

***“There’s my story of you and there’s your story of you”:***

**How clinicians, services, and systems relate to personal meaning-  
making in psychosis**

**James Kiely**

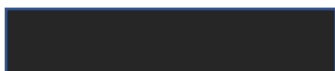
DClinPsy Thesis (Volume 1), 2023

University College London

## **UCL Doctorate in Clinical Psychology Thesis Declaration Form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

**Signature:**



**Name:** James Kiely

**Date:** 22<sup>nd</sup> May 2023

## **Overview**

This thesis explores meaning-making in psychosis within the clinical encounter of Early Intervention in Psychosis (EIP) services in the United Kingdom (UK).

Part One is a Conceptual Introduction. This provides an overview of the varied understandings of psychosis across history, spanning professional literature, service user understandings, and cultural and spiritual frameworks. It reviews the research on meaning-making within mental health services from the perspectives of both service users and professionals. This is embedded within an analysis of the importance of meaning-making to self-understanding, identity and recovery. Limitations within the existing research literature are highlighted.

Part Two is a qualitative research study which explores the process and context of meaning-making within the EIP clinical encounter. 12 EIP mental health professionals are interviewed and a grounded theory is presented across two research questions. The first research question elucidates the journey of co-constructed meaning between the EIP mental health professional and service user. The second explicates the factors and processes which facilitate this journey of meaning-making, spanning personal-professional factors, the team culture and approach, and the demands of the wider mental health system. A discussion of the results embeds the project within the wider research literature, highlighting its clinical implications. Limitations and suggestions for further research are noted.

Part Three is a Critical Reflection on the research process. This includes a discussion of the methodological and ethical issues within the project, including the application of constructivist grounded theory and the value of service user involvement.

## **Impact statement**

This thesis has several clinical implications, both for mental health professionals and the EIP teams within which they work. Throughout the conceptual introduction, meaning-making is demonstrated as an important component of service users' recovery, facilitating greater self-understanding, authorship, integration and identity-making. The empirical paper elucidates a stance and process through which professionals can engage service users collaboratively in meaning-making. This provides guidance for professionals in taking a power-sharing position, prioritising exploration of service users' meaning, and communicating plurality when offering information from the professional or team perspective. The results also highlight deviations from collaborative meaning-making which can serve as guidance for practices to be avoided.

Beyond recommendations to guide individual practitioners, the results have several implications for wider EIP teams. A range of team-level factors which facilitate meaning-making within the clinical encounter are explored. This offers direction to teams on how to foster interpersonal cultures in which meaning-making can flourish. Teams may work to create openness to varied perspectives and voices from across professional groups and positions, where there is psychological safety to take risks and challenge others without the fear of being shut down. This may be supported through flattened team hierarchies, greater access to team-thinking or reflective spaces, and the inclusion and empowerment of peer support workers.

This study highlights the need for varied perspectives held across teams, making a strong case for diversity and representation in professional groups across key social identity categories (e.g., race, ethnicity, socioeconomic status, gender identity, sexual orientation, and spirituality). The results show that where teams lack diversity and representation of varied perspectives, there can be limited knowledge about important aspects of experience and

ways of understanding. This identifies key training needs for particular professional groups, including learning about a range of lived experience perspectives, cultural frameworks, and spiritual understandings. Moreover, the study highlights that diversity represented within teams can best be accessed and shared when conceptualisations of professionalism are broad and inclusive. This has implications for the ways that individual clinicians and teams define and understand the professional role, which may be promoted through changes to clinical training programmes or specific interventions within teams post-qualification.

The study furthers understanding of the demands and limits of the wider mental health system on professionals' capacity for person-centred practice. This has implications for professionals in highlighting the specific skills required to effectively navigate the system, such as thoughtful use of clinical language and concepts when needed, alongside awareness that its use may exclude others. Importantly, the study recognises that professionals can find opportunities for person-centred practice amidst competing demands, highlighting the continued responsibility and onus on individuals to prioritise meaning-making even in restrictive team and system contexts.

Finally, the theoretical model proposed (Figure 1) has direct clinical utility for professionals to use as an orientating 'map'. This can assist them to assess progress on the meaning-making journey with a service user, identify opportunities for collaborative engagement and recognise occasions where this is being neglected.

## Table of Contents

Thesis Declaration Form	2
Overview	3
Impact statement	4
Table of Contents	6
List of Tables and Diagrams	8
Acknowledgements	9
<b>Part 1: Conceptual Introduction</b>	10
<b>Abstract</b>	11
<b>Introduction</b>	12
The experience and impact of psychosis	14
Defining key concepts	14
Professional theories and frameworks	15
Tracing the history of perspectives on madness	15
Psychiatric perspectives and the biomedical model	17
Phenomenological theories	22
Anti-psychiatry and critical mental health approaches	24
Social and psychological theories	27
Integrated frameworks	32
Anthropological, spiritual & cultural models	34
Service user, survivor & Mad perspectives	37
Explanatory models and narrative insight	43
Meaning-making, identity, self, and recovery	44
Studies of meaning-making	46
Early Intervention in Psychosis services and meaning-making	55
<b>Conclusions and research aims</b>	56
<b>References</b>	59
<b>Part 2: Empirical Paper</b>	85
<b>Abstract</b>	86
<b>Introduction</b>	88
<b>Methods</b>	96
Grounded Theory	96
Participants, sampling and recruitment	97
Interviews	99
Data analysis and coding	100
Ethics	101
Service user consultation	102
<b>Results</b>	102
<b>Research Question 1: Process of meaning-making within the clinical encounter</b>	103
Storyline of overall theory	103
Role Construction	106
Awareness of plurality of perspectives	108
Translation and communication of meaning	109
Journey Towards Shared Construction	110
Establishing groundwork for meaning-making	110
Engaging with a service user's meanings	112
Offering a professional perspective	116
Managing differences in perspective	118
Combining aspects from both to create shared meaning	120
Non-Shared Construction	122

Pulling away from and neglecting shared construction	122
<b>Research Question 2: Factors and broader context which influence meaning-making in the clinical encounter</b>	126
Storyline of overall theory	126
<b>Personal-Professional Factors</b>	128
Clinical training	129
Values and interests	130
Cultural background	130
Spirituality	131
Lived experience of psychosis	132
<b>Team Culture and Approach</b>	133
Varied perspectives and network of influence	134
The dominance of certain voices	135
Openness to new ideas	137
Access to resources	138
<b>System Approach and Demands</b>	140
Medical model and diagnosis	141
Clinical language and perspectives	142
System orientation towards certainty and practicality	144
Risk management	146
Processes	148
Time and capacity	149
<b>Discussion</b>	150
Clinical implications	159
Limitations and further research	159
<b>Conclusion</b>	161
<b>References</b>	163
<b>Part 3: Critical Appraisal</b>	180
<b>Reflexivity</b>	181
<b>Participants: Professionals over service users</b>	184
<b>The research process</b>	185
Recruitment	185
Interviews	186
Analysis	187
Write up and presentation	188
<b>Study evaluation</b>	189
<b>Service user involvement</b>	190
<b>Do something that you love</b>	193
<b>References</b>	194
<b>Appendices</b>	196
Appendix 1: Public recruitment advertisement	196
Appendix 2: Interview schedule	197
Appendix 3: Example of coded transcript	199
Appendix 4: Coding through visual representation – hypothesised categories, sub-categories and connections	200
Appendix 5: UCL Ethics Approval	201
Appendix 6 Participant Information Sheet	203
Appendix 7: Informed Consent Form	206

## List of Tables and Figures

<b>Empirical paper</b>	
Table 1: Sociodemographic characteristics of participants	98
Figure 1: Grounded theory diagram for Research Question 1. The process of meaning-making within the clinical encounter	104
Figure 2: Categories and subcategories of Research Question 1	105
Figure 3: Grounded theory diagram for Research Question 2. Explicates the process through which personal-professional, team and system factors influence meaning-making, plurality of perspectives and person-centred practice within the clinical encounter	127
Figure 4: Categories and subcategories of Research Question 2	128



## **Acknowledgements**

I would like to acknowledge the many contributors to this thesis who have offered me intellectual, practical and emotional support and guidance throughout the journey of the project.

I am firstly grateful to the participants for finding time amidst busy schedules for detailed and thoughtful interviews, often lasting up to and beyond 90 minutes. The depths of your knowledge and experience provided the richness of material upon which this study became possible. It was a genuine pleasure to learn from you.

I am thankful to the organisers and participants of the Service User Research Forum (SURF) for shaping the direction of the thesis. I was welcomed twice into your space and left each time with new insights and ideas, as well as reassurance about the value and direction of the project.

I am very grateful to my two supervisors, Sunil Nandha and Vaughan Bell, for their support throughout the project. Sunil, your enthusiasm and interest in this topic enabled me to get it off the ground and has continued to keep me inspired and focused throughout. Thank you for your warmth and encouragement, your methodological guidance, and the many opportunities to talk things through. Numerous ideas and connections arose from those discussions, leaving me with a renewed interest and motivation each time we met.

Vaughan, your wealth of knowledge and research experience provided much guidance and reassurance in the study design and write up. I am grateful for your comprehensive and incisive feedback on draft papers, often delivered at lightning speed, which introduced numerous avenues of further reading, theory and critical reflection that improved this thesis.

I am grateful to my wonderful family and friends who have offered me much-needed laughter, joy and love over the course of this project. I must give particular thanks to Lo and Ed for their extra help with proofreading, draft feedback and moral support. It is with this generosity and encouragement that I have made it through to the end. Thank you.

## **Part 1: Conceptual Introduction**

## **Abstract**

There are myriad ways to make sense of psychosis. Throughout history, different individuals and groups have offered a vast range of conceptualisations. This conceptual introduction traces this history of perspectives on psychosis. First, it explores the development of psychiatric, psychological and social understandings mostly dominated by professionals. It then considers contributions from those with lived experience, alongside cultural and spiritual understandings. Next, it considers how these varied frameworks are applied in practice to make sense of psychosis, firstly by service users within mental health services, and secondly by mental health professionals. The concepts of explanatory models and narrative insight are reviewed to capture the active process through which people make sense of their own lives and the world around them. The importance of meaning-making is presented, particularly for those who experience psychosis, with evidence of improvements in self-understanding, identity formation and recovery outcomes. Early Intervention in Psychosis (EIP) services are explored as a key site for meaning-making in psychosis. Limitations in the literature are considered throughout, particularly the limited exploration of how frameworks for understanding psychosis are applied in clinical reality. The lack of research exploring and theorising meaning-making in the clinical encounter is highlighted. Conclusions are drawn in light of these research gaps, with future research questions proposed.

## **1. Introduction**

Meaning-making is a central human activity, enabling people to make coherent sense of their lives and understand the world around them. It is the process through which people interpret and make sense of events and situations, drawing on previous knowledge and experiences, and contextualising them within their worldview. This is particularly important in early experiences of psychosis, where changes in perception and self-experience can significantly disrupt a person's understanding of their lived reality. Research shows that constructing a meaningful, culturally embedded narrative of the experience is fundamental to a person's recovery from psychosis.

Myriad understandings and explanations exist for the experiences often labelled as psychosis. Across history, numerous definitions and frameworks have been offered by clinicians, academics, religious leaders, philosophers, those with lived experience, and many others, contributing to the search for meaning around experiences outside the realm of 'normality'. To capture this plurality, and the ongoing tensions between understandings, Geekie and Read have suggested psychosis to be an "essentially contested concept" (2009, p142), one defined by these very disagreements.

To begin unpacking this, this paper will review the main historical and theoretical narratives of psychosis, attending primarily to those which continue to influence mental health professionals and service users in the present day. Focusing upon the frameworks and theories which influence meaning-making in the clinical encounter sets the parameters for the scale and scope of the review.

As such, the paper firstly considers a brief history of the definitions of psychosis through the key individuals, collectives and movements who have sought to make sense of it over the years, contributing to this ever-evolving hotbed of understandings. This will include the development of psychiatric models, the critical psychiatry movement, and social and psychological theories, as well as the move towards more integrative frameworks of understanding. It will then consider cultural and spiritual models, the service user-survivor movement and Mad Studies.

Having set out this range of understandings, this paper takes particular interest in which frameworks hold influence in the present day for those confronted with making sense of experiences of psychosis. This applies both in terms of understanding the frameworks which are more or less focused on lived experience perspectives, as well as understanding the landscape of available narratives which can be drawn on in the process of meaning-making for services users and professionals alike.

As such, literature will be presented which has focused on precisely this: firstly, on the varied and complex ways that people with lived experience come to make sense of their psychosis, and secondly, how mental health professionals conceptualise it. Early Intervention in Psychosis (EIP) services emerge in this review as important sites of early meaning-making, due to the nature of dealing with first episodes of psychosis (FEP) and the initiation of the clinical encounter regarding this new experience.

Taken together, this review will demonstrate that while much literature has focused on theorising psychosis from various perspectives, and further research has explored the frameworks that service users or professionals draw on in their understandings, there is a distinct lack of research into the *process* of meaning-making amongst professionals working

in the field. Of particular importance, there is limited understanding of the factors which enable or inhibit clinicians' capacity or willingness to engage in the process.

### **1.1. The experience and impact of psychosis**

Psychosis refers to sets of experiences comprising changes in perception and self-experience, which place people 'out of touch with reality' (Cooke, 2014). This can include hearing or seeing things that others do not ('hallucinations'), holding fixed and strange beliefs ('delusions'), and speaking in ways that are hard to follow ('thought disorder') (Cooke, 2014; DSM-5, American Psychiatric Association [APA], 2013). Accompanying changes in mood, lack of motivation, and social withdrawal are often termed 'negative symptoms'. Affecting around 1% of the global population (Whiteford et al., 2013), psychosis can significantly impact the personal, social and occupational lives of those who experience it. This can include extreme confusion and distress (McCarthy-Jones et al., 2013), stigma and discrimination (Thornicroft, 2006; Vass, Sitko, West, & Bentall, 2017), loss of relationships (McCarthy-Jones et al., 2013), unemployment (Morgan et al., 2014), and reduced life expectancy (Saha, Chant & McGrath, 2007). As such, it is a leading contributor to global health burden and years lived with disability (James et al., 2018), with an acute state of psychosis holding the highest disability weight globally (GBD, 2022).

### **1.2. Defining key concepts**

Language in the field of mental health is often controversial (Campbell and Rose, 2011; Filer, 2019). The field of psychosis is no different. In the literature, a range of terminology is used

interchangeably, often signalling the theoretical or ideological position of the author, including 'mental illness', 'psychosis', 'schizophrenia', 'madness', and 'emotional distress', amongst others. These refer to similar experiences through a particular lens (Davies & Harré, 1990). Similarly, terms such as 'client', 'service user', 'person with lived experience', 'consumer', 'patient', and 'survivor' are spread throughout the literature and represent particular lenses and ideologies (Dickens & Picchioni, 2012; Priebe, 2021).

This review is led by the terminology that authors and groups use in their own literature to capture and honour their perspectives as they are replicated here. For example, in the section on historical perspectives below, the term 'madness' is employed to reflect the language used by historians of psychiatry. However, this paper veers towards the language of 'psychosis', 'lived experience' and 'service user', given its focus on EIP services from a professional perspective. This is a pragmatic choice, since 'psychosis' is a familiar term to EIP clinicians and service users in labelling these experiences. While accepting that there is no truly 'neutral' language, this paper hopes that recognising its own position provides context to the privileging of clinical terminology and frameworks.

## **2. Professional theories and frameworks**

### **2.1. Tracing the history of perspectives on madness**

In tracing the developments of psychiatric knowledge over time, historians of madness have explored the evolving relationship between psychiatry and its patients and the extent to which patients' perspectives have been heard. The two broad historiographical trends that have emerged in the telling of this story will be analysed: those of Michel Foucault and Roy Porter (Condrau, 2007). This will provide a helpful foundation for the rest of the chapter, which will

consider the development and influences of professional and service user perspectives on madness up to the present day.

Foucault's work (1965, 1970, 1973) is perhaps the most influential of these histories. Porter himself describes Foucault's work as by "far the most penetrating work ever written on the history of madness" (Porter, 1990, p47). Writing against the Whiggish histories of psychiatry's progress (Beveridge, 2014), Foucault traces the history of madness alongside the concept of 'unreason' to argue the role that discourses, power and institutions have played in constructing 'the patient' and their perspectives over time. Beginning with the 'Age of Reason', following through institutionalisation, the growth of asylums, and the development of scientific approaches, Foucault maps the changing shape of power and social control over mad people. In Foucault's work, this history paves the way for a medicalisation of madness, establishing a scientific and technical discourse cementing medical authority over lunacy. Central to these arguments, and part of Foucault's legacy in this area, is the silencing of mad people and their perspectives across history. Those who have followed his positioning are cautious of the role of psychiatry as 'experts of the mind' (Boyle, 2012) and the triumphing of objective expertise over subjective understandings (Pilgrim, 2003).

However, numerous historians have been critical of Foucault's account, challenging him empirically and for the universalisation of French history to the rest of Europe (Jones & Porter, 1994; Scull, 1993; Porter, 1990). Porter's seminal 1985 article, which argued for a radical shift in perspective for histories of madness, reflected Porter's dissatisfaction with Foucault's contribution. Porter suggested that the history of psychiatry should not be written from the professional and scientific lens of diagnoses and treatments but rewritten 'from below' such that it captures 'the patient's view' (Porter, 1985). His own 'Social History of Madness' (Porter, 1987), which drew on stories of lived experience, exemplified Porter's assertion that patients had not been historically silenced. This highlighted the dissonance between his and



Foucault's positions regarding the presence or absence of the patient's voice and agency in history (Condrau, 2007). Since then, historians of madness have had to "compromise between the field's two patron saints" (Bacopoulos-Viau & Fauvel, 2016, p.11), emphasising the importance of patient narratives while also highlighting the historical rarity of them.

While the history of patients' perspectives remains something of an enigma, the impact that Foucault and Porter have had on the present-day discourse is perhaps more apparent. Following Porter's plea, 'the patient's view' has indeed been increasingly centred - to the extent that it is now a "classic trope" (Bacopoulos-Viau & Fauvel, 2016, p.1) in historical works. At the time of writing in the 1980s, Porter's work resonated with the shift towards lived experience perspectives and the service user movement. The work of Foucault continues to hold a wide-reaching influence, particularly amongst critical mental health scholars and service users, often highlighting the power of the psy-professions over the voice of lived experience (Rose, 1990). What seems clear, regardless of the history, is that there remains an orientation (or re-orientation) towards perspectives of lived experience in the present day.

## **2.2. Psychiatric perspectives and the biomedical model**

Psychiatry's contributions to understanding psychosis have been numerous and varied in their theoretical orientation and influence on clinical practice.

German psychiatrist Emil Kraepelin is often viewed as the founder of modern psychiatry, establishing his early classification system, the *Compendium der Psychiatrie*, in 1919. Significantly, Kraepelin conceptualised manic depression and dementia praecox from records of asylum inpatients, the blueprints for today's bipolar disorder and schizophrenia (Bürge, 2008; Kraepelin, 1896; Woods, 2011). He considered dementia praecox a degenerative

disease with a biological aetiology (Bentall, 2004; Tueth, 1995; Murray et al., 2017). With his belief in objective science as the route to truth, Kraepelin's work was embedded within a positivist framework that subordinated subjective knowledge and experience in making sense of madness. Eugen Bleuler, a Swiss psychiatrist, built on Kraepelin's ideas from his own clinical observations, coining the term 'schizophrenia' in 1908 (Ashok et al., 2012). Derived from the Greek 'schizein' for splitting and 'phren' for mind, schizophrenia has become the dominant label for experiences of psychosis. It remains in clinical parlance to this day, over a century since its inception. Others, such as Jaspers (1963) and Schneider (1950), also made contributions to characterising psychosis throughout the twentieth century. Jaspers' suggestion about insight was particularly influential, that in "psychosis there is no lasting or complete insight" (Jaspers, in McCarthy-Jones, 2015, p.8). Overall, the 'lack of insight' construct is contentious. While on a broader level, it may function to restrict the knowledge a person can have about their psychosis (Miller, 1986), for individuals the concept can be meaningfully employed to understand their lack of understanding about the experience (see Gong, 2017, p.17).

Psychoanalysis also contributed to understandings of psychosis in the mid-twentieth century, arguing strongly against the notion of biological aetiology. Such theories focused on the impact of early relationships and the resultant impairment of object relations (Willick, 2001), exemplified by the controversial term 'schizophrenogenic mother' (Fromm-Reichmann, 1948). While the psychoanalytic focus on internal conflict suggested there was meaning to psychosis, this remained in the domain of professional expertise, with limited interest in the personal meaning-making of the person experiencing psychosis. Regardless, any influence of psychoanalysis in understanding the aetiology of psychosis has been discredited and extinguished (Willick, 2001).

Adolph Meyer, an influential psychiatrist in the US, was also unsatisfied with Kraepelin's concept of dementia praecox (Double, 2008). Working in the early 20<sup>th</sup> century, Meyer (1906) developed his own sense of the disease as a problem of adaption. He took a holistic approach, positing that schizophrenia resulted from a combination of psychological, environmental, cultural and ecological factors in addition to biological determinants (DeVylder, 2013; Teuth, 1995). In this way, his work began to suggest there may be meaning in psychosis through its connection to a person's life context. While Meyer's influence was in decline by the 1950s, primarily overshadowed by the biomedical approach to psychosis (Double, 2008), his holistic stance was resurrected by Engel's biopsychosocial model in 1977. In this way, the Kraepelinian and Meyerian approaches laid the foundations for the biomedical and biopsychosocial strands of psychiatric thinking today (DeVylder, 2013).

Classification systems and diagnosis have continued to be a cornerstone of biomedical psychiatric approaches. The *International Classification of Diseases* (ICD) was released in 1949 by the World Health Organisation (WHO), and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) was first released in 1952 by the American Psychiatric Association (APA). The DSM-5 (APA, 2013) defines 'primary symptoms' of psychosis as hallucinations, delusions, disorganised thinking and behaviour, and 'negative symptoms' such as avolition (Bürgy, 2008). As McCarthy-Jones (2015) notes, schizophrenia and schizotypal personal disorder are defined under 'psychotic disorders', reflecting the contemporary view of a continuum of psychotic experiences (van Os et al., 2009). In terms of aetiology, medicalised conceptualisations have historically focused on biochemical, genetic and neurological factors in the development of schizophrenia. The 'dopamine hypothesis' is one example of this, implicating the levels of the neurotransmitter dopamine in the brain of people with schizophrenia, though the theory has attracted criticism (Bentall, 2003; Moncrieff & Cohen, 2009). Recent models tend to be more integrative, comprising theories of dopamine with neurocognitive development and social factors (Murray et al., 2017), and firmly leaving behind

the Kraepelinian degenerative model. The move towards integrative models is discussed in more detail later (pp. 32-34).

Diagnostic classification systems have been controversial since their inception (Bentall, 2003; Geekie & Read, 2009), with critics suggesting that they represent a medicalisation of normal human experience and variation. A frequently referenced example is the inclusion of homosexuality as a disorder until 1973 after lobbying by gay rights activists. Schizophrenia as a diagnosis has been challenged for its scientific credibility, with those both inside and outside psychiatry arguing that it lacks validity and reliability as a construct (Bentall, 2003; Boyle, 2012; Woods, 2011). However, there is an increasing shift away from the language of 'schizophrenia' in clinical and research parlance towards psychosis as a more open and less stigmatising alternative (Cooke, 2014; Murray et al., 2017). Despite this, Murray & Quattrone (2021) suggest that while the Kraepelinian concept of schizophrenia is in decline, it is 'not yet dead'.

Psychiatric perspectives predominantly align with medical interventions and treatments for psychosis. While invasive treatments such as psychosurgery, Electroconvulsive Therapy (ECT), and insulin coma were historically practiced, these were fortunately short-lived and replaced by pharmacological treatments from the 1950s (Tueth, 1995). Tueth describes the introduction of antipsychotic medications as a "watershed moment" (1995, p.807), enabling many people to regain independence from overwhelming experiences of psychosis. Antipsychotic medication remains the first line of treatment for psychosis in UK mental health services. In 2009, psychological intervention joined medication as a first line of treatment in the updated National Institute for Health and Care Excellence (NICE) guidelines (Heriot-Maitland, 2010).

Returning to our focus on meaning, a key criticism of biomedical conceptualisations relates to the construction of ‘symptoms’ of psychosis as meaningless aberrations of a disease process (Georgaca, 2013; Hornstein, 2009). This position can restrict the opportunity for meaning to be made and, drawing on Foucault’s concept of ‘unreason’, silence the lived experience perspective (Miller, 1986). Some critics have connected this to a broader context of positivism (Thomas & Bracken, 2004), in which professional expertise dominates subjective experience (Harper, 1995; Hornstein, 2002, 2005). However, as presented so far, there are varied psychiatric conceptualisations of psychosis beyond the purely Kraepelinian, such as in the work of Meyer, psychoanalysis and more integrative frameworks. Further exploration is needed into the psychiatric models of psychosis which remain influential in current clinical practice and how this impacts the capacity for meaning to be made amongst professionals and service users.

Parnas (2014), for example, argues that there is a disconnect between what happens theoretically in psychiatry and everyday clinical practice. He suggests that scientific progress in the field, particularly in neuroscience and molecular biology, is yet to be seen in clinical reality. Many argue that the biomedical paradigm is the dominant approach in UK mental health services (Geekie & Read, 2009) and broader British culture (Cooke & Kinderman, 2018). However, it is unclear whether this accounts for the decline in the concept of schizophrenia and the move towards integrative models of psychosis (Heriot-Matiland, 2010). The formation of EIP services, discussed later in the chapter (pp. 54-56), also brought into the mainstream of clinical practice more integrative and holistic ways of conceptualising and intervening with psychosis. With these debates very much alive in the academic literature, it raises an important question about the extent to which medicalised narratives influence the meaning-making of service users and professionals in clinical reality today.

While this section has highlighted the history of shifting psychiatric perspectives of psychosis, for many the concept of schizophrenia remains central, embedded at the very heartland of psychiatry itself (Goodwin & Geddes, 2007; Woods, 2021). As this review has begun to present, and as Filer succinctly comments, schizophrenia is often the “bloody battleground upon which the fiercest ideological dispute about madness and its meanings are fought” (2019, p.9).

### **2.3. Phenomenological theories**

Phenomenological orientations to understanding psychosis aim to centre the subjective experiences of patients. The role of introducing phenomenology to psychiatry is accorded to Jaspers (1963), with his influential ‘descriptive psychopathology’ which relies on collecting information communicated from the patient to make a diagnosis (Häfner, 2022). This has been highly influential in psychiatry and modern classification systems (Bürge, 2008). However, it remains unclear whether descriptive psychopathology in current practice engages meaningfully and authentically with subjective experience beyond the function it serves for the clinician to make a diagnosis. While it begins with subjective experience, it seems that the journey taken afterwards is towards a diagnosis based upon professional expertise, rather than remaining grounded within that person’s expertise. Further research may helpfully explore how mental health professionals employ this framework in their practice and whether this enables engagement in shared meaning-making with the service user. Indeed, some have challenged whether Jaspers’ work was truly built on phenomenological foundations (Berrios, 1992). Parnas argues that despite claims of its phenomenological roots, the descriptive approach is “behaviourist [and] subjectivity-averse” (2014, p17), such that it does not adequately incorporate descriptions of subjective experience without also relying on nosology. This is particularly the case in Anglophone psychiatry, where phenomenology

has come to refer to a common-sense description of the signs and symptoms from a third-person perspective (Parnas, 2013). Parnas is critical of what he considers an oversimplification of psychopathology, which lacks an overarching phenomenological framework and pays insufficient attention to subjective experience.

A new wave of phenomenological studies aims to counter these criticisms, conceptualising psychosis as a disturbance of self or 'ipseity' (Lysaker & Lysaker, 2010; Lysaker et al., 2012; Nelson, Parnas & Sass, 2014; Sass, 2014; Sass & Parnas, 2001, 2003). It is suggested that this disturbance is central to the subjective experience of psychosis (Cowan et al., 2021; Lysaker & Lysaker, 2002). This captures the sense of fragmentation and disintegration of self, where there are disruptions in the conceptual and perceptual fields as the internal and external worlds collide. As such, there is a loss of agency over experience (Cowan et al., 2021; Sass & Parnas, 2003) and subsequent challenges in personal identity and meaning-making (Ben-David & Kealy, 2019). Such disturbances of self have long been recognised in the experience of psychosis since it was first conceptualised as 'schizophrenia' (Cowan et al., 2021) and may be considered the core aspects of the experience (Sass & Parnas, 2003; Nelson et al., 2014). As Jones & Shattell write, "to experience psychosis...is to experience a radically changed self" (2016, p769).

Phenomenological theories have centred subjective self-experience in their theorising of psychosis and, to some extent, the practice of diagnosis in psychiatry. However, it remains to be seen how these frameworks are employed in the clinical encounter to enable shared meaning-making. As an area of research which appears to remain dominated by professionals, its value on the understandings of those with lived experience needs further exploration.

## **2.4. Anti-psychiatry and critical mental health approaches**

### **2.4.1. Anti-psychiatry**

Those who have taken a critical position towards biomedical frameworks have had much to contribute to conceptualising psychosis. Criticism of psychiatry was propelled in the 1960s amidst the wave of dissent brought about by the counter-cultural movement. ‘Anti-psychiatry’ was coined by David Cooper in 1967. The term now covers a range of diverging critiques of psychiatry, its history and practices, which have a shared goal of abolition (Reaume, 2021). Key early figures include those from within psychiatry, such as Thomas Szasz (1961), David Cooper (1967) and RD Laing (1960), as well as those from the fields of sociology and philosophy, such as Erving Goffman (1961) and Michel Foucault (1960). There were significant ideological differences within this group, for example Szasz’s free-market libertarianism compared to Cooper’s Marxism (Reaume, 2021). Many explicitly rejected the label of ‘anti-psychiatry’ altogether. What they shared was a rejection of illness-based understandings, an interest in alternative conceptualisations and aetiology, and the desire to recognise the harms brought about by the psychiatric institution.

In *The Divided Self* (1960), Laing offered an alternative to the medical model of psychosis, rejecting diagnostic categories and pathology as an explanation for mental distress. Laing believed that psychosis had meaning and was related to the person’s own life, such as internal conflicts or social context. He suggested that a person could be pushed to madness in their attempts to cope with life’s challenges, highlighting issues such as poverty, marginalisation and social ostracisation. Laing was therefore central in the early development of the concept that someone can have a sane reaction to an insane world, conceptualising psychosis as “a special strategy that a person invents in order to live in an unliveable situation” (Laing, 1967, p115). As such, context was vital in his theorising. Laing opened



Kingsley Hall in London (1965) as an alternative to the mental hospitals of the time, providing a space to enable patients to make sense of their crises. Opposed to antipsychotic medication and ECT, Laing believed that the best intervention was a safe space and support to understand the experience. Kingsley Hall put power in the hands of the residents to make decisions about their treatment rather than relying on the expertise of clinical professionals (Mosher et al., 2004). Laing's work can be seen as paving the way for approaches centring meaning-making and valuing subjective expertise over professional understandings.

This can be seen in Loren Mosher's Sorteria House which took inspiration from Kingsley Hall, opening in the 1970s. Sorteria House was set up in the US as a therapeutic space where people experiencing psychosis could be supported by peers and non-clinical staff. Mosher believed in mutual relationships as central to recovery, with expertise about the experience on a level playing field (Mosher et al., 2004). The person's meaning-making was an important focus, with non-medical understandings encouraged, and the use of creative spaces for exploration of meaning. Over the following 20 years, the Sorteria Network expanded and opened houses across Europe. This early success was not maintained and many houses closed. Those that remain today are on the periphery of mental health services.

#### ***2.4.2. Critical psychiatry***

Since the 1980s, different versions of critical psychiatry and psychology have emerged as a more palatable, less abolitionist critique of mainstream psychiatry. These critiques are primarily concerned with making change from within the institution (Reaume, 2021). With contributions from psychiatrists (e.g. Moncrieff & Middleton, 2005; Thomas & Bracken, 2004) and clinical psychologists (e.g. Johnstone, 2017), critical approaches are anti-diagnostic and orientated towards psychological, social and trauma-based theories of psychosis. In recent years collectives of professionals and service users have formed to share and promote these

ideas, such as A Disorder 4 All and the International Society for Psychological and Social Approaches to Psychosis UK (ISPS- UK). Thomas and Bracken (2004) suggest that critical psychiatry reflects an interest in developing more flexible ways of engaging with madness and distress than is possible within mainstream biomedical psychiatry, including paying more attention to the experiences and narratives of service users.

