings indicate that the possession of elevated abilities was seen by participants to confer power over other people and their perceptions and was protective.

Grandiose beliefs about the self may also be fuelled by the presence of positive emotions, along with elevated aspects of self-esteem (Smith et al., 2005). In the current study, the participants' belief in a divine or super-natural self was inseparable from the intensity of their euphoric feelings and self-expectation in relation to others. Some participants expressed feelings of distress over the contrast between a perceived failed or vulnerable self and their expectation of an accomplished self and this tension may have contributed to visions of grandiosity. For instance, Eric detested his well self who he felt was weak: 'I'm a 21, like six-foot guy but I still see myself as a 15 kid' and mania offered the chance to 'wipe out that image'. For others, such as Joel, the battle between two opposing selves was reflected in their delusions, but also held enduring meaning. As theorised in the wider literature, it may be that for some participants delusions performed a protective role (Gunn & Bortolotti, 2018). Moreover, this study suggests that they may protect against an unwanted self that is experienced during euthymic periods.

The emotional intensity and interpersonal nature of persecutory experiences during early psychosis are highlighted by several qualitative studies (e.g. Bögle & Boden, 2019; Dunkley et

al., 2015; Hirschfeld et al., 2005; Hutchins et al., 2016; Lockett et al., 2012). Some suggest that early psychosis involves entering an alternative unsafe reality characterised by persecution from others, giving rise to acute feelings of dread (Attard et al., 2017; Bögle & Boden, 2019). In one study, focusing specifically on spirituality for people with BD, fear was the dominant experience for one third of participants during mania (Ouwehand, Braam, et al., 2019). This study further highlights the significance of dread for people during first episode mania.

In some studies, the content of persecutory delusions was not distressing, while in others it was found to be traumatic (Bögle & Boden, 2019; Hutchins et al., 2016). Negative psychotic experiences have been found to be associated with difficult or traumatic life events prior to the episode and historical or contemporary experiences of abuse (Dunkley et al., 2015; Ouwehand et al., 2018; Upthegrove et al., 2015). In a study by Rhodes et al. (2018) that explored the experience of women with a history of sexual abuse and psychosis, the participants' 'voices' and paranoia were marked by a general theme of condemnation, that involved sexual abusive activities, the imperative to commit self-harm or suicide and body-self entrapment. Findings suggested that major or traumatic experiences in life, such as repeated abuse over time, can shape the meanings found in adult psychotic experience. While the historical experiences of participants were not explored in this study, some participants, such as, Karen, Eric, Craig and Steve described major acts of betrayal prior to their first episode.

Conflicting accounts suggest that persecutory delusions either defend against, or are a direct reflection of, emotional concerns (Freeman, 2007; Garety & Freeman, 2013). A recent review highlights the interplay of negative beliefs about self, vulnerability and interpersonal sensitivity, along with emotions that contribute to the escalation of persecutory beliefs (Freeman & Garety, 2014). In this study, persecutory psychotic experiences were both frightening and reflective of participants' own personal hell. Not only were they trapped by their delusions, but they were controlled by fearful feelings.

The experience of victimisation, entrapment and fear, that characterised negative psychotic experiences, was also prominent in some participants' accounts of being sectioned. Although hospitalisation was not a wholly negative experience for all, it did create challenges to agency, self-respect and personhood. Inpatient units are commonly perceived negatively by adult service

users and several studies describe hospitalisation as a prison rather than a place for therapeutic recovery (Staniszewska et al., 2019). Reports from a recent study focusing on people admitted to hospital during a manic episode are more positive (van Lankeren et al., 2020). Nevertheless, it has been suggested that adult inpatient environments may create specific challenges for young people experiencing their first episode (Fenton et al., 2014). Not only are young people unaccustomed to the challenging environment of adult units, but the loss of independence may be particularly hard to bear at their life stage.

The shock of losing freedom without choice, warning and often explanation was perceived by participants as bringing a level of disrespect and distress that was synonymous with being imprisoned and punished. This is reflected in the wider literature (Perry et al., 2007; Stewart, 2012). For some, humiliation grew from being grouped alongside service users who they perceived to be insane. Other studies suggest that inpatient social environments create an affront to young people's sense of identity, provoking the need for differentiation to maintain sense of self (Fenton et al., 2014). In one study, the threatening, unpredictable and demeaning nature of inpatient environments were seen by nurses to be detrimental to young people's recovery rather than facilitative of it (Thompson et al., 2019).

Although the participants discussed a range of difficulties during involuntary section - such as aggression from, or arguments with other service users and boredom - it was their experience of physical restraint and enforced medication that were most traumatic. The terror of physical restraint has been highlighted in recent reviews of this area and brings with it a risk of activating past vulnerabilities and trauma (Seed et al., 2016). Communication during coercive practices has been found to be pivotal in alleviating fear and distress, as has the potential for persuasion and positive staff-client relationships to reduce coercive measures (Staniszewska et al., 2019). In the current study, while these experiences created emotional distress at the time, they also seemed to have an enduring impact on the participants' sense of agency and humanity.

### Struggling with loss of self during aftermath

Young adulthood is considered a key stage of identity development involving the exploration and adoption of self-defining values, goals and ideals and an important period of psychosocial development (Schwartz et al., 2013). For young people with schizophrenia, dramatic and unusual

psychotic experiences interfere with the development of coherence and meaning (Lysaker et al., 2005). Consistent with this, reviews of qualitative studies suggest that challenges to identity reflect a core aspect of early or first episode psychosis (Ben-David & Kealy, 2020; Boydell et al., 2010). While one review found that two-thirds of studies emphasised experiences of identity disruption (Ben-David & Kealy, 2020), a second highlighted the significance of ongoing identity work during early psychosis (Boydell et al., 2010). Though this work contributes valuable insight into the prominence of identity during first psychotic episode, its primary focus is on first episode schizophrenia rather than BD.

The first year following first episode mania is fragile and associated with high risk of recurrence, in particular depression (Gignac et al., 2015a). Because no work has examined the experience of first episode mania for people with BD, this study provides important insights. Strikingly, all participants struggled with a loss of self after their first episode. For some, this was accompanied by a sense of inadequacy, low feelings, or a period of depression. In reviews, identity disruption following early psychosis encompasses a loss of the person they were prior to the episode (Ben-David & Kealy, 2020). This study, however, highlights a different dynamic, extending understanding of this area. Findings reveal that the root of the participants' sense of loss varied and was intimately related to the meaning of their psychotic manic experiences. Consistent with existing studies, participants who had experienced a persecutory self during first episode struggled with the loss of who they were prior to their episode. However, for those who experienced grandiose delusions a new aspect was revealed, whereby they mourned the loss of the superior person they had become during their episode. For these participants, the sense of loss was particularly acute. Unable to accept this, they tried different ways to re-evoke it.

In the wider literature on BD, some studies suggest that later episodes of mania can instil a sense of personal loss (Cappleman et al., 2015). In one study, participants felt that the validity of their mystical manic experiences was undermined following their episode and they struggled with the despair of a losing a meaningful divine connection (Ouwehand et al., 2018). Other studies highlight compelling experiences of insight and euphoria during mania, leading to feelings of ambivalence and loss during recovery (Lobban et al., 2012; Mansell et al., 2010). Current study findings extend this body of work by emphasising experience of identity loss following first

episode BD and the importance of episode meanings in managing the relationship between mania, identity and feelings of loss.

Overall, study findings highlight the importance of understanding not only the content of first episode for people with BD, but their enduring meaning for a person's identity and wider life. The participant accounts in this study suggest that the relationship between different selves prior to, during and after first episode contributes to the risk of recurrences during this particularly fragile period.

## Chapter 9 – Study Two Results: Part B

### Rebuilding within EI service and managing wellness

The experience of first-episode psychotic mania created major disruption in the lives of all the participants, as the previous chapter demonstrated. On becoming stable, the participants entered EI services where they attempted to rebuild and recuperate. This chapter will focus on that aspect, exploring their experience of the service and their management of a new sense of normalcy when well.

Two themes will be presented that draw on the experiences of the 10 participants who had been in the service for 18-24 months. The first illustrates their path towards recovery, encompassing a range of interventions and relationships that helped them to understand what had happened, reassess their current situation and look to the future. The second then reveals the tension between the participants' sense of renewal and self-management during wellness and their feelings of compromise, shedding light on their experiences of manic relapse and the role of self and stress in driving it.

#### Theme 1: Rebuilding within early intervention service

##### 1.1 Piecing together the past

The participants entered the EI service at a time of acute confusion and vulnerability as they struggled to get to grips with what had happened to them and why. In attempting to piece together different aspects of their first episode, they experienced difficult feelings and even greater uncertainty and confusion.

Take Alex, whose episode became increasingly confusing the more he tried to make sense of it:

Just looking at the damage done and there was confusion, lots of things were missing, like documents, devices. I guess there's certain parts of the episode that I don't remember. [...] So, there's regret, some of things I said to my friends and family in that period, so trying to unpack those things almost seem

distant like, ‘Was that really me?’ [...] I had posted a lot things on Facebook, even stuff on YouTube and couldn’t even watch the stuff, I thought – what? – like I couldn’t connect with it... like what is this like? I didn’t record this! [...] So, I was trying to get a timeline and I was like - "Oh, yeah, I forgot that had happened" - So I guess too, there were memory, my memory that happened, so I was trying to make sense of all of those things, fill in the blanks.

Alex begins to piece together aspects of his past that he cannot fully recall. While he is struck by ‘the damage done’, he can only remember ‘certain parts’ and struggles to make sense of it. He identifies ‘things’ that are ‘missing’, such as ‘documents’ and ‘devices’ that otherwise could have provided evidence of the facts. He turns to his Facebook and YouTube posts hoping they will offer insight, but the content he discovers is difficult to watch and fills him with horror; ‘couldn’t even watch the stuff, I thought, what?’ Alex must clarify his past in order to orientate his present and future, but it is hard to accept. His use of the word, ‘stuff’ to refer to his posts not only expresses his disapproval, but also a rejection of their validity. Ultimately, Alex cannot recognise or ‘connect with’ the facts of his manic self on social media, so to protect himself, he moves into denial; ‘I didn’t record this!’

Other sources of information are his ‘friends and family’ but they also offer a version of himself that he does not recognise; ‘Was that really me?’. Although Alex recalls some of what he said, it feels ‘distant’, as if coming from a separate reality. He is nonetheless filled with ‘regret’ and must try ‘to unpack those things’ and, perhaps, find a way to convince others that he genuinely was not himself. At the same time, he is ‘trying to get a timeline’, a sense of narrative sequence, involving ‘filling in the blanks’, that can reconnect past and present as well as clarify his future.

The participants all stressed the importance of talking about their first episode with EI service staff who could provide the support they needed. Yet the method of discussing it varied, from drawing on the expertise and knowledge of the professionals to simply having a person listen to them. Despite Alex’s own efforts to get to grips with his first episode, many questions needed answering:

It [CBT therapist] was useful to talk about the things that have happened with someone that I had no prior relationship with, so I was able to talk about my

feelings, what went on, what possibly caused it? [...] where did it come from?  
Is it something that's always been there?

To Alex, the service offered the possibility to talk to 'someone that I had no prior relationship with' and who he saw as sufficiently neutral that he could 'talk about my feelings'. His words hint at the difficulty he has in discussing events with close others because they are bound up with a sense of shame. The EI service offers a fresh relationship where he is permitted to express his feelings and openly consider 'what went on'. Inseparable from this process are significant questions of 'what possibly caused it?' and 'where did it come from?' that require professional expertise to be resolved. Notice how his questioning of 'has it always been there?' is deeply personal and may have significant implications for how he sees himself and the attribution of responsibility.

When entering the EI service, Steve was also engaged in piecing together his episode:

By talking to [care coordinator] that's how I was able to put the pieces together, I mean, what is the significance of it all? What I went through and all that. Because I had to still be able to talk it out with a person rather than internally within my mind. Once you say something actually it becomes, it echoes differently in your mind [...] I could actually deal with the internal [...] Once I started talking to him [care coordinator], I start remembering I'll get a flash of an event, yeah and I'll just tell him about it.

Steve feels he is only able to 'put the pieces' of his episode 'together' by talking through his experiences with his care coordinator, enabling him to grasp 'the significance of it'. Like Alex, Steve needs to remember what has happened but also the implications for his sense of self and future. An essential part of this is being able to 'talk it out with a person' rather than 'internally within my mind'. Indeed, what is striking in Steve and the other accounts is the absence of someone who they can talk to about their episode. Consequently, the EI service is the only recourse Steve has and his experience 'echoes differently in your mind', helping him 'deal with the internal'. His words point to the need to vocalise his experiences and that this helps him to cope psychologically. Compared to Alex, Steve is less concerned with expertise and more with having another 'person' with whom he can talk and 'start remembering'. This is not a systematic

intervention, but a consequence of ‘talking’ that is unpredictable and sudden; ‘I’ll get a flash of an event, yeah and I’ll just tell him about it’.

Unlike the others, Edward initially saw no benefit in talking:

At first, I thought, ah, not that it [CBT therapy] was a waste of time but, it’s an extra, maybe unnecessary, couple of hours each week, um, you know, I didn't feel I was benefiting a great deal from it, but, um, yeah, looking back, I think it, it, did play a part, it helped in, umm, getting me back on my feet, um, and, you know, the ,um, like the thought process of analysing what had happened that summer and, you know, what steps can we take to stop it from happening again

Edward saw talking as ‘unnecessary’ for his recovery. His use of the negative, ‘not that it was a waste of time’, reveals his frustration at having to participate in therapy for a ‘couple of hours a week’ when he did not feel he ‘was benefiting’. While the others experienced immediate relief from talking it through, Edward only later appreciated the ‘part’ it played in ‘getting him back on his feet’. It is only after his treatment that he begins to recognise how the ‘process of analysing what had happened that summer’ is fundamental to being able to take control of his present and ‘stop it from happening again’.

## 1.2 Reassessing subjective view

After first episode, all participants struggled with either depression or low moods as well as anxiety and beliefs that impacted both on how they felt and their ability to stabilise and progress. While some feared positive feelings that might tip them into mania, others were debilitated by depression or anxiety that they could not escape.

Edward described being incapacitated by depression:

I wouldn't be able to even like get out of bed in the morning and get on with my normal routine and go to lectures. Yeah, knowing that I'm missing out on, like, the education that, umm, you're paying for and yeah, just feelings that will I even make it through this year, let alone the rest of my time in law school.

Edward cannot return to his 'normal routine and go to lectures', feeling unable to 'get out of bed'. His physical immobility hits him hard emotionally and he sorely regrets 'missing out' on the education he is paying for. As the passage continues, we see that Edward's escalating sense of helplessness at what he cannot do renders him hopelessly anxious. Consequently, he doubts he will 'even make it through the year, let alone the rest of' his 'time in law school'. His debilitating sense of self intensifies, crippling his present, but also his future.

Seven participants described how cognitive behavioural therapy (CBT) helped them to develop awareness of their moods and insight into how to manage them. Not only did they gain understanding of how they interpreted experiences, but also the relationship this might have with their feelings. At the same time, they learnt techniques to evaluate their subjective view or take steps to change it.

Edward began to grasp that his way of seeing himself in the world was bound up with his own interpretation:

The way I was thinking of things is always like glass half empty, rather than half full and, umm, their approach [CBT therapy] was sort of to step out of yourself and think what would someone else think, what would like, like a normal-headed person think? At the time like, I, I, like, just had feelings of like hopelessness and, umm, like I'm a failure and yeah, they, umm, definitely, I think, like, boosted my morale.

During CBT, Edward learns to 'step out of' himself and adopt what he considers to be a 'normal-headed' perspective. What helps is to recognise that his way of thinking may not be shared by others. By considering 'what would someone else think?' he can 'step out' of his perspective and compare it to an alternative and more positive standpoint. Seeing that his perspective was 'always like glass half empty, rather than half full', and learning to balance it, his morale is 'boosted'. This alleviates his sense of 'failure' and through this process he gains agency, feeling more capable as a result.

Like Edward, Dave felt that CBT had taught him to consider his own response to experiences:

The therapy's [CBT] helped me to see that they [other people] probably don't even notice, they're probably more preoccupied with what they're doing, that's in all honesty, they're not even thinking about you. But I'm understanding more now that's where my problem lies, cos I'm thinking like, what are they thinking about me? So, I'm over-thinking [...] it's only, it's only what is that you force, or what you create so it's when you think about it, that's when you're most almost feeding it.