Sedgwick (1973; 1982) argues that anti-psychiatry is built on a flawed logic as it inaccurately suggests psychiatric categories are subjective (in the realm of 'value'), whereas physical medicine is scientific (in the realm of 'fact'). This 'psycho-medical dualism' obscures that, according to Sedgwick, all medicine is value-laden (Cresswell & Spandler, 2009). Chapman (2022) argues that criticals become focused on the presence of biological markers to determine whether a diagnosis is 'real', meaning they are essentialist and objectivist in ways damaging to service users living with non-biological disabilities.

It remains to be seen whether the antipsychiatry and critical mental health approaches offer viable alternatives to psychiatry, or whether they largely remain in a theoretical realm with limited influence over professional practice in the present day. Further exploration is needed to understand whether allegiance with a particular ideology enables professionals to turn towards subjective experience in the clinical encounter or whether the theoretical battles between professional groups are a distraction from this. Indeed, Reaume (2021) highlights the professional domination of both anti-psychiatry and critical approaches, noting that both movements were born amongst professionals and academics who only later sought to include service users. Similarly, Bell (2017) raises concern about the nature of professional debates with take away from those it affects the most: people with mental health problems. Bell, in his call for diversity of opinion around the value of diagnosis, mirrors the position of certain service user activists such as Akiko Hart. Hart (2018) argues that the anti-diagnosis position can be invalidating and risks erasing the voices of those who find a diagnosis helpful

in understanding their experience. Chapman also raises concerns about the broader erasure of minority experiences, such as those who fall outside of bodily norms, due to the upholding and reification of 'normal' bodies and biology in the logic of critical psychiatry (Chapman, 2022) - i.e. 'general medicine is objective because you can use biological tests to prove essential difference'.

Following Bell, Hart and Chapman, it remains critical to prioritise the needs and perspectives of those with lived experience and avoid succumbing to ideological battles that risk diverting attention away. Further research should explore how the varied (and often competing) perspectives of psychosis actually impact those who are trying to make sense of their experiences.

## **2.5. Social and psychological theories**

### ***2.5.1. Theories of adversity, trauma and social context***

Several frameworks conceptualise psychosis in relation to the aetiology of adverse life experiences and the interconnection with social, economic and political factors. There is strong evidence that various types of abuse can be central to the development of psychosis (Read et al., 2004; Varese et al., 2012; Bentall, 2003), particularly childhood sexual abuse (Read et al. 2005). Structural disadvantage, brought about by socioeconomic deprivation and poverty, has also been centred in the debate around causes of psychosis (Kirkbridge & Jones, 2011; Kirkbridge et al., 2012; Morgan et al., 2008; Read et al., 2013). Other researchers have noted the role of urban living environments (van Os, 2004). This may in part relate to the access and use of cannabis in cities, particularly skunk, which can trigger psychosis (Di Forti et al., 2015). The impact of social factors is reflected by the disparities in prevalence of

psychosis between different communities. One study exploring the incidence of psychosis across six countries highlighted that a person from South London is eight times more likely to become psychotic than someone living in Santiago in Spain (Jongsma et al., 2018).

Higher rates of psychosis have been noted in racialised and ethnic minority groups (Hollander et al., 2016; Read, Johnstone, & Taitimu, 2013). While in the UK this disproportionately affects African-Caribbean people, cross-cultural research has shown that ethnic minority groups and immigrant groups in any society globally are at greater risk of experiencing psychosis (Singh & Burns, 2006). Studies have considered the role of racial discrimination (Jansenn et al., 2003), marginalisation and exclusion (Singh & Burns, 2006), refugee status (Hollander et al 2016), and intersections with broader social disadvantage and adversity.

Such epidemiological findings have influenced a range of clinical disciplines and practices. From a psychiatric perspective, these social factors can be used to predict rates of diagnosis. Critics have argued that mental distress is best conceptualised as a normal and understandable way of responding to difficult life events and experiences (Johnstone, 2017). In mainstream clinical practice there has been a shift towards the inclusion of trauma in conceptualising mental health problems, exemplified by ‘trauma-informed care’ which encourages services to cater to the needs of traumatised people. This incorporates a proposed shift in approach to talking with patients in the clinic, where proponents of the model have argued the question should change from ‘what’s wrong with you’ to ‘what’s happened to you’ (Longden, 2013). However, despite the impact of trauma-based perspectives on clinical frameworks and practice, Luhrmann’s (2019) study provides a helpful reminder that trauma is not a catch-all explanation. Investigating the role of trauma in the development of psychosis, the study concludes that sometimes trauma plays a significant role in aetiology, sometimes a minor one, and sometimes no role at all (Luhrmann, 2019).

### ***2.5.2. Psychological theories***

The psychological literature has also been highly influenced by the body of work on trauma, social context and adversity. Psychologists in the UK have made a significant contribution to the field in the last 20 years (Bentall, 2003; Chadwick et al., 1996; Freeman et al., 2012; Garety & Freeman, 2013; Morrison, 2001) elucidating the role of cognitive processes, behaviours and previous life experiences (Bebbington, 2015). Bentall's (2003) work on voice hearing as inner-speech and Freeman et al.'s (2002) work around paranoia are key examples here, taking on a fundamentally normalising approach to the development and experience of psychosis. This includes highlighting cognitive factors involved in the development and maintenance of psychosis, such as schemas (Fowler et al., 2006) and response styles, for example jumping to conclusion bias (Garety et al., 2005). Furthermore, factors such as negative affect, worry and insomnia are theorised to mediate social experiences and life events (Freeman et al., 2002). Through understanding and delineating the processes and determinants of psychosis, such research enables psychosis to be understood and treated using psychological techniques (Bebbington, 2015). As such, developments in the psychological and cognitive literature have tied into the growth of Cognitive Behavioural Therapy (CBT) as a psychotherapeutic intervention for psychosis (Chadwick, Birchwood, Trower, 1996; Carter et al., 2017).

Formulation in CBT synthesises the factors and events relevant to the person's own life with a psychological model or theory to make sense of their difficulties. This collaborative construction of a shared understanding between the service user and the professional is the fundamental bedrock of CBT (Kuyken et al., 2009; Tarrier & Calam, 2002). In CBT for psychosis (CBTp), formulation therefore supports meaning-making around the development, mechanisms and maintenance of psychosis (Chadwick et al., 1996). This includes drawing on the research above to support understanding of a person's idiosyncratic social factors

and life experiences, as well as mental attributes such as cognitive schemas and responses, that may account for their experiences, beliefs and behaviours.

The practice of CBTp is commonplace in mainstream psychosis, as recommended by the NICE guidance (2015). Yet the literature which explores how formulation is received by service users remains limited (Spencer et al., 2022). While the emphasis is on collaboration, there are questions about the extent to which meaning is truly co-created in CBTp. Critics have suggested that CBT is paternalistic, with therapists positioned as an expert over the client (Proctor, 2008). Lowe (1999, in Proctor, 2008) argues that the rhetoric of ‘collaboration’ may mask the power differences within the relationship. Therapists are often aware of the contradiction between the goals of collaboration and the modification of a service users’ beliefs (Messari & Hallam, 2003). However, Brabban et al. (2017) argue that while some anecdotal accounts may suggest that CBTp is delivered in a simplistic and technical way rather than collaboratively, this does not resemble the core values and principles of the model as it should be practiced by skilled therapists.

Using psychological formulation as a basis for understanding spans beyond just the CBT model (Johnstone, 2017). In clinical psychology practice, formulation-based approaches are founded on the premise that mental distress can always be made understandable within a person’s life context and circumstances (Cooke, 2014). These can be a written or diagrammatic story of a person’s past or present, which achieves its value as a meaningful and coherent explanation of events shared between a service user and a professional. The *Power Threat Meaning Framework* (PTMF, Johnstone et al., 2018) was released in 2018 as a multifactorial and contextual alternative to diagnosis. The framework champions a formulation-based approach to mental distress, focusing on trauma and life events through the lenses of ‘power’, ‘threat’ and ‘meaning’. Of central interest is the focus on meaning, which the authors argue is the “thread that holds all the other aspects of PTMF together” (Boyle & Johnstone, 2020, p.72). Suggesting that meaning is central to all human experience

and has an impact on the way distress is experienced and distressed, the PTMF makes a case for centring personal narratives and meanings in psychological formulations (Boyle & Johnstone, 2020). However, the framework has sparked controversy and criticism since its release, particularly concerning whether its critique of diagnoses reflects the heterogeneous range of service user perspectives (Morgan, 2023).

Bebbington (2015) argues that psychosis symptoms become meaningful when they are understood in the context of real-world experiences and events. Recent epidemiological research has begun to do this: mapping the relationship between social and mental entities to specific symptoms of psychosis (Bebbington, 2015). This enables theorising of mediating factors between and within a person's internal and external world, as in Bentall's (2003) book *Madness Explained* where he argues for a symptom-based approach. In focusing on specific complaints rather than a diagnosis, such as the voice-hearing experience or the content of delusions, Bentall argues that it becomes possible to understand the pathways that lead to each of these, be it neurodevelopment or cognitive, attachment-based, or environmental. He makes a compelling case for understanding psychosis through processes that all humans are prone to. Building on the work of Meyer and Laing, Bentall has been a key figure in championing the idea that there is meaning to be made of psychosis.

The British Psychological Society's (BPS) report, *Understanding Psychosis and Schizophrenia* (Cooke, 2014), champions the use of psychological understandings, formulation, and intervention in psychosis. The report argues that hearing voices and paranoia are common experiences, a reaction to difficult life circumstances, which exist on a continuum. Continuum models conceptualise psychosis as sitting at the extreme end of normal human experience. Where illness models may suggest there is a categorical difference between those who are 'psychotic' and those who are 'normal' (Jenkins, 2004), continuum models suggest that all humans share the psychological capacity to move up or down this spectrum in relation to internal or external factors (Bentall, 2003; Verdoux & Van Os, 2002). The report encourages

professionals to avoid a single framework of for understanding psychosis and is particularly vocal against employing an illness model in this way (Cooke, 2014).

Overall, psychological research has contributed a range of theories around the causes of psychosis suggesting that for each individual there is a unique, idiosyncratic combination of interacting causes (Cooke & Kinderman, 2018). While this plurality may open up the possibility for meaning-making, it is clear that further research should explore how frameworks of trauma, adversity, and cognition are applied and received by service users in clinical practice. While psychological formulation may offer a platform for shared meaning-making, both in the professional-service user dyad and amongst clinical teams, further research should understand how this is applied in clinical reality. Indeed, some service users have criticised psychological formulation for prioritising the narratives of professionals rather than their own voices. This is exemplified by the practice of ‘team formulation’, where professionals construct formulations about the service user while they are absent (Aves, 2022c). Aves (2022b) argues in her lived-experience blog that this can be harmful, frightening, and re-traumatising. While this gives an impactful flavour of how psychological theories and formulations may be received by service users, there is a dearth of quality research on how the range of psychological approaches to psychosis are employed by professionals working in the field. The literature is lacking on how approaches orientate professionals towards the meaning-making of the service user in a way that they find helpful (Spencer et al., 2022), if at all (Aves, 2022b).

## **2.6. Integrated frameworks**

Given the array of different, and often competing, approaches to conceptualising psychosis, it is perhaps unsurprising that frameworks have attempted to integrate elements from multiple sides of the debate. Integrative frameworks combine elements from biological and



psychosocial models, aiming to create an inclusive and multi-factorial framework (Pilgrim, 2002). As Heriot-Maitland (2011) notes, current NICE guidance means that integrated biomedical and psychological approaches are a clinical reality in multidisciplinary psychosis services.

The biopsychosocial model combines biological factors with social and psychological factors to theorise the aetiology of mental health problems. This aims to avoid biological or psychosocial reductionism and enable consensus between proponents of the biomedical model and its psychosocial critics (Pilgrim, 2002). While there have been prior attempts to integrate these elements, as described in Meyer's work above, the term biopsychosocial is associated with Engel's 1977 paper (Double, 2008). Indeed, Engel acknowledges the influence of Meyer's 'psychobiology' and the 'reaction-to-life-stress approach' within the biopsychosocial model. Another integrative framework, the stress-vulnerability model, incorporates 'vulnerability factors' (any pre-existing issues), and 'stress factors' (present environment factors) (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977). Vulnerability factors can incorporate both genetic and environmental factors, such as early experiences, which may increase the 'load' of vulnerability. The model posits that enduring factors make a person more or less vulnerable to stress factors, which can lead to experiences of psychosis when they reach a particular level.

Some in the field have raised questions about how the models are theorised. For example, Barker et al. (2015) suggest that the biopsychosocial model requires continued development to better theorise the mechanisms of adversity and maltreatment impacting biological processes. Those from the critical movement have raised criticisms about the overall biological focus of the integrative models, suggesting that they treat psychosocial factors as secondary 'triggers' for biological vulnerability. Geekie and Read (2009) are cautious about whether the stress-vulnerability model actually has explanatory value, or whether it is

somewhat tautological: “only those who *can* develop psychosis will do so, and only when their propensity for doing so is actualised” (2009, p. 135).

Although Double (2008) questions whether the biopsychosocial perspective has permeated the foundations of psychiatry, it is undeniable that these integrative models have gained considerable popularity in mental health services (Cairns et al., 2015). Indeed, Heriot-Maitland argues that such frameworks offer “hope for cultivating an integrative understanding of psychosis” (2011, p.136) and opportunities for psychiatrists and psychologists in mental health services to work together in treating it. However, it is unclear whether these models merely benefit professional understandings by dampening academic disputes about the aetiology of psychosis. The literature is less clear on whether integrative models are meaningfully applied in practice in ways that support people with psychosis to understand their experiences. Further, there remains a question of whether incorporating a wider breadth of aetiological factors opens up opportunities for understanding or may lead to overgeneralisation.

### **3. Anthropological, spiritual & cultural models**

Alongside models of psychosis which have been theorised from a professional or academic standpoint, understandings of altered states often draw on local knowledge within specific communities. Anthropological studies have been invaluable in highlighting the role that culture plays in how psychosis is conceptualised and experienced across the globe (Castillo, 2003; Luhrmann et al., 2015; 2019). In particular, research has shown that understandings draw on frameworks of spirituality, magic and religion. Redko’s (2003) study, for example, highlights the religious conceptualisation of psychosis in São Paulo, Brazil, and Igreja et al. (2008) explore the invoking of spirits in sense-making for communities in Gorongosa,

Mozambique. Further research has looked at localised cultural models of understanding in Latin America (Earl et al., 2015), Ghana (Luhmann et al., 2013) and India (Castillo, 2003). Luhmann et al. (2013) compare the understandings of voice-hearing in the US to those in India and Ghana, where the former were more likely to draw on diagnostic models and the latter on local cultural and spiritual knowledge. Research into people from an Islamic background has identified that experiences of psychosis are commonly attributed to jinn, a form of black magic (Lim et al., 2015). Common to many of these studies is that drawing upon localised cultural and spiritual understandings had positive effects on the experience itself, as well as enabling communities to draw on local resources and support (Castillo, 2003; Luhmann et al., 2019). These studies provide a helpful reminder that knowledge is socially and culturally situated, with varied frameworks of meaning-making available to different communities. However, Taitumi and Lambecht (2012) offer a warning when analysing cross-cultural studies. They highlight risks regarding the validity of cross-cultural findings, as authors can 'whiten' or lose cultural meanings in translation or ignore the subjective experiences of their participants altogether.

Research in the UK and the US has demonstrated that spiritual and religious understandings of psychosis are also common in the West (Geekie & Read, 2009; Jones et al., 2016; Marriott et al., 2019). Attribution of psychosis to Jinn can be common among contemporary British Muslims (Dein & Illaiee, 2018). Indeed, South Asian groups are more likely to use spiritual models to explain their psychosis than their White British counterparts (Mirza et al., 2019). As these studies suggest, the ethnic diversity and multiculturalism of the UK will likely impact the range and availability of cultural and spiritual explanations. The literature is less clear on how particular cultural or spiritual meanings are applied and experienced within minority contexts, such as the UK, compared to their country of origin where meanings may be ever-present, shared, and established in context. Considering the 'ethnic density effect', where own-group density is protective against psychosis (Das-Munshi et al., 2012), this raises

questions about the role of shared cultural narratives in the aetiology and conceptualisation of psychosis. For second-generation immigrants, where rates of psychosis can be higher than first-generation migrants (Bourque et al., 2011), the impact of competing cultural narratives between home and outside is also worthy of further exploration in the literature.

To capture the importance of spirituality for many in making sense of psychosis, Grof and Grof (1986) coined the term 'spiritual emergency'. This built on the literature around transpersonal psychology by figures such as Carl Jung, who wrote of the meaning and purpose that could be found in psychosis through the awareness of the spiritual world and the process of healing (Jung, 1976). Several contemporary authors have also conceptualised out-of-the-ordinary experiences in terms of spiritual emergency or awakening (Kaselionyte & Gumley, 2019; Randal et al., 2008; St Arnaud & Cormier, 2017). Clarke (2000) noted the similarity of spiritual experiences with those of psychosis. Randel, a psychiatrist with lived experience of psychosis, argues that much can be gained from the insights of non-western communities into altered states of consciousness and spiritual experiences, suggesting these offer richer alternatives to reductive pathological explanations (Randal et al., 2008). The Spiritual Crisis Network promotes these ideas across the UK, sharing information with those interested in conceptualising their experience through a spiritual lens.

Given the salience of cultural or spiritual understandings, particularly in an ethnically diverse and multicultural UK, a question is raised about how these models may interact with professional understandings of psychosis when individuals engage with mental health services. Further research may elucidate how clinicians approach the meanings that service users bring and how these may interact with the models of understanding held by the professional and the wider system.

#### **4. Service user, survivor & Mad perspectives**

Having first explored professional frameworks, then moved to spiritual and cultural understandings, this paper lastly considers the contributions of service users themselves. There is a long and rich history of lived experience perspectives on madness (Hornstein, 2005) and historian Roy Porter's (1985) paper stimulated great interest in exploring these accounts 'from below'. However, these accounts have been largely comprised of individuals from white and middle-class backgrounds, and there is little evidence of collectivised accounts and action amongst patients before the nineteenth century (Blayney, 2022). The Alleged Lunatics' Friend Society in 1845, comprising members of the British social elite, is the first well-documented example. Collectives of service users then re-emerge in a serious and organised way in the latter half of the twentieth century, at which point they can first be considered a 'movement' (Blayney, 2022).

In the 1980s and 90s, many service user groups sprang up and diversified (Rashed, 2020), such as the United Kingdom Advocacy Group and the Hearing Voices Network. Service user networks became involved in developing services, policy and legislation, mental health research, and lobbying for patient rights. Many took a critical stance on the psychiatric institution, particularly against coercive practices and the medical model, and highlighted cases of maltreatment and poor care. Some groups took a clear political stance and activist role, channelling their own poor experiences of mental health services and calling for changes in the psychiatric institution. Many have come to view and label themselves as survivors of both their lived experience of distress and iatrogenic harm from mental health services.

Since the 1980s there has been a significant shift towards listening to the voice of lived experience, with the increasing involvement of service users across mental health services, research and policy in the UK (Campbell & Rose, 2011; Reaume, 2021). By the 1990s and

2000s, service users were beginning to be listened to in a way that they never previously had (Rashed, 2020). The reasons for this shift, write Campbell & Rose (2011), are complex. Alongside the influence of advocacy and lobbying groups, this shift can be partly understood in the context of the quasi-marketisation of mental health services, with the orientation toward listening to the ‘consumers’ of services (Roberts, 2010). Policy changes exemplified this, such as the NHS and Community Care Act of 1991 and involvement policy in the early 2000s, encouraging NHS Trusts and Local Authorities to involve patients and the public (PPI) and making more resources available (Blayney, 2022).

#### **4. 1. New understandings**

While a key focus has been on improving psychiatric services, the movement has also been central in promoting new understandings of madness (Campbell, 2012a). Many in the movement are interested in putting forwards alternative understandings around the nature of ‘madness’ or ‘mental illness’, often relating to the diversity of experiences (Campbell & Rose, 2011). Service user involvement has encouraged greater use of non-medical language: talking of distress rather than illness, and hearing voices rather than hallucinations (Campbell & Rose, 2021). The greater visibility of perspectives from service users and people with lived experience has ‘serious consequences’ (Rashed, 2020) for mental health services, which need to evolve and adapt to accommodate them.

It is often assumed that service user voices, and particularly activist groups, take on an anti-medical framework. While this may have been the case towards the start of the movement, this cannot be said for current understandings amongst service users (Campbell & Rose, 2011). The anti-psychiatry movement was highly influential to many service users in the 1980s, particularly the British Network for Alternative to Psychiatry (BNAP), which included both service users and mental health professionals who were aligned with the views of RD

Laing and David Cooper (Campbell & Rose, 2011). This influence was in part because anti-psychiatry provided much of the dominant discourse, language and concepts through which psychiatry could be criticised at the time. Beyond this, however, many service users drew on other areas, such as the disability field, in developing their frameworks.

While many remain opposed to the medical model and aligned with critical perspectives, Campbell & Rose (2011) suggest that a substantial proportion of service users are instead focused on “improving the consequences of medical understandings of madness rather than trying to be rid of them entirely” (2011, p.459). Many more hold diagnosis as important in understanding and labelling their experience, offering them stability, and enabling an identity to be formed around it (Aves, 2022b). Diagnosis may be a preferable shorthand rather than expressing the intimate details of past trauma, particularly in a political context where formal financial and practical support may require personal disclosure to gain access (Aves, 2022a). Some service users have voiced criticism against anti-diagnostic approaches for this reason. Chapman (2022) argues that the denial of diagnosis and disability classification is fundamentally ableist. They suggest that while anti-diagnostic approaches often position themselves as epistemically liberating service users from the ‘myths’ of mental illness, the denial of diagnosis is in itself a form of epistemic violence (Chapman, 2022).

Mad Studies, an academic strand of the service user movement, emerged around the 2000s, reclaiming the term ‘mad’ which had historically been stigmatising and pejorative. A key focus of Mad Studies is to centre and empower the ideas and understandings of those with lived experience of madness and the psychiatric system. This privileges personal experience, consistent with standpoint epistemology (Slade & Sweeney, 2020), and reclaims knowledge from professionals (Menzies et al., 2013). Fundamentally, Mad Studies is not a singular approach but looks to promote and encourage the diversity and plurality of service user perspectives (Campbell, 2021b; Rashed, 2020). Recognising Mad Studies for its diversity,

rather than as an explanatory monolith, accounts for the range of understandings that have emerged across the history of the service user movement and before it. A key hope of these movements is for their own understandings, in their plurality, to be seen as “equally valid as professional understandings” (Campbell & Rose, 2011).

#### **4.2. Service user outputs, writing and material**

Service users have found myriad ways to share and collaborate on their understandings of madness (Slade & Sweeney, 2020). Some of this has been support through groups, collectives and networks, such as Recovery in the Bin, Mad in the UK, and the Hearing Voices Movement.

The use of personal memoirs or writings has been influential since the start of the movement, much as Chamberlain’s (1978) *On Our Own*, or Kayser’s (1993) writing which became the basis for the film *Girl, Interrupted*. Ability to share stories and understandings has proliferated with increased access to the internet, through personal websites, blogs and social media platforms. Online ‘Mad’ spaces allow people to share, make sense, and support one another (Slade & Sweeney, 2020). Twitter appears to be a vital shared space for people to engage with each other, expressing the broad spectrum of different ideas and conceptualisations. Beyond written text, there are an array of creative expressions which also help to express the lived experience of psychosis through art, documentaries and poetry (Geekie & Read, 2009). Asylum Magazine is an example of a medium where a range of service user perspectives are shared through various mediums: articles, drawings and creative writing (Blayney, 2022). The increases in accessible platforms and groups have significantly improved people’s ability to get their voices heard, rather than relying on the tradition of limited access to publication in books or journals.



Influential people who share their personal experiences, journeys and understandings of psychosis include Rai Waddingham (2021), Dolly Sen (2016; 2017), and Jacqui Dillon (2010; 2012). They do so through various mediums, such as public speaking, writing, documentary filmmaking, working within services, and offering training to professionals. The service user movement has also enabled increasing openness from clinicians about their own experiences, breaking down the constructed binary between ‘professional’ and ‘patient’. Several professionals have written of their own experience of psychosis and psychiatric care, including Rufus May (2000), Egan Bidois (2012), Patte Randal (2008), Peter Chadwick (2007), Stephen Williams (2015) and Eleanor Longden (2012; 2013; 2016). Based on their own experiences, they too have promoted the importance of meaning-making in psychosis (Longden et al., 2012; 2016), suggesting that having your own narrative is central to recovery (May, 2000).

#### **4.3. Limited progress and epistemic (in)justice**

While it is evident that mental health services and wider society are increasingly open to listening to the voices of people with lived experience, it is still not an “entirely rosy picture” (Campbell, 2021, p.58). It is unclear how much credibility these ideas are given, with issues such as tokenism evident in services (Campbell & Rose, 2011). Campbell (2021b) suggests that although service user involvement may be underway, services can still demonstrate disinterest or hostility towards their actual understandings of mental illness. Estroff (2004) argues that this is because patient understandings challenge the dominant narratives of professionals. As such, there is still some distance to travel before service users’ knowledge exists on a level playing field with professional knowledge (Campbell, 2021b; Campbell & Rose, 2011).

In the field of philosophy, Miranda Fricker has written on ‘epistemic injustice’: “a wrong done to someone specifically in their capacity as a knower” (2009, p.1). This relates to a judgement of credibility of that person’s knowledge, meaning that the opportunity to gain knowledge from them may be missed. Fricker’s work encompasses both dismissing a person’s perspective because they are psychotic, as well as a professional withholding a psychiatric diagnosis. Some previous authors have applied the concept in the area of psychosis, such as in the realm of delusions (Sanati & Kyratsous, 2015), offering a theoretical framework for considering how different perspectives and knowledges may be heard (or not) in relation to social position and power. As Boyle (2012) notes, those with the least power are more likely to have their authoring rights removed. Chapman (2022) argues that *both* mainstream psychiatry and critical approaches are epistemically unjust, suggesting that the emphasis must remain on prioritising the expertise and needs of people with lived experience. Willig (2012) calls the overriding of another’s meaning ‘interpretative violence’, when someone considered an ‘expert’ silences the perspective of another.

Estroff (2004) writes that the playing out for authoring rights between professional and service user knowledges can create an ‘us versus them’ dichotomy. For service users, the knowledge of lived experience is privileged and expertise outside of this is considered limited in its explanatory capacity. On the other hand, professional knowledge often posits that knowledge must be gained objectively, with first-hand experience discredited as ‘lacking in insight’ (Aves, 2022d; Estroff, 2004). While professional structures may aim to aggregate individual subjective experiences into broader concepts that can inform general intervention approaches and service design, the ‘us and them’ dichotomy indicates that these concepts can become too detached from idiosyncratic personal experiences. The task for mental health services may be better balancing the impersonal need to cater for large groups of people, while also meaningfully attending to the nuanced, personal narratives of individuals.

Indeed, Thornhill et al (2004) suggest that it is essential for multiple perspectives to co-exist together, rather than one framework for understanding claiming it has legitimacy over others.

## **5. Explanatory models and narrative insight**

Having outlined the myriad frameworks, models and understandings amongst professionals and service users, both within and outside of mental health services, it is evident that there is overwhelming possibility in making sense of psychosis. It will now be considered what this means for people who experience psychosis and what they draw on in coming to understand their experience. To begin this thinking, it will be helpful to consider a few theoretical frameworks which have emerged to conceptualise differences in explanation. One such framework is Kleinman's (1986) 'explanatory models': stories that a person constructs around an experience to make sense of it in a culturally-embedded way. Kleinman theorised that these explanations impact the experience themselves. In this way, Geekie & Read note, they are 'constitutive' (2009, p.30).

A range of other theories and findings follow this suggestion that explanatory models are constitutive of experience. This is in keeping, for example, with Romme and Escher's finding that the way a voice-hearer explains their experiences impacts on the distress relating to it (Romme, 2009, 2012; Romme & Escher, 2009). Equally, a central principle of CBT for psychosis is that the appraisal and interpretation of a psychotic experience impacts the emotions and distress associated with it (Chadwick et al., 1996). McGlashan and Carpenter's (1981) model of 'sealing over' and 'integration' further support this, with the suggestion that the relationship a person has with their experience of psychosis impacts the outcome. The model posits 'sealing over' and 'integration' at two ends of a continuum, where the former involves a person shutting out the experience, not thinking about it, and deeming it irrelevant to further meaning-making. The latter involves a more curious approach, where a person may

explore the meaning of the experience, looking for patterns and relationships, and making it possible to integrate it within their lives. Research has suggested that ‘integrators’ may have better overall outcomes (Thompson et al., 2003). Of interest, McGlashan (1987) notes the role others, such as mental health professionals, have in this process and determining where on the continuum a person may be. These studies, which highlight that the interpretation of and relationship to psychosis can impact outcome and distress, are of central importance to mental health services, where there is an invested interest in reducing distress.

The creation of a meaningful, culturally-embedded story about psychiatric experiences has also been termed ‘narrative insight’ (Slade & Sweeney, 2009), with a number of authors relating this specifically to psychosis (Lysaker, 2002; Lysaker et al., 2009; Marriot et al., 2019; Roe et al., 2008). While this is conceptually similar to Kleinman’s ‘explanatory models’, narrative insight is more closely aligned with survivor research and as such is less professionally dominated (Slade & Sweeney, 2020). Narrative insight is aligned with giving people ownership over their own narratives and personal meaning, and theoretically encapsulates the concept of explanatory models within it. Lysaker et al. (2009) suggest that narrative insight is fundamental to understanding life more broadly, where past events are made sense of, and futures can be imagined. From a narrative perspective, personal meaning-making which rejects a diagnostic explanation would not suggest a ‘lack of insight’ but would highlight disagreements about the aetiology or meaning of psychosis (Macnaughton et al., 2015).

## **6. Meaning-making, identity, self, and recovery**

### **6.1. Meaning-making and storytelling**

Meaning-making is a central human endeavour. It is fundamental to our existence (Merleau-Ponty, 1962) and closely bound up with storytelling. As McAdams writes: “like no other animal on the planet, we human beings love to tell stories” (2019, p1). Some writers argue that this is an evolved capacity: that humans have developed to make sense of the world using language and storytelling (McAdams, 2019) which gives meaning and continuity to their lives (Cowan et al., 2021). This has an important role in shaping identities, demonstrating how stories are not merely *descriptive* but *constitutive* (Geekie & Read, 2009) of experience and selfhood. As Geekie and Read note, stories are the “invisible, yet essential, foundations which shape or determine how we understand the world around us” (2009, p.8).

The literature on storytelling describes the active process through which an individual negotiates various systems of meaning, drawing on and taking influence from what is around them, across their social network (friends, family, rivals, religious leaders, mental health professionals) and wider groups, institutions and cultural discourses (Lysaker et al., 2009; McAdams, 2019). In this way, stories are fundamentally interpersonal (Roe et al., 2008) and social (McAdams, 2019), constructed with and alongside others.

Storytelling and meaning-making have their intellectual roots in philosophy, having since broadened out across the social sciences with the turn towards interpretivism and constructionism. This paradigm shift has had significant consequences for psychological research and practice. The storytelling and meaning-making literature, and the constructionist framework in which it sits, has wide-ranging ontological and epistemological implications, suggesting that there are multiple ways of seeing and knowing the social world. This opens up the possibility for multiple stories and truths (Foucault, 1980), upon which an entire research paradigm has been built, as well as the model of Narrative Therapy (White, 1991; White & Epston, 1990) in clinical practice.

## **6.2. Psychosis, storytelling and identity**

The significance of meaning-making, storytelling, and identity construction has important consequences in approaching psychosis. This is because psychosis is “fundamentally bound up with identity and selfhood” (Jones, 2020) and often plays out in the disturbance of first-person self-experience (Lysaker & Lysaker, 2002; Sass & Parnass, 2003), as noted above. Given the related disruption and fragmentation of narrative coherence for people with psychosis, it is clear that storytelling is of central importance in conceptualising and intervening with psychosis. Indeed, developing a meaningful narrative is frequently described as central to recovery in psychosis (Andresen et al., 2003; Dillon, 2019; Lewis, 2014; Longden, et al., 2013; May, 2003, 2008; Roe et al., 2008). Meaning-making can support people with psychosis to develop their voice (Salem, 2011), reclaim ownership over the experience (Thornhill et al., 2004), and move to greater levels of integration and consciousness (Randal, 2008). Perhaps unsurprisingly, this process has been linked to improvements in self-understanding and identity-making (Friesen et al., 2021) and post-traumatic growth (Mapplebeck, Joseph & Sabin-Farrell, 2015; Slade et al., 2019).

Given that narratives are not constructed in isolation (Lysaker et al., 2009), the professional and service user encounter in mental health services come into focus as a central site of meaning-making. It is therefore unsurprising that previous research studies have demonstrated the influence of clinicians upon service users’ understandings of their psychosis (Larsen, 2004).

## **7. Studies of meaning-making**

While this review has covered a wide range of professional perspectives, service user perspectives and cultural models, this has been somewhat disconnected from what happens on the ground in clinical reality. It is therefore important to understand how these frameworks permeate outside the theoretical and academic realm to influence the meaning-making of professionals and service users in clinical reality. To begin doing so, this review will first consider studies which have explored meaning-making from the lived experience perspective, before moving on to those focusing on mental health professionals.

### ***7.1 Studies of service user meaning-making***

These studies make essential contributions to our understanding of meaning-making from the lived experience perspective. They highlight the diversity of explanatory frameworks that people draw on, the challenges of negotiating these, and the role of others and the wider social context in this process (Hutchins et al., 2016; Rosenthal Oren et al., 2021; Sips et al., 2021).

Friesen et al. (2021), interviewing service users from early intervention services in the US, highlighted the range of ways that participants explained their experiences. Some accepted the explanations and diagnoses offered to them by EIP clinicians, describing their psychosis as an 'illness'. Others struggled to integrate illness models with their own explanations, so drew on alternative frameworks instead, such as seeing the experience as spiritual, or understandable in the context of certain life events. These models often overlapped, with participants commonly drawing on multiple explanatory frameworks simultaneously.

This was similar in Geekie and Read's (2009) work, a qualitative study of 15 service users with FEP in New Zealand, which demonstrated a significant range of ideas about aetiology, relating to past experiences, biology and genetics, the brain, drug use, emotions (such as stress, anxiety, jealousy or guilt), meta-cognition, and alternative frameworks like spirituality or good and evil. Participants used metaphors to explain the experience, such as a 'sped up movie' or 'dreaming'. While the majority experienced it negatively or distressing in some way, others found it to be positive, sharing feelings of comfort or happiness. The role of others was also highlighted, with service users reporting feelings of invalidation if others discounted their own narratives and explanations.

Carter et al. (2018) also explored causal beliefs, interviewing 15 participants from mental health services in the UK. They demonstrated that people could hold multiple models about the cause of their psychosis, and these can change over time. Many found the cause challenging to make sense of, considering a range of factors that may explain it. Those who held contradictory beliefs would also be aware that it was unusual for these differing frameworks to co-exist. Some noted negative affect associated with diagnosis. As in other studies, participants noted that professionals in services did not offer them a causal model.

Thornhill et al.'s (2014) paper explores the construction of meanings in recovery from psychosis, interviewing 15 service users with lived experience in the UK. They demonstrated that the search for meaning was important for participants in making sense of difficult or confusing experiences. While some accepted the label or diagnosis, others questioned the narrow definitions of 'mental illness' and developed spiritual insight instead. The authors therefore gauge that mental health professionals must consider the multiple realities and possibilities that can co-exist around the experience of psychosis, which should be mirrored through open-minded exploration.



Larsen's (2004) ethnography, a seminal study in the field, included interviews with 15 service users diagnosed with an FEP in Denmark. The research also demonstrated that service users drew on various discourses and frameworks within the cultural repertoire to make sense of their experiences. Larsen labelled this 'bricolage' to reflect the active process of negotiation, in which frameworks might be accepted, rejected and combined to make meaning. Furthermore, Larsen extends the explanatory model concept to become 'systems of explanation' to capture this bricolage. Spiritual explanations were important to many in the study, describing psychosis to be like entering a spiritual world. Larsen also demonstrated that people held multiple systems of explanation concurrently, even when they may be logically incompatible, such as spiritual and biomedical understanding. Of note, service users in the study felt that clinicians (psychiatrists) did not understand their experience's spiritual aspects, so they did not share these understandings with them.

Jones et al.'s (2016) study, which interviewed 19 individuals with a psychosis diagnosis in the US, also draws attention to the plurality of explanatory models that service users may draw on. The salience of spiritual models is particularly notable. They comment on the complications of how these models overlap and can co-exist, again drawing on the term 'bricolage' to capture this. The authors argue that the 'messy intersections' between illness or religious frameworks in the research calls into question the commonly constructed dichotomy between 'biomedical' and 'psychosocial' approaches. They suggest that caution is needed around overly 'content-orientated' approaches to explanatory frameworks, for the strategies and logics which link them together in the minds of service users are as important as the objects themselves. Of note, the significant majority of participants reported very limited opportunities to explore the meaning of their psychosis with mental health professionals. Clinicians often misunderstood the complicated operation of 'insight' for service users, where delusional frameworks could keep hold over them even during periods of remission.

Several studies helpfully highlight the role of mental health services and clinicians in the process of meaning-making. For Myers and Ziv (2016), in their ethnography of 20 African American men experiencing psychosis, mental health services reduced users' autobiographical power and authorship over their own stories. While it was of great value to service users to have their own stories heard and be given support to make sense of things on their own terms, there was often a sense of powerlessness as their own explanations were rejected. It is notable that at the start of their time in contact with services, it was clear that service users' explanations were different to others, which made it challenging to draw on common sense or culturally relevant frameworks. The primary finding was the sense of social defeat this brought about in those with lived experience.

Some studies noted challenges faced by some service users in contexts where the medical model was dominant. In McGuire et al.'s (2020) study, the normalisation of illness narratives amongst the family members and mental health professionals around the service user impacted their scope for meaning-making, limiting their ability to take on roles and identities outside of illness. Tucker's (2009) study in the UK demonstrated the dilemmas of receiving and accepting a schizophrenia diagnosis. While it could provide relief as an explanation, there were also negative connotations of stigma and 'risk'. Other research has found that service users can feel disempowered if they do not share the medical model as an explanatory framework (Colombo et al., 2003; Stovell et al., 2016).

In Roe et al.'s (2008) study, which draws on the narrative insight framework, routes to understanding went beyond simply accepting or rejecting a diagnostic label. While some actively accepted their diagnosis and attributed experience to it, others showed a more passive acceptance of the label. The authors note the challenge of determining whether a person genuinely believes a diagnosis fits with their lived experience, or whether they say so

because the professional or clinical situation demands it. Beyond this, many went further in searching for other ways to explain their experience through spiritual or magical models. This range of responses, similar to Larsen's (2004) work, highlighted the complex and active negotiation of meaning around the experience and authoring their own narrative.

Overall, these studies evidence the ways that service users draw on a 'bricolage' of multiple frameworks in an active process of making sense of their experiences of psychosis. Furthermore, they highlight important points about the role of mental health professionals in this process. The perspectives of clinicians and services were shown to influence how service users made sense of their psychosis, at times employing an illness model which appeared to be dominant in some settings. In other contexts, clinicians did not offer a causal model at all, nor provide opportunities to explore meaning-making. At times when meaning-making was part of the clinical encounter, service users could find that professionals misunderstood their meanings. Given this context, studies that have explored the meaning-making of mental health professionals will be considered next.

## **7.2. Studies of professional meaning-making**

While ample theoretical literature has been written and formulated by professionals, as reviewed in detail above, there is limited research into their understandings of psychosis in clinical practice (Carter et al., 2017; Rosenthal Oren et al., 2021). While some literature suggests that mental health professionals follow mostly biogenetic models (Baillie et al., 2009; Coffey & Hewitt, 2008), other studies highlight that clinicians draw on a variety of frameworks and theories in making sense of psychosis, including anti-psychiatric ones (Ringer & Holen, 2016).

Rosenthal Oren et al. (2021) compiled a scoping review of the literature on beliefs about the cause of psychosis ('causal beliefs'), including the perspectives of both people with psychosis and mental health professionals. They note that clinicians draw on complex, multifactorial models to explain the cause of psychosis, though these often trend towards biogenetic beliefs over psychosocial ones. Since their review suggests that people who experience psychosis prefer psychosocial explanations over biogenetic ones, the authors note a gap in causal beliefs between the two groups. They suggest that this may impact the relationship and adherence to treatment. Limited studies have directly compared the understandings of mental health professionals directly with their service users (Rosenthal Oren et al., 2021), though studies by Roe et al. (2008) and Tranulis et al. (2008) are two examples of this.

Carter et al. (2017), in their survey of 219 clinicians in the UK, explored causal beliefs of psychosis across professional groups. The research also found that clinicians held multifactorial models of aetiology, though were more likely to endorse more psychosocial over biogenetic models, particularly trauma, stress and drug use. The study highlighted differences between professional groups, where psychiatrists were more likely to favour biological causes, and other clinical groups tended towards psychosocial causes. However, Wahass and Kent's (1997) study, which compared psy-professionals in the UK and Saudi Arabia, suggested that causal beliefs differed due to culture more than profession.

Cooke and Brett (2019) explored conceptualisations of psychosis by clinical psychologists in the UK, focusing on using spiritual or transformative models. Practitioners held a range of explanatory models, with the majority drawing on continuum models. Some drew on 'biopsychosocial' frameworks, though none held purely biological models. Some considered the positive elements in psychosis, such as creativity or sensitivity, or conceptualised it as a meaningful or adaptive response to life events. In this way, some considered the experience

‘transformative’ in that it could lead to post-traumatic growth. Others drew on spiritual frameworks, which influenced their work with service users to explore transformative possibilities. Many in the study felt uncomfortable and unable to engage with spiritual aspects of the client’s psychotic experiences, feeling it was outside their knowledge. Practitioners who were spiritual themselves were more confident in exploring spiritual aspects or interpretations of psychosis with service users.

A common theme in the literature is the limited development of spiritual explanations. In Carter et al.’s (2017) study, spiritual and religious factors were not considered important in the aetiology of psychosis. In Cooke and Brett (2019), clinicians did not feel confident talking about spirituality, unless they had had their own religious experiences. In Larsen’s (2004) ethnography, the staff could only entertain mystical explanations of psychosis when they were having informal or private conversations with other staff members. These explanations were kept out of their formal clinical thinking or interactions with service users.

A few studies have interviewed mental health professionals concerning their conversations about voice-hearing with service users (Bogen-Johnston et al., 2020; Coffey & Hewitt, 2008; McMullan et al., 2018). Bogen-Johnston et al (2020), in their interviews with 10 EIP practitioners, found that clinicians were reluctant to begin conversations about voices with their service users. While many thought conversations about voices were important, few felt confident to do so or felt that they lacked training. In Coffey and Hewitt’s (2008) study, which explored voice hearing from the perspective of 20 service users and 20 mental health nurses in the UK, there were clear differences in how clinical conversations about voices were experienced by each group. While nurses generally felt their conversations about voice-hearing were considered, service users reported that talk with nurses was largely about practical or clinical matters, such as appointment bookings or medication reviews, and with an emphasis on the medical paradigm. Service users identified the desire to speak about the

content and meaning of the voices and felt more of this could happen in services. Following these papers, McMullan et al. (2018) showed clinicians also lacking in confidence in conversations about exploring psychosis with service users.

There is a growing literature around the discursive practices of mental health professionals, which draw on social-constructionist models to elucidate how language and speaking construct and reify the social world. These have shown how medicalised and technical language amongst professionals can justify the position of the professional over the service user (Buus, 2005), maintain the hierarchy of expertise (Coffey & Hewitt, 2008), and perpetuate institutional practices which disempower service users (Parker et al, 1995). In Ringer and Holen (2016), clinician discourses around patients being 'really ill' or 'lacking insight' limited service users in their expressions and explanations of their own mental distress, demonstrating how psychiatric language can create barriers against including service users' perspectives (Coffey & Hewitt, 2008; Ringer & Holen, 2016). These studies show how professional discourses within the broader institutional context construct the possibilities of service users' understanding of mental distress.

Overall, this body of literature highlights a range of multifactorial explanations between and within professional groups, some which tend towards either biological or psychosocial conceptualisations. Taken with the findings from the service-user literature, a picture emerges of the role of professionals in the process of meaning-making. While it is clear that they have influence over a service user's understandings, mental health professionals may not explore psychosis in-depth or create opportunities for meaning-making in the clinical encounter. This reluctance may relate to a perceived lack of training or confidence. Spiritual explanations in particular, while common for service users, seem to be an area of difficulty for clinicians. This sits in a wider context where there may be a gap in causal beliefs between service users and professionals.

As reviewed, this literature has highlighted the ways that mental health professionals engage (or do not engage) in meaning-making with service users. However, evidence of this process is clearly in its infancy. Only a few factors that enable or inhibit engagement have been identified—namely, clinician confidence, training, and differences in frameworks between professionals and service users. While the above studies predominantly focus on either the perspectives of professionals or service users, there is a dearth of studies which either consider both concurrently or explore the perspective of one through the others' eyes. This is restrictive, as meaning-making is evidently a shared process, with others in a person's surrounding network influencing their understanding. What remains to be seen in the literature is an in-depth exploration of the meaning-making process between service users and professionals within the clinical encounter. Beyond this, there is a lack of exploration into the factors which enable or inhibit this in mental health services, and therefore very limited theorising about the context in which meaning-making is best stimulated.

## **8. Early Intervention in Psychosis services and meaning-making**

Early Intervention in Psychosis (EIP) services provide mental health treatment for people presenting with first-episode psychosis (FEP) (Marshall & Rathbone, 2011). FEP is the first time that a person with psychosis is seen in statutory psychosis services (Norman & Malle, 2001). As psychosis often begins in early adulthood (Lester et al., 2009), EIP services cater for those aged 18-35, with most services also expanding across the lifespan up to age 65. Built on the notion that untreated psychosis leads to worse outcomes and timely intervention is important to manage this (Spencer et al., 2001), EIP services provide rapid and intensive mental healthcare for up to three years.

EIP services were founded on an ethos of openness in approach: diagnostic uncertainty, a range of available interventions, and lesser focus on medication. Those under EIP services, therefore, have access to care-coordination, pharmacological treatment, psychological interventions such as CBT and family therapy, educational or employment support, and social therapy (DoH, 1999; NICE, 2014). Studies have suggested that EIP services achieve better outcomes for FEP patients than mainstream services (Neale & Kannair, 2017; Singh & Fischer, 2005; Sullivan et al., 2019).

As EIP services offer support during an FEP, the person's understanding of that experience will also likely be in its infancy. This is a crucial period for influencing a person's first steps towards either 'sealing over' or 'integration' (McGlashan & Carpenter, 1981). As such, EIP services appear to be a key site for supporting meaning-making around experiences of psychosis. Indeed, it has already been demonstrated that mental health professionals have a pivotal role in influencing, shaping and supporting the sense-making of service users (Geekie & Read, 2009; Larsen, 2004). These early interactions with EIP professionals and services will likely prove critical in the person's developing understanding of their psychosis, and ultimately prove consequential for their self-understanding, identity formation, recovery, and growth (Dillon, 2019; Friesen et al., 2021; Longden et al., 2013; Mapplebeck et al., 2015; May, 2003; Roe et al., 2008; Thornhill et al., 2004; Slade et al., 2019). As such, numerous researchers, clinicians and service users have called for mental health professionals to give greater attention to meaning-making in psychosis (Coffee & Hewitt, 2007; Friesen et al., 2021; Harper, 2004; Jones, 2020; Jones et al., 2016; Jones & Shattell, 2016; Kaselionyte & Gumley, 2019; Roe & Lysaker, 2012; Romme et al., 2009; Slade & Sweeney, 2020)

## **9. Conclusions and research aims**



Meaning-making has been shown as a highly beneficial process for people in understanding and narrating their experiences of psychosis. Through exploring the diversity of understandings which span professional, cultural and service-user frameworks, it has been possible to understand the context which facilitates and influences professionals and service users as they begin to make sense of psychosis in the clinical encounter. Reviewing studies into meaning-making from a service user perspective elucidated how a 'bricolage' of available narratives and frameworks are drawn on by people living with psychosis to actively make sense of their experiences. It was clear that professionals were influential in this process, both through the negotiation of professionally-dominated frameworks, and the more direct role of clinicians in services shaping their meaning-making. From studies into professional meaning-making, it was demonstrated that clinicians also have multifactorial explanations and may draw on a range of frameworks, though these may conflict with the frameworks employed by service users.

However, exploration into the *process* of meaning-making between service users and professionals has only been secondary to the primary interest in models which are drawn on. Often, this involves a separate focus on either service users or professionals. There is consequently limited understanding in the literature on what unfolds between service users and professionals as they negotiate, jointly and separately, a sense of meaning around experiences of psychosis. Given mental health professionals' position of power in the clinical encounter, it should be their responsibility to invite service users into spaces where meaning can be made of their experiences should they want to. The dearth of studies exploring the context in which meaning-making becomes possible for professionals and the factors which restrain it, means that there is a significant gap in our understanding of how clinicians and services can orientate towards this important activity. There is a lack of clarity around how this is (or is not) prioritised by clinicians in current clinical practice.

A greater understanding of this would provide guidance to clinicians and services about creating opportunities, professionally and systemically, which enable and centre meaning-making within the clinical encounter. It is mental health professionals themselves who have insight into the priorities, demands and conditions of their clinical practice and the wider systems around them. As EI services work with people at the earliest stage of their sense-making journey, they are fertile ground for positively influencing a person's understanding of their psychosis.

The present study aims to fill these gaps in the literature across two research questions. The first research question (*'How do clinicians working with first-episode psychosis conceptualise and respond to service users' personal meaning-making within the clinical encounter?'*) will explore in detail the meaning-making process by mental health professionals in EIP services. This will include how they relate to and mediate the perspectives of service users.

The second research question (*'What professional or structural factors and processes influence clinicians' conceptualisations and responses?'*), will then embed this process within the broader context that enables or inhibits it. This will include an exploration of the factors at a personal, professional and systemic level which are influential.

Overall, drawing on Constructivist Grounded Theory, the study will theorise the overarching processes through which meaning-making plays out within EIP services.

## References

- Adame, A. & Hornstein, G. (2006). Representing madness: how are subjective experiences of emotional distress presented in first-hand accounts? *The Humanistic Psychologist*, 34(2), 135-158.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37(5), 586-594.
- Ashok, A. H., Baugh, J., & Yeragani, V. K. (2012). Paul Eugen Bleuler and the origin of the term Schizophrenia (Schizopreneigruppe). *Indian Journal of Psychiatry*, 54(1), 95.
- Aves, W. (2022a, Winter). A Pathological 'Diagnosis-Seeker' Speaks Out. *Asylum: The Magazine for Democratic Psychiatry*, 29(4), 22-24
- Aves, W. (2022b, July). Dear Mental Health Professionals, Even 'Good' Formulations Can Harm. *Psychiatry Is Driving Me Mad*. Retrieved from:  
<https://www.psychiatryisdrivingmemad.co.uk/post/even-good-formulations-can-harm>
- Aves, W. (2022c, June). Multidisciplinary Team Meetings: Everything About Us Without Us. *Psychiatry Is Driving Me Mad*. Retrieved from:  
<https://www.psychiatryisdrivingmemad.co.uk/post/everything-about-us-without-us>
- Aves, W. (2022d, May). My Doctor Is Lacking Insight. *Psychiatry Is Driving Me Mad*. Retrieved from: <https://www.psychiatryisdrivingmemad.co.uk/post/my-doctor-is-lacking-insight>

- Bacopoulos-Viau, A., & Fauvel, A. (2016). The patient's turn: Roy Porter and psychiatry's tales, thirty years on. *Medical history*, 60(1), 1-18.
- Baillie, D., McCabe, R., & Priebe, S. (2009). Aetiology of depression and schizophrenia: Current views of British psychiatrists. *The Psychiatrist*, 33, 374–377.
- Barker V., Gumley A., Schwannauer M., Lawrie S. M. (2015). An integrated biopsychosocial model of childhood maltreatment and psychosis. *The British Journal of Psychiatry*, 206, 177–180.
- Bell, V. (2017). Why we need to get better at critiquing psychiatric diagnosis. *Mind Hacks*. Retrieved from: <https://mindhacks.com/2017/09/19/why-we-need-to-get-better-at-critiquing-diagnosis/>
- Berrios, G. E. (1992). Phenomenology, psychopathology and Jaspers: a conceptual history. *History of Psychiatry*, 3(11), 303-327.
- Ben-David S, & Kealy D (2019). Identity in the context of early psychosis: A review of recent research. *Psychosis*, 2(1), 1–11.
- Bentall, R. (2003). *Madness Explained: Psychosis and Human Nature*. London: Penguin Psychology.
- Beveridge, A. (2014). The history of psychiatry: personal reflections. *The Journal of the Royal College of Physicians of Edinburgh*, 44(1), 77-84.
- Bidois, E. (2012). A cultural and personal experience of psychosis. In J. Geekie, P. Randall, D. Lampshire & J. Read (Eds.), *Experiencing Psychosis: Personal and Professional Perspectives* (pp. 35-43). East Sussex: Routledge Press.

- Blayney, S. (2022). Activist Sources and the Survivor Movement. In *Sources in the History of Psychiatry, from 1800 to the Present*. Taylor & Francis.
- Bogen-Johnston, L., deVisser, R., Strauss, C., & Hayward, M. (2020). A qualitative study exploring how Practitioners within Early Intervention in Psychosis Services engage with Service Users' experiences of voice hearing?. *Journal of Psychiatric and Mental Health Nursing*, 27(5), 607-615.
- Bourque, F., van der Ven, E., & Malla, A. (2011). A meta-analysis of the risk for psychotic disorders among first-and second-generation immigrants. *Psychological medicine*, 41(5), 897-910.
- Boyle, M. (2012). *Schizophrenia: A Scientific Delusion?* (2<sup>nd</sup> Ed). New York: Routledge Press.
- Boyle, M. & Johnstone, L. (2020) *A Straight Talking Introduction to the Power Threat Meaning Framework: An Alternative to Psychiatric Diagnosis*, Monmouth: PCCS Books
- Brabban, A., Byrne, R., Longden, E., & Morrison, A. P. (2017). The importance of human relationships, ethics and recovery-orientated values in the delivery of CBT for people with psychosis. *Psychosis*, 9(2), 157-166.
- Bürgy, M. (2008). The concept of psychosis: historical and phenomenological aspects. *Schizophrenia Bulletin*, 34(6), 1200-1210.
- Buus, N. (2005). Nursing scholars appropriating new methods: the use of discourse analysis in scholarly nursing journals 1996-2003. *Nursing Inquiry*, 12(1), 27-33.
- Cairns, D., Reid, D., Murray, D., & Weatherhead, D. (2015). Experience of Psychosocial Formulation within a Biopsychosocial Model of Care for First-Episode Psychosis. *International Journal of Psychosocial Rehabilitation*, 19(2).

- Campbell, P. (2021a, Spring) The Survivor Movement in the 1990s: Collaboration and Change. *Asylum: The Magazine for Democratic Psychiatry*, 28(1), 22-24
- Campbell, P. (2021b). Speaking for ourselves: An early UK survivor activist's account. In *The Routledge International Handbook of Mad Studies* (pp. 57-59). Routledge.
- Campbell, P., & Rose, D. (2011). Action for change in the UK: Thirty years of the user/survivor movement. *The SAGE Handbook of Mental Health and Illness*, 452-470.
- Carter, L., Read, J., Pyle, M., & Morrison, A. (2018). "I Believe I Know Better Even than the Psychiatrists What Caused It": Exploring the Development of Causal Beliefs in People Experiencing Psychosis. *Community Mental Health Journal*, 54(6), 805-813.
- Carter, L., Read, J., Pyle, M., Law, H., & Morrison, A. P. (2017). Mental health clinicians' beliefs about the causes of psychosis: Differences between professions and relationship to treatment preferences. *International Journal of Social Psychiatry*, 63(5), 426-432.
- Castillo, R. (2003). Trance and functional psychosis. *Psychiatry*, 66(1), pp. 9-21.
- Chadwick, P. K. (2007). Peer-professional first-person account: schizophrenia from the inside—phenomenology and the integration of causes and meanings. *Schizophrenia Bulletin*, 33(1), 166-173.
- Chadwick, P., Birchwood, M., & Trower, P. (1996). *Cognitive therapy for delusions, voices and paranoia*. Chichester, United Kingdom: John Wiley & Sons.
- Chamberlin, J. (1978). *On Our Own: Patient controlled alternatives to the mental health system*. New York: Hawthorn Books.
- Clarke, I. (2000a) Psychosis and spirituality: Finding a language. *Changes*, 18: 208–214.

- Coffey, M., & Hewitt, J. (2008). 'You don't talk about the voices': Voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing*, 17, 1591– 1600.
- Colombo, A., Bendelow, G., Fulford, B., & Williams, S. (2003). Evaluating the influence of implicit models of mental disorder on processes of shared decision making within community-based multi-disciplinary teams. *Social Science and Medicine*, 56, 1557-1570.
- Condrau, F. (2007). The patient's view meets the clinical gaze. *Social History of Medicine*, 20(3), 525-540.
- Cooke, A. (Ed.). (2014). *Understanding psychosis and schizophrenia: Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help*. BPS Division of Clinical Psychology. Leicester, England: British Psychological Society. Retrieved from <https://www.bps.org.uk/sites/www.bps.org.uk/files/Page%20-%20Files/Understanding%20Psychosis%20and%20Schizophrenia.pdf>
- Cooke, A., & Brett, C. (2020). Clinical psychologists' use of transformative models of psychosis. *Clinical Psychology & Psychotherapy*, 27(1), 87-96.
- Cooke, A., & Kinderman, P. (2018). But what about real mental illnesses?" Alternatives to the disease model approach to "schizophrenia. *Journal of Humanistic Psychology*, 58(1), 47-71
- Cresswell, M. and Spandler, H. (2009) Psychopolitics: Peter Sedgwick's legacy for mental health movements. *Social Theory and Health*, 7(2) 129-47.

- Das-Munshi, J., Bécaries, L., Boydell, J. E., Dewey, M. E., Morgan, C., Stansfeld, S. A., & Prince, M. J. (2012). Ethnic density as a buffer for psychotic experiences: findings from a national survey (EMPIRIC). *The British Journal of Psychiatry*, 201(4), 282-290.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour*, 20(1), 43-63.
- Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review*, 33(7), 846–861.
- Dein, S., & Illaiee, A. S. (2013). Jinn and mental health: Looking at jinn possession in modern psychiatric practice. *The Psychiatrist*, 37(9), 290-293
- Department of Health. (1999) *National Service Frameworks for Mental Health: Modern Standards and Service Models*. Retrieved from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/198051/National\\_Service\\_Framework\\_for\\_Mental\\_Health.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/198051/National_Service_Framework_for_Mental_Health.pdf)
- DeVylder, J. E. (2013). The Fall and Rise of Adolf Meyer's Psychogenic Etiology of Dementia Praecox (Schizophrenia): 1903–1910 and Beyond. *Smith College Studies in Social Work*, 83(1), 2-17.
- Dickens, G., & Picchioni, M. (2012). A systematic review of the terms used to refer to people who use mental health services: User perspectives. *International Journal of Social Psychiatry*, 58(2), 115-122.
- Di Forti, M., Marconi, A., Carra, E., Fraietta, S., Trotta, A., Bonomo, M., ... & Murray, R. M. (2015). Proportion of patients in south London with first-episode psychosis attributable



- to use of high potency cannabis: a case-control study. *The Lancet Psychiatry*, 2(3), 233-238.
- Dillon, J. (2012). Recovery from 'psychosis.' In J. Geekie, Randall, Lampshire & Read (Eds.), *Experiencing Psychosis: personal and professional perspectives* (pp. 17-22). East Sussex: Routledge Press.
- Earl, T. R., Fortuna, L. R., Gao, S., Williams, D. R., Neighbors, H., Takeuchi, D., & Alegria, M. (2014). An exploration of how psychotic-like symptoms are experienced, endorsed, and understood from the National Latino and Asian American Study and National Survey of American Life. *Ethnicity & Health*, 20(3), 273–292.
- Estroff, S. (2004). "Subject/Subjectivities in dispute." In J. Jenkins & R. Barrett (Eds.), *Schizophrenia, Culture, and Subjectivity: The edge of experience* (pp. 282-302). Cambridge: Cambridge University Press.
- Filer, N. (2019). *The Heartland: Finding and Losing Schizophrenia*. London: Faber & Faber
- Foucault, M. (1965). *Madness and civilization: A history of insanity in the age of reason*. R. Howard (Trans.). Random House Inc.
- Foucault, M. (1970). *The order of things: an archaeology of the human sciences*. Pantheon Books.
- Foucault, M. (1973). *The birth of the clinic: An archaeology of medical perception* (A. M. Sheridan (Trans.)). Tavistock Publications Ltd.
- Fletcher, E. 2017. Uncivilizing "mental illness": Contextualizing diverse mental states and posthuman emotional ecologies within The Icarus Project. *Journal of Medical Humanities* 39(3):29–43.

- Fricker, M. (2009). *Epistemic injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Freeman, D., Garety, P. A., Kuipers, E., Fowler, D., & Bebbington, P. E. (2002). A cognitive model of persecutory delusions. *British Journal of Clinical Psychology*, 41(4), 331-347.
- Fowler, D., Freeman, D., Smith, B. E. N., Kuipers, E., Bebbington, P., Bashforth, H., ... & Garety, P. (2006). The Brief Core Schema Scales (BCSS): psychometric properties and associations with paranoia and grandiosity in non-clinical and psychosis samples. *Psychological medicine*, 36(6), 749-759.
- Friesen, P., Goldstein, J., & Dixon, L. (2021). A “blip in the road”: experiences of identity after a first episode of psychosis. *Psychosis*, 13(4), 327-337.
- Fromm-Reichmann, F. (1948). Notes on the development of treatment of schizophrenics by psychoanalytic psychotherapy. *Psychiatry*, 11(3), 263-273.
- Garety, P. A., & Freeman, D. (2013). The past and future of delusions research: From the inexplicable to the treatable. *British Journal of Psychiatry*, 203, 327-333.
- Garety, P. A., Freeman, D., Jolley, S., Dunn, G., Bebbington, P. E., Fowler, D. G., ... & Dudley, R. (2005). Reasoning, emotions, and delusional conviction in psychosis. *Journal of abnormal psychology*, 114(3), 373.
- GBD 2019 Mental Disorders Collaborators. (2022). Global, regional, and national burden of 12 mental disorders in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Psychiatry*, 9(2), 137-150.
- Georgaca, E. (2013). Social constructionist contributions to critiques of psychiatric diagnosis and classification. *Feminism & Psychology*, 23(1), 56–62.

- Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. Garden City N.Y.: Anchor Books.
- Gong, N. (2017). "That proves you mad, because you know it not": impaired insight and the dilemma of governing psychiatric patients as legal subjects. *Theory and Society*, 46, 201-228.
- Goodwin, G. M., & Geddes, J. R. (2007). What is the heartland of psychiatry?. *The British Journal of Psychiatry*, 191(3), 189-191.
- Grof, C., & Grof, S. (1986). Spiritual emergency: The understanding and treatment of transpersonal crises. *Revision*.
- Häfner, H. (2022). Descriptive psychopathology, phenomenology, and the legacy of Karl Jaspers. *Dialogues in clinical neuroscience*.
- Hart, A. (2018). Pursuing Choice not Truth: debates around diagnosis in mental health, *Asylum: The Magazine for Democratic Psychiatry*, 25 (3) 19–21.
- Hamilton, B., & Roper, C. (2006). Troubling "insight": power and possibilities in mental health care. *Journal of Psychiatric and Mental Health Nursing*, 13(4), 416–22.
- Hamilton, B., Manias, E., Maude, P., Marjoribanks, T., & Cook, K. (2004). Perspectives of a nurse, social worker and a psychiatrist regarding patient assessment in acute inpatient psychiatry settings: A case study approach. *Journal of Psychiatric and Mental Health Nursing*, 11, 683–689.
- Hamilton, B., & Manias, E. (2006). 'She's manipulative and he's right off': A critical analysis of psychiatric nurses' oral and written language in the acute inpatient setting. *International Journal of Mental Health Nursing*, 15(2), 84-92.

- Harper, D. (1995). Discourse analysis and “mental health.” *Journal of Mental Health*, 4(4), 347–358.
- Heriot-Maitland, C. (2011). Exploring the compatibility of biomedical and psychological approaches to treating psychosis. *Psychosis*, 3(2), 133-140.
- Hollander, A.-C., Dal, H., Lewis, G., Magnusson, C., Kirkbride, J. B., & Dalman, C. (2016). Refugee migration and risk of schizophrenia and other non-affective psychoses: cohort study of 1.3 million people in Sweden. *BMJ*, i1030.
- Hornstein, G. (2009). *Agnes’s Jacket: A psychologist’s search for the meanings of madness*. New York: Rodale, Inc.
- Hornstein, G. A. (2005) *Bibliography of first-person accounts of madness in English* (3rd Ed). Retrieved from: [http://webtest.mtholyoke.edu/acad/assets/Academics/Hornstein\\_Bibliography.pdf](http://webtest.mtholyoke.edu/acad/assets/Academics/Hornstein_Bibliography.pdf).
- Hornstein, G. A. (2002). Narratives of madness, as told from within. *Chronicle of Higher Education*, 48(20), B7-B7.
- Hummelvoll, J., & Severinsson, E. (2001). Coping with everyday reality: mental health professionals’ reflections on the care provided in an acute psychiatric ward. *The Australian and New Zealand Journal of Mental Health Nursing*, 10(3).
- Hutchins, J., Rhodes, J., & Keville, S. (2016). Emotional earthquakes in the landscape of psychosis: An interpretative phenomenology. *The Cognitive Behaviour Therapist*, 9, e30.