Dave's struggle is bound up with feelings of anxiety towards other people that are overwhelming; 'What are they thinking about me?' Dave is less preoccupied than Edward with how he sees himself and more concerned with how others see him. Indeed, his first episode and its escalation manifested in acute feelings of paranoia about others. Like Edward, he feels CBT has helped identify 'where my problem lies' and recognises that by 'over-thinking' and giving 'force' to his worries, he has been 'feeding it'. Dave's scrutiny of his interpretation gives rise to alternative possibilities of seeing, where other people are 'more preoccupied with what they're doing' and are 'not even thinking about you'.

As Jenna became more conscious of her changing subjectivity through therapy, she became increasingly wary of her thoughts and feelings:

As soon as abnormal thoughts would come back or something, I would understand that something is wrong and I would no longer chance it and think I'm powerful, you know, extra powers that I have. I would probably the first thing I would do is obviously contact Jack [her care coordinator].

Jenna feels that she can no longer fully trust her thoughts or feelings which at any one moment might turn out to be 'abnormal' or 'wrong'. Like Edward and Dave, she has gained insight into the way she thinks about herself, which she critically evaluates. However, while Edward and Dave focused on negative interpretations, Jenna is wary of seeing herself as 'powerful' or having 'extra powers'. She can 'no longer chance it' and give credence to those thoughts, but must 'understand' that 'something is wrong' and raise the alarm by contacting her care coordinator. Edward and Dave evaluate their

perspectives to activate mood change, but Jenna scrutinises her interpretations to prevent it and maintain stability.

While some participants evaluated their thought patterns and feelings, others, like Craig, reflected upon the significance of their beliefs.

He [the psychologist] will be questioning me about like, how much do you believe that? [the visions are real] [...] He's still really helped me formulate my own logic around them [...] I saw it [the visions] with my own eyes which is, um, I can, I can never unsee it sort of thing [...] I still have it at 80 to 100%, it happened. In some context, it was definitely not my imagination. I might, I may have, it may have started off and then I started seeing things that weren't a part of it, but there's definitely something started.

Craig is challenged over the validity of visions he experienced during first episode; 'How much do you believe that?' The sticking point for Craig is that he saw the 'visions' with his 'own eyes' which he 'can never unsee' and therefore cannot label them as hallucinations. He still has 'it at 80 to 100%' that it happened. Questioning the credibility of his experience brings into doubt the viability of his own existence. Unlike the others, Craig is unwilling to evaluate his subjectivity, perhaps because he is more invested in the meaning of it for his sense of purpose. While the others are keen to alleviate their sense of suffering or prevent relapse, Craig has limited motivation. Notice, however, the glimmer of uncertainty in his suggestion that maybe he was 'seeing things that weren't part of it'. By being encouraged during therapy to construct 'his own logic around' his visions, Craig begins to admit the possibility of an alternative reality.

### 1.3. Being empowered

Following the destabilising and demoralising experience of first episode and hospitalisation, participants struggled with feelings of disempowerment and distrust of services. While this posed potential barriers to treatment, it also impinged on their ability to self-manage and get back on their feet. Eight participants, however, expressed the sense of empowerment that arose from their interactions with professionals and the support offered. Several felt that being involved in decisions around their treatment promoted feelings of agency and gave rise to a sense of engagement and trust in services.

Jane described her experience of the service as one where her opinion mattered:

I felt like I was in charge [...] I felt like my opinion was definitely taken into account of what I wanted... it was never, 'You have to take this medication', or you or you know, I came off the medication earlier than they suggested, and it was always what would work for you and Dr. Garesh [psychiatrist] was very, you know I felt very listened to, I was treated like a, like a person, I suppose empowering, yeah.

Jane stresses the importance of feeling she 'was in charge' of her treatment and that her 'opinion' had been 'taken into account'. In contrast to her depersonalised detainment, this approach made her feel 'like a person'. Indeed, she is quick to stress the significance of a change from having 'to take medication' to 'what would work for you'. Through being 'very listened to' and involved in medication decisions, she felt respected and considered as an individual. Her use of the word 'very' implies that not only did she feel 'listened to' but that her choices were translated into decisions; 'I came off the medication earlier than they suggested'. Although it is not clear whether her decision led to better outcomes in terms of her stability, she nonetheless sees this decision as 'empowering' and helping her regain agency.

Like Jane, Alex needed to be involved in decision-making about his treatment:

Whichever way I want to go, they're providing the support in times of I guess...of crisis, but times when things are most difficult, then you get seen more frequently, times when kind of more self-sufficient and doing well, then they'll, I don't need to see them as often. So, I think it was something that adapted to where I was and respected the choices that I wanted to make. And so I felt empowered enough to take my medications.

Having had treatment enforced, Alex welcomes an approach that 'respected his choices'. While Alex's words evoke his sense of empowerment from being involved in decision-making, his sense of agency also derives from the flexibility of treatment intensity that 'adapted to where I was'. During times of crisis, Alex is 'seen more frequently', when 'doing well' he is more 'self-sufficient'. Indeed, Alex's return to wellness is not linear and relies on the adaptability of the service to enable self-sufficiency and independence during well periods. Like Jane, he feels that

adaptability around individual choices and his changing trajectory has ‘empowered him enough to take my medications’.

While Dave felt validated by being given a choice, he also saw value in trusting the professionals:

So, I think it's open, you get the chance to express your feelings and concerns. So, it's in that, in that sense, you know I feel I have a choice, but you know you gotta do the right thing too cos it's kind of up to you in the end. But, just sometimes you just have to believe what they [the practitioners] say and just, just try and that just take it.

Dave describes his experience of treatment as ‘open’ and with the ‘chance to express your feelings and concerns’. Like Alex and Jane, by being included in treatment decisions, he is validated and acknowledged. However, Dave’s experience of collaboration is more complex than being given a choice and involves both parties doing ‘the right thing’ together. At one moment, this may amount to expressing ‘your feelings’ and having a ‘choice’; at another, it may require having to ‘believe what they [the practitioners] say’ and ‘just take it’. Although his decisions are ‘up to’ him ‘in the end’, to be make the ‘right’ choice he must sometimes defer to the team. In this, Dave illustrates a collaborative process that not only changes from one moment to the next but also involves flexibility on the part of client and practitioner.

Although the participants developed agency through equitable decision-making with practitioners, they also relied on the advocacy and information provided by staff to strengthen their position and get themselves back on their feet.

Liam illustrated the advocacy afforded by his care-coordinator in negotiating challenging social systems:

I wouldn't have been able to do things by myself like getting PIP [Personal independence payments] I had to go to an assessment centre in Kent and Susan, my care coordinator came with me. [...] It was horrible, it felt like, it felt like I was being sort of like, erm, on an assembly line and you just get points assigned to you according to like, if you tick this box or that box, it was

really quite dehumanizing, um, it made me feel very anxious [...] and I wouldn't have been able to like, talk about what I was going through without her.

Liam is clear that there were certain 'things', 'like getting PIP [personal independence payments]' that he could not have done 'by myself'. In retrospect, he is acutely aware that without his care coordinator he would not have managed such a 'dehumanizing' situation that made him 'feel very anxious'. It strikes Liam that he simply 'wouldn't have been able to, like, talk about what I was going through without her'. When put in a situation where the trauma of his episode is reduced to a matter of assigning 'points' and ticking 'this box, or that box' on an 'assembly line', Liam feels unable to explain. And yet the likelihood of being given the financial support he needs to get back on his feet is contingent on him doing just that. So we begin to see that, with the help of his care coordinator, Liam's case is heard and he is now in a stronger position.

Like Liam, Steve considered his care coordinator to be a constant source of encouragement and advocacy:

All of a sudden, I was inside, I wouldn't go out, very hermetic, yeah, so um, so he wanted to, like help out. So, he's like, err - 'get up apply for this freedom pass' - so you get like freedom transports, like free transportation, wherever you want to go to stuff like that. So, then he [care coordinator] helped me apply for a, you know, and he's like - 'Oh you can apply for like PIP'.

Steve values the practical advice and encouragement at a time when he is struggling to get going; 'I wouldn't go out, very hermetic'. His care coordinator spurs him to 'get up and apply for this freedom pass' and take advantage of 'freedom transports' to 'wherever you want to go'. Like Liam, Steve feels that the advocacy of his care coordinator has helped improve his position; 'helped me apply for like PIP'. Although both relied on their coordinators to successfully negotiate social systems, the type of advocacy differed. While Liam needed help in vocalising his case, Steve requires insider information about the support available to him, how to access it and how it might benefit his situation.

#### 1.4 Seeing a future

First episode was experienced by the participants as a major interruption in their lives that posed a significant disruption to employment, studies or career path. Although they faced distinct challenges, for all, it created acute uncertainty over their prospects for the future.

Once discharged from hospital, Liam was struck by a loss of hope:

Just felt like I'd lost all purpose, dropped out of university, so I'd lost what I was rooting for, working hard towards and I'm still a bit like, I'll never having a degree and like not feeling great about that.

By having 'dropped out of' university during his episode, Liam feels he has 'lost what I was rooting for' and no longer has 'purpose'. The effort of 'working hard towards' his degree has been wasted and he has also lost sight of the goals that motivated him and brought meaning to his present. This represents a major loss of who he is but also who he can become; 'I'll never have a degree and like not feeling great about that'. His goals are forever beyond reach, something he is 'not feeling great about'.

Seven participants stressed the importance of EI in managing a sense of the future. For the majority, this involved working towards new employment goals and finding a new purpose, but for some, it was a chance to stop moving and disregard them.

Liam felt that the EI service offered support and opportunities that were necessary to help him move beyond his sense of loss:

My employment specialist got me on to being a peer support, peer mentor worker for charity called the Advisory projects, which has been really helpful like getting out there and into the community and actually trying to like, do some sort of work [...] Not everyone has a degree, I think I can achieve what I want to achieve without a degree and I can always go back and I didn't really, I don't really, I don't really care about that anymore. [...] She [care coordinator] really pushes me to like, actually to do things whilst I'm there, like call people and write emails and stuff whereas you feel, you know, I don't want to call anyone.

Liam feels rejuvenated from being given the chance to get ‘out there in the community’ and gain ‘some experience’. Previously he felt lost, but with the help of the employment specialist at the service, he feels activated by ‘getting out there’ and making progress towards doing ‘some sort of work’. There is a sense that Liam is not only making practical progress, but proving to himself that he can ‘achieve what I want to achieve without a degree’. As a result, he reconsiders the significance of dropping out of university and no longer sees it as a major self-defining setback; ‘I can always go back’. By the end of the passage, however, we are reminded of the pivotal role of the service in pushing Liam to ‘actually do things’ and to ‘call people and write emails.’ Although Liam knows he has made progress, he admits that sometimes he does not want ‘to call anyone’ and relies on his care coordinator to drive him forward.

Like Liam, Alex described being encouraged by the service to consider his future:

Talking about what my ideas are, plans, goals [with care coordinator] [...] kind of encouragement helping me, I guess, some points, it's kind of reality check as well, which is important. Kind of encouragement, thinking about jobs and, and just I guess, being told, ‘Yeah, you can do it, you should apply for this’. [...] Getting back into some routines being, being, back in work, just trying to kind of move forward and find the direction again after kind of an interruption.

A key part of Alex’s recuperation is ‘talking’ through his ‘ideas, plans’ and ‘goals’ with his coordinator. Whereas Liam depended on professionals to motivate him, Alex needs their ‘encouragement’ balanced by a ‘reality check’. He feels incentivised by ‘being told’ ‘you can do it’, but must keep his aspirations grounded in ‘reality’. Like all the participants, Alex’s sense of the future is now shaped by his first episode, bringing a sense of uncertainty and a need for ‘reality checks’ that can help him to stay well. Nonetheless, the need to find ‘direction’ after the ‘interruption’ of first episode remains imperative and is facilitated by ‘getting back into some routines’, ‘being back at work’ and ‘trying to kind of move forward’.

While Liam and Alex valued the service in helping them progress, Karen felt she benefitted from being allowed to stand still:

He [the psychiatrist] sometimes puts my mind at rest, err, also gives me some recommendation, umm, as to how to think about things and how you should kind of try and move forward and think ahead, but also would, um, I suppose just tell me it's alright to not be moving at all (laughs). Again, it's normal, um, this happens and he has seen it in other patients and, err, you don't have to get back to, the high functioning self if you feel not ready to so, well, it's kind of a relief to, to, hear things from a professional's mouth, it's not like my mom telling me - 'it's fine, take it easy' - it feels different.

Karen's psychiatrist puts her 'mind at rest' while offering tips on 'how to think about things' to 'move forward and think ahead'. Karen's words hint at the anxiety she feels at 'not moving' ahead, leaving her without direction. However, unlike Alex and Liam, she needs reassurance and perhaps permission from her psychiatrist that 'it's alright to not be moving at all'. Karen is relieved that the pressure she feels to return to her 'high functioning self' has been assuaged. Her escalation into first episode occurred within the context of her work and, at this stage, she is not 'ready' to go back. Nonetheless, like the others, she craves some sense of normalcy and is consoled to learn from her psychiatrist that her situation is 'normal' and 'he has seen it' before. Although Karen receives similar forms of comfort from her mother, telling her, 'it's fine, take it easy,' when she hears it from 'a professional's mouth' it has a more convincing ring.

### 1.5. Having a safety net

The participants all stressed the sense of safety that came from being cared for within the EI service during their journey. Some were reassured by having access to a holistic team of experts, while others valued being closely monitored for risk of relapse.

Jane described being supported by a diverse team:

Feeling OK is down to them [the early intervention team], pivotal [...]. I feel like I've been held by a great team people, different disciplines and different ways, whether it be the doctor in terms of medication, and that kind of thing, or whether it's, you know, it's like psychology therapy weekly, or Carl [care coordinator] just literally checking in on me saying, how you doing? [...] I was

so upset I said I couldn't even go outside, he even offered to go for a bike ride with me, which is like, so sweet (laughs).

Jane attributes 'feeling OK' to being 'held by a great team of people' from 'different disciplines' and with 'different ways'. Her choice of the word 'held' expresses the sense of safety and comfort she feels in being cared for by a team of professionals, providing holistic, wrap-around care. This involves a multifaceted approach to meeting her needs, from 'medication' and 'psychology therapy' to 'literally checking in on me'. By the end of the passage, however, we realise that for Jane, being 'held' also reflects a level of individual care that goes beyond her expectations. As she describes her 'inability to 'go outside' during depression, she laughingly recalls the devotion of her care coordinator, who 'even offered to go for a bike ride' with her, which now feels 'so sweet' and touching.

Edward also felt a sense of safety within the service, but attributed it to a different aspect of his care:

They [the early intervention service] were always looking out for you, umm, like, whether it be by telephone conversation or, umm, you know, whenever you came in to see them here they were, you know, the first thing they'd asked would be like, 'How's your mood? How, how have you been?'. Closely monitoring everything. If, like, I'd even hint at that, that I was, err, swinging one way or the other, elated or lower than, um, yeah, they'd recognize that and, um, make sure that, you know, I was like sticking to my medication as, or the help that I was getting was beneficial.

Edward feels that the service is 'always looking out for' him, whether by 'telephone conversation', or seeing him in person. He stresses the degree of attention, being constantly asked 'How's your mood? How, how have you been?' Whereas Jane felt safe in having access to a network of experts, Edward feels protected from relapse by being 'closely monitored'. The service acts as a form of surveillance that checks his moods and acts quickly 'even if he 'hints' at 'swinging one way or another'. Edward may not always see the significance of his own shifts in mood, but he feels secure knowing that 'they'd recognise that' and check he is 'sticking' to his

‘medication’. He fears the risk of relapse, yet appears to be acutely conscious of being scrutinised.

When Dave reflected on the meaning of the service, he felt it provided safety in times of crisis:

I was displaying threatening behaviour and I was feeling suicidal and then my sibling contacted the like, like crisis number and then rearranged, um like then they got the home treatment team back involved. So, I think basically prevented err complete readmission which would have not been good for me [...] it’s kind of a huge relief, and even though there’s a bump in the road, I’m not stuck again [...] So, as I say, a safety net.

Dave feels crisis was averted by his ‘sibling’ using the ‘crisis number’ and receiving a timely response; ‘basically prevented complete readmission’. Like the others, Dave sees the service as a ‘safety net’ that will catch him should he lapse. However, he is less focused on staying well within the care of the team, and more concerned with preventing ‘readmission’. The real danger for Dave is being hospitalised, which he feels ‘would not have been good for me’. While mood changes, such as ‘threatening behaviour’ and ‘feeling suicidal’, are ‘bumps in the road’ that hinder his progress, being sectioned renders him ‘stuck’ and unable to move forward. For Dave, being sectioned poses a greater threat to his safety than either psychotic mania or depression.

### Summary

Following first episode, the participants struggled to make sense of what had happened, assess their present situation and consider the future. Being in the EI service helped them to come to terms with their episode and its implications, while also feeling empowered, developing new techniques and goals, and gaining a viable future. Their journey involved assessing and rebuilding who they were, but this was closely interrelated with the quality of their relationships with staff and the holistic approach that offered tailored interventions to meet individual needs. Although the reliance of the participants on service support fluctuated over time, the longevity of care, along with the provision of expertise within a holistic and equitable approach, afforded the security they needed to help them to move forward.