- Igreja, V., Dias-Lambranca, B., & Richters, A. (2008). Gamba spirits, gender relations, and healing in post-civil war Gorongosa, Mozambique. *Journal of the Royal Anthropological Institute*, 14(2), 353–371.
- Jablensky, A., & Sartorius, N. (2008). What did the WHO studies really find? *Schizophrenia Bulletin*, 34(2), 253–5.
- James, S. L., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., ... & Briggs, A. M. (2018). Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 392(10159), 1789-1858.
- Janssen, I., Krabbendam, L., Bak, M., Hanssen, M., Vollebergh, W. and De Graaf, R. (2003) Discrimination and delusional ideation. *British Journal of Psychiatry*, 1, 71–76.
- Jaspers, K. (1963) *General psychopathology*. Manchester: Manchester University Press.
- Jenkins, J. (2004). Schizophrenia as a paradigm case for understanding fundamental human processes. In J. Jenkins & R. Barrett (Eds.), *Schizophrenia, Culture, and Subjectivity: The edge of experience*. New York: Cambridge University Press.
- Johnstone, L. (2017) Psychological Formulation as an Alternative to Psychiatric Diagnosis. *Journal of Humanistic Psychology*.
- Johnstone, L, Boyle, M., Cromby, J., Dillon, J., Harper, D., and Kinderman, P. (2018). *The Power Threat Meaning Framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. BPS Division of Clinical Psychology. Leicester,

England: British Psychological Society. Retrieved from:  
<https://explore.bps.org.uk/content/report-guideline/bpsrep.2018.inf299b>

Jongsma, H. E., Gayer-Anderson, C., Lasalvia, A., Quattrone, D., Mulè, A., Szöke, A., ... & Kirkbride, J. B. (2018). Treated incidence of psychotic disorders in the multinational EU-GEI study. *JAMA psychiatry*, 75(1), 36-46.

Jones, N (2020, September 22) A conversation with Nev Jones. *Mad in America*. Retrieved from: <https://www.madinamerica.com/2020/09/a-conversation-with-nev-jones/>

Jones, N., Kelly, T., & Shattell, M. (2016). God in the brain: Experiencing psychosis in the postsecular United States. *Transcultural Psychiatry*, 53(4), 488-505.

Jones, N., & Shattell, M. (2016). Not what the textbooks describe: Challenging clinical conventions about psychosis. *Issues in Mental Health Nursing*, 37(10), 769-772.

Jung, C. G. (1976). *Abstracts of the collected works of C. G. Jung: A guide to the collected works, volumes I-XVII*, Rockville: Princeton University Press.

Kaselionyte, J., & Gumley, A. (2019). Psychosis or spiritual emergency? A Foucauldian discourse analysis of case reports of extreme mental states in the context of meditation. *Transcultural Psychiatry*, 56(5), 1094-1115.

Kinderman, P., Setzu, E., Lobban, F., & Salmon, P. (2006). Illness beliefs in schizophrenia. *Social Science & Medicine*, 63(7), 1900-11.

Kirkbride, J. & Jones, P. (2011). The prevention of schizophrenia—what can we learn from eco- epidemiology? *Schizophrenia Bulletin*, 37 (Suppl 2), pp. 262-271.

- Kirkbride, J. B., Jones, P. B., Ullrich, S., & Coid, J. W. (2012). Social Deprivation, Inequality, and the Neighborhood-Level Incidence of Psychotic Syndromes in East London. *Schizophrenia Bulletin*, 40(1), 169–180.
- Kleinman, A. (1986) Illness meanings and illness behaviour. In McHugh, S. and Vallis, M. T. (eds) *Illness behaviour: A multidisciplinary model*. New York: Plenum. Kleinman, A. (1988) *The illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
- Kraepelin, E (1896). *Psychiatrie*. 5th ed. Leipzig, Germany: Barth.
- Kuyken, W., Padesky, C. A., & Dudley, R. (2009). *Collaborative case conceptualization: Working effectively with clients in cognitive-behavioral therapy*. The Guilford Press.
- Laing, R. D. (1960) *The Divided Self: A study of Sanity and Madness*. London: Tavistock.
- Laing, R. D. (1967) *The Politics of Experience*. London: Penguin Books.
- Larsen, J. A. (2004) Finding meaning in first episode psychosis: Experience, agency and the cultural repertoire. *Medical Anthropology Quarterly*, 18: 447–471.
- Lambrecht, I. & Taitimu, M. (2012). Exploring culture, subjectivity & psychosis. In J. Geekie, P. Randall, D. Lampshire, & J. Read (Eds.), *Experiencing Psychosis: personal and professional perspectives*. East Sussex: Routledge Press.
- Lester, H., Birchwood, M., Stirling, B., England, E., Rogers, H. & Sirvastava, N. (2009). Development and implementation of early intervention services for young people with psychosis: case study. *The British Journal of Psychiatry*, 194, 446- 450.
- Lim, A., Hoek, H. W., & Blom, J. D. (2014). The attribution of psychotic symptoms to jinn in Islamic patients. *Transcultural Psychiatry*, 52(1), 18–32.

- Longden, E., D. Corstens, and J. Dillon. 2013. Recovery, discovery, and revolution: The work of intervoice and the hearing voices movements. In *Madness Contested: Power and Practice*, eds. S. Coles, S. Keenan, and B. Diamond, 161–80. Herefordshire, United Kingdom: PCCS Books.
- Longden, E., Corstens, D., Escher, S., & Romme, M. (2012). Voice hearing in a biographical context: A model for formulating the relationship between voices and life history. *Psychosis*, 4(3), 224-234.
- Longden, E. (2013). *The voices in my head*. TED Conferences. Retrieved from: [https://www.ted.com/talks/eleanor\\_longden\\_the\\_voices\\_in\\_my\\_head/up-next](https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head/up-next)
- Longden, E., Read, J., & Dillon, J. (2016). Improving community mental health services: The need for a paradigm shift. *Israel Journal of Psychiatry and Related Sciences*, 53(1), 22-30.
- Luhrmann, T. M., Alderson-Day, B., Bell, V., Bless, J. J., Corlett, P., Hugdahl, K., ... & Waters, F. (2019). Beyond trauma: A multiple pathways approach to auditory hallucinations in clinical and nonclinical populations. *Schizophrenia Bulletin*, 45(1), 24-31.
- Luhrmann, T. M., Padmavati, R., Tharoor, H., & Osei, A. (2015). Differences in voice-hearing experiences of people with psychosis in the USA, India and Ghana: interview-based study. *The British Journal of Psychiatry*, 206(1), 41-44.
- Lysaker, P. H., Buck, B., & Lysaker, J. T. (2012). Schizophrenia and alterations in the experience of self and agency: comparisons of dialogical and phenomenological views. *Theory & Psychology*, 22(6), 738-755.
- Lysaker, P. H., & Lysaker, J. T. (2002). Narrative structure in psychosis: Schizophrenia and disruptions in the dialogical self. *Theory & Psychology*, 12(2), 207-220.



- Lysaker, P. H., & Lysaker, J. T. (2010). Schizophrenia and alterations in self-experience: a comparison of 6 perspectives. *Schizophrenia bulletin*, 36(2), 331-340.
- Macnaughton, E., Sheps, S., Frankish, J., & Irwin, D. (2015). Understanding the development of narrative insight in early psychosis: A qualitative approach. *Psychosis*, 7(4), 291-301.
- Marriott, M. R., Thompson, A. R., Cockshutt, G., & Rowse, G. (2019). Narrative insight in psychosis: The relationship with spiritual and religious explanatory frameworks. *Psychology and Psychotherapy: Theory, Research and Practice*, 92(1), 74-90.
- Marshall, M., & Rathbone, J. (2011). Early intervention for psychosis. Cochrane Database of Systematic Reviews.
- May, R. (2003) *Understanding psychotic experience and working towards recovery*. Retrieved from: <https://rufusmay.com/2008/04/20/understanding-psychotic-experience-and-working-towards-recovery/> (Accessed 10th Feb 2023)
- May, R. (2012). Relating to alternative realities. In M. Romme & S. Escher (Eds.), *Psychosis as a personal crisis: An experience-based approach* (pp. 140-152). East Sussex: Routledge
- McAdams, D. P. (2019). “First we invented stories, then they changed us”: The evolution of narrative identity. *Evolutionary Studies in Imaginative Culture*, 3(1), 1-18.
- McCarthy-Jones, S. (2015). History of concepts about psychosis: What was it, what is it?. In Waters, F. & Stephane, M. (Eds) *The Assessment of Psychosis: A Reference Book and Rating Scales for Research and Practice*, Routledge: London, pp. 3-16

- McCarthy-Jones, S., Marriott, M., Knowles, R. E., Rowse, G., & Thompson, A. R. (2013). What is psychosis? A meta-synthesis of inductive qualitative studies exploring the experience of psychosis. *Psychosis*, 5, 1–16.
- McGuire, N., Melville, C., Karadzhov, D., & Gumley, A. (2020). “She is more about my illness than me”: A qualitative study exploring social support in individuals with experiences of psychosis. *Psychosis*, 12(2), 128-138
- McGlashan, T.H. (1987). Recovery style from mental illness and long-term outcome. *Journal of Nervous and Mental Disease*, 175, 681-685.
- McGlashan, T. H. and Carpenter, W. T. (1981) Does attitude toward psychosis relate to outcome? *American Journal of Psychiatry*, 138: 797–810.
- McMullan, E., Gupta, A., & Collins, S. C. (2018). Experiences of mental health nursing staff working with voice hearers in an acute setting: An interpretive phenomenological approach. *Journal of Psychiatric and Mental Health Nursing*, 25, 157–166.
- Merleau-Ponty, M. (1962 / 2003). *Phenomenology of Perception* (C. Smith, Trans.). Routledge & Kegan Paul Ltd.
- Menzies, R., LeFrançois, B. & Reaume G (2013) Introducing mad studies. In LeFrançois, B., Menzies, R. & Reaume, G. (Eds) *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholars’ Press, 1–22.
- Messari, S., & Hallam, R. (2003). CBT for psychosis: A qualitative analysis of clients' experiences. *British Journal of Clinical Psychology*, 42(2), 171-188.
- Meyer, A. 1906. Fundamental conceptions of dementia praecox. *British Medical Journal*, 2, 757–760.

- Miller, P. (1986). Critiques of psychiatry and critical sociologies of madness. In P. Miller & N. Rose (Eds.), *The Power of Psychiatry*. Cambridge, Polity Press; Blackwell.
- Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural Differences in Psychosis: The Role of Causal Beliefs and Stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, 50(3), 441–459.
- Moncrieff, J., & Cohen, D. (2009). How do psychiatric drugs work? *British Medical Journal*, 338.
- Moncrieff, J. & Middleton, H. (2015). Schizophrenia: a critical psychiatry perspective. *Current Opinion in Psychiatry*, 28, 264–268.
- Morgan, A. (2023). Power, threat, meaning framework: A philosophical critique. *Philosophy, Psychiatry, & Psychology*, 30(1), 53-67.
- Morgan, C., Kirkbride, J., Hutchinson, G., Craig, T., Morgan, K., Dazzan, P., Boydell, J., Doody, G. A., Jones, P. B., Murray, R. M., Leff, J., & Fearon, P. (2008). Cumulative social disadvantage, ethnicity and first-episode psychosis: a case- control study. *Psychological Medicine*, 38(12), 1701–1715.
- Morgan, C., Lappin, J., Heslin, M., Donoghue, K., Lomas, B., Reininghaus, U., ... & Dazzan, P. (2014). Reappraising the long-term course and outcome of psychotic disorders: the AESOP-10 study. *Psychological Medicine*, 44(13), 2713-2726.
- Morrison, A. P. (2001). The interpretation of intrusions in psychosis: an integrative cognitive approach to hallucinations and delusions. *Behavioural and cognitive psychotherapy*, 29(3), 257-276.

- Mosher, L. Hendrix, V. and Fort, D.C. (2004) *Soteria: Through Madness to Deliverance*. Philadelphia: Xlibris Corporation.
- Moth, R. (2020). 'The business end': Neoliberal policy reforms and biomedical residualism in frontline community mental health practice in England. *Competition & Change*, 24(2), 133–153.
- Murray, R. M., Bhavsar, V., Tripoli, G., & Howes, O. (2017). 30 years on: how the neurodevelopmental hypothesis of schizophrenia morphed into the developmental risk factor model of psychosis. *Schizophrenia Bulletin*, 43(6), 1190-1196.
- Myers, N. A. L., & Ziv, T. (2016). "No one ever even asked me that before": Autobiographical power, social defeat, and recovery among African Americans with lived experiences of psychosis. *Medical Anthropology Quarterly*, 30(3), 395-413.
- Neale, A. & Kinnair, D. (2017). Early Intervention in Psychosis Services. *British Journal of General Practice*, 67(661), 370-371.
- Nelson, B., Parnas, J. & Sass, L.A. (2014). Disturbance of Minimal Self (Ipseity) in Schizophrenia: Clarification and Current Status. *Schizophrenia Bulletin*, 40(3), 479–482.
- Norman, R. M. & Malla, A. K. (2001). Duration of untreated psychosis: A critical examination of the concept and its importance. *Psychological Medicine*, 31(3), 381-400.
- Nuechterlein, K. H. and Dawson, M. E. (1984) A heuristic vulnerability/stress model of schizophrenic episodes. *Schizophrenia Bulletin*, 10: 300–312.
- Parker, I., Georgaca, E., & Harper, D. (1995) *Deconstructing Psychopathology*, London: SAGE.

- Parnas, J. (2013). On psychosis: Karl Jaspers and beyond. In Stanghellini, G., & Fuchs, T. (Eds.). *One century of Karl Jaspers' general psychopathology*. Oxford University Press. Pp 208-228.
- Parnas, J. (2014). Philosophical and phenomenological perspectives on psychosis. In Waters, F. & Stephane, M. (Eds) *The Assessment of Psychosis: A Reference Book and Rating Scales for Research and Practice*, Routledge: London, pp. 39-65
- Porter, R. (1985). The patient's view: doing medical history from below. *Theory and Society*, 14, 175-198.
- Porter, R. (1987). A Social History of Madness: Stories of the Insane. *London: Phoenix-Orion*.
- Porter, R. (1990). Foucault's great confinement. *History of the Human Sciences*, 3(1), 47-54.
- Pilgrim, D. (2002). The biopsychosocial model in Anglo-American psychiatry: Past, present and future?. *Journal of Mental Health*, 11(6), 585-594.
- Priebe, S. (2021). Patients in mental healthcare should be referred to as patients and not service users. *BJPsych Bulletin*, 45(6), 327-328.
- Proctor, G. (2008). CBT: The obscuring of power in the name of science. *European Journal of Psychotherapy and Counselling*, 10(3), 231-245
- Randal, P., Geekie, J., Lambrecht, I., & M. Taitimu. (2008). Dissociation, psychosis and spirituality: Whose voices are we hearing? In A. Moskowitz et al. (Eds.), *Psychosis, Trauma and Dissociation: Emerging perspectives on severe psychopathology* (pp. 319-331). West Sussex, United Kingdom: John Wiley & Sons, Ltd.

- Rashed, M. A. (2020). The identity of psychiatry and the challenge of mad activism: Rethinking the clinical encounter. In *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*, 45 (6), 598-622.
- Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiology and Psychiatric Sciences*, 18(4), 299–310.
- Read, J., Johnstone, L., & Taitimu, M. (2013). 'Psychosis, Poverty and Ethnicity.' In Read, J., Mosher, L. R., & Bentall, R. P. (Eds.). (2004). *Models of madness: Psychological, Social and Biological Approaches to Schizophrenia*, London: Routledge. (pp. 217-235).
- Read, J., Os, J., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112(5), 330–350.
- Reaume, G. (2021). How is mad studies different from anti-psychiatry and critical psychiatry?. In *The Routledge International Handbook of Mad Studies* (pp. 98-107). Routledge.
- Redko, C. (2003). Religious Construction of a First Episode of Psychosis in Urban Brazil. *Transcultural Psychiatry*, 40(4), 507–530.
- Ringer, A., & Holen, M. (2016). “Hell no, they’ll think you’re mad as a hatter”: Illness discourses and their implications for patients in mental health practice. *Health*. 20(2), 161-175.

- Roberts, M. (2010). Service user involvement and the restrictive sense of psychiatric categories: the challenge facing mental health nurses. *Journal of Psychiatric and Mental Health Nursing*, 17(4), 289–94.
- Murray, R. M., & Quattrone, D. (2021). The Kraepelian concept of schizophrenia: Dying but not yet dead. *Schizophrenia Research*, 242, 102–105.
- Roe, D., Hasson-Ohayon, I., Kravetz, S., Yanos, P. T., & Lysaker, P. H. (2008). Call it a monster for lack of anything else: narrative insight in psychosis. *The Journal of Nervous and Mental Disease*, 196(12), 859.
- Roe, D. & Lysaker, P.H. (2012). Recovery from ‘psychosis.’ In J. Geekie, Randall, Lampshire & Read (Eds.), *Experiencing Psychosis: personal and professional perspectives* (pp. 17-22). East Sussex: Routledge Press.
- Rogers, A., & Pilgrim, D. (2010). *A Sociology of Mental Health and Illness* (3rd Ed.). London: Open University Press.
- Romme, M. (2009). The disease concept of hearing voices and its harmful aspects. In Romme, M. et al. (Eds.), *Living with Voices: 50 stories of recovery* (pp. 23-38). Herefordshire, UK: PCCS Books.
- Romme, M. (2012). Accepting and making sense of voices: a recovery-focused therapy plan. In Romme, M. & Escher, S. (Eds.), *Psychosis as a personal crisis: An experience-based approach* (pp. 153-162). New York: Routledge/Taylor & Francis Group.
- Romme, M. & Escher, S. (2012). *Making Sense of Voices: A guide for mental health professionals working with voice-hearers*. London, United Kingdom: Mind Publications.
- Romme, M. & Escher, S. (2012). *Psychosis as a personal crisis: An experience-based approach*. New York: Routledge/Taylor & Francis Group.

- Romme, M., Escher, S., Dillon, J., Corstens, D. & Morris, M. (2009). *Living with Voices: 50 stories of recovery*. Birmingham, United Kingdom: PCCS Books in association with Birmingham City University.
- Rose, N. (1990). *Governing The Soul: The Shaping of the Private Self*. Taylor & Frances.
- Rosenthal Oren, R., Roe, D., Hasson-Ohayon, I., Roth, S., Thomas, E. C., & Zisman-Ilani, Y. (2021). Beliefs about the causes of psychosis among persons with psychosis and mental health professionals: a scoping review. *Psychiatric Services*, 72(10), 1178-1192.
- Saha, S., Chant, D., & McGrath, J. (2007). A systematic review of mortality in schizophrenia: is the differential mortality gap worsening over time?. *Archives of general psychiatry*, 64(10), 1123-1131.
- Salem, D. (2011). Voices from the ground up: The use of narrative in understanding recovery from serious mental illness. In M. S. Aber, K. I. Maton, E. Seidman (Eds.), *Empowering settings and voices for social change* (pp. 107-133). Oxford: Oxford University Press.
- Sanati, A., & Kyratsous, M. (2015). Epistemic injustice in assessment of delusions. *Journal of Evaluation in Clinical Practice*, 21(3), 479-485.
- Sass, L. A. (2014). Self-disturbance and schizophrenia: structure, specificity, pathogenesis (current issues, new directions). *Schizophrenia Research*, 152(1), 5-11.
- Sass, L. & Parnas, J. (2003) Schizophrenia, consciousness and the self. *Schizophrenia Bulletin*, 29: 427-444.
- Schneider, K. (1950). *Klinische Psychopathologie*. (3. vermehrte Auflage der Beiträge zur Psychiatrie ed.) Stuttgart, Germany: Thieme. Trans. M. W. Hamilton & E. W. Anderson (1959). New York, NY: Grune & Stratton.



- Scull, A. (1993). Museums of madness revisited. *Social History of Medicine*, 6(1), 3-23.
- Sedgwick, P. (1973). Illness: Mental and Otherwise. *The Hastings Center Studies*. 1(3). 19-40.
- Sedgwick, P. (1982) *Psycho politics: Laing, Foucault, Goffman, Szasz, and the Future of Mass Psychiatry*. London: Pluto Press.
- Sen, D. (2017) *DSM 69: Dolly Sen's manual of psychiatric disorder*, London: Eleusinian Press
- Sen, D. & Sexton, A. (2016) More voice, less ventriloquism: building a mental health recovery archive. In Russo, J. & Sweeney, A. (Eds) *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies*, Monmouth: PCCS Books.
- Singh, S. P., & Burns, T. (2006). Race and mental health: There is more to race than racism. *BMJ*, 333(7569), 648-651.
- Singh, S.P. & Fisher, H.L. (2005). Early intervention in psychosis: obstacles and opportunities. *Journal of Continuing Professional Development*, 11, 71-78.
- Sips, R., Van Duppen, Z., Kasanova, Z., De Thurah, L., Teixeira, A., Feyaerts, J., & Myin-Germeys, I. (2021). Psychosis as a dialectic of aha-and anti-aha-experiences: a qualitative study. *Psychosis*, 13(1), 47-57.
- Spandler, H., & Calton, T. (2009). Psychosis and Human Rights: Conflicts in Mental Health Policy and Practice. *Social Policy and Society*, 8(2), 245-256.
- Slade, M., & Sweeney, A. (2020). Rethinking the concept of insight. *World Psychiatry*, 19(3), 389-390.

- Spencer, E., Birchwood, M. & McGovern, D. (2001). Management of first-episode psychosis. *Journal of Continuing Professional Development*, 7, 133-140.
- St Arnaud, K. O., & Cormier, D. C. (2017). Psychosis or spiritual emergency: The potential of developmental psychopathology for differential diagnosis. *International Journal of Transpersonal Studies*. 34, 44-59.
- Stovell, D., Wearden, A., Morrison, A. P., & Hutton, P. (2016). Service users' experiences of the treatment decision-making process in psychosis: A phenomenological analysis. *Psychosis*, 8(4), 311-323.
- Sullivan, S. A., Carroll, R., Peters, T. J., Amos, T., Jones, P. B., Marshall, M., Birchwood, M., Fowler, D., Johnson, S., Fisher, H. L., Major, B., Rahaman, N., Joyce, J., Chamberlain-Kent, N., Lawrence, J., Moran, P., & Tilling, K. (2019). Duration of untreated psychosis and clinical outcomes of first episode psychosis: An observational and an instrumental variables analysis. *Early Intervention in Psychiatry*, 13(4), 841-847.
- Tarrier, N., & Calam, R. (2002). New developments in cognitive-behavioural case formulation. Epidemiological, systemic and social context: An integrative approach. *Behavioural and Cognitive Psychotherapy*, 30(3), 311-328.
- Thompson, K. N., McGorry, P. D., & Harrigan, S. M. (2003). Recovery style and outcome in first-episode psychosis. *Schizophrenia research*, 62(1-2), 31-36.
- Thornhill, H., Clare, L. & May, R. (2004). Escape, enlightenment and endurance: Narratives of recovery from psychosis. *Anthropology and Medicine*, 11(2), pp. 181-199.
- Thornicroft, G. (2006). *Shunned: Discrimination against people with mental illness*. Oxford: University Press

- Tucker, I. (2009). "This is for life": a discursive analysis of the dilemmas of constructing diagnostic identities. *Forum: Qualitative Social Research*, 10(3), Art. 24.
- Tueth, M. J. (1995). Schizophrenia: Emil Kraepelin, Adolph Meyer, and Beyond. *The Journal of Emergency Medicine*, 13(6), 805-809.
- van Os, J. (2004) Does the urban environment cause psychosis? *British Journal of Psychiatry*, 184: 287–288.
- van Os, J., Linscott, R. J., Myin-Germeys, I., Delespaul, P., & Krabbendam, L. (2009). A systematic review and meta-analysis of the psychosis continuum: Evidence for a psychosis proneness–persistence–impairment model of psychotic disorder. *Psychological Medicine*, 39, 179–195.
- Varese, F., Smeets, F., Drukker, M., Lieveise, R., Lataster, T., Viechtbauer, W., Read, J., van Os, J., & Bentall, R. P. (2012). Childhood Adversities Increase the Risk of Psychosis: A Meta-analysis of Patient-Control, Prospective- and Cross-sectional Cohort Studies. *Schizophrenia Bulletin*, 38(4), 661–671.
- Vass, V., Sitko, K., West, S., & Bentall, R. P. (2017). How stigma gets under the skin: the role of stigma, self-stigma and self-esteem in subjective recovery from psychosis. *Psychosis*, 9(3), 235-244.
- Waddingham, R. (2021, March) Our Family Was Forged In Fire: Living Through Postnatal Psychosis, *Behind The Label*. Retrieved from:  
<https://www.behindthelabel.co.uk/forged-in-fire/>
- Whiteford, H. A., Degenhardt, L., Rehm, J., Baxter, A. J., Ferrari, A. J., Erskine, H. E., ... & Vos, T. (2013). Global burden of disease attributable to mental and substance use

- disorders: findings from the Global Burden of Disease Study 2010. *The Lancet*, 382(9904), 1575-1586.
- Williams, C. (2008). Insight, stigma and post-diagnosis identities in schizophrenia. *Psychiatry, Interpersonal & Biological Processes*, 71(3), 246–256.
- Williams, S. (2015). *Recovering from psychosis: Empirical evidence and lived experience*. Routledge.
- Willick, M. S. (2001). Psychoanalysis and schizophrenia: A cautionary tale. *Journal of the American Psychoanalytic Association*, 49(1), 27-56.
- Willig, C., 1964. (2012). *Qualitative interpretation and analysis in psychology*. Maidenhead: Open University Press.
- Woods, A. (2011). Memoir and the diagnosis of schizophrenia: reflections on The center cannot hold, me, myself, and them, and the ‘crumbling twin pillars’ of Kraepelinian psychiatry. *Mental Health Review*, 16(3), 102–106.
- Zubin, J. and Spring, B. (1977) Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology*, 86: 103–126.

## **Part 2: Empirical Paper**

*“There’s my story of you and there’s your story of you”:*

How clinicians, services, and systems  
relate to personal meaning-making in psychosis

## Abstract

**Aims:** Research highlights the central role of meaning-making in experiences of psychosis. Consequently, mental health professionals working with psychosis have been urged to prioritise service users' narratives. This study looks to explore this in two ways: by exploring how mental health professionals conceptualise and respond to service users' meaning-making and, by exploring the personal, professional and systemic factors which influence these conceptualisations and responses.

**Method:** 12 in-depth semi-structured interviews were conducted with mental health professionals working within Early Intervention in Psychosis services. Transcriptions from these interviews were analysed using Constructivist Grounded Theory (Charmaz, 2014). Service users were consulted during the project via a Service User Research Forum (SURF).

**Results:** The process of meaning-making within the clinical encounter is illustrated, comprising the exploration of service user meanings, information shared by the professional, and management of differences in perspective. A range of factors are demonstrated to influence this process. Personal-professional factors, such as clinical training, cultural background, spirituality, and lived experience of psychosis, contributed to professionals' necessary awareness of the plurality of perspectives on psychosis. Contextual factors, such as team culture and system demands, fluidly influence professionals' meaning-making capacity.

**Discussion:** Results are discussed in relation to their implications for clinical practice. Primarily, these highlight the need for professional awareness of multiple perspectives of psychosis, alongside skills to elicit communication around them. EIP teams and systems

should support cultures of openness, tolerance of uncertainty, and the use of pluralistic language via flattened hierarchies, reflective spaces, peer support workers, and broader conceptualisations of professional roles and practices.

## Introduction

Meaning-making is a fundamental human endeavour, allowing people to understand their experiences and place them within the context of their own life story (Merleau-Ponty, 1962; Ritunnano et al., 2021). In early experiences of psychosis, where narrative coherence and understanding can be severely disrupted, an individual's opportunity to engage in meaning-making is of particular importance (Boydell et al., 2010; Geekie & Read, 2009; Gumley & Clark, 2012; Larsen, 2004). Indeed, research indicates that people who experience psychosis are active in trying to make sense of their experiences in various ways (Carter et al., 2017; Cooke et al., 2014; Geekie & Read, 2009; Larson, 2004; Rashed, 2020; Mapplebeck, Joseph & Sabin-Farrell, 2015; Read, 2020).

Psychosis is characterised by changes in perception and self-experience, such as hearing or seeing things, holding fixed and unusual beliefs, or speaking in convoluted ways (Cooke, 2014). Through the biomedical lens of the DSM-5 (American Psychiatric Association [APA], 2013) these experiences are conceptualised as primary symptoms: hallucinations, delusions, and thought disorder. While biomedical frameworks remain highly influential in explaining altered states of mind, particularly within mental health services (Cooke & Kinderman, 2018), these reflect just one aspect of a far wider range of professional contributions to the field. Among them are psychiatric and psychological theories focusing on cognitive processes (Bentall, 2003; Chadwick et al., 1996; Freeman et al., 2002; Garety & Freeman, 2013; Morrison, 2001), the role of trauma, adversity and disadvantage (Kirkbride et al., 2012; Read et al., 2005; Varese et al., 2012), phenomenological theories orientated towards subjective experience (Lysaker & Lysaker, 2010; Lysaker et al., 2012; Nelson et al., 2014; Sass, 2014; Sass & Parnas, 2003), and integrative frameworks which seek to combine aspects from many (Pilgrim, 2002; Zubin & Spring, 1977).



There continues to be fierce debate about which theories have the greatest explanatory hegemony (Woods, 2011). However, while this most greatly affects those with mental health problems (Bell, 2017), there is a risk that inter-professional rivalries can minimise or neglect the voice of lived experience who may be somewhat side-lined in the debate (Hart, 2018). As Hart notes, “individual meaning-making may be lost in the search for ideological purity” (2018, n.p.). Within this context, the service user/survivor movement and Mad Studies have emerged to amplify and empower the voices of experts by experience within both mental health services and wider culture (Campbell & Rose, 2011; Rashed, 2020; Reaume, 2021). Symbolising their dissatisfaction with professional authority, ideology and practice (Forgione, 2019; Woods, 2011), service user groups and networks have sought to reclaim knowledge from professionals (Menzies et al., 2013) and privilege their own ways of conceptualising their experiences (Campbell, 2021). One prominent example is the Hearing Voices Network which provides non-hierarchical peer-support groups where people who hear voices come together to share experiences, understandings and ways of coping (Longden et al., 2013). The groups take on a holistic, pluralistic approach in conceptualising voice-hearing, where multiple understandings are possible, and the ideas of the voice-hearers are privileged (Longden et al., 2013; Campbell & Rose, 2011). As such, they include the range of cultural, spiritual or magical frameworks which are evidenced in the literature as prevalent in the UK (Geekie & Read, 2009; Jones et al., 2016; Marriott et al., 2019; Mirza et al., 2019) and across the world (Castillo, 2003; Luhrmann et al., 2015; 2019; Randal et al., 2008; Redko, 2003).

Given the burgeoning Mad Studies movement and the development of conceptual frameworks and support systems outside of mainstream services, there remain questions about how collaboratively and meaningfully mental health services are meeting the needs of people with psychosis (Forgione, 2019). If this is a priority for mainstream services, there

must be an orientation towards engaging with and catering for the range of diverse service user perspectives. This has “serious consequences” (Rashed, 2020) for mental health services, where alternative perspectives can be “radically diluted” (Campbell & Rose, 2011, p 460) by existing institutional and bureaucratic practices, lack of shared power and limited meaningful service user involvement (Salem, 2011). There is a need for qualitative research to better understand what happens when a person with psychosis accesses mental health services and brings their own understandings with them, to be confronted by professional and institutional theories and practices which may understand them in a different way. While qualitative research is growing in the field, there remains a lack of rigorous theorising around the experience of psychosis and the support that is received from mental health services (Boydell et al., 2010).

Existing research into meaning-making within a clinical context tends to explore how psychosis is conceptualised by either service users<sup>1</sup> or professionals somewhat independently. In the service user literature, studies reflect that people draw on a variety of explanatory frameworks in making sense of their experiences (Carter et al., 2018; Cooke et al., 2014; Thornhill et al., 2014; Roe et al., 2008). These can relate to trauma or stress, biomedical or clinical models, culturally-specific beliefs, and magical, spiritual or religious frameworks (Dudley et al., 2009; Geekie & Read, 2009; Friesen et al., 2021; Islam et al., 2015; Jones, Kelly & Shattell, 2016; Longden, Corstens & Dillon, 2013; Mcnaughton et al., 2015; Read, 2020). Moreover, individuals often combine multiple intersecting frameworks to make sense of their experiences (Friesen et al., 2021; Jones et al., 2016; Larsen, 2004). Such a bricolage of explanatory models symbolises the active process of negotiating meaning,

---

<sup>1</sup> A range of terms exist within the literature to describe people with lived experience of psychosis, representing particular lenses and ideological positions. There remains much debate about which terms are best to use, such as expert by experience, survivor, client, consumer, patient, and service user (e.g. Christmas & Sweeney, 2016; Gilfoyle, 2017; Priebe, 2021). While acknowledging that no language is neutral, this paper employs ‘service user’ given its focus on the clinical encounter.

where different frameworks may be accepted, rejected or combined in complex ways (Jones et al., 2016; Larsen, 2004; Roe et al., 2008).

Research into the understandings of mental health professionals suggests they can also draw on multifactorial models of aetiology (Rosenthal-Oren et al., 2021). While some literature suggests greater orientation towards biomedical models (Coffey & Hewitt, 2008; Baillie, McCabe Priebe, 2009; Rosenthal-Oren et al., 2021), others highlight professional preference for psychosocial frameworks (Carter et al., 2017), continuum models (Cooke & Brett, 2019) and anti-psychiatric theories (Ringer & Holen, 2016), with noted differences between professional groups (Carter et al., 2017). As explanatory frameworks are not universal (Slade & Sweeney, 2020), differences in sense-making between service users and clinicians are common (Coffey & Hewitt, 2007; Friesen et al., 2021; Geekie & Read, 2007; Read, 2020; Werbart & Levander, 2005), which Rosenthal-Oren et al. (2021) describe as a 'gap' in causal beliefs.

Creating a meaningful, culturally-embedded story about psychiatric experiences has been termed 'narrative insight' (Slade & Sweeney, 2009), with several authors relating this specifically to psychosis (Lysaker, 2002; Marriot et al., 2019; Roe et al., 2008). Such a process of meaning-making allows a person to construct a helpful narrative about their experiences, giving coherence to events which may be confusing or distressing, and placing this within the cultural and social context of their lives. As Lysaker and Lysaker (2002) note, people make sense of problems in terms of the stories that they tell about themselves. These stories are fundamentally interpersonal (Roe et al., 2008), in that they can be influenced by significant others in their network and wider social context (Coren, 1988; Carter et al., 2017). Within mental health services, the clinical encounter comes into focus as an interpersonal space where meaning is made between the professional and the service user (Rosenthal Oren et al., 2021; Sips et al., 2021). However, there remain questions about how collaboratively this

may be achieved in practice when mental health professionals hold greater power in the relationship (Boyle, 2013; Ljungberg et al., 2017). These power relations are embedded within structural differences in socioeconomic status, education, ethnicity and gender (Masterson & Owen, 2006), and the broader ideological, legislative and institutional context of professional practice (Newman et al., 2019).

Developing a meaningful narrative is frequently described as central to recovery in psychosis (Gumley & Clark, 2012; Lewis, 2014; Longden et al., 2013; Lysaker et al., 2010; May, 2003; Roe et al., 2008; Andresen et al., 2003). It has been linked with a number of favourable outcomes, including improvements in self-understanding and identity-making (Friesen et al., 2021), post-traumatic growth (Mapplebeck, Joseph & Sabin-Farrell, 2015; Slade et al., 2019) and therapeutic relationships with clinicians (Lysaker et al., 2009). Moreover, service users themselves often want to talk about and explore meaning within the clinical encounter (Coffey & Hewitt, 2008; Myers & Ziv, 2016; Brabben et al., 2017). Dillon (2012) highlights the significance of simply having one's perspective believed and acknowledged. This relates to developing a voice (Salem, 2011), reclaiming autobiographical power over one's experiences (Thornhill et al., 2004), and moving towards greater levels of integration and awareness (Randal et al., 2008). Simultaneously, studies note that inattention to service users' own stories and meaning-making can bring a number of risks. These include perpetuating social defeat and powerlessness (Luhrmann, 2007; Myers & Ziv, 2016), further disrupting self-experience (Berkhout et al., 2019), misunderstanding and conflict in the therapeutic relationship (Geekie & Read, 2009) and disengagement or withdrawal from services (Jones & Shattell, 2016).

Despite this, there is significant variation in how mental health professionals and services currently attend to meaning-making. Some statutory psychosis services demonstrate advances in this process, with greater emphasis on recovery models (Slade et al., 2019),

narrative storytelling (Place, Foxcroft & Shaw, 2011) or utilising expertise from peer-support networks such as the Hearing Voices Movement (Longden et al., 2013).<sup>2</sup> In many clinical contexts, however, the perspectives of service users are neglected (Mosher, 2001), with limited attention given to meaning-making (Jones & Shattell, 2016; Myers & Ziv 2016). In previous research, there were few or no opportunities for service users to explore meaning-making (Jones et al., 2016), with clinicians offering no causal models for understanding the experience (Carter et al., 2018). In instances where meaning was explored, professionals could misunderstand what service users shared (Jones, Kelly & Shattel, 2016) or reject their explanatory frameworks altogether (Myers & Ziv, 2006). This resulted in service users feeling defeated (Myers & Ziv, 2006) and withholding aspects of their experience from professionals (Larsen, 2004). In some contexts, the dominance of illness explanations limited explanatory possibilities (McGuire et al., 2020) and disempowered service users (Stovell et al., 2016; Colombo, et al., 2003). Taken together, the research evidence suggests that the perspectives and approaches of clinicians and services can exert a powerful influence on service users' sense-making in the clinical encounter, however there is a risk that personal meanings may be mismanaged, ignored or rejected.

Jones & Shattell (2016) note that clinicians often have a keen interest in engaging with meaning-making but may feel ill-equipped to do so. Mental health professionals have reported avoiding deep conversations with service users about psychosis due to a lack of confidence, anxiety or fear of 'making things worse' (Bogen-Johnston et al., 2020; Coffey & Hewitt, 2007; McMullan, Gupta & Collins, 2017). Spirituality is frequently cited as an area of discomfort for clinicians, who often report lacking skills and knowledge to engage service users in conversations about spiritual aspects of their experience (Cooke & Brett, 2019;

---

<sup>2</sup> Critics argue that even purportedly positive steps towards recovery and service user involvement fail to genuinely empower patients, foreclosing the kinds of narratives they can tell and limiting the exploration of social and political context (Papoulias & Callard, 2022; Recovery in the Bin, 2019; Woods et al., 2022).

Carter et al., 2017; Larsen, 2004). Mental health nurses in Coffey & Hewitt's (2007) study felt their training and service context limited them to certain conversations, such as those focusing on medication.

With the benefits of meaning-making explicit within the literature, many researchers, clinicians and services have argued for mental health professionals to give it greater attention within the clinical encounter (Jones et al., 2016; Friesen et al., 2021; Jones & Shattell, 2016; Coffee & Hewitt, 2007; Slade & Sweeney, 2020; Thornhill et al., 2014). Despite these calls, there is a notable lack of research exploring the process and practice of effective meaning-making within the clinical encounter. This means there is a limited understanding in the literature of what unfolds between professionals and service users as they negotiate, jointly and separately, a sense of meaning around experiences of psychosis. Given the prevalence of studies highlighting poor or limited engagement by professionals, gaining an understanding of how effective meaning-making takes place in practice is an essential first step.

The research into factors which enable or inhibit meaning-making within the clinical encounter is also limited. So far, the literature has highlighted clinician confidence, training, the 'causal belief gap', and the hegemony of particular explanations in some services. This indicates a few factors which may determine meaning-making in the clinical encounter, however these remain very limited, poorly understood, and under-theorised. While these indicate the role of both personal or professional factors, such as confidence or training, and broader system factors, such as the dominance of illness explanations, further research is needed to elucidate and theorise the broader range of factors which may be involved. Developing such an understanding could guide clinicians and services concerning the professional and systemic factors which can enable meaning-making and therefore offer a blueprint for creating a clinical context where it can flourish.

As Early Intervention in Psychosis (EIP) services offer professional support at the earliest stage of psychosis, a person's meaning-making journey is likely in its infancy. It is at this stage that they are likely confronted by a set of professional and system understandings together with a long-term relational context in which meaning can be explored. As such, the EIP clinical encounter is a key site for meaning-making in psychosis, with perhaps the most significant impact on a service user's understanding and the greatest capacity for meaningful intervention (Larsen, 2004; Transulic et al., 2008). It is within this encounter that the interface of professional and service user frameworks may be most usefully studied and theorised.

Aiming to bridge the gaps within the existing literature, this study is interested in two critical areas: the *process* and *context* of meaning-making. While previous literature has been primarily interested in the frameworks on which service users or professionals draw, this is limited in scope and cannot usefully theorise how meaning is alternately addressed or ignored within the clinical encounter. In addition, by elucidating the factors and context in which this takes place, this paper aims to contribute a breadth of understanding in the field of meaning-making which has previously been neglected. To do so, the study draws on the following two research questions:

- 1) *How do clinicians working with first-episode psychosis conceptualise and respond to service users' personal meaning-making within the clinical encounter?*
- 2) *What professional or structural factors and processes influence clinicians' conceptualisations and responses?*

The first research question will explore in-depth the process and practice of effective meaning-making within an EIP clinical encounter, including how professionals relate to and

mediate the perspectives of service users. The second research question will embed this process within the broader context that enables or inhibits it, exploring the personal, professional, team and system factors that influence meaning-making. Constructivist Grounded Theory (CGT) is well placed to support the qualitative exploration of research topics which are in their infancy by providing a framework for investigation and subsequent theorisation. As such, this study utilises CGT to theorise the overarching processes through which meaning-making unfolds within EIP services.

## **Methods**

### **Grounded Theory**

This study draws on Constructivist Grounded Theory (Charmaz, 2014; Clarke 2005). Rooted within qualitative approaches that value rich first-hand data, Grounded Theory (GT) was established as a set of flexible practices to guide researchers in data collection and analysis where the focus is generating theory (Charmaz & Thornberg, 2021; Glaser & Strauss, 1987; Strauss & Corbin, 1990). In its focus on constructing codes and categories *from* the data (rather than applying preconceived hypotheses), the approach is particularly well-suited to under-researched phenomena, as in the present study (Pidgeon & Henwood, 1997).

CGT evolved amidst criticism of Grounded Theory's positivism, positing that knowledge cannot exist independently of researchers nor preconceived hypotheses truly avoided (Miller et al., 2006). CGT therefore orientates towards the active role and positioning of the researcher in theory construction. The theory is not 'discovered' in the data but is born from the active sense-making of those doing the analysis (Charmaz, 2014; Charmaz & Thornberg, 2021; Geekie & Read, 2009). This recognises that, as researchers, "we are part of the world



we study and the data we collect” (Charmaz, 2014, p17). Charmaz (2017) argues that researchers must strive for methodological self-consciousness. Following this, my own positioning is one of constructionism and pluralism, where I consider there to be multiple, constructed ways of seeing and knowing the social world according to specific social contexts and structures. This positioning is well aligned with the methodology of CGT.

Grounded Theory involves a cyclical and ongoing process of data collection, analysis and theory generation (Glaser & Strauss, 1987). This will be outlined below in reference to the present study.

### **Participants, sampling and recruitment**

The participants in the study are mental health professionals with experience working in EIP services in the United Kingdom. Participants had a minimum of three months experience working in an EIP service at the time of interview and were either currently employed in a service or had left within the last year.

Purposive sampling was used to identify and select mental health professionals with relevant knowledge of the area of study. Participants were initially recruited in this way through a public advertisement circulated via social media (Appendix 1). Using snowball sampling, existing participants were then asked to share the recruitment advert with those in their network who may be interested. As the study progressed, sampling was influenced by theory development (Charmaz, 2014; Glaser & Strauss, 1987). Participants were then sought based on the required perspective they could offer the emerging analyses, for example in their specific professional or cultural background.

12 EIP clinicians took part in the study. Table 1 outlines key demographic information, with further information limited to preserve anonymity. Participants’ ages ranged from 26 to 49,

with a mean of 35.3 years old. Nine identified as woman and three as men. Nine participants described themselves as white British, one as white Irish, one Turkish and one Indian. The participants captured a range of professional roles within EIP teams, spanning care-coordinators (of nursing, social work, and occupational therapy backgrounds, clinical psychologists, psychiatrists, support workers, and peer support workers. Participants represented a range of perspectives across the country, coming from eight different EIP services in the UK. Nine clinicians were working in an EIP service at the time of interview, with three participants having recently left psychosis services.

**Table 1.** Sociodemographic characteristics of participants (*N* = 12)

Professional background	<i>N</i>	%
<i>Mental health nurse</i>	3	25
<i>Occupational therapist (OT)</i>	1	8
<i>Social worker</i>	1	8
<i>Clinical psychologist (CP)</i>	3	25
<i>Consultant psychiatrist</i>	1	8
<i>Support worker</i>	1	8
<i>Peer support worker (PSW)</i>	2	17
Gender		
Man	3	25
Woman	9	75
Age		
20-29	3	25
30-39	7	58
40-49	2	17
Ethnicity		
White British	9	75
White Irish	1	8
Indian	1	8
Turkish	1	8

## Interviews

Participants took part in semi-structured interviews, allowing for an in-depth exploration of the topics from their perspective. Offering both structure and flexibility, this format provides “the best of both worlds” (Thomas, 2009, p164). I used the schedule as a flexible guide of topics to be covered, while keeping the interview informal and conversational. Follow-up questions and prompts helped to elicit more detail and exploration of a topic (i.e. “Can you say a little more about that?”). This approach of flexibility and curiosity appeared successful in allowing the participants’ stories to unfold, particularly in enabling them to “reflect anew on phenomena” (Charmez, 2006, p 32). Multiple participants acknowledged that the questioning elicited thinking and reflection around topics they had not attended to previously, and gave praise to the content and quality of the questions in this regard.

The interview schedule (Appendix 2) covered a range of topics, including the participants’ approach to working with psychosis, their own conceptualisation of psychosis, their perspective on their service users’ understandings and narratives, and their process for exploring this with service users. I was particularly interested in the broader context around participants’ perspectives and experiences, either asking directly about the histories and factors which informed their position, or noting the broader context in which they lived and worked that enabled or muted certain perspectives. As is common in Grounded Theory methodology, the interview schedule evolved over the course of the research in response to emerging hypotheses. For example, questions specific to certain professional groups were used at a later stage to confirm or amend aspects of the evolving theory.

Interviews were conducted between June 2022 and February 2023 and all took place via video call. They lasted between 52 minutes and 104 minutes (average 82 minutes). Interviews were audio recorded with consent and transcribed verbatim.

## Data Analysis and Coding

In GT methodology, data collection and analysis is simultaneous and dynamic (Corbin & Strauss, 1990). This meant an ongoing process of transcription, interview coding, theory generation, and further interviews. Each of these areas influenced the other, such that further sampling and interviewing was shaped by prior coding and the developing theory. The analytic process followed guidelines as set out by Charmaz (2014):

Coding is the foundation of analysis in GT, and moves through layers of increasing abstraction towards theory generation. This began with *initial coding*, where transcripts were coded line-by-line with short and simple labels and descriptions (Appendix 3). This captured the actions and processes, remaining closely tied to the data without making conceptual leaps. This moved to more *focused coding* which condensed and synthesised the main themes and processes across the data, based on the most significant or frequent codes. Analysis moved towards *axial* and *theoretical coding* where categories were more clearly defined and delineated, capturing shared processes across the data. As interviewing and analysis continued, these categories were refined and adapted, with some synthesised or separated, and others forming sub-categories. Theoretical codes consider possible patterns and relationships between categories and their underlying codes to give coherence to the analytic story. At the highest level of abstraction, categories were grouped together to form *concepts* or *schemes* which were able to say something more broad and generalisable about the social process across the data, while remaining grounded within it.

Although presented here as linear, the research process was truly fluid, iterative and inductive. I frequently moved between different levels of coding, making constant comparisons between and within the data, and read transcripts throughout to check the ‘fit’ with developing theory. Data collection eased as I approached theoretical saturation

(Charmaz, 2014), whereby the theory was sufficiently comprehensive and additional interviews made no further conceptual contributions.

Coding was mostly achieved by hand using pens and post-it notes, with the support of digital aids such as word processing software (Appendix 4). Diagramming was essential to this, allowing for a visual representation of codes and categories, and the exploring of possible relationships and conceptual linkages between them. A personal research diary was kept throughout to take notes of ideas and insights as they occurred to me, often arising after interviews or supervision meetings. This process of 'memoing' is central to GT (Strauss & Corbin, 1990; Charmaz, 2014) and contributed significantly to the generation of theory and reflections on my research reflexivity throughout the process.

## **Ethics**

The study received ethical approval from the UCL Research Ethics Committee (Appendix 5). Participants received an information sheet (Appendix 6) before providing written informed consent to take part (Appendix 7). They were reassured that their personal information would be treated with strict confidentiality and that any quotes used in the study would be anonymised.

Service user involvement is also an important ethical consideration in research. Incorporating service users in research can promote more equal social relations in knowledge production, contribute to service user empowerment and therefore impact broader social and political change (Abma et al., 2019; Glasby & Beresford, 2006). Pragmatically, ensuring that topics are of importance to service users improves the chances that they will be applicable in clinical practice and reduces wasted resources on unnecessary research (Staley & Minogue, 2006).

Combining the expertise of both service users and professionals can therefore improve research and the mental healthcare it informs (Faulker & Thomas, 2002).

### **Service user consultation**

A service user research forum (SURF) was consulted twice during the research, which consisted of a panel of eight service users and three mental health professionals. The first consultation was in November 2021 during the early study design and proposal. The second consultation was in March 2022 before the recruitment and interview phase, where the panel commented and gave feedback on the recruitment materials and interview schedule. The use of consultation in the project reflected my genuine belief in the value of participation and I hoped to take seriously the views and opinions of those within the SURF to avoid ‘tokenism’ in involvement (Trivedi & Wykes, 2002). This is explored in greater depth in the critical appraisal (pp.183-184).

Across both meetings, comments were positive about the purpose and design of the project. The panel shared numerous helpful ideas and questions which positively influenced the direction of the study, with adjustments to the design and materials made based on their suggestions.

## **Results**

This section will present the results, beginning with the first research question and following with the second. Presenting findings is often a challenge within Grounded Theory, with the need to balance both the depth and breadth of the findings and to produce a summary while retaining richness (Urquhart, 2013). In view of this, readers are first offered a diagram and storyline of the overall grounded theory to highlight and emphasise the central message of the findings. Next, an outline of the results is presented in a table to orient readers towards

the categories, sub-categories and codes of which the grounded theory comprises. Finally, these categories and codes are each considered in turn, using quotes to illustrate them, thus grounding the theory within the words of participants.

## **Research Question 1:**

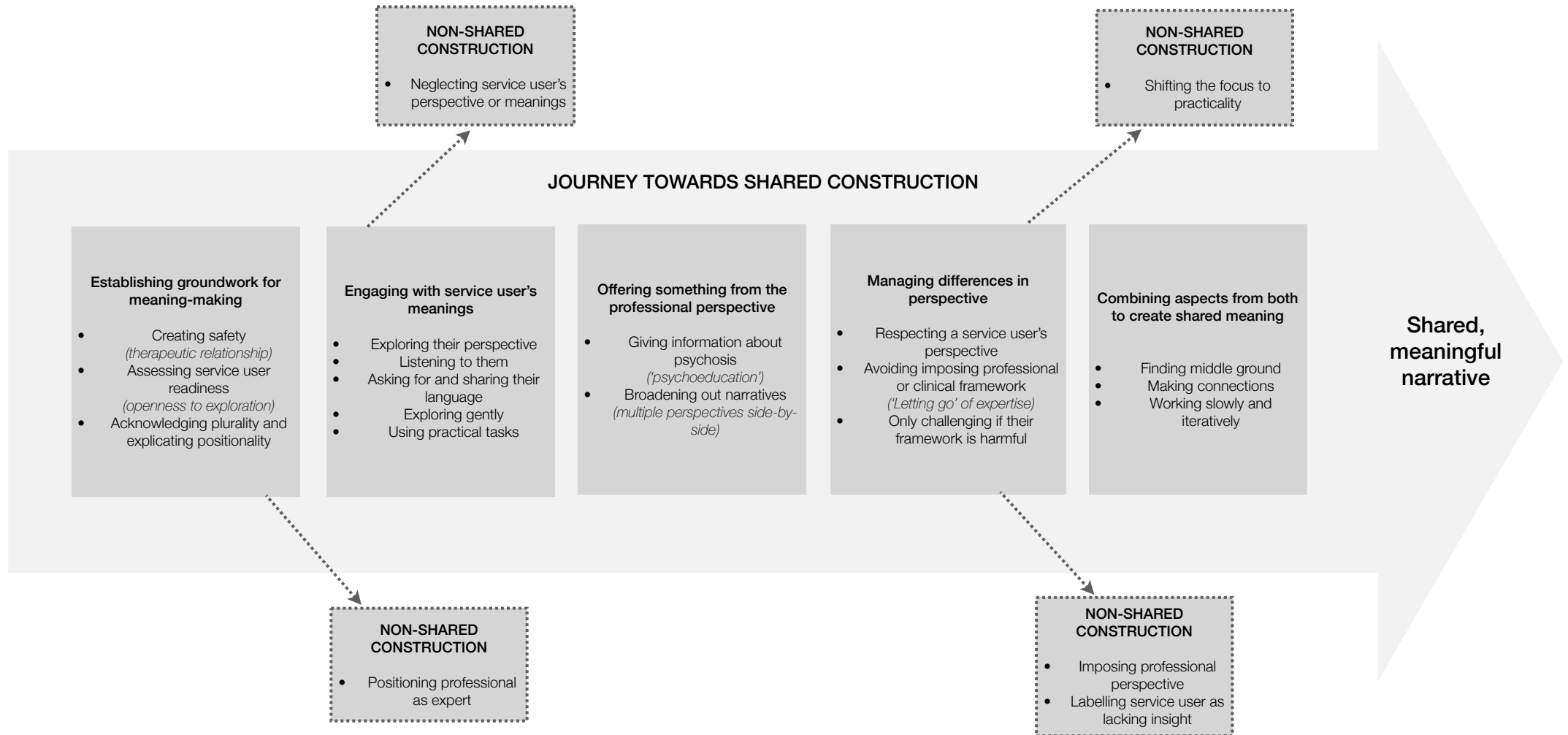
### **Process of meaning-making within the clinical encounter**

#### **Storyline of overall theory**

Drawing on its findings, this paper conceptualised the process of meaning-making in the clinical encounter as steps on a journey. These are presented in Figure 1. The professional was responsible for initiating these steps, inviting the service user on the journey towards a meaningful and shared narrative. As shown in the diagram, this process began with establishing the groundwork, then exploring a service user's perspective and meanings, next making contributions from the professional perspective, and finally negotiating differences to co-construct shared meaning. At each of these stages, a professional could act or position themselves in ways that defied this shared meaning-making process, as represented by the arrows pulling away towards 'non-shared construction'.

This journey became possible when professionals had particular ways of constructing and enacting their role, comprised of certain skills, knowledge and orientations to practice which facilitate meaning-making. This construction and enactment was conceptualised here as the process of 'role construction': the highest-order category in the grounded theory. Feeding into role construction was a professional's awareness of a 'plurality of perspectives' and skills in 'translation and communication of meaning'. Each of these areas will now be considered in order, as represented in Figure 2.

**Figure 1.** Grounded theory diagram for Research Question 1: The process of meaning-making within the clinical encounter.





**Figure 2.** *Categories and subcategories of research question 1.*

Role construction	
	Awareness of plurality of perspectives
	Translation and communication of meaning
(Journey towards) shared construction of meaning	
	Establishing groundwork for meaning-making
	Creating safety and trust
	Assessing service user readiness
	Acknowledging plurality and explicating positionality
	Engaging with service user's meaning
	Exploring their perspective
	Listening to them
	Asking for and sharing their language
	Exploring slowly and gently
	Using practical tasks
	Offering a professional perspective
	Giving information about psychosis
	Broadening out the narratives
	Managing differences in perspective
	Respecting service user's perspective
	Avoiding imposing professional framework
	Only challenging if their framework is harmful
	Bringing together aspects from both to create shared meaning
	Finding the middle ground
	Making meaningful connections
	Working slowly and iteratively
Non-shared construction of meaning	
	Pulling away from and neglecting shared construction
	Not exploring a service user's perspective
	Positioning professional as expert
	Imposing a professional perspective
	Labelling service users as lacking insight
	Shifting the focus to practicality

## **1. Role construction**

Role construction was a dynamic and ongoing process through which a person became and practiced as a professional, comprising the application of their interests, orientation, and skillset. This encompassed both their own individual conceptions of their role as a 'professional' and the conceptions of the wider mental health system, including the boundaries and capacities of their role and practice in comparison to others around them. This also included the skills, knowledge and perspectives that a person could access and utilise within their professional role, as well as those which were constructed as impermissible. The construction of the role came to define what was possible, including a person's perceived confidence and capability in relation to the constructed roles and responsibilities of other team members. Role construction was influenced by factors at the personal, professional, team culture and system levels, further elucidated below in RQ2.

Within the grounded theory, role construction was the process that determines a professional's orientation to a person-centred, meaning-making approach and their ability to employ the skills and knowledge within the clinical encounter to engage with and communicate a range of meanings. As this paper will suggest, the categories of 'plurality of perspectives' and 'translation and communication' also feed into role construction.

Grounding this process within the words of participants, role construction was shown to reflect the differences in approach and orientation between individual professionals based on their interests, knowledge, confidence, and skills:

*“some clinicians [...] have a very holistic and very open-minded view of what can be going on and there are others who have a much more narrow lens through which they see clients” (Nurse 2)*

*“the people [care-coordinators] who feel confident to or who have an interest in doing that [therapeutic] stuff do [it], and the people who don’t I think...get by without doing it” (CP3)*

This captured how individuals constructed what it means to be a ‘professional’ and enact particular roles. This was conceptualised against the roles and responsibilities of other professionals, defining who does what within a team:

*“My experience is that everyone has their place and they will not step out of that boundary. So as a nurse, you will do nurse things, and when there’s anything else that needs to happen we’ll draw in that discipline to do those things” (OT)*

*“if you’re a peer support worker you’re not providing psychological support and that [meaning-making] is not part of your job role” (PSW2)*

This process of individual construction drew on and took influence from broader team and system narratives of being a ‘professional’. In combination, boundaries were drawn around what was possible or off-limits in that role, such as the perspectives or experiences from a clinician’s personal life:

*“general staff can have their own history of mental health but culturally people kind of don’t normally come forward and talk so openly [...] whereas our [peer support] role specifically you’re employed really for your insights” (PSW1)*

*“clinicians don’t feel able to bring themselves, all of their own understandings and history and story to work. Because it’s only the richer for it, but people feel that they have to kind of be professional [...] but, you know, it’s about being able to bring all of their perspectives, really bring themselves, bring their interests, bring their understandings...Yet we don’t often hear them because people feel, oh I can’t say anything, I shouldn’t bring that work” (Nurse 2)*

### **1.1. Awareness of plurality of perspectives**

Effective meaning-making was built upon clinicians’ awareness of, and openness to, a range of perspectives about psychosis at any one time, including those which may be brought by service users and those held across the professional system:

*“I see myself as non-partisan, I’m not particularly fused with any explanatory model myself... different things can co-exist at the same time” (CP1)*

*“It’s about including and incorporating everything, not saying it’s either this or that” (Nurse2)*

This awareness of plurality provided the bedrock upon which meaning-making became possible within the clinical encounter, providing an acknowledgement and acceptance of a great range of conceivable perspectives that may be brought by service users.

## **1.2. Translation and communication of meaning**

Built upon this awareness of plurality was the skill of a professional to communicate and translate meanings between those in the team or wider mental health system who held different perspectives. This included connecting with and using the language and meanings of the service user, while also being able to speak to the ‘system’ aspects and requirements of their care in understandable ways:

*“I think our role, you know, we [...] are consciously aware that, you know, we want to be relatable, I mean we’re supposed to be relatable...we are a bit more sensitive to not wanting to become too clinical in the way that we speak” (PSW1)*

*“we even said to him, look, if you read your notes you’re going to have a psychiatrist that says you’re having an acute transient psychotic episode. What that means is if it’s acute, yep we both agree it was intense. It’s transient, well it’s not happening now is it. And psychotic, well what an umbrella term for what we don’t understand” (Nurse 2)*

Likewise, a service user’s meanings needed to be communicated beyond the clinical encounter into the wider team and system in digestible ways to increase its chance to be heard and acted upon. Professionals therefore needed to speak to the language and

perspectives of service users, other clinicians, and the wider system, while being able to translate between them:

*“you’ve got to...couch it and frame it and explain it in a way that, you know, your audience in the wider framework and the commissioners and whatever can understand as well” (Nurse2)*

## **2. Journey Towards Shared Construction**

### **2.1. Establishing groundwork for meaning-making**

#### ***2.1.1. Creating safety and trust***

Meaning-making was built upon a safe therapeutic relationship, requiring “*rapport building and...trust*” (CP3). Challenges in establishing trust, often influenced by service users’ psychosis or negative past experiences, could preclude taking further steps towards shared construction. Clinicians would acknowledge and navigate these experiences with service users in order to establish trust:

*“what’s happened to them already in mental health services, in the NHS [...] or by the authority, by the government or by the police [...] that also gets in the way of having meaningful discussions with people” (Social worker)*

#### ***2.1.2. Assessing service user readiness***

Professionals would assess whether they considered a service user to be 'ready' for meaning-making before exploration began. Aiming to be guided by a service user's needs, professionals would delay or slow down deeper exploration if a service user did not appear sufficiently open to making sense of their experiences.

The passing of the acute phase of psychosis, often with the assistance of medication, was usually necessary:

*"[When] the difficulties are no longer occurring in that extreme form there seems to be more readiness to perhaps begin that exploratory work" (CP2)*

*"the medication gets someone to a point where they can, kind of, get their thoughts in line" (SuW1)*

A 'sealing over' effect could mean service users were not ready to explore their experiences:

*"when they have their psychotic episode they want to forget all about it because it's an awful experience" (psychiatrist)*

### ***2.1.3.. Acknowledging plurality and explicating positionality***

Acknowledging the 'plurality of perspectives', professionals would be transparent about their approach, positioning themselves and their orientation as one among many:

*“we’ll always present our explanation about psychosis [...] as one explanation. That doesn’t mean that it’s right or wrong, or one that you need to consider, but this is one explanation. This is the one that we are offering, and if you find that useful then you find that useful, if not then let’s discuss what it is that you find useful” (Nurse 2)*

*“I own it quite transparently in sessions [...] as a psychologist I’m really interested in the things that have happened to people and how they’ve made sense of it” (CP3)*

## **2.2. Engaging with a service user’s meanings**

### **2.2.1. Exploring their perspective**

To start the process of exploration, professionals would ask about a service user’s own perspective and meanings:

*“So first and foremost [...] I’m really just being curious to understand what exactly is going on for the, for the person” (CP2)*

*“a good place to start would be: why do you think you developed, let’s say, psychosis?” (CP1)*



*“I sort of ask people about if this holds any meaning [...] or if they know where it came from” (Nurse1)*

This was embedded within a broader exploration, such as considering *“a person’s interests and hobbies, and their hopes and dreams”* (CP2), which allowed for a richer understanding of their life. This process of exploration enabled professionals to develop their sense of what may be happening, alongside understanding and connecting with a service user’s sense-making through the meanings that they expressed:

*“All the different accounts I’ve heard, ‘this is what I’ve experienced’, ‘this is what I believe to be true’, ‘this is what I know’, ‘this is what I’ve had’... it’s only then that I’ve been really able to understand it [...] But you just have to literally listen to what the client is saying” (Nurse2)*

### **2.2.2. Listening to them**

Listening was highlighted as central to this work by many participants. Listening to service users’ perspectives not only aided professional understanding, as above, but also gave *“people a space to be heard”* (Nurse 1). This enabled service users to express themselves and feel validated within the clinical encounter:

*“a lot of listening is important to give that person a space for themselves”*  
(PSW2)

*"you need to give people time to talk and, you know, people want to be listened to" (support worker)*

*"there's a lot of times where people don't have a voice in mental health services and I think it gives people that chance" (Nurse1)*

### **2.2.3. Asking for and sharing their language**

Asking about service users' own descriptions and using their preferred language was important in the process of exploration and co-construction. Professionals recognised that the term 'psychosis', while used within EIP services, may not be a service user's "way of explaining what's happening to them" (CP1). As such, professionals would ask service users their preferred language and check how different terms and concepts fitted for them:

*"I would say [...] so is this [psychosis] a term you are comfortable with, is this a term you would like me not to use, how would you describe your, your difficulties, [...] what would you frame it as?" (Nurse1)*

Professionals would then respect these choices and "make sure I was sharing their language" (CP1). For some service users, ill-fitting terms or frameworks could be experienced as painful and upsetting:

*"if you ever said psychosis, you know, she'd just start crying because it was devastating to her" (Nurse2)*

By asking and sharing a service user's language, professionals were able to respect their perspective and avoid damage to the therapeutic relationship:

*"it was better to say delirium because [...] it just was counterproductive to insist on saying you have first episode of psychosis" (Nurse2)*

#### **2.2.4. Exploring slowly and gently**

Exploration needed to be measured and considerate, with professionals recognising that it often took time. This helped to build trust and develop an in-depth understanding, often over multiple sessions:

*"you can't just do 10 minutes [...] You have to spend, you know, quite a lot of time with someone to really tease [it] out..." (Nurse2)*

Clinicians also acknowledged that uncovering personal meanings could be complex and potentially distressing. By practising *"a kind of gentle quality to that exploration"* (CP2), professionals hoped to proceed at a pace which was attuned and sensitive to the service user.