## **Theme 2: Managing self during wellness and relapse**

As the participants began to feel more stable, they needed to manage their changing sense of themselves and their wider aspirations and balance that against their efforts to stay well. They described a sense of self-renewal that was reflected in new pursuits as well as the motivation to use what they had learnt to remain stable. Alongside this, however, they also felt a sense of compromise arising from the need to maintain mental health, that could be difficult to accept. For those participants who described manic relapse, their escalation into mania was fuelled by the pressure to achieve objectives or negotiate challenges that they felt incapable of managing.

### 2.1. Balancing self-renewal and staying well

After going through a period of adjustment in the EI service, the participants described a sense of renewal but it relied on staying well. This reflected changes in aspirations and a subsequent move towards prioritising their mental health to realise them. Over half the participants described feeling motivated to focus efforts and activities towards improving their mental health, maintaining stability and combating mood change.

When Steve reflected on his life after being in early intervention, he described a new sense of purpose that helped combat depressive feelings:

For the first time in my life I feel I have purpose. Before, I used to do things like, - 'Okay, I'm gonna be like, I'm gonna be a drummer in a band, okay, I'll do that, check. Or, I'm gonna write songs. I'm going to be a poet. I'm gonna do that. I'm gonna do that. I was just going through the waves... but now it's like, no, I'm gonna be a visual artist. This is my purpose. I'm gonna be Picasso. [...]  
I feel it coming, like a sort of downness in my thoughts, I can feel it coming like a wave, I just create, I just create whenever I feel it. I know I have to go create, so then I create something and actually I feel better.

Steve feels that he has now hit a point where, 'for the first time', he has a 'purpose'. Having lost himself following first episode, he now feels irrevocably changed. While previously his goals would shift from 'I'm gonna be a drummer in a band' to 'I'm gonna write songs' or 'I'm gonna be poet', he now possesses a single ambition to

become 'a visual artist'. Before his episode he was 'going through the waves', but he now expresses greater certainty. Steve's use of metaphor suggests that he was lacking direction and riding with 'the waves' of his mood. As the passage unfolds, we learn that Steve's new purpose 'to be Picasso' helps curtail depression. When he feels the 'downness' in his 'thoughts' 'coming like a wave', he knows that 'I have to go create' and by doing so he begins to 'feel better'. Rather than riding the wave of depression, Steve staves off low mood by engaging in creative activity and working towards wider aspirations that now seem indispensable for his wellbeing.

Liam describes his renewal in more pragmatic and tentative terms:

Mood's good, things are going pretty well, um, I'm doing peer mentor work, so I do, do, a little bit of work but I'm spending like an hour a week, so next year my goal is to get a full-time job. I want to be a support worker actually, ideally here [early intervention service]. So, yeah, things are going pretty well, my mood's good, my anxiety's low, things just seem to be getting better as time goes on.

Liam feels that 'things are going pretty well', his 'mood's good' and anxiety's low', which allows him to do 'peer mentor work' and advance his 'goal' of becoming a 'support worker'. Like Steve, Liam's renewal is bound up with his ability to find a sense of purpose. However, whereas Steve's creative aspirations help him stabilise, Liam's goal is contingent on his ability to stay well. Liam is acutely aware that the reality of his new aspirations is contingent on effective management of his moods and his anxiety, that seem 'to be getting better as time goes on'. In contrast to Steve, Liam sees his progress as incremental and he tentatively recognises a gradual improvement in both his moods and work activities over time.

Edward also felt that realising his dreams relied on maintaining his mental health:

I want to, you know, maintain, err, my health, to, you know, see how far I can go and, umm, hopefully I capitalise on it to make the most of my, the time I have left in law school. [...] I'd say it's a relief that after everything, there's like some light at the end of the tunnel, umm, it's feelings of, umm (pause), feelings of, umm, well, happiness really. There's a sense that, you know with, as long

as I take care of it, then I can, like, lead a normal life, umm, a sense that because I stick to my medication and because I'm in contact with, err, the services here, um, I could not have to worry about my mental health.

Edward already has a clear goal, and his short-term priority is to 'make the most' of the 'time' he has 'left in law school'. Unlike the others, Edward's career goals remain the same, but his route towards them now looks different. To become a lawyer and to 'lead a normal life', he must maintain his mental health by sticking 'to my medication' and staying 'in contact' with services. This realisation provides him with 'light at the end of the tunnel' and gives rise to a sense of 'happiness' and hope. Like Liam, he sees medication adherence and mood management as giving life to who he wants to be. Although his journey now feels less certain and he must 'see how far' he 'can go', he expresses determination and hope in the claim that he will 'capitalise on it'.

In contrast to the others, Jane perceived her self-renewal in terms of how she felt about herself:

I do like a lot of aspects of myself and that's just one area that needs a substantial amount of work, but other than that I feel very happy and I would say I'm probably in a better place than I've been in many, many years, even before the episode.

Jane admits that at the end of her time in the EI service she feels 'probably in a better place than I've been in for years'. She recognises that she feels 'very happy' and she does 'like a lot of aspects of myself'. Compared to the others, Jane is less goal-orientated but more focused on reaching a form of peace with herself. Although she feels 'in a better place' than she has been 'even before the episode', she concedes that a 'substantial amount of work' will be needed in the future to get where she wants to be.

## 2.2. Coping with compromise

The sense of normalcy experienced by participants when they became well was accompanied by an enduring sense of compromise. The need to maintain and monitor their mental health during well periods led to feelings of frustration and diminishment. While some participants persisted with maintaining mental health, others could not accept it and initiated risky periods of respite.

Once Karen was feeling better, she soon felt compromised:

Since it's [her mind] been broken before (laughs), who, who says it couldn't be broken again? I've obviously imagined lots of things and it all came here, and it's still here with me, you know, it just, it's just gonna, like be like, like a ticking bomb thing, umm, I've learned not to trust my brain one hundred percent and for me, this is very frightening. because I have only one thinking tool and I don't know how else to process things? For me, that's a huge loss.

Karen is acutely aware that having 'been broken before', there is no reason why she 'couldn't be broken again'. Although stable, she feels acutely vulnerable and fears that at any moment her mental health could be 'broken again'. It is 'like a ticking time bomb' and only a matter of time before she relapses. Her use of metaphor vividly expresses her sense of fear and vulnerability, continually at risk of exploding into psychotic mania, that she feels would destroy her. To assuage her fear of relapse, she has learnt 'not to trust' her 'brain one hundred percent', but 'this is 'very frightening' as she has no other way 'to process things'. While she has developed ways to monitor her stability, Karen nonetheless feels that living in fear of her mind is 'a huge loss'.

Like Karen, Jenna's monitoring of her moods led to feelings of depletion:

You always have to question yourself, you can't just be generally happy because every single time that little happiness comes in you think - 'Okay, hold on. Is it happy, happy? Or is it now leading me back to psychosis?'

Although Jenna experiences 'little' moments of happiness, she has learnt to question the validity of those feelings; 'is it happy, happy or is it leading me back to psychosis?'. Like Karen, she has learnt strategies to monitor herself and stay well but feels that they have inhibited her emotional world. Whereas Karen struggled with her inability to trust her mind, Jenna feels her happiness has been curtailed. Instead of embracing the 'little happiness' that 'comes in', she feels obliged 'every single time' to scrutinise and reduce it. Her compromise is never-ending, 'every single time', and has diminished her normal way of being.

Most participants struggled to cope with their new normalcy. Steve cannot accept it:

Sometimes I will just stop taking the meds so that... and I'll be like - 'Oh my God. This is what I'm missing. I love thinking, I'm a thinker. What the fuck? [...] What the hell? Like these drugs like, Oh my god, they suppress everything. I can't think'. You know? So yeah, that was something too. So yeah, sometimes I'd go off of the meds just so that I could just like, be my old self.

Steve feels that the 'drugs' 'suppress everything' and prevent him from being who he wants to be. Whereas Jane and Jenna felt diminished by monitoring their moods and thoughts, Steve sees his medication as untenable because it means he 'can't think'. He is not prepared to reconcile himself to his new way of being and 'sometimes' will 'just stop taking the meds'. Once off medication, he is hit by his 'love' of 'thinking' and realises 'oh my god, this is what I'm missing'. By becoming 'a thinker' again, he can relive his 'old self'. As he exclaims, 'What the fuck? What the hell?', we sense his outrage at an unacceptable compromise, something that makes going 'off of the meds' a risk worth taking.

In contrast, Craig was the only one who felt excited about returning to who he was prior to first episode:

I can get back to how I used to be and now I'm feeling really, really like I, prior to how when I went in there [ward] [...] so seeing it [the visions] a bit of like encouragement that I'm not, that my life isn't going completely down the, the..., do you know what I mean? Generally, like a sort of thumbs up that's the way I see it.

Craig feels pleased that he is now 'back to how I used to be' prior to his hospitalisation. Unlike the others, Craig's experience of wellness is not contingent on staying stable but provides the 'encouragement' he needs to reconnect with the visions and purpose that heralded his first episode. In contrast to Steve and the others, Craig is unwilling to give credence to either his diagnosis or his mental health issues. Once he starts 'seeing' visions again, rather than take steps to prevent it, he sees it as a 'thumbs up' and feels rejuvenated. For Craig, therefore, the re-emergence of symptoms is a sign that his 'life isn't going completely down' and confirmation of

his higher purpose. Compared to the others, Craig does not feel compromised, but by embracing his symptoms he may be at greater risk of relapse.

### 2.3 Pressure, change and proving self

Two participants, Dave and Liam, experienced manic relapse during their time in the EI service, while Eric relapsed prior to entering the service. These participants described an escalation of stress and pressure that arose from either the need to prove themselves or challenges in their wider life that they felt unable to cope with.

Eric, who had only just started being seen by the EI team, described being driven back into mania by an acute urge to prove his superiority:

I've got obsessive to the point where I wasn't sleeping again and I convinced myself, for some godforsaken reason, that I needed not just to write my exam, which is already difficult considering I just left the fucking ward, but I needed to leave every single exam an hour earlier - an hour earlier! No one had put that pressure on me. No one. It's insane [...] you need to be like, you need to be your old self for this, because otherwise you're gonna be crying on the fucking paper (laughs) [...] the only way that I could ever get back to that old version of myself is by going in and proving to people that I'm the best thing that they have ever fucking seen and slowly that has led over those next few months into ramping up into another manic episode.

Eric convinces himself that he must not only sit his exam but he must also 'leave every' exam one 'hour earlier' than everyone else. Consequently, he feels 'obsessive' 'to the point' of 'not sleeping'. Although he knows this is 'insane', he sees it as the only way to demonstrate his superiority, while also preventing the humiliating failure of 'crying on the fucking paper'. His words vividly express his sense of dissatisfaction with himself and the fear that he will be publicly shamed. To avoid this, he tells himself, 'you need to be your old self', and yet the only way to evoke 'that old version' is 'by going in and proving that I'm the best thing fucking thing they have ever seen'. Eric is trapped between a rock and a hard place. While he fears failure, his only escape is to be a super version of himself: the person he was during first episode. For Eric, there is no moderate way forward and he finds himself 'ramping up into another manic episode'.

Like Eric, Dave felt he was faced by tasks that he could not achieve:

This job now, I want to learn, but it's that there's so much technical stuff, there's so much legislation and rules and regulations you need to learn, and I feel like it's just not, I can't compute it, I can't concentrate enough. So I'll be sitting there like trying to read something, like, literally staring at it and it's just not going in [...] Having to juggle studying and learning and then trying to like, not have a social life, but try, at least you wanna try to enjoy your week a little bit relax. So it just felt too, too, intense like [...] So it just all got on top of me then that's, that thing, that's what led to my second admission.

Dave 'wants to learn' his new job, but struggles with the complexity of 'technical stuff' and 'rules and regulations' that are unfamiliar. Although he knows 'you need to learn', he finds himself 'sitting there' and 'literally staring at it', but 'it's just not going in'. Like Eric, he expects himself to learn and achieve, but feels the task is beyond him. Notice his use of the words 'can't compute it', suggesting that, in his eyes, the machinery of his brain is not working as it should. As he sits there, blankly, he is acutely aware of it 'not going in' and, all the while, his stress and frustration begin to mount. Although Dave pressurises himself to progress, unlike Eric, he does not evoke his former manic self, perhaps because first episode had made him feel suppressed and persecuted rather than exceptional. He now feels overwhelmed by having to 'juggle' 'studying', 'learning' and 'a social life' which he finds 'just too, too, intense'. Although he wants the opportunity to 'relax' 'a little bit', the stress he feels in trying to fit it all in, 'just got on top of' him and leads to his 'second admission'.

#### Summary:

On becoming well, the participants expressed a tension between feelings of self-renewal and a sense of self-compromise. While optimism motivated them to prioritise their mental health, the effort this required instilled a sense of compromise that was hard to accept. Those who could not come to terms with this change sometimes engaged in riskier choices that could jeopardise stability. Three participants described manic relapse, driven by the pressure of facing a task or event that was seen as insurmountable. While one of these was intent on demonstrating a better self, the others were driven to collapse in being unable to cope.

## Discussion

### Rebuilding within EI service

Existing literature provides extensive insight into the experience of EI services for people with first episode psychosis (e.g. Hansen et al., 2017; Loughlin et al., 2020), but no studies have focused on young people diagnosed with BD. However, understanding the experiences of this group is a priority. Outcomes for young people following first episode mania have been found to be poor (Chang et al., 2016) and little is known about the suitability of EI services, that were designed for first episode schizophrenia, for this group (Jauhar et al., 2019).

This study suggests that the participants' journey within the EI psychosis service involved a process of piecing together and coming to terms with their episode, learning techniques to reassess their perspective and manage their moods as well as receive practical help and build hope for their future. The quality of relationships with staff was pivotal in enabling them to talk through their experiences and instil feelings of empowerment.

The notion of personal recovery from serious mental illness is rooted in an individual's unique experience of change and involves hope for the future, a sense of identity, feeling empowered to make decisions, connectedness to others and meaning in life beyond the event of having a mental illness (Anthony, 1993; Leamy et al., 2011). For young people who have experienced first episode psychosis, the recovery journey is conceived as a process of developing meaningful interpretations of the illness, strengthened relationships, restoring agency and a more coherent self (Connell et al., 2015a; Leonhardt et al., 2017).

The importance of sense-making is echoed by participants in the current study who felt that piecing together their episode was fundamental in enabling them to overcome confusion, take control and move forward. Recent reviews of the experience of recovering from psychosis more generally indicate the importance of rebuilding reality, self and meaning, as well as enabling people to move forward (McCarthy-Jones et al., 2013). According to Allard et al. (2018), young people's search to understand and normalise their first psychotic episode dominates the first few months of EI intervention and is a precursor to progress. This period is delicate, however, with

young people often struggling with identity disruption, stigmatising input from society and services, along with an elevated risk of relapse and suicide (Ben-David & Kealy, 2020; Loughlin et al., 2020).

This study highlights the importance of discussing episode experiences with staff at the service in prompting memories, finding clarity and making sense of diagnosis. The helpful features of those interactions were shaped by individual needs. Alex found the expertise and knowledge of staff reassuring and normalising, while Steve needed a sounding board to help him remember and reflect upon past events. In a recent review of BD interventions, expert knowledge from clinicians promoted the confidence of participants in over half of studies, while other findings highlighted the need for young people to talk freely and formulate their own personal narrative (Davenport et al., 2019; Loughlin et al., 2020).

Talking to close others about psychotic experiences is often seen by young people as pivotal to alleviating loneliness and shame but those experiences are not always easy to articulate (Hansen et al., 2017). In the current study, most participants felt unable to discuss their episode with close others as this involved facing events or behaviours that were shameful, difficult to recall and elicited difficult reactions. Studies focusing on recovery from grandiose delusions and mania suggest that secrecy is common, despite a keen desire to share experiences (Isham et al., 2021; Ouwehand, Zock, et al., 2019). For participants in the current study, the opportunity to discuss experiences with EI staff who were impartial and non-judgemental was pivotal.

Although the experience of CBT is not highlighted by work in this area, participants in this study valued learning techniques to manage depression or anxiety, high moods and tackle beliefs. For instance, Edward struggled with feelings of failure during depression, Alex contended with mounting anxiety and Craig sustained unusual beliefs. Depression is common during the early stages of BD and markedly impacts quality of life following first episode psychotic mania (Macmillan et al., 2007; Michalak et al., 2013; Oldis et al., 2016). Although not all participants found CBT immediately helpful, most recognised the utility of techniques in gaining an awareness of the subjectivity of their thoughts, an alternative perspective and an improved sense of self.