#### **2.2.5. Using practical tasks**

Alongside talking, professionals would use practical tasks to support exploration. This included “*relapse prevention work*” (CP3), where connections could be made between a service user’s life experiences and their experiences of psychosis:

*“relapse prevention is part of the EI work which is thinking about stressors that can cause, cause you to become unwell in any kind of way” (Nurse3)*

*“staying well planning, relapse prevention planning, um...creating a timeline [...] doing the card sort [...] and us being able to have a discussion about it [...] so that maybe they can understand that, oh, do you know what maybe I was struggling to sleep, or I was, um, you know, not going to university, or I was smoking a lot of cannabis” (Nurse1)*

## **2.3. Offering a professional perspective**

Meaning-making involved professionals offering ‘something’ to service users from their perspective, such as information, resources or a framework of understanding. These were influenced by and acquired from a range of personal, professional, team and system sources (see Research Question 2). Embedded within an awareness of plurality, these were best shared and communicated with service users as one framework for understanding among many.

### **2.3.1. Giving information about psychosis**

Professionals acknowledged that they had a “*repertoire of tools and resources that could help*” (CP1), including a “*big educational element*” (OT). ‘Psychoeducation’ was shared

through conversations, leaflets, videos or websites. This predominantly occupied a mainstream evidence-based clinical perspective, explaining multifactorial aetiology, episodes, relapses, and the role of different interventions:

*“we would always give information about what can cause psychosis”*

*(Nurse1)*

*“there are a lot of conversations about an episode of psychosis, how things are different for everyone, how they might develop, how they might actually be treated and how you can kind of get back to normal. So a lot of it is...psychoeducation about the actual illness and recovery” (Nurse3)*

Professionals would check with service users whether clinical psychoeducation fitted with their experience. Information could also be non-clinical and adapted to the service user's own framework:

*“I’ve printed out some information on kundalini awakening because this was very in keeping with it. He was delighted because he said I can’t believe I’ve come to the NHS and someone knew about kundalini” (Nurse2)*

Psychoeducation was either embedded within a team's strategy, shared by *“care-coordinators when people first come into the team” (CP1)* or during psychological work, or left to the approach of individual clinicians. This meant that in some clinical encounters, psychoeducation was not routinely shared.

### **2.3.2. Broadening out the narratives**

Professionals could introduce co-existing frameworks to sit alongside a service user's understanding, aiming to *broaden* their understanding rather than overwriting it. This could, for example, enable multifaceted consideration of the emotional, physical, mental and spiritual aspects of all experience:

*“one point of view is going to feel too stifling, it's going to feel too constraining, it's going to feel too reductive. So I think it's about saying, do you know what, let's, let's hold that in mind, absolutely, that is what feels true and right but here are some other ways of looking at it as well” (Nurse2)*

## **2.4. Managing differences in perspective**

In moving towards co-construction, differences in perspective between professional and service user were common: *“with different explanations that they might have [...] and we might have” (CP1).*

### **2.4.1. Respecting a service user's perspective**

Professionals managed these differences in perspective by leaning into the service user's framework and respecting their perspective even when it differed from their professional understanding:

*“a person can have a very different cultural explanation, but [...] they should be harmonious” (CP1)*

Clinicians may continue to be guided by their own understanding ‘backstage’, such as using a psychological formulation, but in the ‘frontstage’ continue to explore and validate the service user’s framework with interest and respect:

*“when somebody is making sense of their psychotic experiences through a spiritual framework I’m genuinely curious [...] And I won’t necessarily think [...] that is the voice of God speaking to you [...] I’m sort of agnostic on that point. But I’m genuinely curious and so I’m not here to assert my own psychological framework on that experience” (CP2)*

#### **2.4.2. Avoiding imposing professional or clinical framework**

Clinicians were cautious to “not impose” (Nurse 2) their own frameworks when co-constructing a narrative, considering that this “would be trespassing on the expertise and, and culture of somebody else” (CP1). Many professionals considered it needless to challenge a service user where there were differences in professional, cultural or aetiological frameworks:

*“And even when I don’t necessarily agree with some ideological frameworks that a client might, might draw on such as genetics [...] I’m not going to directly challenge that because I feel like that’s their framework and I really just want to understand [...] rather than necessarily having to change it” (CP2)*

This involved the awareness of multiple ways of seeing and knowing psychosis ('plurality of perspectives'), alongside the recognition that one's own professional or cultural perspective was not superior:

*"I don't want to impose the way I see things as somebody from, you know, a white person from the West to impose how I see mental illness because [...] symptoms of psychosis are seen very differently in different communities" (Nurse1)*

#### **2.4.3. Only challenging if their framework is harmful**

Professionals would, however, consider challenging a service user's framework in instances where they perceived it brought negative consequences, such as distress or harm:

*"[I would challenge] when it feels as though that's not necessarily something they've come to themselves and it's something that causes them some distress" (CP3)*

*"where I have sometimes exercised some challenge [...] I can remember one client [...] questioning whether to have children in case they were to give this onto their children, genetically speaking. And in such instances I did feel a need to just give my own thoughts around that" (CP2)*



## **2.5. Combining aspects from both to create shared meaning**

### ***2.5.1. Finding the middle ground***

The final key aspect of shared meaning-making was to *“find the middle ground”* (Nurse 2) by consolidating the perspectival expertise of both service user and professional. While conceptualised in the model as a ‘step’ on the journey, this process of negotiation could play out across the entire process of exploration, information sharing, and integration.

### ***2.5.2. Making meaningful connections***

This category comprised the process by which meaning was integrated and established within the clinical encounter. Professionals took an exploratory, curious stance in making connections that may feel meaningful to the service user, *“holding [suggestions] quite tentatively as well”* (CP3). This may include noticing possible connections and reflecting this back to the service user:

*“isn’t it interesting that when you’re feeling really threatened you start to hear threatening things?”* (CP3)

This was a process of *“really just trying to connect the dots”* (CP2) to make meaning through significant connections, which could originate from the professional or the service user:

*“[A service user may say:] ‘these things were things I was experiencing but I hadn’t popped the two together’”* (Nurse1).

It was important for professionals to check whether this developing narrative fitted for service users, creating a to-and-fro of meaning-making which was negotiated rather than imposed:

*“Does that fit with what you’ve experienced?” (CP1).*

### **2.5.3. Working slowly and iteratively**

This process of creating shared meaning was usually slow and iterative across multiple meetings, rather than being in *“one neat package”* (Nurse3). As noted above, there is greater fluidity to the process of negotiating and integrating meaning within the clinical encounter than it being a simple ‘step’ or singular occurrence:

*“it feels like a much more iterative process where you’re kind of like dropping it in here and there and wondering about it across the course of sessions [...] it happens bit by bit rather than being a really clearly defined thing that you kind of do with someone” (CP3)*

## **3. Non-Shared Construction**

### **3.1. Pulling away from and neglecting shared construction**

At each stage of the journey, it was possible for professionals to deviate from, or totally neglect, effective meaning-making and co-construction. These examples of non-shared construction were largely reflected in participants’ observations of other clinicians’ practice rather than their own. These categories, detailed below, are expressed in Figure 1 as boxes pulling away from the centred journey of meaning-making.

### **3.1.1. Not exploring a service user's perspective**

Some clinicians within participants' teams did not explore or ask about meaning. Instead, their 'role construction' focused on practical activities or one-way information-sharing, which was reflected within their practice:

*"they [a service user] didn't want their care coordinator [...] because they say that 'they don't listen [...] all they do is check my weight and tell me to do bloods'" (OT1)*

As noted, some participants did not consider meaning-making *"part of [their] job role"* (PSW2), resulting in limited exploration of a service user's perspective. Others struggled to identify or comment on certain aspects of personal meaning, particularly spiritual and cultural frameworks, which suggested they too were not orientated towards this in their practice:

*"I don't think I have had a person who has kind of formulated it like that after the episode" (Nurse3)*

### **3.1.2. Positioning professional as expert**

Some professionals positioned themselves as the specialist within the clinical encounter, constructing their role as an educator and expert:

*"Sometimes [...] I believe that they are not psychotic anymore, they've responded very well to their medication but they keep coming and saying 'oh I hear voices, I hear my abuser talking to me'. And then telling them that*

*actually what they're having is not psychotic [...] So it's become quite difficult for the patient as well to know which one is which" (Psychiatrist)*

This could leave professionals closed off to the service user's own knowledge or understanding, which risked dismissing it in favour of the professional perspective.

### **3.1.3. Imposing a professional perspective**

Attempting to resolve differences in perspective, clinicians could impose their own professional perspective on service users. This could include using terms or frameworks which did not align with a service user or convincing them to comply with a model of understanding:

*"you get psychologists who are doing CBTp and sometimes I've seen them [...] trying to persuade people that they are, you know, that they do have 'psychosis'" (Social worker)*

Equally, a professional's cultural understanding or approach could be imposed on a service user, whether from a minority or majority perspective:

*"You can be culturally sensitive to things, but [professionals can also be] kind of imposing [...] cultural perspectives on somebody and how they should manage things [...] You'd never know how much of that is imposed or how much of that is appropriate and welcomed and supportive" (OT)*

### **3.1.4. Labelling service users as lacking insight**

Multiple participants explicated the “*lacking insight*” (SW1) discourse prevalent in some teams. Service users could be labelled as ‘lacking insight’ when they were “*not accepting a mental health explanation of what’s going on*” (CP2). This discredited service user perspectives that differed from clinical frameworks of explanation:

*“it does make me uncomfortable. Because I think [...] when we say do they have insight or not, they mean, we mean do they agree with us about what’s going on” (SW1)*

### **3.1.5. *Shifting the focus to practicality***

Professionals could revert to the practical elements of care when differences in explanation emerged between them and service users:

*“[That] resulted in like, right let’s just sidestep this whole thing and let’s just think about what we’re going to do” (OT)*

*“Yes [...] we have different opinions on that but what can I do for you, let me help you with that” (psychiatrist)*

This focus on ‘doing’ sidestepped issues around meaning, prioritising practical input and interventions within the clinical encounter. This circumvented further exploration of differences in understanding and the opportunity to explicate the plurality of perspectives.

## **Research Question 2:**

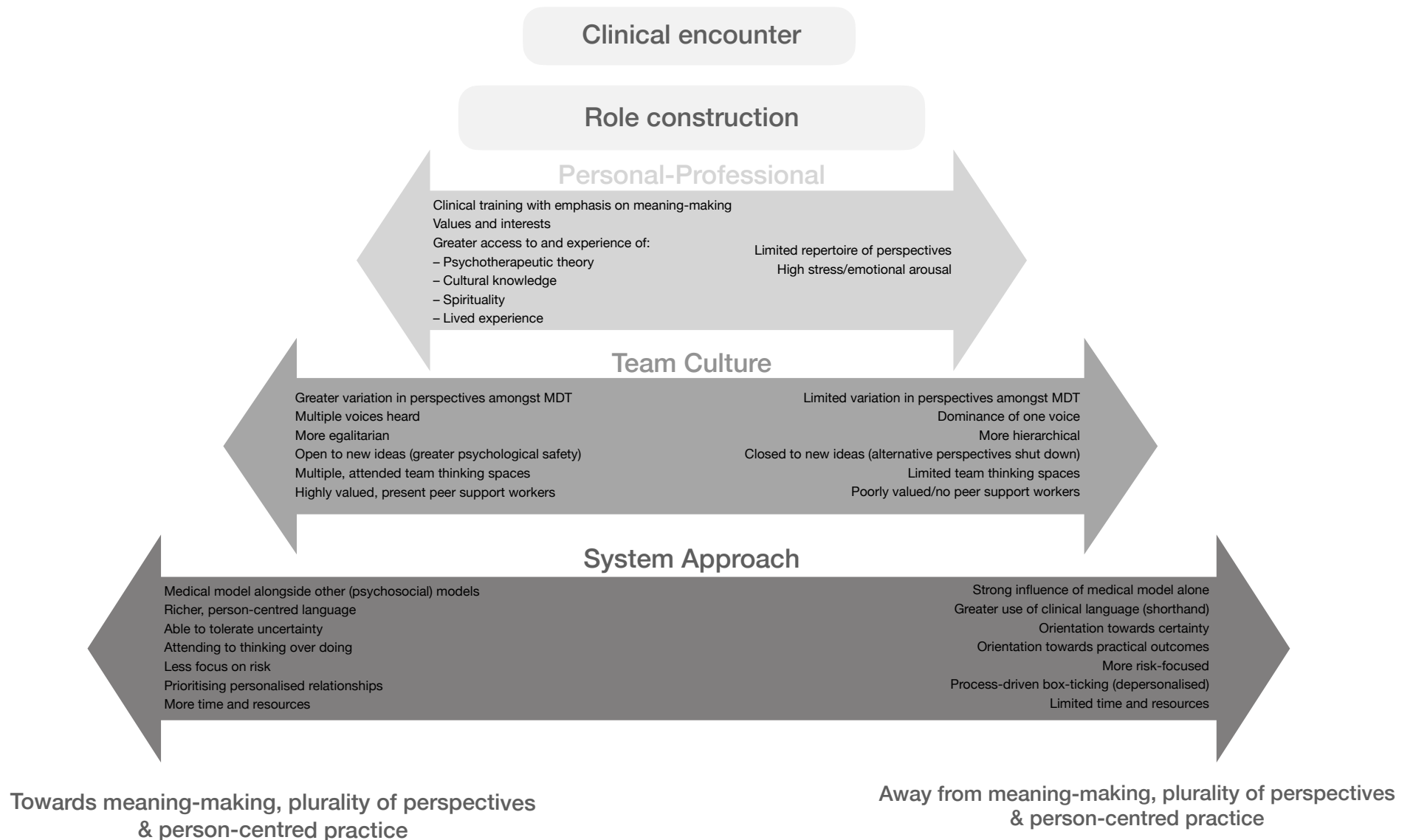
### **Factors and broader context which influence meaning-making in the clinical encounter**

#### **Storyline of overall theory**

At the top of the diagram (Figure 3), the professional brought to the clinical encounter their idiosyncratic orientation, skills and knowledge ('role construction') which determined whether they engaged a service user in meaning-making. The most proximal determinant of this process was the personal-professional level directly below it, followed by the broader context of the EIP team culture and then the approach of the wider mental health system. At each of these levels, there are pulls towards meaning-making, plurality of perspectives and person-centred practice (to the left) and away from this (to the right). Each level comprised of multiple individual factors along an axis (e.g., less hierarchical-more hierarchical), reflecting the spectrum across which a particular professional, team or system may be positioned at a particular moment. These positions were not fixed or engrained within a particular person, team or system, but move up and down the axis, signifying changes in context or approach, or responding to shifts in other interconnected axes. This included variation in the degree to which different organisations and management structures exerted 'top down' pressures and influence.

Taken together, at any moment within the clinical encounter, a range of factors and processes across each level will be at play. These levels, and the axes which comprise them, create specific conditions which impact the professional's role construction and, consequently, their practice of meaning-making. Each level (scheme) will now be explored in turn via the core categories and sub-categories of which they comprise, as represented in Figure 4.

**Figure 3.** Grounded Theory Diagram for Research Question 2. Explicates the process through which personal-professional, team and system factors influence meaning-making, plurality of perspectives and person-centred practice within the clinical encounter.



**Figure 4.** *Categories and subcategories of Research Question 2.*

Personal and professional	
	Clinical training
	Values and interests
	Cultural background
	Spirituality
	Lived experience of psychosis
Team culture and approach	
	Varied perspectives and network of influence
	The dominance of certain voices
	Team hierarchy and psychiatry
	Openness to new ideas
	Access to resources
	Reflective and discussion spaces
	Peer support workers
System approach and demands	
	Medical model and diagnosis
	Clinical language and perspectives
	Use of shorthand, loss of meaning
	Exclusivity
	Certainty and practicality
	Teams as decision-makers
	Difficulty tolerating uncertainty
	Risk management
	Processes
	Time and capacity

## 1. Personal-Professional Factors

Factors relating to a clinician's personal and professional life influenced how they conceptualised psychosis, constructed their professional role, and enacted this in practice within the clinical encounter. These factors include a professional's clinical training, values



and interests, cultural background, spirituality, and lived experience of psychosis. Each category is considered briefly below, using participant quotes to ground the theory within the data.

### **1.1. Clinical training**

Differences in clinical training had a general influence upon professionals' perspectives and approach, meaning there were *"patterns based on profession"* (CP2) but not always *"clear difference[s] between different professional groups"* (SW1). Nursing training, for example, could offer a limited repertoire of understandings of psychosis with a focus on practical tasks over meaning-making: *"just get them to take their medication"* (Nurse 2). Whereas access to psychological or psychotherapeutic training often made available a wider range of perspectives, with greater emphasis on meaning-making:

*"it was only when I [...] started doing my psychotherapy training that I actually had a whole new understanding of what psychosis is...all these different explanations. Now [as a nurse] certainly my day-to-day explanation, understanding of it was [...] just get on with it and not really understand. And I think it does a real disservice to a lot of staff. It would be lovely if we had a lot more training in it. It's very much seen as CBT is the preserve of the psychologists"* (Nurse2)

*"being a care coordinator [...] I was quite lucky that I had like time to think about particular psychological perspectives, but not everybody does"*  
(social worker)

## 1.2. Values and interests

An individual's own values, beliefs and interests could influence their clinical practice and orientation towards or away from meaning-making:

*"I, like, believe that we should always treat other people with respect [...] with compassion and with empathy. And that means listening to them and trying to work things out with them. And I suppose that's like my personal belief which drives some of it and the perspective that I've come from"*  
(social worker)

Personal values and orientation were often informed and strengthened through previous clinical experiences, inspirational professionals, or their own personal reading:

*"I read beautiful books that helped me to understand"* (consultant psychiatrist)

## 1.3. Cultural background

Cultural knowledge, embedded within a professional's own background or experience, increased understanding of their own perspective alongside an enhanced awareness of cultural frameworks in general. This could be drawn on in direct work with service users in the clinical encounter:

*"the person was labelled as being very very paranoid...Now this person was actually of the same background as myself and...I was actually listening to*

*him thinking, my god these things could actually be happening because I know in our culture this is actually very classic and very typical” (OT)*

Conversely, a lack of appropriate cultural knowledge in teams risked cultural understandings being ignored and the needs of minority groups being unmet:

*“when he was being assessed around these things, that wasn’t taken into consideration [...] to no fault of the person assessing because they’re not within that community or that culture to know that” (OT)*

*“we should have had provision for him to have somebody...who could see his, his worldview [...] culturally we were not meeting his needs” (Nurse1)*

#### **1.4. Spirituality**

Clinicians’ own faith influenced their orientation towards spiritual understandings of psychosis and often embedded this within their practice. Professionals without personal religiosity often lacked the confidence to engage service users in conversations about faith:

*“religion is just not even vaguely part of my life and never has been, so it feels like a complete, almost like foreign territory to even know the language to talk about it with people in. Um, whereas I think people in the team who are religious or who have been religious, even if it’s not the same match, I think I guess it’s more, it’s just more part of their vocabulary to talk about it” (CP3)*

*“all too often staff feel too afraid of the whole area and they either feel because they have a faith they shouldn’t speak about it and can’t engage with the client about it; or they don’t have faith and they feel under-resourced or under-equipped to manage” (Nurse2)*

A lack of clinician confidence or training risked service users’ spiritual perspectives being ignored or dismissed:

*“I think there’s a sense of not really knowing what to do with it, and so it quite often gets lumped into the ‘no insight’ category [...] But I think there’s a sense amongst the team that they kind of know there’s maybe a little bit more thinking that we can do around it but they just don’t really feel that equipped to” (CP3)*

### **1.5. Lived experience of psychosis**

Clinicians’ own lived experience of psychosis could influence their perspective and subsequent approach:

*“lived or past experience of things is a big contributing factor to why maybe my approach to things was different because [...] I am clinician, but I am also a service user” (OT)*

This could enhance awareness of particular aspects of the lived reality of psychosis, which either created allegiance to a particular explanation, such as a clinical understanding, or invited greater openness to alternative frameworks:

*“you can quite easily be quite unsure what the hell happened. Is there another explanation to it, you know? Have you tapped into something else? I mean, personally I think if I had another explanation for it, I wonder if you, if you’re tapping into something else” (PSW1)*

Routing through ‘role construction’, there was variation in how explicitly their lived experience was drawn on in their clinical practice. This was particularly evident for clinicians not titled as peers, though there was also variation between PSWs:

*“different peer support workers have different styles in terms of how much you want to talk about your own experience” (PSW2)*

## **2. Team Culture and Approach**

The clinical encounter took place within a broader team context. Factors relating to the culture and approach of teams influenced professional role construction and practice, either facilitating or impeding meaning-making in the clinical encounter (Figure 3). The categories of team culture impacting upon these processes include varied perspectives and network of influence, the dominance of certain voices, openness to new ideas, and access to resources. These will be considered briefly in turn, with the words of participants grounding each category within the data.

## 2.1. Varied perspectives and network of influence

A range of perspectives were held within teams, as characterised by variations in personal and professional factors. Professionals would hold, represent and actively share particular perspectives within the team, such as in clinical meetings or multidisciplinary team (MDT) discussions, which could impact how psychosis was conceptualised in the team:

*“[I may be] drawing attention to something like a big stress pile-up and then emotional changes” (CP1)*

*“I did actually go back [to the team] and say, let’s not just write this off entirely as just being paranoid, because I certainly know many instances in our culture where this happens” (OT)*

The presence or absence of particular perspectives could influence team functioning and clinical decision-making:

*“I would always say with the EI teams [...] it depends on who’s in the room as to whether they get accepted” (Nurse 1)*

Influential perspectives, frequently shared and heard, could permeate throughout the team to embed cultural change:

*“[The] CBT therapist [...] is very kind of trauma-focused [...] and that’s become a bigger thing within the team since she joined [...], I think people*

*just have, they have that in their mind [...] And it influences the way people do the assessments” (support worker)*

*“everybody’s influencing everybody else” (CP1)*

## **2.2. The dominance of certain voices**

Some voices could be louder than others in team spaces and discussions, such that certain perspectives were more regularly heard and imposed within teams:

*“we have these formulations and all you hear are the psychologists, no one else gets to speak” (support worker)*

The dominance of certain voices in teams was based on professional background, power, and seniority, as well as personal factors like personality and confidence:

*“I think it’s more down to personality actually in the sense that some people are louder, some people are more opinionated and that’s definitely a way in which to exercise power” (CP2)*

*“it does take confidence to like step outside [...] the way that everybody else is thinking about things [and] to speak in meetings” (Social Worker)*

### **2.2.1. Team hierarchy and psychiatry**

Professionals frequently referred to the hierarchy within NHS mental health teams. In more hierarchical teams, this structure influenced which voices and perspectives were heard and acted upon, while others were minimised:

*"there's a hierarchy [...] within the trust and peer support workers are somewhat, they're in the bottom pile" (PSW1)*

*"care-coordinators or nurses...defer in every sense to medics" (CP1)*

The perspectives and approaches of senior clinicians and managers could *"filter down"* (OT) to the rest of the team. Consultant Psychiatrists, holding clinical responsibility, often had the *"final say"* (Nurse 3) and could override other perspectives:

*"[the consultant] would say 'oh they are for the team' or 'they're not for the team' and maybe they would go against the person that did the assessment" (Nurse1)*

*"the consultant has the sort of final say [...] some people kind of start to give up at that point in arguing back their views" (Nurse3)*

This dynamic could reduce contributions from other professionals who would seek out the authority of the lead clinician, even in instances where they took an explicitly non-hierarchical approach:



*“Consultants [...] would very often say [...] I don’t want to take a lead on this, I want to hear from the care coordinators [and] the rest of the team. And often we were saying, well [...] now we’re asking for you to give that final say on what we do because actually you are the consultant” (Nurse2)*

### **2.3. Openness to new ideas**

Team cultures varied in the extent to which clinicians felt empowered and valued to speak up and share new ideas. Teams which offered safety around expressing alternative perspectives encouraged clinicians to make contributions:

*“our team in particular I always felt like we could discuss [...] the way people see psychosis” (Nurse1)*

*“the psychological safety in the team has [...] really improved. So I think it’s probably more comfortable being curious and sharing a bit more vulnerability” (CP1)*

However, in some teams there could be resistance to new or alternative perspectives:

*“I do recall getting a few funny looks as well, but I think it did kind of sink in or get acknowledged that actually there’s a different perspective here on this” (OT)*

This could leave professionals feeling shut down and reluctant to share these perspectives in future, maintaining the team’s cultural status quo:

*“I [...] tried to gently broach the fact that [the service user] felt like his kind of theory about what had happened had just been like ignored and side-lined...And the care coordinator was quite dismissive and was quite like, well yeah, if I had a pound for every time someone thought that Allah had sent them on this spiritual mission then I wouldn’t be working here...That didn’t make me massively keen to have similar conversations in future”*  
(CP3)

Holding a position or perspective which challenged colleagues or the team approach was often perceived as aversive. There was a risk that team-members would *“look at you as a bit of a problem”* (PSW1) rather than *“actually mak[ing] change”* (PSW1). Professionals would therefore employ strategies to share new ideas in ways which avoided conflict and maintained team cohesion:

*“I’ve sort of gone with the approach now where rather than being overtly critical of an idea, I’m more interested in asking questions to challenge that, sort of, in subtler ways”* (CP2)

*“you’ve gotta be strategic otherwise you just piss people off”* (CP3)

## **2.4. Access to resources**

Access to certain resources, such as shared discussion spaces and peer support workers, could broaden the range of perspectives available and orient teams towards meaning-

making. Some services had access to religious leaders, such as Imams or priests, who could support service users to conceptualise their experiences within spiritual frameworks.

#### **2.4.1. Reflective and discussion spaces**

Reflective practice and formulation meetings offered "*time and space to...pause and reflect*" (CP2) about the meanings and aetiology of psychosis:

*"[An] open space to think about why someone might be experiencing psychosis [...] There's a real sensitivity to the person behind that diagnosis"*  
(PSW2)

Access to spaces enabled professionals to engage in meaning-making with other team members and give greater consideration to varied perspectives:

*"there's time to sit and think about a person, I think that's when there's a bit more plurality and a bit more consideration of, yeah, their life story and where they're coming from"* (CP1)

This was a limited resource, with "*relatively few forums*" (CP3) dedicated to thinking about meaning.

Service users were not present in these spaces, "*which is...not including their voice in quite a major way*" (CP3), though some teams employed strategies to support attendees to hold in mind and centre particular perspectives:

*“I kind of invite the rest of the team to listen out for different perspectives, so for like someone to listen out for [...] what the client might hope and what their challenges are, someone else to listen out for the family perceptive. To try and draw in a little bit more of what the client might be making of it all” (CP3).*

#### **2.4.2. Peer support workers**

The presence of peer support workers could positively impact team culture, influencing the way that professionals thought and talked about psychosis:

*“we should [...] bring experts by experience and peer support workers more into discussions because I think that then you’re more careful about how you say things, and then as soon as you’re more careful, you’re more thoughtful about how you say things” (social worker 1)*

While many clinicians welcomed and encouraged this shift within services, others were more resistant:

*“some people are supportive and get it totally and as I say there are other clinicians that have never given me a piece of work since the day I got here” (PSW1)*

### **3. System Approach and Demands**

The broader context of the mental health system impacted upon team culture, role construction, and the practice of professionals working within it. As such, factors relating to the approach and demands of this system also influenced the clinical encounter and the extent to which meaning-making was prioritised within it (Figure 3). These categories include the medical model and diagnosis, clinical language and perspectives, orientation towards certainty and practicality, risk management, processes, and time and capacity. Each factor is elucidated below through participant quotes to ground them within the data.

### **3.1. Medical model and diagnosis**

Medical and diagnostic conceptualisations remained influential across the mental health system, particularly in services that interfaced with EIP, such as wards or crisis teams:

*“the medical-psychiatric one [is] probably the first thing that happens because most people who’ve had a first episode of psychosis come to our team via hospital. So it’s kind of medication, diagnosis, that inpatient-type experience” (CP1)*

While EI teams were considered more holistic in approach, medical understandings would still take primacy or sit in parallel to other understandings held in the team.

*“generally it’s always back to like the diagnosis model” (social worker)*

*“there is still a strong medical component, definitely, but because we’re a well-resourced service there’s at least opportunity for lots of emphasis on the psychosocial” (CP2)*

The dominance of medical understandings risked overwriting other ways of conceptualising psychosis in some teams. This could permeate through the team culture, the practice of individual professionals, and the experience of service users in the clinical encounter. For example, there was a risk of ‘diagnostic overshadowing’ dismissing service users’ perspectives:

*"once you have this label or this diagnosis against your name [...] everything you say gets thrown into question and nobody will necessarily just take you at face value for your words or experiences" (OT)*

### **3.2. Clinical language and perspectives**

#### **3.2.1. Use of shorthand, loss of meaning**

Clinical language was employed across the mental health system to talk about psychosis, which in turn often permeated through EIP teams. This was reflected in interviews with participants, where medical and professional terminology was frequently used. Professionals acknowledged that clinical language lacked richness and could perpetuate simplistic perspectives:

*"generic terms will be used like thought disordered, er, hallucinations, delusional thinking. And really [...] it doesn't really tell you very much about the individual's personal experiences" (CP2)*

Used as a 'shorthand' for expressing particular concepts, it was used by professionals to communicate quickly and easily in language that the team or system would understand and act upon:

*"it may be a little more blasé when you're describing someone's case or presenting it to make the decision about do they meet the criteria for EI. Like yeah, 'they're hearing voices', 'they're guarded', 'they're...' (OT)*

*"if I called the crisis team and said something very tentative about how her and I disagreed on what might be going on or how I wondered if it [...] like I don't think that would necessarily be heard as a crisis [...] sometimes these words like come across as more urgent if we use them" (social worker)*

Professionals were more likely to revert to clinical language when stressed or time-pressured:

*"people, when they're stressed out or they're worried or when they need to communicate a lot of information, I think a lot of these words kind of exist to, to communicate more quickly. Like saying 'hallucinations' is a lot faster" (social worker)*

Clinical language also served to detach and distance professionals from the intense reality of EIP practice at times, functioning as a means for emotional regulation and coping:

*"it like disconnects you a bit and maybe it's useful to be disconnected" (social worker)*

### 3.2.2. Exclusivity

Clinical language was described as a highly intellectualised and professionalised form of communicating about psychosis:

*"clinical language has a certain flow to it, has a certain structure in the way everybody thinks [...] or explain[s] things" (PSW1)*

This risked excluding others who experienced it as *"worlds apart"* (PSW1) from their own language, such as peer support workers or service users:

*"it's quite a, an intellectual business that we work in [which] respect[s] intellectual insights [...] the pressure that I see peer support workers in, in general, is, is blending in, when they might not have an educational background to communicate in ways in which other clinicians respect. Because [...] in meetings and things like that [...] sometimes they feel it's somewhat of 'who's going to make the most intellectual point here?'" (PSW1)*

### 3.3. System orientation towards certainty and practicality

Working with psychosis was often considered complex, multifaceted, and uncertain for professionals. The capacity of clinicians to tolerate this, and find the space to engage with meaning-making, related to the orientation of the system towards or away from certainty and practicality:



*“we’d like to think it [psychosis] is really precise, like it’s the system that operates as if it is like a precise label, this is what you have. But I don’t think that it’s that precise really” (Social worker)*

### **3.3.1. Teams as decision-makers**

The shift towards certainty within the mental health system was exemplified by the need for teams to function as decision-makers. Service and funding structures, which required service users to meet specific criteria, often necessitated this:

*“We have to make a decision in two weeks because of the waiting time standard so you didn’t have the time to maybe meet that person a few times to make that decision” (Nurse 1)*

This pulled system thinking away from plurality towards making simple distinctions or decisions about whether a person does or does not have psychosis:

*“I sit down and I’m like is this psychosis or is it not psychosis and you’re like dividing everything into two categories” (Social worker)*

Person-centred thinking and discussion within teams could still be orientated towards a decisive conclusion, moving the focus onto practical outcomes of a service user’s care:

*“there’ll be like a big beautiful, nuanced discussion in an MDT and then someone at the end has to say, okay well what are we going to do, and how*

*are we going to record what we are going to do. And that probably requires putting the hat back on” (Social Worker)*

### **3.3.2. Difficulty tolerating uncertainty**

The need for decision-making and certainty within the broader mental health system permeated through team cultures and into the practice and approach of individual professionals. As such, the pull towards conceptual certainty within the system was reflected at the professional level, where clinicians could struggle with uncertainty in their clinical work. Particular contexts, such as emotional and psychological demands, could further a clinician’s intolerance of uncertainty and shift their practice towards certainty and decisiveness:

*“the more confident I feel in a piece of work with someone, or kind of thinking about a particular person, the more I’m likely to be able to, to like tolerate the muddiness of it as a concept. I think when I’m finding working with someone really difficult I definitely notice internally that I’m more inclined to think of this as an issue that someone does or doesn’t have”*  
(CP3)

*“when people feel fearful they often become a lot more reactive in their decision-making and there isn’t always so much time and space to just pause and reflect...It leads to kind of a, an agenda being imposed as a way to try and obtain certainty”* (CP2)

## **3.4. Risk management**

Risk management took precedence across the system and was highlighted as a key part of professionals' clinical work. The presence of risk, such as during a person's mental health crisis, had the systemic effect of 'trumping' and pulling attention away from other elements of practice. This could mean that service users who were not 'risky' were deprioritised, person-centred aspects of care were limited, and team reflective spaces were not attended:

*"when you're at the crisis side it feels like maybe there isn't the space to do that when someone's not very safe" (social worker)*

*"we have a reflective space once a week, and [...] I stop going to them when things get under pressure for me and that's probably when I need to go to them the most" (Social worker)*

Instances of risk management often aligned with more restrictive ways of thinking about and intervening with service users, such that *"in crisis there's much more [...] restrictive measures"* (Nurse 1). There would include a reduced focus on a service user's perspective, with the balance tipping in favour of professional and system expertise:

*"we obviously take everything that the person's saying into consideration but [...] it all depends on what the level of risk is at the time" (Nurse 1)*

Several professionals expressed their personal discomfort working within a coercive structure which enables service user detention, highlighting the pressure that this exerts upon trusting therapeutic relationships.