In research on BD, CBT is associated with improvements in depressed mood and quality of life (Costa et al., 2012; Parikh et al., 2012; Scott et al., 2006) While it can help people consider alternative responses to negative thoughts (Davenport et al., 2019), it is considered less effective in preventing manic episodes or managing beliefs in a superior self (Lam et al., 2005). Grandiose delusions tend to involve greater conviction than other delusions and the success of behavioural strategies may be limited (Knowles et al., 2011). In the current study, this dynamic aspect is illustrated by Craig who remained convinced that his visions were proof of a divine connection despite discussing alternative perspectives. Through collaborative discussion with his psychologist, he began to acknowledge the subjectivity of his view, but he was the only participant who could not accept his diagnosis or prioritise his mental health once well. This study, therefore, reveals new insights into CBT provision in EI services: CBT was found to be particularly helpful, but the management of grandiose beliefs, which are common for people with BD and mania, was a particular challenge, suggesting the need for further investigation of this aspect.

For people recovering from mental health difficulties, the notion of empowerment is considered a significant touchstone (Leamy et al., 2011). In the present study, participants struggled with feelings of powerlessness on entering the service, but over time gained an increased sense of agency. The demeanour of staff helped participants feel valued and accepted, but it was their readiness to involve participants in decisions that engendered feelings of autonomy and control. For instance, Jane felt that she gained agency through making decisions over her medication while Alex valued the degree of flexibility over his treatment which was orientated around his needs.

Studies suggest that when young people are excluded from treatment decisions in EI services, they feel powerless but, by becoming active agents in decisions, their sense of agency, confidence and responsibility is promoted (Harris et al., 2012; Lester et al., 2012; O'Toole et al., 2004). Moreover, agency is seen as a central mechanism driving recovery from first episode psychosis and may help combat negative symptoms (Bjornestad et al., 2017). In studies focusing on BD, decision-making over medication requires a collaborative approach that recognises the

expertise of both client and clinician (Inder et al., 2019). In this study, Dave saw decision-making as a fluid process that shifted between his own insights and preferences and the expertise of his clinician. Shared decision-making is seen to help older adults actively take charge of their illness and may promote medication adherence (Inder et al., 2019). This study extends this by suggesting that shared decision-making may promote medication adherence in young people following first episode BD: Alex felt sufficiently empowered through his involvement in treatment decisions to take responsibility for wellbeing and take his medication.

Participants were also empowered by the provision of advocacy, advice and information that helped them to reintegrate. Social reintegration is a common goal for young people recovering from first episode psychosis, yet is not related to empowerment (Lester et al., 2012; O'Toole et al., 2004; van Schalkwyk et al., 2015). Tindall et al.'s (2015) study suggests that young people's needs are both practical and emotional and meeting both aspects is paramount to maintaining service engagement. Moreover, a recent review highlights the loss of financial security and living arrangements during psychosis; solving these issues are key to promoting personal safety and hope (McCarthy-Jones et al., 2013). An additional aspect emphasised by participants in this study was the support offered by care coordinators in communicating their situation to others during stressful environments or periods of low mood. Unlike shared decision-making, this approach evolved through the active support, but was ultimately seen to promote autonomy.

In the present study, the participants' sense of hope and progress following their first episode was intimately connected with their relationship with the future. Several participants felt that the goals or roles that had orientated their lives prior to their episode were no longer viable, leaving them feeling lost and hopeless. In the wider literature, first episode can coincide with a loss of direction and a rise in anxiety (Ben-David & Kealy, 2020; Noiriell et al., 2020). While the importance of establishing direction and a hopeful future is understood to inform the process of personal recovery (Leamy et al., 2011), it is not exactly clear how this occurs in practice.

This study offers new insight into the experience of reconnecting with the future after the disruption of first episode. Some participants were supported to return to previous roles and employment goals, while others felt that their previous path was no longer viable and needed to

adjust. One participant also needed permission to stop and reflect. The reconnection with the future involved a delicate balance between being realistic and developing hope, which staff helped to negotiate. Returning to work or education has been found to be a source of hope for young people following first episode psychosis (Perry et al., 2007; Sandhu et al., 2013). EI support is seen to support occupational spheres, social identity and promote self-renewal at a time when young people feel they are missing out (Lester et al., 2012; Tindall et al., 2015; van Schalkwyk et al., 2015). This study echoes extant findings, but also highlights the need for a flexible approach, tailored to individual needs, that sees the value of encouraging new goals, taking stock and reflecting.

Following first episode, participants' sense of security was underpinned by being in the EI service. Overall, the holistic team-based approach was seen as a safety net, but with different levels of meaning. Jane felt cared for, Karen's future was protected, while others valued service scrutiny and crisis response. Other studies also highlight the longevity and intensity that the EI service model affords along with the ability to access the expertise of a multi-faceted team (Harris et al., 2012; O'Toole et al., 2004).

Fear of relapse and hospitalisation was expressed strongly by all participants and was seen to pose a significant risk to wellness. Reviews of EI services suggest that although young people describe themselves as being in recovery, they are aware of their ongoing vulnerability and the risk of relapse (Hansen et al., 2017). Overall, current study findings resonate with both individual priorities of personal recovery and the clinical emphasis on relapse prevention. While some writers see conflict between the priorities of clinical and personal recovery (Macpherson, 2016), this study suggests that they can be complementary. Indeed, participants saw the service as both a safety net against relapse and also supportive of their progression towards personal recovery.

### Managing self during wellness and relapse

This study provides fresh insight into the way young people in EI services balance self-renewal and compromise during recovery from first episode. This is shown to be a difficult balancing act. On becoming well, the participants expressed a sense of hope with the impetus and confidence to

manage their moods, but the strategies they had developed at the service could create feelings of compromise that not all were prepared to accept. Participants also felt a sense of self-renewal in being able to achieve goals and aspirations but were aware of the need to manage their moods in order to stay well. The meaning of self-renewal varied. For most, working and studying was seen to offer a sense of normalcy and hope for a positive future. Participants such as Steve, Liam and Edward were motivated by the idea of taking on a role related to who they were or wanted to become.

Social roles have been found to be the highest correlate of personal recovery in BD, while occupational contexts instil normalcy and the possibility to develop an identity outside mental illness (Borg et al., 2011; Kraiss et al., 2021). Identifying goals associated with occupational achievement may be particularly meaningful for men managing mental health difficulties who associate it with manly pride and feeling accomplished (Fogarty et al., 2015). In this study, however, occupational goals were not meaningful to all: for instance, Jane felt inspired by continuing to work on her emotional wellbeing to develop a sense of peace.

The maintenance of a hopeful future is one of the four factors that promote BD mood balance and prevent mania (Michalak et al., 2016). Following BD diagnosis, meaningful activities, including remaining in the workforce, was found to be one of the key factors that help young people manage their moods (Nicholas et al., 2017). This study, similarly, emphasises the importance to young people of fulfilling meaningful roles and activities during early onset BD. However, it further highlights that the sense of optimism this creates can motivate efforts to stay well, such as managing moods and taking medication. These strategies, however, also could create feelings of self-compromise.

Other studies that examine the experience of managing moods in BD present a mixed picture that points to the importance of illness stage. Two studies suggest that mood monitoring can create feelings of autonomy and are seen positively (Morton et al., 2018; Murray et al., 2011). However, these are focused on older adults with established BD who expressed relief at regaining control over their lives. Meanwhile, one study of young people following BD

diagnosis found that mood management was seen to be less beneficial than engaging in meaningful activities (Nicholas et al., 2017).

Although the value of mood awareness and monitoring is widely endorsed in treatment and self-management of BD, a recent commentary postulates that in some cases it may be unhelpful and needs to be individually tailored (Palmier-Claus et al., 2021). The authors propose that, at times, it may increase anxiety or catastrophic interpretations and can also lead to restrictive lifestyles. This study further highlights that monitoring moods can create ambiguous feelings for young people following first episode BD: though the participants felt it promoted wellness and protected the realisations of aspirations, it also created self-compromise.

The negative impact of medication on clarity of thought and sense of self is widely recognised in the BD literature (Blixen et al., 2016; Mandla et al., 2017; Mansell et al., 2010). The decision over whether to continue to take medication is influenced by its perceived impact and by weighing pros and cons (Horne & Weinman, 1999). In the current study, the erosion of Steve's sense of self prompted him to take medication breaks despite knowing the risks. While the negotiation of costs and benefits has been linked specifically to medication use, it may reflect a more general approach to deciding whether or not to adopt strategies that maintain mental health.

This study brings to light novel insights into manic relapse at this early stage of BD that may be particularly relevant to the treatment of people diagnosed with BD within EI services. Findings reveal a new layer of complexity in the relationship between self-renewal, motivating mood management and compromise. On the one hand, realising goals alleviated the participants' sense of compromise, while on the other, they were seen to create additional stress and fuel relapse. Eric's need to prove his superiority and Dave's experience of multiple stressors appeared to contribute to their escalation into mania. BD is associated with a high frequency of stressful life events that have been found to predict episode recurrence for people with BD (Gilman et al., 2015; Lex et al., 2017). In one study focused on occupational experiences, long hours and work stressors were seen to contribute to manic relapse (Borg et al., 2011).

In this study, Dave's work stress escalated his manic relapse, but his account highlights the role of self-perception in contributing to the feelings of stress. Meanwhile, Eric's sense of self drove his efforts to attain unachievable goals that he felt led to mania. There is some evidence that people with a high behavioural activation system sensitivity, resulting in increased goal directed behaviour may be vulnerable to develop BD episodes (Alloy et al., 2012). In the BAS dysregulation model, life events involving rewards, goal-striving or attainment initiate manic symptoms (Urosević et al., 2008). Eric's case supports this model, but also points to the role of self-perception in this process. His manic escalation was driven not only by the goal of passing exams, but also by an acute dissatisfaction with his normal self, that he saw as woefully inferior to his alternative idealised self that was only attainable through mania. Taken together, this points to the need for EI clinicians to consider the role of goal-related events and identity meanings in increasing relapse risk for this group.

## Chapter 10 - Conclusions and evaluation

### Summary of aims

This thesis explored the experience of mood change and early intervention for people diagnosed with BD. For those affected, living with successive episode change is widely recognised to impact identity, sense of control, the ability to progress and envisage a positive future.

Qualitative work in this area derives from a cross-sectional approach that has focused on the impact of mood change rather than the process of change itself. A person's experience of change, however, occurs within a temporal flow whereby changes are interrelated to each other through time, requiring a longitudinal lens to access its unfolding trajectory. To fully capture the complexity of change, an holistic and idiographic mode of enquiry is also required.

Taking a longitudinal IPA approach, study one aimed to explore the personal experience of change during BD moods and euthymia and the way it interrelated with a person's sense of self, other people and their environment.

Study two extended the investigation of BD mood change to examine the experience of first psychotic episode mania and early intervention services. People with first psychotic episode BD are often treated within NHS EI psychosis services, but services are not tailored to this group. A literature review revealed that no work had examined first episode psychotic mania for people with BD or their involvement in EI psychosis services. Study two, therefore, aimed to capture idiographic insights into young people's experience of first episode psychotic mania and their subsequent involvement in NHS EI services.

The table below provides an overview of the results.

*Table 8. Overview of study one and two results*

<b>Study One: Capturing the experience of bipolar disorder through time: investigating change and self-coherence</b>	
<b>Extreme change and disconnection with self, others and world</b>	<b>Searching for self-coherence: confusion, disruption and shame prevail</b>
Extreme changes in activity assault agency	Struggling for self-coherency during confusion and disruption
Changes in feeling impact connection with world	Feelings of shame threaten self-coherency
Shifting perceptions of future disrupt progression	
Changing sense of others impacts relatedness	
<b>Study Two: An experiential investigation of first episode psychotic mania and early intervention services</b>	
<b>Power, persecution, confinement and collapse</b>	<b>Rebuilding within EI service and managing wellness</b>
Control, persecution and imprisonment	Rebuilding within service
Struggling with loss of self during aftermath	<ul style="list-style-type: none"> <li>• Piecing together the past</li> <li>• Reassessing subjective view</li> <li>• Being empowered</li> <li>• Seeing a future</li> <li>• Having a safety net</li> </ul>
	Managing self during wellness and relapse <ul style="list-style-type: none"> <li>• Balancing self-renewal and staying well</li> <li>• Coping with self-compromise</li> <li>• Pressure, change and proving self</li> </ul>

## Summary of findings and clinical implications

### Study One findings

The first study to date to take a longitudinal approach to exploring the experience of change during depression, euthymia and mania, Study one tracked three participants at two time points during stability and depression, a design that enabled four trajectories of change to be revealed. These included a changing sense of activity and agency, feelings and connectivity, perceptions of the future and relatedness to others. Two further themes illustrated the participants' ongoing struggle for self-coherency and the confusion and shame this instilled.

The longitudinal approach revealed and demonstrated new insights into the experience of change for people with BD. Well-recognised changes brought about by BD moods, such as activity levels, future uncertainty and interpersonal difficulties, were revealed to have novel significance when construed through time. For example, idiographic trajectories revealed that changing activity levels impacted agency, fluctuating feelings shaped connectivity, shifts in the future undermined temporality and switches in relational balance created interpersonal disconnection. Significant patterns within and between episodes were emphasised that, for participants, created a changing sense of disconnection with self, others and their environment.

The cumulative impact of this change and its erosion of well periods was also a new aspect highlighted by findings. The participants' sense of recovery during stability varied and was shaped by their experience of other episodes and their subsequent negotiation of change through time.

Confusion and chaos in BD are widely recognised, but in this study they manifested as part of an enduring struggle for self-coherency that created confusion and disruption. Moreover, this process evolved during different states, further exacerbating instability. Feelings of shame deriving from extreme behaviours during mania and depression were particularly pertinent during this process, highlighting a complex dynamic. Findings suggest that participants who assimilated shameful behaviours into their self-concept felt diminished while those who were able to disassociate from them were protected. Yet resistance seemed to contribute to an ongoing inability to integrate different selves and establish self-coherency over time.

### Study One clinical implications

Findings point to the clinical value of developing a person's insight into their changing mood patterns over time, rather than focusing on discrete episodes or symptoms. The notion of discrete, unrelated, episode symptoms in the prevailing diagnostic criteria and medical models seems inadequate and perhaps counterproductive. Rather than being separable or observable behaviours or feelings, the flow of change for participants in this study encompassed interrelated shifts in the way they connected to themselves, other people and the world. The need to see a person's BD moods as unfolding through their temporal, situated and related experiences, as opposed to something that happens to them, is key. Gaining an understanding of the interrelationships between different BD states, including stability, may promote the management of, and tolerance to, mood change (Joyce et al., 2016).

Findings also point to the potential benefit of going beyond the assessment of residual mood symptoms during euthymia highlighted in the literature (Samalin et al., 2016) to focus on the recovery of key connections between self and world, including agency, feelings, temporality and relationships with others. Mindfulness may be well-placed to improve emotional and empathic awareness, as well as help moderate anxiety, and could help manage disruptions to feelings and relational aspects (Murray et al., 2017). Alternative approaches that focus on the body and building self-awareness may also offer potential for improving self-reflection, self-perception and connectivity (Röhricht et al., 2011).

The need for psychotherapeutic interventions that assist in managing identity incoherence and developing identity integration is highlighted. Acceptance of extreme mood BD states is a goal of third wave therapies, such as Acceptance and Commitment Therapy (ACT) (Hayes et al., 1999; Herbert & Forman, 2011), that integrate mindfulness as a means of therapeutic change. In ACT, the acceptance of distress is a key touchstone, while in mindfulness generally there is a focus on developing self-compassion (Hayes & Smith, 2005; Murray et al., 2011). Findings also point to the potential benefit of therapeutic approaches, such as compassion focused therapy (Gilbert, 2014) that recognise the pivotal role of shame in formulating and maintaining a positive and integrated self.

## Study Two findings

This is the first study to explore how people with BD experience first episode psychotic mania, its aftermath and NHS early intervention services. Eleven participants were interviewed on one occasion shortly after first episode and during their treatment in NHS early intervention services.

Four themes were reported, the first two illustrating dramatic changes in the participants' sense of interpersonal control during first episode psychotic mania, fuelled by an intensity of feeling and leading to a loss of self. Participants felt transformed into either an omnipotent self that overpowered other people or a victimised self that was persecuted by them. Feelings of persecution were exacerbated by restrictive practices during hospitalisation. The loss of self and confusion experienced by all participants was closely interrelated with episode meanings.

Two further themes illustrated the participants' journey within early intervention services and their management of a new sense of normalcy when well. The first illustrated their efforts to rebuild and recuperate, involving a range of interventions that helped them to piece together their past, make sense of their present and see a hopeful future. In the second theme, a complex tension was revealed between their sense of self-renewal, that motivated efforts to stay well, and their feelings of self-compromise that could lead to poor decision-making.