### 3.5. Processes

Administrative and managerial duties, such as documentation and paperwork, often dominated professional workload and conflicted with what clinicians considered to be the person-centred aspects of their work:

*“I don’t like all the kind of tick-boxy kinda stuff” (support worker)*

*“meeting those requirements within the system, they mean that you don’t have the time or the space to have these kinds of conversations with clients”  
(social worker)*

Tasks imposed by the system with the original intention of ‘care’ would often become systematised, meaning authenticity would be lost and the task subsumed into another ‘tick box’ process:

*“the stuff that’s in this document can come up more organically in a conversation without presenting this person with a wad of paperwork which makes it feel very depersonalised and a process” (OT)*

Professionals could feel pressurised to prioritise this work through performance reminders, targets, and a culture of fear around ‘Serious Incidents’ relating to service user safety:

*“constant emails [...] are circulated directly to people about their caseloads, the processes that need to be followed and done” (OT)*

*“if you have a [...] serious incident [...] and you’ve not done the right amount of up-to-date notes then you’ll get interviewed and questioned about that”*  
(Nurse3)

### **3.6. Time and capacity**

Professionals’ ability to engage in meaning-making was impacted by their time capacity amidst competing demands. Services were often “*massively overstretched*” (CP1), with professionals holding large caseloads. Care-coordinators in particular were only able to offer limited time to service users:

*“when you’re a care coordinator you’ve got so many other things going on, you’re just onto the next”* (Nurse1)

*“smaller caseloads [...] would then give people more time, and with more time you can do therapeutic work with people rather than just checking in with them”* (OT)

Even those who demonstrated an interest and capacity to engage in deeper person-centred work were often unable to:

*“when you do catch care-coordinators and you’re able to have a bit of time to talk to them, very often they are really thoughtful about the clients. I just think they almost like don’t have time to put that into action, or it doesn’t fit with the nature of their job”* (CP3)

Professionals who sustained person-centred thinking and practice in their work drew on their own motivation and creativity in “*creating those opportunities*” (OT) amidst all other demands. These often comprised informal ‘micro-moments’ within clinical practice:

*“even if it takes 5 minutes [...] just having the ongoing conversation with myself and with others has allowed me to maintain and keep that sense of perspective [...] to think, okay what is going on for them, what is it like to be in their shoes, what is it like to be with them, how is it to experience life as they do” (Nurse2)*

## **Discussion**

The paper suggests a stance, position, and process through which mental health professionals may engage service users in collaborative meaning-making around the experience of psychosis. A proposed journey of meaning-making has been laid out, starting with establishing readiness, before moving to the exploration of both service user and professional perspectives, and bringing these together within an iterative process of co-construction. This ultimately comprises of the mutual, respectful and gentle exploration of the meaning of psychosis with a person, embedded within a trusting therapeutic relationship (Geekie & Read, 2009). This illuminates desired types of clinical encounter that may best foster meaning-making, as well as the broader personal, professional, team and system factors which facilitate it. Overall, the findings mirror existing literature that the EIP clinical encounter is an important site for meaning-making in psychosis (Larsen, 2004).

Gillett (2012) writes of needing a “guide...who forms a partnership with you and who empowers you to play your part” (p. 249). The present findings speak to the particular skills, knowledge and positions that a mental health professional can employ in taking on the role of ‘guide’. Professionals’ awareness of a plurality of perspectives on psychosis, alongside their ability to remain open to the explanatory capacity of many of these perspectives, was a necessary foundation. This knowledge included awareness of perspectives from their own clinical training, as well as those from their own personal and cultural contexts, from spiritual and magical frameworks, spanning a diversity of reading, exploration and experience. Professionals having access to a broad range of perspectives and narratives - such as ‘hearing voices’, ‘thought disorder’ or ‘kundalini’ – became the blueprints through which a service user could be supported to make sense of their experiences within the clinical encounter (Rashed, 2020). This involved professionals being able to establish a shared language service users, without that always being the language of the organisation.

This process requires professionals to ‘give up’ the explanatory power they are afforded within the clinical encounter and ‘level the field’. This involves a shift where professionals acknowledge that multiple perspectives can be valid and useful ways of conceptualising the experience and give equal credence to the service user’s explanations (Read, 2020). Previous literature has also expressed the need for professionals to exhibit and validate an awareness of plurality as a precondition for meaning-making (Geekie & Read, 2009; Roe & Davidson, 2005). In the present study, this positioning was theorised to enable a conversation where service users could compose and share their own narratives, without having a perspective imposed upon them. When the professional perspective can be held more lightly, it is more usefully integrated with the meanings that are brought by the service user.

The acknowledgement of diverse views provided the foundation upon which differences across the system could be effectively communicated (Roe & Davidson, 2005). Professionals needed to both recognise perspectives as ‘one among many’ and be able to communicate

within and between them. This included having knowledge of the workings and language of the mental health system and drawing on skills of translation and scaffolding to empower and inform service users (Gillet, 2012). Within the clinical encounter, this could include professionals actively naming and explaining to service users the different perspectives and approaches held by clinicians in the team and system. When these perspectives were less accessible to service users and existed outside of their world, such as more clinical language in some cases, professionals needed to be able to translate these into language and concepts which were understandable and meaningful to the service user. This process would support service users to recognise the plurality of perspectives across the system, to hold certain professional and organisational concepts more lightly, and ultimately enable them to develop their own skills and confidence to navigate this system of meanings. This orientation embeds collaboration, respect and partnership within the clinical encounter, mirroring the principles of the recovery model (Forgione, 2019). The CHIME values of Connectedness, Hope, Identity, Meaning and Empowerment (Brabben, 2017; Deegan, 1996) are well aligned with principles of effective meaning-making proposed in this paper: listening, taking a non-expert position, exploring the person's perspective, and giving up power.<sup>3</sup>

Equally, professionals needed to be able to translate the range of meanings from a service user's cultural repertoire to other professionals in the system, such as other EIP clinicians, crisis teams, wards, or commissioners. This form of translation was the process through which meaning established within the clinical encounter was transmitted out into the wider organisation. By transforming these meanings into language that was acceptable to those in

---

<sup>3</sup> While this paper has so far theorised that the empowered position of clinicians means they should take responsibility for positionality, engagement and power-sharing (Tranulis et al., 2008), this should not undermine the skills, knowledge and capacities that service users bring to the clinical encounter. Meaning-making is an interpersonal process and the literature which is focused on service users better represents the mastery and skills through which they actively negotiate explanatory frameworks and challenge the meanings brought by professionals (e.g. Larsen, 2004; Jones et al, 2016).



the system, it was more likely they would be heard and acted upon. While this process of translation appears an essential skill for professionals working in organisations that rely on clinical language and concepts, this does not preclude teams from learning and practicing to speak about service users in markedly different ways. Professional education courses with this focus may enable new forms of clinical thinking and practice which prioritise the meanings of service users (Newman et al., 2019).

The findings suggest the journey by which meaning can be co-constructed within the clinical encounter, comprising of assessing readiness, exploring service users' perspectives, sharing professional knowledge, and bringing aspects from both sides together. This requires professionals to strike the balance between respect for the service user's own meanings and their own clinical judgement and knowledge (Power & McGorry, 1999), including of what may be helpful or harmful. Indeed, deep exploration can only begin if a service user is assessed as being ready and available to it. In contexts where acute experiences of psychosis impede engagement, the priority may be for the person to regain their basic cognitive and psychological functions (Rashed, 2020). Simultaneously, caution must be taken so that individuals who are more avoidant of exploration and meaning-making are not neglected, particularly as they may be less able to express distress readily (Gumley & Clark, 2012).

One key aspect of co-construction was the professional sharing of information with the service user. In previous studies 'psychoeducation' has also served to support a greater understanding of experiences (Larsen, 2007), with service users suggesting that receiving information is the most highly valued treatment preference (Byrne & Morison, 2014). While 'normalising', evidence-based psychoeducation from a clinical perspective can be helpful to many service users, this is not the case for all (Larsen, 2004). This cements the need for the explication of plurality and checking understanding alongside a service user's own

developing framework. Indeed, in Kilkku et al.'s (2003) study, psychoeducation was best received when based on the service user's own experiences and understanding.

Although proposing a process of co-construction, this paper does not comment on what type of meaning could or should be made. Previous studies provide a helpful reminder about the multiplicity and intersectional complexity of service user understandings (Carter et al., 2018; Friesen et al., 2021; Jones et al., Larsen, 2004; 2016; Roe et al., 2008) highlighting that the end 'result' of shared meaning-construction does not need to be singular, unitary or fully coherent. Jones et al.'s (2016) point that "No single explanation need be endorsed and conversely, no possibility definitively foreclosed" (496) captures the importance of the position of plurality and a willingness to broaden and expand perspectives rather than closing them down. Moreover, this process of exploration may also include consideration of what each perspective (or combination of perspectives) may offer or limit for a person (Macnaughton et al., 2015), including any 'paradoxical' impacts (Lysaker et al. 2007) where there are both gains and losses.

A number of professional, team and system factors were highlighted in the findings which impacted the availability of the plurality of perspectives within the clinical encounter. The findings also highlighted a range of factors which determined which perspectives were shared, included, hidden, or ignored. Of primary importance was role construction, which captured the boundaries, limits and possibilities of a professional's role, including their skills, knowledge, confidence, interests and orientation. The interpretation and enactment of an organisational role has been explored within the sociological literature on 'role theory' (Fitzgerald et al., 2006), influenced by the interactions and expectations of the role holder and other colleagues in the system. As in the present findings, professional roles are constructed in comparison to 'others', including both professionals and service users (Leishman, 2004). The discursive literature highlights how this is reified through social interaction, with

perceptions, practices and the scope of the role arising in dialogue with others (Zeeman & Simons, 2011). Moreover, this happens within sociohistorical, political and discursive contexts, where broader narratives impact this construction (Zeeman & Simons, 2011). Indeed, the way that healthcare professionals understood and enacted their role was influenced by portrayals of professionalism within the wider cultural psyche, comprising of particular codes of behaviour, character and practice (Evetts, 2011). This impacted whether clinicians felt able to practice in particular ways, such as bringing personal perspectives into their professional role. Such professional neutrality has been noted elsewhere (Ljunberg et al., 2017). Given the limitations of constructing and enacting the role of 'professional', clinicians may benefit from access to broader understandings of what it means to be a professional. In Laugharne et al.'s (2011) study, service users with psychosis valued professionals bringing 'the personal touch' to relationships, including personal disclosure about their own lives.

Lack of confidence was central to clinicians' resistance to engage in particular aspects of the work. This included avoidance of exploring and talking about aspects of service user experiences and feeling unable to hold or express alternative perspectives within their team. Having limited confidence to share perspectives within certain team cultures reflected the interrelated personal and structural influences that kept certain perspectives hidden and therefore limited capacity for meaning-making. Equally, professionals could be reticent to explore service user experiences when lacking confidence in that domain, such as trauma and adversity, faith, or cultural understandings. This mirrors findings in previous studies, where professionals lacked the confidence to engage in meaning-making conversations (Bogen-Johnston et al., 2020; Coffey & Hewitt, 2008; McMullan et al., 2018), most commonly around spirituality (Carter et al., 2017; Cooke & Brett, 2019; Larsen, 2004). As a perceived lack of skills can feed into low confidence (Coffey & Hewitt, 2008), additional training in

relevant areas may be beneficial, particularly for professionals where this is absent in their clinical training or personal experience.

Beyond factors relating to role construction, team factors also impacted the capacity for perspectives to be shared and heard within clinical spaces. In this paper, team cultures fostered greater psychological safety and openness to multiple perspectives, which enabled professionals to bring new or potentially challenging perspectives into teams. These aligned with flattened hierarchies and democratic leadership (O'Donovan et al., 2021; Smart et al., 2019), fostering openness to hearing from multiple voices from within the team. These findings mirror previous literature, where psychological safety enabled healthcare professionals to take engage in open communication, share information and voice concerns (Nembhard & Edmondson, 2006; Pearsall & Ellies, 2011). This improved team creativity (Kessel et al., 2012) and enabled them to adapt to changes in knowledge and practice (Nembhard & Edmondson, 2006). Teams which exhibited aggression or defensiveness towards alternative perspectives left clinicians feeling unable to share and maintained the cultural status quo. Indeed, in previous research, professionals feeling silenced made them reluctant to share (Attree, 2007; O'Donovan et al., 2021).

The present findings speak to the importance of creating cohesive, psychologically safe and open-minded team cultures where many voices are welcomed and heard. Previous research has highlighted the influence of leadership, safety, collaboration and interdisciplinary relationships on team culture within organisations (Jung et al, 2009), which in turn impact upon the construction and practice of professional roles (Fitzgerald et al., 2006). However, it is important to recognise that even where team cultures are mostly comprised of these features and therefore often positioned towards the left of the model (Figure 3), certain contexts or situations can pull the system, team and workers towards the right. For example, a risk incident may impact across multiple factors and axes, increasing the pressure to seek

certainty, greater pragmatism, stress, and use of clinical language, while reducing time, team thinking space, and openness to new ideas. This speaks to the fluid and interrelated dynamics of the model and reflecting that professionals, teams and systems are never in stasis. While teams may develop unique ways to recover from pulls to the right and re-establish safety, plurality and person-centred practice, this paper suggests that supervision, reflective practice and debriefing spaces may be useful safeguards.

By comparison, some systems and teams may sit more towards the right in general (Figure 3). Under such conditions, it is still possible for individual professionals to create opportunities to do meaning-making work. While the team and system may be less facilitating, individuals were shown to create 'micro-moments' amidst their many other demands. This demonstrates that clinicians' positions are also not fixed, nor fully dictated by the limits imposed by their team or system. Importantly, this suggests that individual professionals should feel empowered to find opportunities for person-centred practice, even within contexts where it may seem restricting. Moreover, team dynamics were influenced by the individual practices and stances of members. This highlights the value of professionals holding and engaging with alternative perspectives and practices, with the possibility that this may positively influence the practices of their colleagues and the wider team culture.

A number of further team and system factors identified in this study have been written about elsewhere, including the limitations of time capacity (Zeeman & Simons, 2011); administrative and managerial duties (Coffey & Hewitt, 2008); the use of clinical language (Barker and Buchanan-Barker, 2006; Hamilton & Manias, 2006; Kemp and Howard, 2017); team power and hierarchy (Smart et al., 2019; Walton, 2006); uncertainty (Geekie & Read, 2009); practicality (Zeeman & Simons, 2011); and risk-management (Rose, 2005). In the present study, interactions of these factors influenced professionals' role construction and could either limit or facilitate meaning-making in the clinical encounter. Previous studies mirror our

findings that entrenched hierarchies within mental health teams (Smart et al., 2019) play into the power of psychiatry (Nancarrow & Borthwick, 2005) and can exclude service user and peer perspectives (Walton, 2006). The findings also have implications for EI services in tolerating uncertainty. While conceptual certainty and focusing on practical tasks served functions for professionals in managing stress at times, this had a detrimental impact on meaning-making and person-centred practice. This is mirrored within the sociological literature on bureaucracy, which highlights the management of uncertainty in public organisations through standardisation and hierarchical control (Raaphorst, 2019). Mirroring mental health professionals in the present study, sociological research shows that workers employ strategies of simplification and stereotyping to cope with limited resources and work pressure (Raaphorst & Groeneveld, 2018). Geekie & Read (2009) also comment on the need for tolerating uncertainty within clinical spaces, arguing that certainty may rely on unfounded professional confidence that a particular definition or intervention will ‘work’. Indeed, this may be a more realistic and plural way of interpreting the evidence base, recognising the multiplicity of valid explanations and the challenge of reducing this down to a single model.

The use of clinical language within teams and across the mental health system described here is also reflected in the broader literature. As in previous studies, the words used in interviews reflected a clinical, medicalised discourse employed by professionals (Hamilton & Manias, 2006). Although professional proficiency in translation and communication of meaning were central in our findings, capturing the need for professionals to work within and across varied clinical and non-clinical discourses, challenges and limitations with clinical language remain. Primarily, there are issues of exclusion, where using clinical discourses with certain groups may be oppressive and disabling (Sewell, 2018; Zeeman & Simons, 2011). As highlighted in these findings, such professional-technical language can disadvantage those without a formal clinical training background (Barker and Buchanan-Barker, 2006; Kemp and Howard, 2017). Even kept solely within the professional field, clinical language constructs

and maintains particular roles and practices which may be limiting for both professionals and service users (Ringer & Holen, 2016; Zeeman & Simons, 2011).

#### **4.1. Clinical implications**

Many clinical implications have already been discussed above. These include the need for broader definitions of ‘professional’; greater diversity in professional backgrounds and perspectives; more thoughtful or ‘marked’ use of clinical language with service users; flattened team hierarchies and power sharing; greater psychological safety; greater access to team-thinking and reflective spaces; and team-training which focuses specifically on service user perspectives, including cultural and spiritual understandings. Beyond this, it is suggested that the model (Figure 1) has a more direct clinical utility. Professionals in EIP services may be able to use the diagram as an orientating ‘map’ to explore progress with meaning-making in the clinical encounter. This may be a flexible step-by-step guide, indicating the optimum stance and process of co-constructing meaning with a service user. The map may also assist professionals to consider points where they are veering away from co-construction and exploring possible explanations for why a service user may be disengaging from the process. For instance, a clinician might notice having become stuck at an early- or mid-stage of the journey with a service user and identify this as a moment to seek support. In this respect, the model can be a prompt for when to discuss a situation in a team formulation or reflective space.

#### **4.2. Limitations**

While the present study has produced a model that may have clinical utility, this needs to be further explored and validated in the practice of EIP professionals and teams. As the study is

rooted within the constructivist paradigm of grounded theory, it is acknowledged that the findings represent one particular construction of the data.

As participants were self-selecting, the results may be biased towards clinicians with a particular interest or orientation towards the topic of meaning-making. Furthermore, social or professional desirability bias may have influenced participants' responses in interview. This may have biased the data towards more idealised accounts of meaning-making in clinical practice.

Service users were not participants in the study, meaning that their perspective of the process and challenges of meaning-making in the clinical encounter are not accounted for in the findings. While the focus on clinicians enabled an understanding of the professional and systemic factors which influence the meaning-making process, the factors which impact the service user perspective have not been captured. A more complete understanding of the meaning-making process during the clinical encounter will be possible with further research exploring the service user perspective. Furthermore, clinicians' perspectives of their service users' understandings presented in the findings were not confirmed by the service users themselves. Studies which include the perspectives of both professional and service user simultaneously are limited, and further research of this type is recommended. The issue of service user participation is explored in greater depth in the critical appraisal (pp.183-184).

The study had reasonable diversity across professional groups, experience, and positions within teams. The gender imbalance in the sample is broadly representative of the wider NHS workforce, where around 77% are women (NHS England, 2021). However, there were greater challenges in recruiting an ethnically and culturally diverse sample. While active attempts were made to recruit a more ethnically diverse sample in the study, these were ineffective. Researchers are often unsuccessful in recruiting from diverse populations (McClellan &



Campbell, 2003; Williams et al., 2013). This reflects broader issues with existing research paradigms and recruitment processes which can exclude marginalised groups (Williams, et al., 2013) and risks perpetuating power imbalances and inequalities within research (Rugkåsa & Canvin, 2011). In this study, the use of adverts for recruitment may have been a limiting factor as such recruitment strategies can be more effective for recruiting White British people (McClean & Campbell, 2003) and less effective for ethnic minorities (Eide & Allen, 2005). Exploring more flexible and culturally-sensitive methods of recruitment may have improved access to ethnic minority professionals (Rugkåsa & Canvin, 2011), such as forming face-to-face relationships with participants (Eide & Allen, 2005) and recruiting via organisational or interpersonal contacts (McClean & Campbell, 2003).

The lack of representation likely limits the explanatory richness of the study in this domain. This is especially true given that the ethnically under-representative sample still highlighted the significance of cultural explanations and perspectives on meaning-making, and the negative impact of poor representation within EIP teams. Since clinicians from minoritised ethnic and cultural backgrounds demonstrated awareness and confidence to discuss cultural meanings in the findings, a more ethnically diverse sample would likely have provided greater insight into the experiences of both professionals and service users in engaging with cultural meanings. The lack of Black clinicians recruited to the study must be noted, particularly given the over-representation of Black service users in psychosis services (Moffat et al., 2009). Future studies should specifically aim to include and explore the approaches of Black and minority ethnic staff as they engage with service users' meanings in the clinical encounter.

## **Conclusion**

This study proposes the process of meaning-making within the EIP clinical encounter, suggesting that a journey of co-construction between both a service user and a professional can result in the emergence of a meaningful narrative. The findings place the onus on professionals to occupy power-sharing positions within this process, by inviting service users to explore and express their own meanings within the clinical encounter. These meanings can be complemented by information and knowledge from the professional perspective. Conversely, routes to non-collaborative engagement, such as practices which neglected service user perspectives and imposed professional meanings were identified as less helpful. Giving context to this clinical encounter, the study highlighted particular factors which facilitated meaning-making. These spanned personal-professional characteristics and interests, the cultures and approaches of particular EIP teams, and the demands of the wider mental health system. Professional awareness of the plurality of perspectives on psychosis and applied skills in communication between and within perspectives across the system were found to be central to effective meaning-making. This suggests the need for training programmes in diverse meanings and understandings for professional groups, spanning those of lived experience, spirituality and culture. While clinicians' personal experiences and interests such as their spirituality, cultural knowledge or lived experience of psychosis could shape their professional identities and practices, they often felt unable to openly share and apply these within a clinical context. Broader conceptualisations of professional roles and practices within EIP teams will further facilitate the presence and acceptance of varied meanings. Furthermore, this study suggests that team cultures can facilitate greater openness to alternative perspectives through diversity in recruitment; flattened hierarchies; respect for varied contributions; supportive interpersonal relationships; access to reflective team thinking spaces; and incorporation of peer support workers. Demands of the broader mental health system were shown to reduce professional capacity and interest in meaning-making, with a focus on risk management, certainty and practicality, and excessive administrative and managerial duties. Despite this, the study encourages professionals to

feel empowered to engage in meaning-making, finding 'micro-moments' amidst other competing demands and recognising the positive influence this can have in shaping the practice of colleagues and the culture of their teams.

## References

- Abma, T., Groot, B., & Widdershoven, G. (2019). The ethics of public and service user involvement in health research: The need for participatory reflection on everyday ethical issues. *The American Journal of Bioethics*, 19(8), 23-25.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37(5), 586-594.
- Attree, M. (2007). Factors influencing nurses' decisions to raise concerns about care quality. *Journal of nursing management*, 15(4), 392-402.
- Barker P, Buchanan-Barker P. (2006) Post-psychiatry: good ideas, bad language and getting out of the box. *Journal of Psychiatric and Mental Health Nursing*, 13(5), 619-25.
- Bell, V. (2017). Why we need to get better at critiquing psychiatric diagnosis. *Mind Hacks*. Retrieved from: <https://mindhacks.com/2017/09/19/why-we-need-to-get-better-at-critiquing-diagnosis/>
- Bentall, R. (2003). *Madness Explained: Psychosis and Human Nature*. London: Penguin Psychology.
- Berkhout, S. G., Zaheer, J., & Remington, G. (2019). Identity, subjectivity, and disorders of self in psychosis. *Culture, Medicine, and Psychiatry*, 43(3), 442-467.
- Bogen-Johnston, L., deVisser, R., Strauss, C., & Hayward, M. (2020). A qualitative study exploring how Practitioners within Early Intervention in Psychosis Services engage with

- Service Users' experiences of voice hearing?. *Journal of Psychiatric and Mental Health Nursing*, 27(5), 607-615.
- Boydell, K. M., Stasiulis, E., Volpe, T., & Gladstone, B. (2010). A descriptive review of qualitative studies in first episode psychosis. *Early intervention in psychiatry*, 4(1), 7-24.
- Boyle, M. (2012). *Schizophrenia: A Scientific Delusion?* (2<sup>nd</sup> Ed). New York: Routledge Press.
- Brabban, A., Byrne, R., Longden, E., & Morrison, A. P. (2017). The importance of human relationships, ethics and recovery-orientated values in the delivery of CBT for people with psychosis. *Psychosis*, 9(2), 157-166.
- Byrne, R., & Morrison, A. P. (2013). Young people at risk of psychosis: Their subjective experiences of monitoring and cognitive behaviour therapy in the early detection and intervention evaluation 2 trial. *Psychology and Psychotherapy: Theory, Research and Practice*, 87, 357-371
- Campbell, P. (2021, Spring) The Survivor Movement in the 1990s: Collaboration and Change. *Asylum: The Magazine for Democratic Psychiatry*, 28(1), 22-24
- Campbell, P., & Rose, D. (2011). Action for change in the UK: Thirty years of the user/survivor movement. *The SAGE Handbook of Mental Health and Illness*, 452-470.
- Carter, L., Read, J., Pyle, M., & Morrison, A. (2017). "I Believe I Know Better Even than the Psychiatrists What Caused It": Exploring the Development of Causal Beliefs in People Experiencing Psychosis. *Community Mental Health Journal*, 54(6), 805-813.
- Castillo, R. (2003). Trance and functional psychosis. *Psychiatry*, 66(1), pp. 9-21.
- Chadwick, P., Birchwood, M., & Trower, P. (1996). *Cognitive therapy for delusions, voices and paranoia*. Chichester, United Kingdom: John Wiley & Sons.

- Charmaz, K. (2014). *Constructing Grounded Theory*. London: SAGE.
- Charmaz, K. (2017). The power of constructivist grounded theory for critical inquiry. *Qualitative inquiry*, 23(1), 34-45.
- Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative research in psychology*, 18(3), 305-327.
- Christmas, D. M., & Sweeney, A. (2016). Service user, patient, survivor or client... has the time come to return to 'patient'? *The British Journal of Psychiatry*, 209(1), 9-13.
- Clarke, A. (2005). *Situational Analysis: Grounded Theory after the Postmodern Turn*. London: SAGE.
- Coffey, M., & Hewitt, J. (2008). 'You don't talk about the voices': Voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing*, 17(12), 1591-1600.
- Colombo, A., Bendelow, G., Fulford, B., & Williams, S. (2003). Evaluating the influence of implicit models of mental disorder on processes of shared decision making within community-based multi-disciplinary teams. *Social Science and Medicine*, 56, 1557-1570.
- Cooke, A. (Ed.). (2014). *Understanding psychosis and schizophrenia: Why people sometimes hear voices, believe things that others find strange, or appear out of touch with reality, and what can help*. BPS Division of Clinical Psychology. Leicester, England: British Psychological Society. Retrieved from <https://www.bps.org.uk/sites/www.bps.org.uk/files/Page%20-%20Files/Understanding%20Psychosis%20and%20Schizophrenia.pdf>

- Cooke, A., & Brett, C. (2020). Clinical psychologists' use of transformative models of psychosis. *Clinical Psychology & Psychotherapy*, 27(1), 87-96.
- Cooke, A., & Kinderman, P. (2018). But what about real mental illnesses?" Alternatives to the disease model approach to "schizophrenia. *Journal of Humanistic Psychology*, 58(1), 47-71.
- Corin, E. (1998). The thickness of being: Intentional worlds, strategies of identity, and experience among schizophrenics. *Psychiatry*, 61(2), 133-146.
- Dillon, J. (2012). Recovery from 'psychosis.' In J. Geekie, Randall, Lampshire & Read (Eds.), *Experiencing Psychosis: personal and professional perspectives* (pp. 17-22). East Sussex: Routledge Press.
- Deegan, P. E. (1996). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19(3), 91-97.
- Dudley, R., Siitarinen, J., James, I., & Dodgson, G. (2009). What do people with psychosis think caused their psychosis? AQ methodology study. *Behavioural and Cognitive Psychotherapy*, 37(1), 11-24
- Eide, P., & Allen, C. B. (2005). Recruiting transcultural qualitative research participants: A conceptual model. *International Journal of Qualitative Methods*, 4(2), 44-56.
- Evetts, J. (2011). Sociological analysis of professionalism: Past, present and future. *Comparative Sociology*, 10 (1), 1-37.
- Faulkner, A., & Thomas, P. (2002). User-led research and evidence-based medicine. *The British Journal of Psychiatry*, 180(1), 1-3.

- Fitzgerald, L., Cerian, L., Ferlie, E., Addicot, R., McGiven, R., Buchanan, D. (2006). *Managing Change and Role Enactment in the Professionalised Organisation*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation (NCCSDO). London: NCCSDO
- Forgione, F. A. (2019). Diagnostic dissent: Experiences of perceived misdiagnosis and stigma in persons diagnosed with schizophrenia. *Journal of Humanistic Psychology*, 59(1), 69-98.
- Freeman, D., Garety, P. A., Kuipers, E., Fowler, D., & Bebbington, P. E. (2002). A cognitive model of persecutory delusions. *British Journal of Clinical Psychology*, 41(4), 331-347.
- Friesen, P., Goldstein, J., & Dixon, L. (2021). A “blip in the road”: experiences of identity after a first episode of psychosis. *Psychosis*, 1-11.
- Garety, P. A., & Freeman, D. (2013). The past and future of delusions research: From the inexplicable to the treatable. *British Journal of Psychiatry*, 203, 327-333. doi:10.1192/bjp.bp.113.126953.
- Geekie, J., & Read, J. (2009). *Making sense of madness: Contesting the meaning of schizophrenia*. Routledge: East Sussex
- Gilfoyle, S. A. (2017). Mind your language!. *Mental Health and Social Inclusion*, 21(1), 47-52.
- Gillett, G. (2012). How do I learn to be me again? Autonomy, life skills, and identity. In Radoilska, L., (Ed), *Autonomy and Mental Disorder*. Oxford, United Kingdom: Oxford University Press, pp. 233–51.
- Glasby, J., & Beresford, P. (2006). Commentary and issues: Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy*, 26(1), 268-284.



- Glaser, B. and Strauss, A. (1967) *The discovery of grounded theory*. Chicago, IL: Aldine.
- Gumley, A., & Clark, S. (2012). Risk of arrested recovery following first episode psychosis: An integrative approach to psychotherapy. *Journal of Psychotherapy Integration*, 22(4), 298.
- Haigh, M., Kapur, N. & Cooper, J. (2014). Suicidal behavior among ethnic minorities in England. In D.D. van Bergen, A.H. Montesinos & M. Schouler-Ocak (Eds.) *Suicidal behavior of immigrants and ethnic minorities in Europe* (pp. 45-60). Boston, MA: Hogrefe
- Hart, A. (2018). Pursuing Choice not Truth: debates around diagnosis in mental health, *Asylum: The Magazine for Democratic Psychiatry*, 25 (3) 19–21.
- Health and Social Care Information Centre. (2013). NHS workforce, summary of staff in the NHS: Results from September 2012 census.
- Islam, Z., Rabiee, F., & Singh, S. P. (2015). Black and minority ethnic groups' perception and experience of early intervention in psychosis services in the United Kingdom. *Journal of Cross-Cultural Psychology*, 46(5), 737-753.
- Jones, N., Kelly, T., & Shattell, M. (2016). God in the brain: Experiencing psychosis in the postsecular United States. *Transcultural Psychiatry*, 53(4), 488-505.
- Jones, N., & Shattell, M. (2016). Not what the textbooks describe: Challenging clinical conventions about psychosis. *Issues in Mental Health Nursing*, 37(10), 769-772.