Findings offer new insight into the prominence of meaning-making during first episode psychosis and its aftermath, extending understanding of this area. Extreme changes in interpersonal control indicated the significance of relational and social meanings in constituting psychotic experiences. Identity loss was also highlighted as a key aspect. For example, grandiose delusions during first episode could protect against an inferior sense of self, but this created profound feelings of loss afterwards and prompted efforts to re-evolve mania. Conversely, persecutory experiences led to a sense of loss of who they had been prior to first episode.

As the first study to examine EI services for this group, findings highlight the importance of meaning-making, empowerment, reassessing perspectives, formulating a future and feeling safe. The value of CBT in forming alternative perspectives brings new emphasis to this area, along with the challenge of tackling grandiose delusions. Fresh insight is also offered on young

people's management of a new sense of normalcy during early intervention. Findings point to a complex relationship between the need for renewal through goals and the risk of manic relapse.

### Study Two clinical implications

This study indicates the limitations of an objective clinical view of psychosis that overlooks the role of meaning in shaping emotional and anomalous experiences. It points to the need for models of psychosis that reflect and harness the agentic role of the person in forming and narrating psychotic experiences (Ritunnano et al., 2021). The potential clinical benefit of exploring people's interpretations of first episode psychotic mania and the meaning it holds for identity and relational aspects is indicated. This would promote insight into a person's sense of conflict or loss and might also help resolve this and support key clinical targets, such as relapse prevention (National Institute for Health and Clinical Excellence, 2014).

Findings support recent recommendations for reform to the provision of inpatient care, including reduced restrictive practices, increasing patient choice and a greater focus on therapeutic benefit (Department of Health & Social Care, 2018).

EI services were seen as pivotal in supporting progress after first episode BD, pointing to the benefit of existing services in supporting this group. Aspects of service provision that facilitated included equitable relationships with staff, the promotion of open discussion and personalised care and developing empowerment and opportunities through holistic and multi-faceted support. As argued elsewhere, these aspects seem to reflect the basic principles underpinning mental health service delivery for young people with first episode psychosis and may hold transdiagnostic value (Griffiths et al., 2018).

There may be scope to better tailor CBT for people with BD by focusing on the management of high moods and allowing sufficient time to process the meaning of episode and diagnosis for identity (Jones et al., 2015). However, mood management strategies were also found to prompt feelings of self-compromise and risky decisions, pointing to the need for individually tailored interventions (Palmier-Claus et al., 2021). Findings suggest the need for EI clinicians to consider the role of goal-related events and identity meanings in fuelling manic relapse, which may be particularly pertinent for young people with BD. Gathering information about high-goal setting,

perseverance in pursuit of goals and its meaning for self-worth may be of benefit (Ironside et al., 2020).

### Comparing Study One and Two findings

Identity is the key construct across the results of both studies, highlighting the prominence of this aspect during first episode and throughout the illness course. During first episode, findings illustrated the participants' profound loss of self after psychotic mania and the pivotal role of early intervention in helping them to adjust and rebuild after significant self-disruption. For some, the loss of identity contributed to low feelings or episodes of depression after first episode, particularly for those participants who had experienced grandiose delusions during psychotic mania. Challenges to identity were also integral to the experience of successive episodes over time, where changes between states created an ongoing struggle for identity coherence. This caused significant suffering and exacerbated the participants' instability, further undermining their sense of self.

Clinical recovery in BD has typically been defined as symptom resolution and relapse prevention. But this perspective has overlooked the subjective experiences of people with BD and may not fully reflect treatment success from their perspective (Mezes et al., 2021).

Recently, with increasing momentum of the personal recovery movement, the establishment of a positive identity has been recognised as a priority for people recovering from severe mental health issues (Leamy et al., 2011). In a review, the personal recovery experiences in bipolar disorder were synthesised, highlighting the importance of identity in the process (Jagfeld et al., 2021). Three aspects were identified: i) Rebuilding positive sense of self; ii) Dimensions of identity; and iii) Overcoming stigma. Findings suggested that episodic mood swings, particularly when viewed as separate to the self, caused identity crisis and loss. Coping with the challenges of a repeated loss of self due to sporadic and recurrent mood episodes is therefore an important part of the journey towards personal recovery. During this process, mindful acceptance of the self and related limitations and contradictions help manage the repeated sense loss as well as help find ways to move forward and adjust (Todd et al., 2012).

While the results of both studies offer strong support for prioritising the establishment of a positive identity during personal recovery, they also point to the relevance of identity to clinical

recovery aims. Findings suggest that identity and its management during different phases of BD was integral to the participants' ability to gain a sense of control over themselves, their moods and their wider lives. The participants' struggle to establish a coherent sense of self, that could help them to navigate change, created feelings of confusion and shame that compounded their sense of instability. From this perspective, identity for people with BD needs to be considered as an important mediator of well-established clinical recovery priorities, such as relapse prevention and mood management, and a key focus of psychological interventions. Findings point to the need to not only support the acceptance of difficult feelings and experiences, but also help individuals manage their sense of incoherency and negative self-perceptions.

### Methodological reflections on LIPA: accessing complexity, connections and possibilities

Study one is the first longitudinal IPA study to examine changes in state rather change arising from life events or interventions. Though the practical challenges of collecting data during unpredictable periods of change were significant, the longitudinal approach was pivotal in revealing the processual nature of BD mood change and its complexity. By demonstrating how change evolves within and between BD moods, the results bring to light previously unreported processes, such as the way activity impacts agency. Neale (2021) emphasises that trajectories bring to light the complexity of causal processes that consist of multiple interlinking experiential threads. The ability to see changing trajectories as they dynamically evolve within states and through time, however, is only possible through the illustration of idiographic case studies.

As Neale (2021, p. 55) suggests:

'Methods need to be attuned to the flux of unfolding lives and events, including a sustained, longitudinal engagement in the field, and the generation and analysis of rich case narratives that can capture and convey how processes unfold'

Through IPA's idiographic lens, it became apparent that BD mood change manifests as a flow of distinct trajectories, including shifting activity and agency, shifting sense of the future and progress, and changing interpersonal power. Importantly, the idiographic approach brought a level of detail that enabled the comparison of trajectories during different states, within and

across participants. The temporal context helped understand why an experience might occur for one person but not another, illuminating subjective cause. For instance, Caroline's inability to regain a sense of the future during stability can be seen as arising from her uniquely acute disconnection from time during depression. Similarly, her struggle to reconnect with the future during stability resonated with her difficulty in reconnecting across other trajectories at that time.

The complex picture of idiographic trajectories also provided a rich context from which to understand the participants' battle for self-coherency. From this perspective, it became possible to consider the impact of mood change on identity, without reducing the process to linear or unitary cause and effect. For instance, the cross-case comparison revealed that Julia was more able to disassociate herself from shame than the others. However, she had also regained activity and agency during the same period, bringing to light a possible relationship between the ability to resist shame and agency. The idiographic trajectories shed light on the co-occurrence of significant possibilities and relationships that together shaped each participants' world. Each individual participant, however, provided a constancy from which to make sense of evolving processes over time.

## Evaluating the quality of IPA

The importance of evaluating the quality and validity of qualitative research in psychology according to criteria is widely acknowledged in the field (Levitt et al., 2018; Shaw et al., 2019). It enables researchers to reflect on what is expected of them, demonstrate the quality and rigour of their work and engage in the longer-term and collective process of forging high-quality qualitative work in the field. Quality criteria have a key role in coordinating expectations and assessments of reviewers and editors of qualitative work and ideally encourage an informed dialogue and understanding between authors and those who critique their work.

The guide to assessing the quality of IPA specifically (Smith, 2011a, 2011b) sets out key criteria for different levels of quality with the aim of assisting both authors and reviewers make a judgement on the quality of work reporting IPA. Seven core benchmarks of 'Good' IPA drawn from Smith (2011a) will now be used to assess the quality of this thesis. Where relevant, I will also describe how specific quality indicators of IPA identified by Nizza et al. (2021) have helped meet these benchmarks. These are: Constructing a compelling, unfolding narrative, Developing a

vigorous experiential and/or experiential account, Close analytic reading of participants' words and Attending to convergence and divergence.

### 1. Strong data

The development of an in-depth and vivid account of the personal meaning of experience relies on the elucidation of rich data. One aspect that can impact the quality of data is the timing of data collection in relation to the experience under scrutiny. In Study One, gathering data during each state helped capture the emotional intensity of that state. For instance, the participants' expressed a greater intensity of feelings and fear when interviewed during depression than when they talked about that state afterwards.

To gather strong data, the interview schedule and interviewing technique are critical. My interview schedules were developed with a view to helping the participants speak freely and describe their experiences in their own terms. Where possible, clinical terminology was avoided, as was language that carried assumptions around their experience. Prompts were also used to support the elucidation of meaning for each state. Some prompts aimed to dig deeper into the participants' experience (e.g. Can you tell me more about that?). Others evoked the use of imagery to help participants express the vividness of their state as well as those aspects that were difficult to describe (e.g. What images best describe it?). Careful attention to temporal shifts supported the participants' engagement in different aspects of their experiences. The use of the same interview schedule during each state helped the interviews to remain participant-led.

The interview style helped the participants to speak freely and become immersed in their experiences and sense-making. Attentive listening and empathic responses appeared to help the participants relax and feel acknowledged, supporting rapport and the flow of their reflections and feelings. The elucidation of meaningful data was facilitated by following the participants' lead, while also coaxing them to delve more deeply into their experiences.

### 2. Clarity of focus

While this thesis was focused on the experience of mood change for people with BD, that could have been interpreted broadly so it was important to home in on specifics. In Part One, the primary focus was on real-time experience of BD states and change rather than its wider impact.

The longitudinal approach enabled the investigation to zoom in on the process of change through time. Although findings brought to light wide-ranging dimensions of change in multiple domains, a sharp focus was achieved through the elucidation of idiographic trajectories. The state-by-state write-up supported a clear elucidation of each state and the differences between them.

Study Two extended the investigation of BD mood change by exploring the experience of first episode psychosis for people with psychotic mania and early intervention services. By looking specifically at this aspect, it was able to illuminate an unexplored area. The development of one quality, constructing a compelling narrative within and between themes, helped develop focus and clarity. Within a theme, the development of a story through the alternation of carefully selected quotes brought a sharper focus while the formation of a coherent narrative across themes helped drive clarity. The particular focus of findings was also supported by the development of experiential and existential aspects within the narrative, such as identity loss and interpersonal control.

### 3. The work should be rigorous

A core aspect of 'Good' IPA is that the quotes selected provide a proportionate representation of the corpus and illustrate convergence, divergence and variability. Guidelines suggest that small samples (1-3 participants) should include quotes from all participants for each theme, while samples of more than 8 participants should include three or four quotes from participants and some indication of prevalence. The illustration of representativeness, prevalence and variability through the selection of data presented not only supports the persuasiveness of the findings but also helps maintain transparency and enables the reader to also grasp the significance of findings.

Study One (n=3), included extracts from all participants across themes. By attending to both divergences and convergences, significant differences were highlighted, such as Caroline's disconnection during stability, compared to the other participants. Moreover, the formation of idiographic trajectories enabled the reader to follow each participant through each change in mood, bringing clarity and transparency to findings and conclusions.

In Study Two (n=11) a minimum of seven participants were represented in all but one theme and each included at least three quotes. Care was taken that the quotes presented were proportionately sampled and did not favour specific participants. One theme illustrated manic relapse for only three of the group but was included because it illustrated the potential fragility of all the participants' journey towards wellness.

The analysis and findings were verified through supervision during each phase of the analysis. This dynamic enabled a triangulation of perspectives, supporting the transparency of analytic procedures. Tables were viewed against the transcripts and discussed to verify how data and emergent themes had been used to construct themes and tables. At each analytic stage, the process of developing data, emergent themes and themes was discussed, reviewed and consolidated. The validity of interpretations was supported via discussion of the meaning of quotes and their relationship to the construction of themes. Paper trails of analytic steps demonstrated that the analysis had been conducted through a thorough and rigorous procedure.

#### 4. Sufficient space must be given to the elaboration of each theme

During the analysis process, I aimed to develop the idiographic depth, variability and complexity within each theme, facilitated by the quality indicators of IPA. The themes were formed through careful selection of participant quotes that progressed the theme narrative a step further and offered a distinct perspective or development. For instance, in theme one of Study Two ('Control, persecution and imprisonment'), a narrative was developed around the different experiences of interpersonal control during psychotic mania. After starting with the participants' experience of supernatural control, the narrative was developed to include different experiential elements including being under attack, being destroyed and going on the offensive. A close reading of participant quotes explored the idiographic meaning of each participant's words while situating it within the unfolding narrative. This created a coherent story around interpersonal control that progressed via interrelated quotes and idiographic meanings. In other instances, narrative coherence was built around a sequence of themes that illustrated the participants' journey through early intervention within one superordinate theme.

The close analysis of quotes and progression between time-points within a theme in Study One helped drive temporal momentum and orientate the narrative around change. This enabled the

narrative to look backwards and forwards through time, bringing to light the temporal dynamics of change and elucidating the changing relationship between the participants' immediate experience of each state.

#### 5. The analysis should be interpretative not just descriptive

Another hallmark of 'Good' IPA is the revelation of experiential meanings, but elucidation of this dynamic relies on the quality of the researcher's interpretative work and their engagement in IPA's double hermeneutic. Moving back and forth between the meaning of the participants' language in the quotes and the wider transcript helped deepen my engagement in the participants' sense-making and also awareness of my own interpretations and preconceptions. This reflects the iterative dynamic of the hermeneutic circle, enabling greater interpretative depth and nuance (Smith, 2007). Through this process, different layers of meaning attributed by the participants to their experiences came to light (Smith, 2019).

The elucidation of different levels of meaning also evolved by developing the experiential and existential significance of experiences during the write up. For instance, in Study Two, theme two ('Struggling with loss of self during aftermath'), interpretative depth was developed by elucidating the different levels of meaning related to the participants' loss of self. While all participants expressed a sense of loss after first episode, some also experienced a weak and unwanted self that intensified their sense of loss at an existential level.

A close reading of each participant's quotes, including the consideration of all facets of their language, brought to light different levels of meaning. For instance, in Study One, theme four ('Changing sense of others impacts relatedness'), the language used revealed the sense of suffering and entrapment experienced by participants and the way this structured their personal and social world. At times, multiple quotes from the same participant were used to extend and convey the meaning of this dynamic at differing experiential levels and in distinct contexts.

#### 6. The analysis should be pointing to convergence and divergence

Convergence and divergence was pivotal to creating idiographic depth and nuance, highlighting similarity and variability within and between participants and illuminating uniqueness. In Study One, this was developed through the state-by-state analysis of participant trajectories, enabling

elucidation of convergence and divergence within each state. For instance, findings highlight the inability of one participant to reconnect with relationships or regain a sense of the future during a stable state. This aspect not only brings to light idiographic depth but highlights interesting variations between participants that can be considered in relation to their unfolding experience during other states.

The use of convergence and divergence is also key to developing the flow of a coherent narrative. This dynamic reflects the power of comparison in making manifest how an experience unfolds and conveying it to the reader. The movement between unique characteristics, divergences and those aspects or higher order qualities that are shared by participants progresses the narrative and builds an illuminating account. In Study One, with a sample size of three, the interplay between convergence and divergence consistently compared two participants against one, which instilled significant depth.

In Study Two, involving 11 participants, divergence was illustrated by comparing groups of participants, while also highlighting the uniqueness of individual cases. For instance, to illustrate the higher order quality of interpersonal control during psychotic mania, two groups of participants were contrasted who experienced either omnipotence over others or persecution from others. Within each group, nuanced idiographic similarities and differences were further highlighted that helped illustrate how this experience manifested for each participant. In the unfolding narrative, the two groups were also compared with the unique experience of one participant who experienced both persecution and omnipotence during the same episode.

#### 7. The work should be carefully written

I have attempted to develop a clear and illuminating set of findings that are easily accessible to the reader. This has been facilitated by the use of clear language, a coherent narrative flow, a logical ordering of themes along with the introduction of speaker quotes and the labelling of quotes. What ties this all together, however, and presents it to the reader is a clear narrative voice which guides the reader through the time-points or narrative and signposts what is to come (Farr & Nizza, 2019).

The requirement for 'Good' IPA to be engaging and enlightening partly relies on a writing style that connects with the reader. Two aspects contributing to this endeavour were the clarity of expression and the use of language to convey the texture of the participants' experience. To sustain the reader's attention, I have attempted to create variation within the results by moving between more expressive language and nuanced inference. In this respect, significant time was devoted to honing the writing.

### Evaluating the quality of the longitudinal approach

Neale (2021) argues that the integrity of longitudinal qualitative work is reflected by its fidelity to the notion of real-time fluid enquiry which is processual and interpretative. Two interrelated dimensions are identified and these will be used to evaluate the processes and results of Study One. The first, *temporal integrity*, is 'fidelity to the real-time flux and dynamism of the world.' In practice, temporal integrity 'ensures that a dynamic and processual logic runs through the whole research process, from the way questions are framed, to the way data are generated and analysed, how findings are presented (Neale, 2021, p. 352). The second, *interpretative integrity*, 'accords priority to the generation of situated, case-rich and thick (interpretative) descriptions' that help illuminate 'real-world, lived experiences and inner logic of lives' (Neale, 2021, p. 352).

In Study One, the priority to capture the complexity and immediacy of real-time change underpinned all stages of the research process. The aim to explore the in-depth experience of BD mood change through the examination of participants' experience during each state reflected a commitment to accessing the flux and dynamism of change in BD. The use of IPA in this endeavour prioritised the generation of rich interpretative and idiographic accounts of participants' experience of change.

Close attention was paid to temporal dynamics during the development of the interview schedules. The first section of the interview explored how the participants felt at the time, encouraging them to express their current experience of themselves, other people and their world. Focusing questions on the experience of their current state, rather than how they had changed, helped access their more immediate awareness of themselves. Temporal focus, use of prompts and active listening helped access rich descriptions of the participants' experiences embedded in real-time.

Later questions on changes in state precipitated a more reflective and comparative perspective, encouraging participants to look backwards and forwards through time. However, the decision to use the same schedule during different states and time-points avoided the presumption of change within the research process. Instead, the analysis of change was able to evolve through the interpretative comparison of experiences during distinct states.

Key features of the interpretative analytic process prioritised the elucidation of temporal dynamics. The idiographic cross-sectional analysis of each participant's state was the basis for the formation of idiographic trajectories. By making manifest the significance of experiences during each state, it became possible to see how they interrelated through time. This required a shift in view from first examining the meaning of an experience at the time to exploring its significance through time and in relation to past states or future expectations. The systematic analytic process and the scrutiny of quotes helped ensure that these iterations are rooted in the real-time experiences of participants.

Engagement in IPA's double-hermeneutic throughout this process, along with an iterative checking of emerging interpretations revealed significant temporal relationships. The idiographic interpretative approach is pivotal in enabling a clear sight of the temporal interrelationship between states, underpinning the process of change.

The decision to present the write up as state by state rather than by participant trajectory helped capture the temporal texture of the changes in state that were often extreme and dislocated rather than gradual.

## Research limitations

Study findings need to be considered within the following limitations. First, given the homogenous sampling and small sample size, the claims made may be specific to a limited context and may not be generalisable. All the participants in Study One are female, making this essentially an account of the female experience of mood change. Some studies show differences in the clinical course as well as outcomes of BD in individuals with male versus female gender, including higher incidence of depression in women than men and a higher frequency in women of attempted or completed suicide (Clements et al., 2013; Nivoli et al., 2011). It seems that

women also place a higher value on social support and maintaining relationships, whereas men with BD have relationships that are perceived to be of lower value (Kriegshauser et al., 2010). In view of this, the dimensions of change emphasised by participants in Study One may be different for men and the transferability of the findings to males should be treated with caution.

The context of the study meant that the experiences of participants were limited to those within NHS services and may not reflect the experiences of people outside services who do not have access to psychotherapeutic interventions or medication. While Study Two offers positive illustration of the journey after first episode BD within EI services, the significance of findings is difficult to gauge without some knowledge of how people manage outside services, which is currently not known. Participants were recruited by practitioners within the service which could provide a bias toward a more positive view of the service: when recruiting within services power dynamics are likely particularly when conducting research with vulnerable groups. Therefore, the transferability of findings to those not invited, or who declined to participate, is not known.

The claims of Study One may be limited to a specific temporal context. Notably, the data collected was limited to a few weeks or months and may not reflect the experience of change across longer time scales or a higher number of episodes. It is important to consider that the data reported for mania was not drawn from the participants' experience during this state and therefore may fall short of expressing certain aspects of a person's real-time experience of being in this state.

### Suggestions for future research

Findings highlight several areas for future research including the experience of mood change longitudinally during the early stages of BD. Idiographic longitudinal work provides a clear picture of the journey of change, thus informing the type of interventions that help manage it and prevent it. Future studies also need to explore the male experience of the process of mood change which is currently not known.

Given the prominence of identity challenges in the results, more work is required to explore how self-acceptance can be promoted for people with BD. A better understanding is needed of the relationship between accepting and resisting BD moods as part of the self. While this is likely to

be complex and dynamic, it seems important to understanding how to support the achievement of identity coherence over time.

Considerable future research is needed to assess and evaluate whether existing EI service models and interventions are optimal for people with BD and first episode psychotic mania. Work is required to understand better the efficacy of individual psychological interventions, such as CBT and family interventions for this specific group, compared to others with first episode psychosis. Though some work has started to evaluate CBT tailored for early-stage BD, more is required to compare outcomes with existing models. Goal-setting and occupational interventions in EI contexts need to be explored to better understand both the benefits and risks of these approaches for people with BD.

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# Appendices

## Appendix 1A: Ethics approval letters for study one and two

  
**Health Research Authority**  
 London - Camden & Kings Cross Research Ethics Committee  
 Room 001  
 Jarrow Business Centre  
 Rolling Mill Road  
 Jarrow  
 Tyne & Wear  
 NE32 3DT  
 Telephone: 0191 4283548

06 January 2016

Ms Joanna Farr  
 PhD Student and Honorary Assistant Psychologist  
 CNWL NHS Foundation Trust  
 Park Royal Centre for Mental Health  
 Central Way  
 NW10 7NS

Dear Ms Farr

**Study title:** An exploration of the experience of mood episodes for individuals diagnosed with bipolar disorder and the relationship of these experiences with their sense of themselves, other people and their environment.

**REC reference:** 15/LO/1875

**Protocol number:** n/a

**IRAS project ID:** 186814

Thank you for your letter of 24<sup>th</sup> December 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Christie Ord, [nrescommittee.london-camdenandkingscross@nhs.net](mailto:nrescommittee.london-camdenandkingscross@nhs.net).

### Confirmation of ethical opinion

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

### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of

the study.

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

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

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

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

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

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

### **Registration of Clinical Trials**

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

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

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

If a sponsor wishes to contest the need for [registration](#) they should contact Catherine ~~Blewett~~ Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

### **Ethical review of research sites**

#### **NHS sites**

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

"Conditions of the favourable opinion" below).

### Approved documents

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

Document	Version	Date
Copies of advertisement materials for research participants [Participant publicity flyer for participant identification centre]	0.1	10 August 2015
Covering letter on headed paper [Covering Letter]	0.1	08 October 2015
Evidence of Sponsor insurance or indemnity ( <a href="#">non-NHS</a> Sponsors only) [Birkbeck (sponsor) insurance certificate]	0.1	
GP/consultant information sheets or letters [Letter to participant's GP]	0.1	09 September 2015
Interview schedules or topic guides for participants [Interview schedule - (Experience of mood episodes for people diagnosed with bipolar disorder)]	4.0	01 October 2015
IRAS Checklist XML [Checklist_09102015]		08 October 2015
Letters of invitation to participant [Letter to participant from clinician]	0.1	08 August 2015
Other [Birkbeck University ethics approval certificate]	1	02 September 2015
Other [Cover letter]		22 December 2015
Participant consent form [Consent form (The experience of mood episodes for people diagnosed with bipolar <a href="#">disorder</a> .)]	0.2	20 December 2015
Participant information sheet (PIS) [Participant information sheet]	0.2	20 December 2015
REC Application Form [REC_Form_09102015]		09 October 2015
Referee's report or other scientific critique report [Independent scientific peer review <a href="#">report</a> .]	0.1	05 October 2015
Research protocol or project proposal [Study Protocol - Experience of mood episodes for people diagnosed with bipolar disorder]	0.4	08 October 2015
Summary CV for Chief Investigator (CI) [CV Chief Investigator]	0.1	
Summary CV for supervisor (student research) [Academic supervisor NHS CV]	0.1	08 October 2015
Summary, synopsis or diagram (flowchart) of protocol in <a href="#">non technical</a> language [Protocol (version 0.4) flow chart]	0.1	05 October 2015
Validated questionnaire [Altman self-rating mania questionnaire]	0.1	09 August 2015
Validated questionnaire [Beck depression inventory self-report questionnaire]	0.1	09 August 2015

### Statement of compliance

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

## After ethical review

### Reporting requirements

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

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

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

### User Feedback

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

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

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

15/LO/1875
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Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



pp

**Mrs Rosie ~~Glazebrook~~**  
Chair

[Email:nrescommittee.london-camdenandkingscross@nhs.net](mailto:nrescommittee.london-camdenandkingscross@nhs.net)

Enclosures: "After ethical review – guidance for researchers"



**Departmental Ethics Committee  
DEPARTMENT OF PSYCHOLOGICAL SCIENCES  
BIRKBECK COLLEGE UNIVERSITY OF LONDON**

**CLASSIFICATION OF RESEARCH PROPOSAL**

**Date of approval:** September 2015  
**Investigator:** Joanna Farr and Jonathan Smith  
**Reference Number:** 141579  
**Title of project:** The phenomenology of moods in bipolar disorder

Dear Joanna and Jonathan

The above application has been given ethical approval by the departmental ethics committee.

You should be aware that it is your responsibility to report any unexpected problems or events arising from the research which might have adverse consequences for you and/or your participants. In the first instance, please discuss with your supervisor who will advise you as to whether the problem causes a change to the planned research and needs further ethical approval from the committee. If so, please submit a revised application giving details of why this is necessary.

Approval for this study expires September 2018. If the study is still ongoing at this time please submit a renewal of ethical approval form which can be found on the departmental webpage.

Please retain this certificate for your records.

Good luck with the research.

Virginia Eatough  
 Chair of the departmental ethics committee  
 Date: 02-09-2015

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 Sciences

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**Appendix 1B: Minor amendment approvals:**

Dear Joanna



<b>IRAS Project ID:</b>	186814
<b>Short Study Title:</b>	Experience of mood episodes for people diagnosed with bipolar disorder
<b>Date complete amendment submission received:</b>	19th January 2017
<b>Amendment No./ Sponsor Ref:</b>	Amendment 1.1 - 17th January 2017
<b>Amendment Date:</b>	17th January 2017
<b>Amendment Type:</b>	Non-substantial

Thank you for submitting the above referenced amendment. In line with the [UK Process for Handling UK Study Amendments](#) I can confirm that this amendment has been categorised as:

**Category C** - An amendment that has no implications that require management or oversight by the participating NHS organisations

As such, the sponsor may implement this amendment **as soon as any relevant regulatory approvals are in place** (for participating organisations in England, please see 'Confirmation of Assessment Arrangements' below).

As Chief Investigator/Sponsor, it remains your responsibility to ensure that the research management offices and local research teams (if applicable) at each of your participating organisations are informed of this amendment.

**Note:** you may only implement changes described in the amendment notice or letter.

Dear Ms Farr,



<b>IRAS Project ID:</b>	186814
<b>Short Study Title:</b>	Experience of mood episodes for people diagnosed with bipolar disorder
<b>Date complete amendment submission received:</b>	4 April 2019
<b>Amendment No./ Sponsor Ref:</b>	Amendment 2
<b>Amendment Date:</b>	04 April 2019
<b>Amendment Type:</b>	Non-substantial
<b>Outcome of HRA and HCRW Assessment</b>	<b>This email also constitutes HRA and HCRW Approval for the amendment, and you should not expect anything further.</b>
<b>Implementation date in NHS organisations in England and Wales</b>	35 days from date amendment <u>information together</u> with this email, is supplied to participating organisations ( <b>providing conditions are met</b> )
<b>For NHS/HSC R&amp;D Office information</b>	
<b>Amendment Category</b>	<b>A</b>

Thank you for submitting an amendment to your project. We have now categorised your amendment and please find this, as well as other relevant information, in the table above.

#### Appendix 1C: Participant Information Sheet



Central and North West London   
NHS Foundation Trust

### PARTICIPANT INFORMATION SHEET

**Title of study: The personal experience of mood episodes for people diagnosed with bipolar disorder**

Before you decide to take part in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

## **Why is the research being done?**

Little is currently known about people's own feelings and experiences of living with bipolar disorder condition. This study aims to further the understanding of people's personal experience of living with bipolar disorder. We are interested in how people experience different moods over time and how their moods impact on their wider life. To be able to do this we need to interview people at different times because this gives us a more realistic picture of what it is like for a person to live with this condition.

This study is being done as part of a PhD in the Department of Psychological Sciences, Birkbeck University of London. The study has received ethical approval from NHS and University committees.

## **Why You?**

You have been approached for this study because you have experience of living with bipolar disorder and therefore are able to contribute to this study by describing your own insights and experiences.

## **What does participating in the study involve?**

a. Three interviews with the same researcher during the following mood states:

- 1) Depressed Mood
- 2) Stable Mood
- 3) Manic Mood

b. The interviews would take place in a private room at Park Royal Centre for Mental Health / Brondesbury Road Community Mental Health Centre (\*delete as appropriate), will take approximately 1 hour and will be audio-recorded. A 5 minute assessment will also be done to check your mood level at the time of interview.

c. Reasonable transportation costs will be covered to and from the interview.

## **Staying in contact during the study?**

We will need to stay in contact with you during the study so that we can interview you during different mood states. We will do this in the following ways:

a. During the first meeting, the researcher will establish how you would like us to stay in contact with you during the study, for example; by phone, text message or email.

b. We will maintain contact with you via your regular appointments.

c. If you think it would be helpful, the researcher can meet with you along with a family member or friend, to explain the study so that they can help you to remember to make contact with the researcher at the appropriate time.

### **What are the possible benefits or risks of taking part?**

Participating in an interview can be a liberating experience that gives you the opportunity to discuss your own concerns. The interview is also managed to minimise the risk of feeling uncomfortable or upset. You will be encouraged to discuss your own concerns and only answer questions you are comfortable with. You are also free to stop the interview at any time.

If you become upset during the interview a member of the healthcare team will be available at the site to provide support and advise to you. They will also assess what further action may need to be taken. The clinical supervisor of the study will also be informed to ensure appropriate follow up.

### **My confidentiality?**

Nobody outside your existing healthcare team will have access to your medical records. All information will be treated with the upmost confidentiality . A participant code will be attached to the written transcription of your interview and a pseudonym will be used in place of your name to guarantee that your identity remains anonymous. Any identifiable data will be held securely at the researcher's university site and will only be accessed the researcher. On completion of the study all the data will be destroyed.

### **My consent ?**

My written consent will be will be requested to participate in part 1 of the study. Prior to the interviews conducted during a mood episode, the researcher will check your capacity to consent. We do not expect that you will not be able to give consent at any point. However, if there is any doubt over your capacity to consent then the interview will not be conducted and any existing data will not be retained. You may also withdraw consent for the study up to three months after the interview without giving any reason. If you wish to do this you need to contact the researcher.

### **What will happen to my interview data?**

Your anonymised interview data may be included in conferences on mental health and research publications and a PhD thesis.

### ***Further information and study contact details:***

Please contact the researcher, Joanna Farr, Email: joanna.farr@nhs.net or telephone: (*number: TBC*) if you would like further information.

### ***Complaint procedure:***

If you have a complaint please contact the supervisor of the study, Jonathan Smith, Rm 529, Birkbeck University of London, Malet Street, London WC1E 7HX. Email: ja.smith@bbk.ac.uk.

**Appendix 1D: Participant Consent Form****Central and North West London**   
NHS Foundation Trust**CONSENT FORM****Title of project: The experience of moods for people diagnosed with bipolar disorder****Name of researcher: Joanna Farr**

- |    |  | <b>Please initial<br/>box</b> |
|----|--|-------------------------------|
| 1) | I confirm that I have read the information sheet dated 14/12/2015 (version 0.2) for the study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/>      |
| 2) | I understand that my participation is voluntary, does not affect my medical care or my legal rights.   | <input type="checkbox"/>      |
| 3) | I understand that I can refuse to answer any specific questions without giving reason at any time.   | <input type="checkbox"/>      |
| 4) | I understand I have the right to stop the interview at any point and can withdraw from the study up to 3 months after the interview without giving any reason.   | <input type="checkbox"/>      |
| 5) | Should I indicate a desire to hurt myself or others during interview I understand that this may lead to a breach in confidentiality.   | <input type="checkbox"/>      |
| 6) | I understand that relevant sections of anonymised data collected during my interview may be looked at by members of the research team.   | <input type="checkbox"/>      |
| 7) | I agree to my General Practitioner being informed of my participation in the study.  | <input type="checkbox"/>      |
| 8) | I agree that my interview will be audio-recorded and stored securely at the researcher's university site.  | <input type="checkbox"/>      |

- 9) I understand that my data may be presented in publicly available literature. If any individual data is presented, the data will be totally anonymous, without any means of identifying the people involved
- 10) I agree to taking part in a feedback group to discuss the results at the end of the study but understand that this is voluntary.
- 11) I agree to take part in this study

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

### **Appendix 2A:** Beck depression inventory self-report questionnaire

#### Sadness

0. I do not feel sad.
1. I feel sad much of the time.
2. I am sad all the time.
3. I am so sad or unhappy that I can't stand it.

#### Pessimism

0. I am not discouraged about my future.
1. I feel more discouraged about my future than I used to be.
2. I do not expect things to work out for me.
3. I feel my future is hopeless and will only get worse.

#### Past Failure

0. I do not feel like a failure.
1. I have failed more than I should have.
2. As I look back I see a lot of failures.
3. I feel I am a total failure as a person.

#### Loss of Pleasure

0. I get as much pleasure as I ever did from the things I enjoy.
1. I don't enjoy things as much as I used to.
2. I get very little pleasure from the things I used to enjoy.

3. I can't get any pleasure from the things I used to enjoy.

#### Guilty Feelings

1. I don't feel particularly guilty.
2. I feel guilty over many things I have done or should have done.
3. I feel guilty most of the time.
4. I feel guilty all the time.

#### Punishment Feelings

1. I don't feel I am being punished.
2. I feel I may be punished.
3. I expect to be punished.
4. I feel I am being punished.

#### Self-Dislike

0. I feel the same about myself as ever.
1. I have lost confidence in myself.
2. I am disappointed in myself.
3. I dislike myself.

#### Self-Criticalness

0. I don't criticize or blame myself more than usual.
1. I am more critical of myself than I used to be.
2. I criticize myself for all of my faults.
3. I blame myself for everything bad that happens.

#### Suicidal Thoughts or Wishes

0. I don't have any thoughts of killing myself.
1. I have thoughts of killing myself, but I would not carry them out.
2. I would like to kill myself.
3. I would kill myself if I had the chance.

#### Crying

0. I don't cry anymore than I used to.
1. I cry more than I used to.
2. I cry over every little thing.
3. I feel like crying, but I can't.

#### Agitation

0. I am no more restless or wound up than usual.
1. I feel more restless or wound up than usual.
2. I am so restless or agitated that it's hard to stay still.
3. I am so restless or agitated that I have to keep moving or doing something.

#### Loss of Interest

0. I have not lost interest in other people or activities.
1. I am less interested in other people or things than before.
2. I have lost most of my interest in other people or things.
3. It's hard to get interested in anything.

#### Indecisiveness

0. I make decisions about as well as ever.
1. I find it is more difficult to make decisions than usual.
2. I have much greater difficulty in making decisions than I used to.
3. I have trouble making any decisions.

#### Worthlessness

0. I do not feel I am worthless.
1. I don't consider myself as worthwhile and useful as I used to.
2. I feel more worthless as compare to other people.
3. I feel utterly worthless.

#### Loss of Energy

0. I have as much energy as ever.
1. I have less energy than I used to have.
2. I don't have enough energy to do very much.
3. I don't have enough energy to do anything.

#### Changes in Sleeping Pattern

0. I have not experienced any change in my sleeping pattern.
1. I sleep somewhat less than usual. –or– I sleep somewhat more than usual.
2. I sleep a lot less than usual. –or– I sleep a lot more than usual.
3. I sleep most of the day. –or– I wake up 1-2 hours early and can't get back to sleep.

#### Irritability

0. I am no more irritable than usual.
1. I am more irritable than usual.
2. I am much more irritable than usual.
3. I am irritable all the time.

#### Changes in Appetite

0. I have not experienced any change in my appetite.
1. My appetite is somewhat less than usual. –or– My appetite is somewhat greater than usual.
2. My appetite is much less than usual. –or– My appetite is much greater than usual.
3. I have no appetite at all. –or– I crave food all the time.

#### Concentration Difficulty

0. I can concentrate as well as ever.
1. I can't concentrate as well as usual.
2. It's hard to keep my mind on anything for very long.
3. I find I can't concentrate on anything.

#### Tiredness or Fatigue

0. I am no more tired or fatigued than usual.
1. I get more tired or fatigued more easily than usual.
2. I am too tired or fatigued to do a lot of the things I used to do.
3. I am too tired or fatigued to do most of the things I used to do.

#### Loss of Interest in Sex

- 0. I have not noticed any recent change in my interest in sex.
- 1. I am less interested in sex than I used to be.
- 2. I am much less interested in sex now.
- 3. I have lost interest in sex completely.

#### Sadness

- 0. I do not feel sad.
- 1. I feel sad much of the time.
- 2. I am sad all the time.
- 3. I am so sad or unhappy that I can't stand it.

#### Pessimism

- 0. I am not discouraged about my future.
- 1. I feel more discouraged about my future than I used to be.
- 2. I do not expect things to work out for me.
- 3. I feel my future is hopeless and will only get worse.

#### Past Failure

- 0. I do not feel like a failure.
- 1. I have failed more than I should have.
- 2. As I look back I see a lot of failures.
- 3. I feel I am a total failure as a person.

#### Loss of Pleasure

- 0. I get as much pleasure as I ever did from the things I enjoy.
- 1. I don't enjoy things as much as I used to.
- 2. I get very little pleasure from the things I used to enjoy.
- 3. I can't get any pleasure from the things I used to enjoy.

#### Guilty Feelings

- 1. I don't feel particularly guilty.
- 2. I feel guilty over many things I have done or should have done.
- 3. I feel guilty most of the time.
- 4. I feel guilty all the time.

#### Punishment Feelings

- 1. I don't feel I am being punished.
- 2. I feel I may be punished.
- 3. I expect to be punished.
- 4. I feel I am being punished.

#### Self-Dislike

- 0. I feel the same about myself as ever.
- 1. I have lost confidence in myself.
- 2. I am disappointed in myself.
- 3. I dislike myself.

#### Self-Criticalness

- 0. I don't criticize or blame myself more than usual.
- 1. I am more critical of myself than I used to be.

2. I criticize myself for all of my faults.
3. I blame myself for everything bad than happens.

#### Suicidal Thoughts or Wishes

0. I don't have any thoughts of killing myself.
  1. I have thoughts of killing myself, but I would not carry them out.
  2. I would like to kill myself.
  3. I would kill myself if I had the chance.

#### Crying

0. I don't cry anymore than I used to.
  1. I cry more than I used to.
  2. I cry over every little thing.
  3. I feel like crying, but I can't.

#### Agitation

0. I am no more restless or wound up than usual.
  1. I feel more restless or wound up than usual.
  2. I am so restless or agitated that it's hard to stay still.
  3. I am so restless or agitated that I have to keep moving or doing something.

#### Loss of Interest

0. I have not lost interest in other people or activities.
  1. I am less interested in other people or things than before.
  2. I have lost most of my interest in other people or things.
  3. It's hard to get interested in anything.

#### Indecisiveness

0. I make decisions about as well as ever.
  1. I find it is more difficult to make decisions than usual.
  2. I have much greater difficulty in making decisions than I used to.
  3. I have trouble making any decisions.

#### Worthlessness

0. I do not feel I am worthless.
  1. I don't consider myself as worthwhile and useful as I used to.
  2. I feel more worthless as compare to other people.
  3. I feel utterly worthless.

#### Loss of Energy

0. I have as much energy as ever.
  1. I have less energy than I used to have.
  2. I don't have enough energy to do very much.
  3. I don't have enough energy to do anything.

#### Changes in Sleeping Pattern

0. I have not experienced any change in my sleeping pattern.
  1. I sleep somewhat less than usual. –or– I sleep somewhat more than usual.
  2. I sleep a lot less than usual. –or– I sleep a lot more than usual.
  3. I sleep most of the day. –or– I wake up 1-2 hours early and can't get back to sleep.

**Irritability**

- 0. I am no more irritable than usual.
- 1. I am more irritable than usual.
- 2. I am much more irritable than usual.
- 3. I am irritable all the time.

**Changes in Appetite**

- 0. I have not experienced any change in my appetite.
- 1. My appetite is somewhat less than usual. –or– My appetite is somewhat greater than usual.
- 2. My appetite is much less than usual. –or– My appetite is much greater than usual.
- 3. I have no appetite at all. –or– I crave food all the time.

**Concentration Difficulty**

- 0. I can concentrate as well as ever.
- 1. I can't concentrate as well as usual.
- 2. It's hard to keep my mind on anything for very long.
- 3. I find I can't concentrate on anything.

**Tiredness or Fatigue**

- 0. I am no more tired or fatigued than usual.
- 1. I get more tired or fatigued more easily than usual.
- 2. I am too tired or fatigued to do a lot of the things I used to do.
- 3. I am too tired or fatigued to do most of the things I used to do.

**Loss of Interest in Sex**

- 0. I have not noticed any recent change in my interest in sex.
- 1. I am less interested in sex than I used to be.
- 2. I am much less interested in sex now.
- 3. I have lost interest in sex completely.

**Appendix 2B: Altman self-rating mania questionnaire****1. Positive Mood**

- I do not feel happier or more cheerful than usual.
- I occasionally feel happier or more cheerful than usual.
- I often feel happier or more cheerful than usual.
- I feel happier or more cheerful than usual most of the time.
- I feel happier or more cheerful than usual all of the time.

**2. Self-Confidence**

- I do not feel more self-confident than usual.

- I occasionally feel more self-confident than usual.
- I often feel more self-confident than usual.
- I feel more self-confident than usual.
- I feel extremely self-confident all of the time.

### 3. Sleep Patterns

- I do not need less sleep than usual.
- I occasionally need less sleep than usual.
- I often need less sleep than usual.
- I frequently need less sleep than usual.
- I can go all day and night without any sleep and still not feel tired.

### 4. Speech

- I do not talk more than usual.
- I occasionally talk more than usual.
- I often talk more than usual.
- I frequently talk more than usual.
- I talk constantly and cannot be interrupted.

### 5. Activity Level

- I have not been more active (either socially, sexually, at work, home or school) than usual.
- I have occasionally been more active than usual.
- I have often been more active than usual.
- I have frequently been more active than usual.
- I am constantly active or on the go all the time.

### 6. Positive Mood

- I do not feel happier or more cheerful than usual.
- I occasionally feel happier or more cheerful than usual.
- I often feel happier or more cheerful than usual.
- I feel happier or more cheerful than usual most of the time.
- I feel happier or more cheerful than usual all of the time.

### 7. Self-Confidence

- I do not feel more self-confident than usual.
- I occasionally feel more self-confident than usual.
- I often feel more self-confident than usual.
- I feel more self-confident than usual.
- I feel extremely self-confident all of the time.

**8. Sleep Patterns**

- I do not need less sleep than usual.
- I occasionally need less sleep than usual.
- I often need less sleep than usual.
- I frequently need less sleep than usual.
- I can go all day and night without any sleep and still not feel tired.

**9. Speech**

- I do not talk more than usual.
- I occasionally talk more than usual.
- I often talk more than usual.
- I frequently talk more than usual.
- I talk constantly and cannot be interrupted.

**10. Activity Level**

- I have not been more active (either socially, sexually, at work, home or school) than usual.
- I have occasionally been more active than usual.
- I have often been more active than usual.
- I have frequently been more active than usual.
- I am constantly active or on the go all the time.

**Appendix 3A:** Participant details for study two

Participant	Diagnosis	Time from first episode to interview	Sectioning information	First contact with care coordinator	Depression after first episode (Yes/No)	Psychological therapy (CBT)	Family therapy	Employment occupational therapist	Group art therapy	Relapse
Edward (P1) 22	Bipolar Affective Disorder F312	20 months	Involuntary section for 2 months (first episode)	When sectioned	Yes (8 months)	Yes	No	No	No	No
Alex (P2) 27	Bipolar Affective Disorder F312	19 months	Involuntary section for 4 months, first episode	When sectioned	Yes	Yes	No	No (care coordinator tackled employment)	No	No
Jane (P3) 25	Bipolar Affective Disorder F312	20 months	Involuntary section for two months, first episode	When sectioned	Yes (6 months)	Yes	Yes	No	No	No
Dave (P4) 26	Bipolar Affective Disorder F312	20 months	Involuntary section 2 months, first episode	When sectioned	No	Yes	No	Yes	No	Yes
Karen (P5) 32	Bipolar Affective Disorder F312	12 months	Involuntary section (4 months), first episode	When sectioned	Yes (after a few months of being OK)	On waiting list for psychology	No	Yes (just started)	Yes	No

Participant	Diagnosis	Time from first episode to interview	Sectioning information	First contact with care coordinator	Depression after first episode (Yes/No)	Psychological therapy (CBT)	Family therapy	Employment occupational therapist	Group art therapy	Relapse
Steve (P6) 30	Bipolar Affective Disorder F312	14 months	Involuntary section for 6 weeks, first episode	When sectioned	Yes (several months)	No	No	Yes	Yes	No
Jenna (P7) 24	Bipolar Affective Disorder F312	24 months	Involuntary section (4 weeks), first episode	Assigned to early intervention team after discharge	Low periods but no distinct depressive episode	Yes	No	No (returned to work 8 weeks after discharge)	No	No
Joel (P8) 26	Bipolar Affective Disorder F312	14 months	Involuntary section	Assigned to early intervention after discharge	Low periods	No	No	No	Yes	No
Craig (P10) 35	Bipolar Affective Disorder F312	10 months	Involuntary section, 4 months, first episode	When sectioned	Low periods	Yes (CBT & psychotherapy)	Yes	No	No	No
Eric (P10) 21	Bipolar Affective Disorder F312	10 months	Sectioned voluntarily during depression AFTER first episode (suicide attempt)	After discharge	Yes (severe depression lead to hospitalisation)	Waiting for therapy	Too early	Too early	Too early	Yes
Liam (P11) 24	Bipolar Affective Disorder (psychotic features) F312	15 months	Involuntary section, 1 month, first episode	When sectioned	Yes (severe episode)	Yes (CBT)	No	Yes	Tbc	Yes

**Appendix 3B:** Ethics approval letter for major amendment (study two)

  
**Health Research  
 Authority**  
 London - Camden & Kings Cross Research Ethics Committee  
 Jarrow Business Centre  
 Rolling Mill Road  
 Jarrow  
 NE32 3DT  
 Tel: 0207 104 8117

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

23 January 2018

Ms Joanna Farr  
 Department of Psychological Sciences  
 Birkbeck University of London  
 Malet Street  
 London  
 TW11 9JS

Dear Ms Farr

<b>Study title:</b>	<b>An exploration of the experience of mood episodes for individuals diagnosed with bipolar disorder and the relationship of these experiences with their sense of themselves, other people and their environment.</b>
<b>REC reference:</b>	<b>15/LO/1875</b>
<b>Protocol number:</b>	<b>n/a</b>
<b>Amendment number:</b>	<b>SA1</b>
<b>Amendment date:</b>	<b>20 December 2017</b>
<b>IRAS project ID:</b>	<b>186814</b>

The above amendment was reviewed at the meeting of the Sub-Committee held in correspondence.

**Summary of amendment**

This substantial amendment was submitted to seek approval to add an additional research question, to interview eight participants on two occasions, to add an additional six participants, and to revise the consent process. This amendment was also submitted to add two new sites hosted by East London Foundation Trust, Tower Hamlets Early Intervention Service (Under 35's) and Equip team: Hackney and City Early Intervention Service (Under 35's). Due to these changes the protocol, participant information sheets and consent forms were updated.

### Ethical opinion

The Sub-Committee did not raise any ethical issues.

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

### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview schedules or topic guides for participants [Interview schedule]	0.5	20 December 2017
Notice of Substantial Amendment (non-CTIMP) [Substantial amendment form]	SA1	20 December 2017
Participant consent form [Consent form 2 - tracked]	0.3-2	20 December 2017
Participant consent form [Consent form 1 - tracked]	0.3-1	20 December 2017
Participant information sheet (PIS) [Participant information sheet 2 - tracked]	0.3-2	20 December 2017
Participant information sheet (PIS) [Participant information sheet 1 - tracked]	0.3-1	20 December 2017
Research protocol or project proposal [Protocol - tracked]	0.7	20 December 2017

### Membership of the Committee

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

### Working with NHS Care Organisations

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

### Statement of compliance

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

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

<b>15/LO/1875:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely  
pp



**Ms Eleni Yerolaki**  
Vice Chair

E-mail: [nrescommittee.london-camdenandkingcross@nhs.net](mailto:nrescommittee.london-camdenandkingcross@nhs.net)

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

*Copy to: Ms Angela Williams, Noclor*

**Appendix 3C: HRA approval for the study**

Ms Joanna Farr  
 PhD Student and Honorary Assistant Psychologist  
 CNWL NHS Foundation Trust  
 Park Royal Centre for Mental Health  
 Central Way  
 NW10 7NS

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

05 February 2018

Dear Ms Farr

**Letter of HRA Approval for a study processed  
 through pre-HRA Approval systems**

**Study title:** An exploration of the experience of mood episodes for individuals diagnosed with bipolar disorder and the relationship of these experiences with their sense of themselves, other people and their environment.

**IRAS project ID:** 186814

**Sponsor** Birkbeck University of London

Thank you for your request to bring the above referenced study, processed under pre-HRA Approval systems, under HRA Approval.

I am pleased to confirm that the study has been given **HRA Approval**. This has been issued on the basis of an existing assessment of regulatory compliance, which has confirmed that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

**Participation of NHS Organisations in England**

Please note that full information to enable set up of participating NHS organisations in England is not provided in this letter, on the basis that activities to set up these NHS organisations is likely to be underway already.

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are

being set up in accordance with [HRA Approval Processes](#). It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package provided to NHS organisations should include an appropriate [Statement of Activities and HRA Schedule of Events](#). The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and Schedule of Events for this study have not been validated by the HRA, but the HRA expects that the sponsor provides these to participating NHS organisations. Any changes that are appropriate to the content of the Statement of Activities and Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study.

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

If subsequent NHS organisations in England are added, an amendment should be submitted to the HRA.

### **After HRA Approval**

In addition to the document, "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval.

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

IRAS project ID	186814
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**Scope**

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

**User Feedback**

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

**HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>.

Your IRAS project ID is 186814. Please quote this on all correspondence.

Yours sincerely

HRA Assessment Team

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Professor Jonathan Smith, Birkbeck University of London  
Ms Angela Williams, Noclor*

### Appendix 3D: Research passport for study two



1<sup>st</sup> Floor, Bloomsbury Building  
St Pancras Hospital  
4St Pancras Way  
London, NW1 0PE  
Tel: 020 3317 3046  
Fax: 020 7685 5830  
Email: [contact.noclor@nhs.net](mailto:contact.noclor@nhs.net)  
[www.noclor.nhs.uk](http://www.noclor.nhs.uk)  
09 April 2018

Ms. Joanna Elizabeth Farr  
Birkbeck University of London  
Malet Street  
Bloomsbury  
WC1E 7HX

Dear Ms Joanna Elizabeth Farr,

**Employer:** Birkbeck University of London  
**Accountable to:** Professor J.A Smith

This letter confirms your right of access to conduct research through the trust(s) identified in the box below, for the purpose and under the terms and conditions set out in page 2 & page 3.

<b>Study Title:</b> An exploration of the experience of mood episodes for individuals diagnosed with bipolar disorder and the relationship of these experiences with their sense of themselves, other people and their environment		
<b>R&amp;D reference:</b> 186814		
<b>REC reference:</b> 15/LO/1875		
<b>Letter of access duration:</b>	<b>Start date:</b> 09/04/2018	<b>End date:</b> 01/03/2020
East London NHS Foundation Trust	--	--
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<i>If any information on this document is altered after the date of issue, this document will be deemed INVALID</i>		

Yours sincerely,

Mabel Saill  
Research Management & Governance Manager

**Appendix 3E: Full version of master table of themes for study two****First episode psychotic mania: control, persecution and imprisonment**Conjuring powerful and persecuted states of self

- Eric: It literally felt like a form of power, the idea that somehow been gifted and my responsibility to use it
- Craig: Epitome, the highest point of being alive, I guess in regards to feeling free
- Alex: Freer than the best of them, just going to another country on a whim
- Steve: Evil spirits trying to get me, and then um finding ways to hide [...] if I stood still under an open sky they wouldn't be able to see me
- Dave: Everybody's after you, don't know who you can trust [...] fearing they'll come down on you
- Liam: The president of something, like of America as trying to kill me, kill my family
- Jenna: I was some sort of a, witch, or a good witch or whatever was going through my head [...] I was imagining that I'm some sort of person with special powers.
- Karen: My anger, it just felt like 'the scream' [the painting], you know, a furious scream at like everyone...it's like not being understood
- Joel: Inside this basement, there's a very, very dark person, beast, it's a beast, the beast comes out, and when the beast comes out, it's unexpected, it doesn't announce that it's coming out, it just pops out.

Imprisoned, restricted and depersonalised

- Craig: Put in a straight-jacket in the hospital and there's like - 'no, you're not free and no, you're not allowed to go outside for more than an hour
- Alex: Super aggressive pulled me to the ground tried to turn like my face forward you know, like, you know I'm a piece of nothing
- Edward: like my like, liberty, my independence, had just been like taken away [...] when they like hold you down and sometimes they put like a depo or injection or something that, that was (pause) like a...a very humbling like (line 80)
- Dave: they're not gonna let me out [...] it's just you're confined, it's, your freedom's gone basically
- Jane: I was as worthy or unworthy as a dog, so much so that I kind of ate my food on my hands and knees.
- Jenna: I was in hospital, then it hit me, it, it, it, it hit me badly, I just couldn't believe I'm in a mental institution sectioned [...] to go from being a rational person at work, to being in two days taken to A&E and sectioned for me.
- Karen: People around me were all a bit weird. You know, or, sick people, it is like, err, 'One fly over Cuckoo's Nest' - you know, you, once you're there, you have to demonstrate you're not mad and all that, and it's just, you know, it's horrible

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**Struggling with loss of self during aftermath**

- Steve: I lost my complete self, so that's what I said it was death, lost my past self completely [...] all of a sudden it just (whish) burns away, that's how it felt

- Eric: literally felt like someone had come in and just cut off a part of my body and taken it and said - 'No, this isn't you anymore' [...] grieving that version of myself that had just disappeared
- Liam: I was quite suicidal [...] I was just kind of dying really, had just no idea where I'd gone
- Alex: I kind of lost the sense of what my normal self is - so it kind of skewed that for me
- Craig: be elevated to a sort of someone that's got, that's um, qualified to talk about these subjects on a global scale sort of thing [...] so when that all collapsed, then, um, that made me depressed
- Karen: It was almost like well, I burnt everything I have, as a candle, like, that calm (laughs) and it's -whooff - and it's gone [...] It's like the pure self was gone.
- Jenna: I couldn't understand what's real and what's not. Where is me? Am I the real me now? The one which is quiet, the one more calm?
- Edward: Just as this crazy, umm, this, this like, like psycho who had lost his mind
- Jane: before it happened, I was running, you know, 10k a day and then doing a yoga class every evening and at the end, then afterwards I like, I couldn't run around the block

## **Rebuilding with early intervention service**

### Piecing together the past

- Alex: Trying to make sense of all of those things, fill in the blanks [...] It was useful probably to talk about the things that have happened with someone [in service] [...] so I was able to talk about my feelings, what went, what possibly caused it and I guess I have that rapport to draw back on
- Liam: I was anxious, like, confused and you know talking about [with care coordinator], it just really helped to kind of get to a point of what had happened, unscrambled it really
- Steve: [talking to care coordinator] That's how I was able to put the pieces together, I mean, what is the significance of it all? [...] once you say something, actually it becomes, it echoes differently in your mind
- Edward: At first, I thought, ah, not that it [psychotherapy] was a waste of time [...] helped in, umm, getting me back on my feet, umm, and, you know, the ,umm, like the thought process of analysing what had happened that summer and, you know, what steps can we take to stop it from happening again
- Craig: I was so fearful about like - 'Oh, red flag!' - let's get him back into the hospital (trust change) so I sort of hide a little bit of my depression [from service], So, I built up so much confidence in Daniel [therapist] [...] knows everything about me
- Jenna: Cause, it was all new to me, I've never been diagnosed before. So, when I had the psychosis attack, this was the first time I ever knew I have bipolar disorder. So, I started to weigh it up myself to, to, see you know, what's different, how does it affect me?
- Karen: Very confusing and somewhat embarrassing and also, it's like, why is this? Why is this happening to me?
- Eric: [mania] was essentially reclaiming a lot of that control sexually that I felt like I never had when I was younger and um and then losing that all meant back I just felt like I was that 15 year old kid again

Joel: So, I've put some pieces together, and certain things do make sense in the sense that I look at the past, and I realise okay, maybe that area, that time, I was like this, I was like that, I wasn't so. I've really done that analysis. And now, I can actually look forward to the future.

### Reassessing subjective view

Liam: Able to identify negative thought patterns and like, um, a lot of like, a lot of list making and reducing my tendency to catastrophise situations

Dave: Therapy's helped me to see that they [other people] probably don't even notice [...] I'm understanding more now that's where my problem lies, cos I'm thinking like, what are they thinking about me? So, I'm over-thinking

Edward: I was thinking of things is always like glass half empty, rather than half full [...] sort of to step out of yourself and think what would someone else think, what would like, like a normal-headed person think?

Craig: You know – 'How much do you believe that [vision] at this point? And like, even right now, after having a long time to think about it and been through the process [of therapy]. I still have it at 80 to 100%, it happened

Jenner: As soon as abnormal thoughts would come back or something, I would understand that something is wrong and I would no longer chance it and think I'm powerful, you know, extra powers that I have. I would probably the first thing I would do is obviously contact Jack

Jane: They've kind of helped me to see the other me, you know, like, the better one, you know what I mean? It's just having another look really.

Steve: Yeah, I kind of think over those thoughts a bit, turn them in mind, and kind of think, well, you know, is this real, or am I just imaging it

Joel: It's a mind chatter that I do inside my brain. I need to be more... that is the sense of self inside my mind. Because there are thoughts that pop in and feelings that pop in unexpectedly, and I need to say no to those thoughts. I need to put them in a corner.

### Feeling empowered

Liam: I wouldn't have been able to do things by myself like getting PIP and having to go to... I had to go to an assessment centre in Kent and Susan, my care coordinator came with me and I wouldn't have been able to like, talk about what I was going through without her

Steve: All of a sudden I was inside, I wouldn't go out, very her-, hermetic, yeah, so um, so he wanted to, like help out. So, he's like, err - 'get up apply for this freedom pass' - so you get like freedom transports, like free transportation, wherever you want to go

Edward: I did have regular meetings with my, umm, student support team at the university and they were kept in the loop they were talking with the early intervention service here and they, so they were well aware that I was going through a very low period and err depressed periods as well where, umm, I couldn't, I was just in no mood to sit my first exam of the second year.

Jane: I felt like I was in charge [...] I felt like my opinion was definitely taken into account of what I wanted... it was never you have to take this medication.

- Alex: I think just kind of listening to what I'm saying to where I'm coming from um and not imposing or I guess, I didn't feel threatened like in that home treatment situation. I felt that I can make a decision.
- Jenna: [The service would say] It's absolutely normal for you to think like that. And um, you know, they were just always reassuring me that the way, what I'm feeling is absolutely okay and I shouldn't even be feeling like that because I need to give my body and mind time to recover.
- Karen: So, I had help [from care coordinator] on that front as well because I had to go to police station and then basically well, prove with a letter saying that okay, this is what happened with my illness

### Seeing a future

- Alex: Talking about what my ideas are, plans goals [with care coordinator] [...] kind of encouragement helping me, I guess, some points, it's kind of reality check as well, which is important.
- Edward: They were very encouraging in telling me that as long as you take care of your mental health and you will hopefully be able to, err, complete your degree and qualify as a doctor, umm, but it's very, it's paramount that you take care of your, err, mental health
- Dave: [Care coordinator] put me in touch with this employment advisor who put me in touch, cos I think cos even telling, maybe, might be telling Matt [care coordinator] that time was kinda lucky, that I didn't wanna go back to my job and then through, through, that is sort of domino effect sort of thing
- Steve: How can I start actually doing something about it [get a job]? Yeah, I've realized. So, I want to do so I want to get myself in that state of mind. So that's what we talked about. How like how I can actually get there. My, my aims and goals. You know what I mean? Right. Yeah, my plan for the future
- Liam: Like pushing me to like think about a job and she's [employment advisor] going to be there for me next year to like, get me a job, help me get a job
- Karen: He [the psychiatrist] sometimes puts my mind at rest, err, also gives me some recommendation, umm, as to how to think about things and how you should kind of try and move forward and think ahead, but also would, um, I suppose just tell me it's alright to not be moving at all (laughs).
- Jane: Just talking over what I can do, you know, maybe not immediately, but finding ways of having something I can do, cos, you know, that gives me hope really, just makes things better.

### Having a safety net

- Jane: Feeling OK is down to them (EIS team), pivotal [...]. I feel like I've been held by a great team people, different disciplines and different ways
- Edward: They were always looking out for you, umm, like, whether it be by telephone conversation or, umm, you know, whenever you came in to see them here they were, you know, the first thing they'd asked would be like – 'How's your mood?
- Karen: Like a safety net [...] so it wasn't just about the medication for me it was the other things that were quite useful to have and also the sheer knowledge, you know, she, she's there and her being there is quite a relief for me [...]

- Dave: But I think if I'm looking back in hindsight, the stuff that I've done is probably kept me more on a straight and narrow. I know if there is a crisis, you can contact them
- Liam: I had suicidal thoughts but I didn't act on them and I felt really low and confused, but that was very quickly sort of nipped in the bud here at [early intervention service 1] because I told my therapist and she was like - 'Okay, this is how we're going to deal with it'
- Joel: It's just reassuring really, just having a team behind, always checking and knowing you are...it just helps you focus on yourself and feel calmer

## **Managing wellness and relapse**

### Balancing self-renewal and staying well

- Steve: Before [...] I was just going through the waves, but now it's like, no, I'm gonna be a visual artist like that. This is my purpose. I'm gonna be Picasso
- Liam: I want to be a support worker actually, ideally [...] my mood's good, my anxiety's low, things just seem to be getting better as time goes on
- Alex: What is normal for you? So, it [extreme moods] kind of skewed that for me. But I think now, where I am, um I think there is a good level of optimism [...] now we'll find out whether teaching is something that I can really carve up as a career
- Edward: See how far I can go and, umm, hopefully I capitalise on it to make the most of my, the time I have left in medical school
- Jane: I do like a lot of aspects of myself and that's just one area that needs a substantial amount of work, but other than that I feel very happy and I would say I'm probably in a better place than I've been in many, many years, even before the episode
- Joel: If I just keep looking for those triggers, you know, paying attention and using what I know, I think I can stay on the right track, you know, make something, if that makes sense.

### Coping with compromise

- Edward: There's like some light at the end of the tunnel [...] there's a sense that, you know with as long as I take care of it, then I can, like, lead a normal life
- Dave: I'm not so paranoid, but there's still there's always I feel like there's always maybe a little niggling doubt there's always something there. So, I'd like to be free of that
- Liam: I feel like I am, I feel like maybe, I'm not as fit as I used to be [...]
- Steve: I can feel lazy at times I wish I was more of the social butterfly I used to be I'm a thinker! 'What the fuck? What the hell? Like these drugs like, Oh my god, they suppress everything I can't think!' [...] sometimes I go off of the meds just so that I can just like, be my old self.
- Craig: I can get back to how I used to be and now I'm feeling really, really like I, prior to how when I went in there [ward] [...] so seeing it [the signs] a bit of like encouragement that I'm not, that my life isn't going completely down the, the..., do you know what I mean? Generally, like a sort of thumbs up that's the way I see it.
- Jenna: You always have to question yourself, you can't just be generally happy because every single time that little happiness comes in you

think - 'Okay, hold on. Is it happy, happy? Or is it now leading me back to psychosis?'

- Karen: Since it's been broken before (laughs), who, who says it couldn't be broken again? I've obviously imagined lots of things and it all came here, and it's still here with me, you know, it just, it's just gonna, like be like, like a ticking bomb thing, umm, I just I've learned not to trust my brain a hundred per cent and for me, this is very frightening. because I have only one thinking tool and I don't know how else to process things? For me, that's a huge loss
- Jane: I just feel like that I've kind of let it all go completely, you know, I suppose I did like a part of myself when I was still in, within the episodes [...] I mean, I was not well, but I did feel like I had a bit more purpose

Change, pressure and proving self

- Eric: You need to be like, you need to be your old self for this, because otherwise you're gonna be crying on the fucking paper (laughs) [...] the only way that I could ever get back to that old version of myself is by going in and proving to people that I'm the best thing that they have ever fucking seen
- Dave: Felt too, too intense like I had to, I was doing another course in conjunction with it so it just got all on top of me then that's that thing that's what led to my second admission
- Liam: Just like the first time really, lots of stuff happening, I got out of a relationship, moved house, lost my job, just everything went up in smoke
-