- Jung T, Scott T, Davies H, Bower P, Whalley D, McNally R, Mannion R: Instruments for exploring organisational culture: a review of the literature. *Public Administration Review*. 2009, 69 (6): 1087-1096. 10.1111/j.1540-6210.2009.02066.x.
- Kilkku, N., Munnukka, T., & Lehtinen, K. (2003). From information to knowledge: the meaning of information-giving to patients who had experienced first-episode psychosis. *Journal of psychiatric and mental health nursing*, 10(1), 57-64.
- Kinderman, P., Setzu, E., Lobban, F., & Salmon, P. (2006). Illness beliefs in schizophrenia. *Social Science & Medicine*, 63(7), 1900–11.
- Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J., Murray, R. M., & Jones, P. B. (2012a). Incidence of Schizophrenia and Other Psychoses in England, 1950–2009: A Systematic Review and Meta- Analyses. *PLoS ONE*, 7(3), e31660
- Kemp, P., & Howard, M. (2017). Language use and recovery-oriented practice: a preliminary outline. *Mental Health Practice*, 20(8).
- Kessel, M., Kratzer, J., & Schultz, C. (2012). Psychological safety, knowledge sharing, and creative performance in healthcare teams. *Creativity and innovation management*, 21(2), 147-157.
- Larsen, J. 2004. Finding meaning in first episode psychosis: Experience, agency and the cultural repertoire. *Medical Anthropology Quarterly* 18(4), 447–71.
- Larsen, J. (2007). Understanding a complex intervention: Person-centred ethnography in early psychosis. *Journal of Mental Health*, 16(3), 333-345.

- Laugharne, R., Priebe, S., McCabe, R., Garland, N., & Clifford, D. (2012). Trust, choice and power in mental health care: Experiences of patients with psychosis. *International Journal of Social Psychiatry*, 58(5), 496-504.
- Leishman J.L. (2004) Talking the talk: a discourse analysis of mental health nurses talking about their practice. *The International Journal of Psychiatric Nursing Research* **10**, 1136– 1145.
- Lewis, B. (2014). Taking a narrative turn in psychiatry. *The Lancet*, 383(9911), 22-23.
- Ljungberg, A., Denhov, A., & Topor, A. (2017). A balancing act—how mental health professionals experience being personal in their relationships with service users. *Issues in mental health nursing*, 38(7), 578-583.
- Longden, E., D. Corstens, and J. Dillon. (2013). Recovery, discovery, and revolution: The work of intervoice and the hearing voices movements. In *Madness Contested: Power and Practice*, eds. S. Coles, S. Keenan, and B. Diamond, 161–80. PCCS Books: Herefordshire.
- Luhrmann, T. M., Alderson-Day, B., Bell, V., Bless, J. J., Corlett, P., Hugdahl, K., ... & Waters, F. (2019). Beyond trauma: A multiple pathways approach to auditory hallucinations in clinical and nonclinical populations. *Schizophrenia Bulletin*, 45(1), 24-31.
- Luhrmann, T. M., Padmavati, R., Tharoor, H., & Osei, A. (2015). Differences in voice-hearing experiences of people with psychosis in the USA, India and Ghana: interview-based study. *The British Journal of Psychiatry*, 206(1), 41-44.
- Lysaker, P. H., Buck, B., & Lysaker, J. T. (2012). Schizophrenia and alterations in the experience of self and agency: comparisons of dialogical and phenomenological views. *Theory & Psychology*, 22(6), 738-755.

- Lysaker, P. H., & Lysaker, J. T. (2002). Narrative structure in psychosis: Schizophrenia and disruptions in the dialogical self. *Theory & Psychology*, 12(2), 207-220.
- Lysaker, P. H., & Lysaker, J. T. (2010). Schizophrenia and alterations in self-experience: a comparison of 6 perspectives. *Schizophrenia bulletin*, 36(2), 331-340.
- Lysaker, P. H., Ringer, J., Maxwell, C., McGuire, A., & Lecomte, T. (2010). Personal narratives and recovery from schizophrenia. *Schizophrenia Research*, 121, 271-276
- Lysaker, P., Yanos, P. & Roe, D. (2009). The role of insight in the process of recovery from schizophrenia: a review of three views. *Psychosis: Psychological, Social & Integrative Approaches*, 1, 113-121.
- Macnaughton, E., Sheps, S., Frankish, J., & Irwin, D. (2015). Understanding the development of narrative insight in early psychosis: A qualitative approach. *Psychosis*, 7(4), 291-301.
- Mapplebeck, C., Joseph, S., & Sabin-Farrell, R. (2015). An interpretative phenomenological analysis of posttraumatic growth in people with psychosis. *Journal of Loss and Trauma*, 20(1), 34-45.
- Marriott, M. R., Thompson, A. R., Cockshutt, G., & Rowse, G. (2019). Narrative insight in psychosis: The relationship with spiritual and religious explanatory frameworks. *Psychology and Psychotherapy: Theory, Research and Practice*, 92(1), 74-90.
- Masterson, S., & Owen, S. (2006). Mental health service user's social and individual empowerment: Using theories of power to elucidate far-reaching strategies. *Journal of Mental Health*, 15(1), 19-34.

- May, R. (2003) *Understanding psychotic experience and working towards recovery*. Available online: [www.brad.ac.uk/acad/health/research/cccmh/articles.php](http://www.brad.ac.uk/acad/health/research/cccmh/articles.php)
- McGuire, N., Melville, C., Karadzhov, D., & Gumley, A. (2020). "She is more about my illness than me": A qualitative study exploring social support in individuals with experiences of psychosis. *12*(2), 128-138.
- McLean, C. A., & Campbell, C. M. (2003). Locating research informants in a multi-ethnic community: ethnic identities, social networks and recruitment methods. *Ethnicity and health*, 8(1), 41-61.
- McMullan, E., Gupta, A., & Collins, S. C. (2018). Experiences of mental health nursing staff working with voice hearers in an acute setting: An interpretive phenomenological approach. *Journal of psychiatric and mental health nursing*, 25(3), 157-166
- Menzies, R., LeFrançois, B. & Reaume G (2013) Introducing mad studies. In LeFrançois, B., Menzies, R. & Reaume, G. (Eds) *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholars' Press, 1-22.
- Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International journal of qualitative methods*, 5(1), 25-35
- Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural Differences in Psychosis: The Role of Causal Beliefs and Stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, 50(3), 441-459.
- Moffat, J., Sass, B., McKenzie, K., & Bhui, K. (2009). Improving pathways into mental health care for black and ethnic minority groups: a systematic review of the grey literature. *International Review of Psychiatry*, 21(5), 439-449.

- Morrison, A. P. (2001). The interpretation of intrusions in psychosis: an integrative cognitive approach to hallucinations and delusions. *Behavioural and cognitive psychotherapy*, 29(3), 257-276.
- Myers, N. A. L., & Ziv, T. (2016). “No One Ever Even Asked Me that Before”: Autobiographical Power, Social Defeat, and Recovery among African Americans with Lived Experiences of Psychosis. *Medical Anthropology Quarterly*, 30(3), 395-413.
- Nancarrow, S. A., & Borthwick, A. M. (2005). Dynamic professional boundaries in the healthcare workforce. *Sociology of Health and Illness*, 27(7), 897-919.
- Nelson, B., Parnas, J. & Sass, L.A. (2014). Disturbance of Minimal Self (Ipseity) in Schizophrenia: Clarification and Current Status. *Schizophrenia Bulletin*, 40(3), 479-482.
- Nembhard, I. M., & Edmondson, A. C. (2006). Making it safe: The effects of leader inclusiveness and professional status on psychological safety and improvement efforts in health care teams. *Journal of Organizational Behavior: The International Journal of Industrial, Occupational and Organizational Psychology and Behavior*, 27(7), 941-966.
- Newman, J., Boxall, K., Jury, R., & Dickinson, J. (2019). Professional education and Mad Studies: learning and teaching about service users’ understandings of mental and emotional distress. *Disability & Society*, 34(9-10), 1523-1547.
- NHS England. (2021, March 8). NHS celebrates the vital role hundreds of thousands of women have played in the pandemic. *NHS England*. Retrieved from: <https://www.england.nhs.uk/2021/03/nhs-celebrates-the-vital-role-hundreds-of-thousands-of-women-have-played-in-the-pandemic/>
- O'Donovan, R., De Brún, A., & McAuliffe, E. (2021). Healthcare professionals experience of psychological safety, voice, and silence. *Frontiers in Psychology*, 12, 626689.

- Papoulias, S. C., & Callard, F. (2022). Material and epistemic precarity: It's time to talk about labour exploitation in mental health research. *Social Science & Medicine*, 306, 115102.
- Pearsall, M. J., & Ellis, A. P. (2011). Thick as thieves: the effects of ethical orientation and psychological safety on unethical team behavior. *Journal of Applied Psychology*, 96(2), 401.
- Pidgeon, N. and Henwood, K. (1997) Using grounded theory in psychological research. In Hayes, N. (Ed.) *Doing qualitative analysis in psychology*. Hove, UK: Psychology Press.
- Pilgrim, D. (2002). The biopsychosocial model in Anglo-American psychiatry: Past, present and future?. *Journal of Mental Health*, 11(6), 585-594.
- Place, C., Foxcroft, R., & Shaw, J. (2011). Telling stories and hearing voices: Narrative work with voice hearers in acute care. *Journal of Psychiatric and Mental Health Nursing*, 18, 837–842. <https://doi.org/10.1111/j.1365-2850.2011.01787.x>
- Power, P. and McGorry, P. D. (1999) Initial assessment in first-episode psychosis. In McGorry, P. D. and Jackson, H. J. (eds) *The recognition and management of early psychosis: A preventative approach*. Cambridge: Cambridge University Press.
- Priebe, S. (2021). Patients in mental healthcare should be referred to as patients and not service users. *BJPsych Bulletin*, 45(6), 327-328.
- Raaphorst, N. (2019). Studying uncertainty in decision making by street-level inspectors. *Inspectors and enforcement at the front line of government*, 11-33.
- Raaphorst, N., & Groeneveld, S. (2018). Double standards in frontline decision making: A theoretical and empirical exploration. *Administration & Society*, 50(8), 1175-1201.

- Randal, P. and Argyle, N. (2005) 'Spiritual emergency': A useful explanatory model? A literature review and discussion paper. Spirituality and Psychiatry Special Interest Group of the Royal College of Psychiatrists: Publications Archive.
- Randal, P., Geekie, J., Lambrecht, I., & M. Taitimu. (2008). Dissociation, psychosis and spirituality: Whose voices are we hearing? In A. Moskowitz et al. (Eds.), *Psychosis, Trauma and Dissociation: Emerging perspectives on severe psychopathology* (pp. 319-331). West Sussex, United Kingdom: John Wiley & Sons, Ltd.
- Rashed, M. A. (2020). The identity of psychiatry and the challenge of Mad activism: Rethinking the clinical encounter. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine*. 45 (6), 598-622
- Recovery in the Bin, Edwards, B. M., Burgess, R., and Thomas, E. (2019, September). *Neorecovery: A survivor led conceptualisation and critique* [Transcript]. Keynote presented at the 25th International Mental Health Nursing Research Conference, The Royal College of Nursing, London, UK.
- Read, J. (2020). Bad things happen and can drive you crazy: The causal beliefs of 701 people taking antipsychotics. *Psychiatry Research*, 285, 1-37.
- Read, J., Os, J., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112(5), 330-350.
- Reaume, G. (2021). How is mad studies different from anti-psychiatry and critical psychiatry?. In *The Routledge International Handbook of Mad Studies* (pp. 98-107). Routledge.
- Redko, C. (2003). Religious Construction of a First Episode of Psychosis in Urban Brazil. *Transcultural Psychiatry*, 40(4), 507-530.



- Ringer, A., & Holen, M. (2016). "Hell no, they'll think you're mad as a hatter": Illness discourses and their implications for patients in mental health practice. *Health*, 20(2), 161-175.
- Ritunnano, R., Stanghellini, G., & Broome, M. R. (2021). Self-interpretation and meaning-making processes: re-humanizing research on early psychosis. *World psychiatry*, 20(2), 304.
- Roe, D. and Davidson, L. (2005) Self and narrative in schizophrenia: Time to author a new story. *Medical Humanities*, 31: 89–94.
- Roe, D., Hasson-Ohayon, I., Kravetz, S., Yanos, P. T., & Lysaker, P. H. (2008). Call it a monster for lack of anything else: narrative insight in psychosis. *The Journal of Nervous and Mental Disease*, 196(12), 859-72.
- Rose, N. (2005). In search of certainty: Risk management in a biological age. *Journal of public mental health*, 4(3), 14-22.
- Rosenthal Oren, R., Roe, D., Hasson-Ohayon, I., Roth, S., Thomas, E. C., & Zisman-Ilani, Y. (2021). Beliefs about the causes of psychosis among persons with psychosis and mental health professionals: a scoping review. *Psychiatric services*, 72(10), 1178-1192.
- Rugkåsa, J., & Canvin, K. (2011). Researching mental health in minority ethnic communities: reflections on recruitment. *Qualitative Health Research*, 21(1), 132-143.
- Salem, D. (2011). Voices from the ground up: The use of narrative in understanding recovery from serious mental illness. In M. S. Aber, K. I. Maton, E. Seidman (Eds.), *Empowering Settings and Voices for Social Change* (pp. 107-133). Oxford: Oxford University Press.
- Sass, L. A. (2014). Self-disturbance and schizophrenia: structure, specificity, pathogenesis (current issues, new directions). *Schizophrenia Research*, 152(1), 5-11.

- Sass, L. & Parnas, J. (2003) Schizophrenia, consciousness and the self. *Schizophrenia Bulletin*, 29(1), 427–444.
- Sips, R., Van Duppen, Z., Kasanova, Z., De Thurah, L., Teixeira, A., Feyaerts, J., & Myin-Germeys, I. (2021). Psychosis as a dialectic of aha-and anti-aha-experiences: a qualitative study. *Psychosis*, 13(1), 47-57.
- Slade, M., Blackie, L., & Longden, E. (2019). Personal growth in psychosis. *World Psychiatry*, 18(1), 29.
- Slade, M., & Sweeney, A. (2020). Rethinking the concept of insight. *World Psychiatry*, 19(3), 389-390
- Smart, C., Pollock, C., Aikman, L., & Willoughby, E. (2018). Power struggles in MDT meetings: Using different orders of interaction to understand the interplay of hierarchy, knowledge and accountability. In *Interprofessional Care and Mental Health: A Discursive Exploration of Team Meeting Practices* (pp. 97-121). Springer International Publishing.
- Staley, K., & Minogue, V. (2006). User involvement leads to more ethically sound research. *Clinical Ethics*, 1(2), 95-100.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded Theory Procedures and Techniques*. London: SAGE.
- Stovell, D., Wearden, A., Morrison, A. P., & Hutton, P. (2016). Service users' experiences of the treatment decision-making process in psychosis: A phenomenological analysis. *Psychosis*, 8(4), 311-323. <https://doi.org/10.1080/17522439.2016.1145730>
- Sewell, F. (2018). The language of psychiatric discourse: power and imbalance. *Mental Health Nursing*, 38(3).

- Thomas, G. (2009) *How To Do Your Research Project*, London: SAGE
- Thornhill, H., Clare, L. & May, R. (2004). Escape, enlightenment and endurance: Narratives of recovery from psychosis. *Anthropology and Medicine*, 11(2), 181-199.
- Tranulis, C., Corin, E., & Kirmayer, L. J. (2008). Insight and psychosis: comparing the perspectives of patient, entourage and clinician. *International Journal of Social Psychiatry*, 54(3), 225-241.
- Urquhart, C. (2013). *Grounded theory for qualitative research*. SAGE: London
- Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., Read, J., van Os, J., & Bentall, R. P. (2012). Childhood Adversities Increase the Risk of Psychosis: A Meta-analysis of Patient-Control, Prospective- and Cross-sectional Cohort Studies. *Schizophrenia Bulletin*, 38(4), 661–671. <https://doi.org/10.1093/schbul/sbs050>
- Walton, M. M. (2006). Hierarchies: the Berlin Wall of patient safety. *Quality and Safety in Health Care*, 15(4), 229–230.
- Werbart, A., & Levander, S. (2005). Understanding the incomprehensible: Private theories of first-episode psychotic patients and their therapists. *Bulletin of the Menninger Clinic*, 69(2), 103-136.
- Williams, M., Tellawi, G., Wetterneck, C. T., & Chapman, L. K. (2013). Recruitment of ethnoracial minorities for mental health research. *Drugs*, 67(2), 236-244.
- Woods, A. (2011). Memoir and the diagnosis of schizophrenia: reflections on the centre cannot hold, me, myself, and them, and the ‘crumbling twin pillars’ of Kraepelinian psychiatry. *Mental Health Review*, 16(3), 102–106.

Woods, A., Hart, A., & Spandler, H. (2022). The recovery narrative: politics and possibilities of a genre. *Culture, Medicine, and Psychiatry*, 1-27.

Zeeman, L., & Simons, L. (2011). An analysis of discourses shaping mental health practitioners. *Journal of Psychiatric and Mental Health Nursing*, 18(8), 712-720.

Zubin, J. and Spring, B. (1977) Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology*, 86: 103–126.

## **Part 3: Critical Appraisal**

In this critical reflection, I will consider key aspects and challenges of the research process relating to its methodology, spanning reflexivity, recruitment, interviews, and analysis. I will consider conceptual and presentational issues relating to the findings. Finally, I reflect on the role of service user involvement in the study. Charmaz (2014) writes a chapter about reflecting on the research process of constructivist grounded theory (CGT). I found this helpful in looking back at the journey I have taken in this project and reflecting on the impact of the concluding grounded theory.

### **Reflexivity**

Within academic psychology, the interpretative nature of qualitative research continues to breed concerns around its validity, reliability and replicability (Charmaz & Thornberg, 2021). This is under the guise that 'objectivity' is always best in data collection. CGT challenges this sentiment, questioning the extent to which objectivity is desirable or even possible within qualitative research. CGT pulls Grounded Theory away from its more objectivist foundations, repositioning the methodology to fully embrace what individual researchers bring to the research process. Knowledge is seen to be co-constructed, such that findings in CGT studies are produced through a dynamic interplay between researchers and participants (Veseth et al., 2017). By acknowledging that researchers bring with them their own worldviews, standpoints and contexts in this co-construction, CGT positions researchers as part of what they study rather than separate from it (Charmaz, 2014). Importantly, this creates opportunities for understanding and recognising how hidden beliefs and perspectives can enter the research process. Charmaz (2017) calls this reflexive approach 'methodological self-consciousness'. By taking this reflexive stance, one can become aware of and interested in the process by which meaning is produced in research (Underwood, Satterthwait, & Bartlett, 2010).

I have tapped into my reflexivity during the research process by considering and holding questions such as: Why have I chosen this topic and these methods? What is my motivation to explore this area? How does this fit with my objectives and motivations? How does my background and worldview impact how I understand my research participants? How does my role influence my engagement with participants? How does my perspective impact my questions, understandings and interpretations? What are my ontological and epistemological assumptions? (Adapted from Charmaz & Thornberg, 2021; Veseth et al., 2017).

This has enabled me to reflect on my starting point for this project, namely having had previous experience of working in EIP services. This clinical experience was highly influential for this research, laying the groundwork for the topic in the first place and consequently impacting how I interpreted, responded to, and made meaning of participants' descriptions. Ultimately, I came from a perspective which valued meaning-making, considered this to be helpful in a person's recovery, and wanted mental health services to engage more actively with it when supporting people through psychosis. Actively engaging with the reflexivity that is afforded by this methodology has been central. It would have seemed almost impossible to 'switch off' my prior knowledge of how I related to the words and meanings of participants. While a pretence of neutrality may have kept these preconceived ideas hidden, the reflexive engagement with my perspectives and expectations enabled me to acknowledge and manage them during the research process.

Many professionals had different ways to me of relating to meaning-making in their clinical practice, perhaps holding it with disinterest or considering it a low priority. By holding a reflexive awareness of my position and responses, I was better able to avoid making subconscious judgements of these practices, dismissing a participant's approach or conceptualisation on some level. In one example, I noticed myself taking a judgemental and

dismissive position against the perspectives and practices of one interviewee as they conflicted with my own preconceived ideas. By acknowledging this, I was able to redirect myself towards a questioning which explored the personal, professional and systemic context which enabled them to be positioned in that way. I could then understand how and why *they* held a set of perspectives or practiced in particular ways, rather than having this coloured by *my* own hidden assumptions or critiques. The relationship with this particular participant's responses was central in the development of 'role construction' as a category during analysis. By paying particular attention to the contexts which enabled or disabled particular ideas and practices, I was able to understand the process through which a clinician becomes open or closed to ways of thinking and doing.

It is interesting to consider my position as a researcher-clinician and how this was received by participants. While I attempted to be seen as a 'researcher', participants' knowledge that I was a trainee clinician may have played into the interview process in varied ways. I did not reveal my own experience of having worked in EIP services in the hope that this presented 'fresh ground' upon which to explore the topic, rather than one where concepts, ideas or ways of working may be assumed as common ground between myself and participants.

My position on the research topic changed over the course of the data collection and analysis. At the starting point I predicted certain 'fixed' factors which would impact meaning-making, such that professionals or systems may have 'more' or 'less' of particular factors or qualities that enabled meaning-making. What became clear during the process was the emphasis on motion. I began to understand and conceptualise this movement towards or away from meaning-making, across the personal-professional, team culture and system levels, where access to these 'factors' or resources ever-changing and influencing one another. This highlights the preconceptions that I initially brought to the research questions, while at the same time demonstrating how the theory was constructed *from* the data rather



than purely imposed from preconceived ideas. This came from a deep engagement with the data, attending closely to the details of the interview transcripts, and gradually stepping back so that it took shape at a broader level.

### **Participants: Professionals over service users**

It is worth commenting on the decision to focus on the professional perspective within the project rather than service users. It is noted in the limitations of the empirical study that the interpretations by professionals of service users' meanings cannot be confirmed or disconfirmed since service users were not included in the study. There is a risk here of epistemic injustice in the exclusion of service users in this way, particularly as they are key players in the co-construction of meaning within the clinical encounter. The ideal study design for research question one may have recruited dyads of professionals and service users to explore the clinical encounter from both perspectives. This would have elucidated the experience of meaning-making, negotiation of difference, and co-construction of a narrative from both sides. Indeed, my initial study design did include service users. However, I was unable to find a supervisor willing to accept the proposal as they predicted challenges around gaining ethical clearance. I was therefore advised against pursuing the recruitment of service users on ethical and pragmatic grounds. While this was initially disappointing, the focus purely on professionals opened up other possibilities for exploration. Namely, professional knowledge of the barriers and facilitators which existed within their professional and systemic contexts offered insights which may not have been so easily identified by service users. Nonetheless, it may be that a future project could explore the service user perspective on meaning-making in the clinical encounter and how they experience the proposed model from research question one. While the topic of service user involvement is discussed later in

reference to this study, it may be that a project which recruits and interviews service users directly would be better implemented as service-user-led or co-produced.

## **The research process**

### **Recruitment**

Despite early predictions of recruitment challenges, and plans to use multiple strategies to access participants, online recruitment alone proved successful. Social media, namely Twitter, was effective at reaching EIP professionals across the country. My initial post was liked and shared ('retweeted') many times which helped to spread the message. On reflection, I think the power of a well-designed research poster was significant. I would recommend others spend time designing a poster which captures the eye of potential participants, using a core message or question with concise and punchy phrasing to invite interest. On the point, however, there was a challenge in recruiting willing volunteers from varied and diverse backgrounds. While there was a fair spread across professional groups, and broadly representative gender split, there was a notable lack of representation across ethnic groups. This is certainly a limitation for considering in greater depth the contribution of diverse perspectives, particularly on instances of culture which was a central factor in influencing understandings of psychosis amongst service users and professionals. Moreover, as this lack of representation is a common theme in health research (McClean & Campbell, 2003; Williams et al., 2013), there is a risk that the exclusion of marginalised voices will perpetuate inequalities in research (Rugkåsa & Canvin, 2011).

Power dynamics within the research process will have played into why certain participants felt unable to take part in this project. Previous studies have noted that issues around mistrust

of ethnic majority researchers can impact certain communities (Williams et al., 2013) and there is an additional onus on such researchers to explore and engage with these groups prior to recruitment (McClean & Campbell, 2003). While I was grateful to have supervision during the research process which enabled conversations and thinking around cultural sensitivity (Jackson et al., 2004), in future projects I would hope to more actively consider ways to improve accessibility for a diverse population and minimise the risk of excluding marginalised voices.

## **Interviews**

On reflection, I am grateful for how the interviews unfolded producing such rich and broad data. Being able to draw on clinical and relational expertise as a (developing) psychologist and therapist was highly valuable in this process. My skills in establishing trusting relationships, taking an open and interested stance, and being non-judgemental applied directly in my interactions with participants (Charmaz & Thornberg, 2021). Skills in asking open-ended questions and formulating meaningful follow-ups and probes also contributed to getting the best out of interviews. While the interview schedule certainly provided a degree of structure throughout, I found that it was my ability to create an organic flow of conversation which was most well-received by participants in opening up about what they shared. It was by asking genuine questions when I was curious or wanted further elaboration, and not sticking too rigidly to the structure or form of the questions in the schedule, that made this possible. I received positive feedback from participants about the questions and style of the interview, for enabling in their minds the exploration of topics which were interesting and rarely given time. The adaptation of the interview schedule throughout the process was also important, sticking more closely to the specific experiences of the participants and their

professional positions, depending on what was required to confirm or expand the developing theory.

While the interviews had initially been proposed for 60 minutes, it was quickly apparent that many were lasting longer than this, often towards or above 90 minutes. I began to check with participants whether they were on a tight schedule or had some flexibility. Many were surprised that they would have much to say on the topic, expecting that an hour would be more than enough, but often happily conversed beyond this as we entered a depth of discussion. I think this signifies the value of the topic for clinicians in and of itself. It also signifies the need to create the space in clinical teams to have more reflective, and sometimes philosophical or existential, conversations about the nature and meaning of psychosis and how this relates to clinical practice.

## **Analysis**

The data collection and analysis were concurrent, as is central to grounded theory methodology. Moving back and forth between gathering and analysing data meant that the theory development was iterative, spreading analysis across the whole process rather than as an overwhelming end to data collection. This enabled a much deeper exploration throughout the process, where I could consider what was missing in the data, develop tentative hypotheses and ask questions about my developing findings before taking these back to the interviews. This was very much supported by CGT methods of memoing, where I was taking notes during and after interviews, as coding developed, and into the write-up stage. I kept a lot of research notes throughout, which aligns with how I work best, getting ideas down on paper so they can develop from immediate responses to more fully-formed thoughts later on. This is part of the deep engagement with the material throughout the process: asking questions of the data, wondering how different ideas connect, considering

what may be missing, seeking more data, thinking about the conceptual links, and trying to see the bigger picture in the data. This is something I sat with throughout the process, and often those connections would come at strange moments, taking inspiration just before bed, when cycling to work, or when enjoying breakfast in the morning. My mobile at these times proved an excellent depository for fleeting ideas, ways to construct a sentence or get a point across, for explicating a connection between different categories in the theory.

I initially found it challenging to make leaps away from the details of the data itself towards conceptual abstraction, as I really valued the richness of staying close to participants' own words. This was in part because of the challenge to 'trust' in my own analytic instinct at times, to make the conceptual jump about what may be happening at the bigger level to tie the smaller processes together. However, I found that the CGT process did enable this to organically unfold. By trusting in the process this initially amorphous structure of the material (ideas, connections, notes, factors, categories, and thoughts written on loose bits of paper, on phone notes or Word documents) did eventually come together in a coherent and meaningful theory. Charmaz and Thornbeg (2021) speak about the need to 'tolerate ambiguity' in CGT while you struggle to gain familiarity with what is going on. I can certainly connect with this, as at points I was trying to hold so much data in mind, alongside different trends and conceptual links that it can be difficult to comprehend how it will become an understandable theory. I am grateful to the security that CGT provided, as a 'handrail' to guide me through the research process and give indicators about how to orient myself and envisage what was coming next.

### **Write up and presentation**

Having analysed and established the theory, the next challenge was presenting it effectively to readers in the write-up. This is a common problem with grounded theory given the breadth

and depth of the data and findings that are produced. In the write-up stage I was aware of the need to present a coherent theory which was sufficiently rich and detailed, while also succinct enough to be digested by a reader. The spanning of this project across two research questions provided further challenges to balancing depth with conciseness. Having started with 115,000 words in the transcripts and consolidated these into categories and sub-categories, it felt important to capture the richness and depth of what was shared by participants in the interviews. I wanted to do justice to their own words in the write-up, grounding each category in the data, while also giving precedence to the overall theory. I felt as though the main headlines of the empirical paper were the bigger picture processes, rather than readers getting too bogged down in the precise components of the sub-categories. In the end, I found that the use of diagrams for each research question enormously aided this, enabling me to consolidate and present the overall processes in a digestible way. These diagrams took great thought (and multiple drafts) to best capture and display the multifarious aspects of the theory. Given the demands of journal articles for increasingly concise word counts, the diagrams may carry much of explanatory weight of the study in the write-up for publication. Splitting the project into two brief studies for each research question may better meet these demands.

### **Study evaluation**

Charmaz (2006) suggests four criteria through which researchers can consider the value and impact of their studies. She talks of credibility, originality, resonance and usefulness in evaluating theory development. I have centred these elements during the process of data collection, analysis and presentation here, in the hope to embed the research in principles of rigour, interest and effectiveness. Credibility includes having sufficient data for developing a thorough analysis which convinces readers (Charmaz & Thornberg, 2021). Originality captures research which offers new insights or a fresh conceptualisation of an area.

Resonance includes concepts which are not just about the study participants, but have sufficient generality to offer useful insights and explanatory power for others. Usefulness requires the study to have a practical application. The clinical implications of this study are captured in the discussion and summarised in the impact statement which serves as a reflection of this study's value: on practice and process within services, ideally contributing to 'a better world' (Charmaz & Thornberg, 2021, p.185). In holding these criteria close in constructing my study, I hope that it is sufficiently grounded in the values and purpose of the methodology, and I recommend to future CGT researchers to ground and evaluate your study against these criteria.

### **Service user involvement**

Involving service users in the study felt of real importance, particularly given that the topic was invested in organisations orienting towards service user perspectives and interests. This involvement took the form of twice consulting a local service user research forum (SURF). The SURF was well-established, providing space for researchers and service users to come together and share ideas. I was grateful to find an established group which catered for a range of different service user voices and importantly paid them for their time and knowledge, both of which are essential elements for involvement (Trivedi & Wykes, 2002; Wallcraft et al., 2009). The level of involvement in my project was at the lower end of the co-production continuum, which spans consultation, collaboration and service user-controlled research (Syrett, 2011). Some commentators have been critical of consultation, arguing that it is mere 'lip-service involvement' (Trivedi & Wykes, 2002, p468) as it does not involve power-sharing. This means that researchers maintain authority over the project and any contributions from involvement may or may not be taken on (Syrett, 2011; Williamson, 2001). The engagement with service users' experiences and contributions in a way that could actually impact the project felt of real importance, going some way towards challenging the power balances in

knowledge production. I found a blog post by one service user particularly impactful in highlighting this relationship:

*“Please sit with my words long enough for them to actually mean something...before using my words to advance your own agenda. Survivors are not here to bolster your egos or help you push your ideologies. Writing these blogs is not easy. I am sharing little pieces of myself with you, please respect that and do me the courtesy of reflecting on your power, your privilege and your practice. That doesn’t seem too big of a request” (Aves, 2022).*

In sitting with and reflecting on how to include service user involvement in this project, I have been well aware of the limitations of my approach. I acknowledge that I was not enacting genuine power-sharing or co-production in the project and there is far to go in my research approach to get nearer to this. This doctoral research process has made me acutely aware of the time and resource constraints which are present when carrying out a major research project and juggling this with multiple other demands. This is even more so the case when including service users in a meaningful way. I am sure that this will be as much the case in other professional or clinical research settings as it has been within this doctoral course. One advantage of consultation is that it can be used flexibly at any stage of the project or multiple time points (Williams, 2001), as was the case here. If researchers are to genuinely prioritise involvement and want to benefit from its ethical and pragmatic advantages, then effort must be put in from the start to make it happen.

I hope that in this case that doing something (consultation) has been better than nothing and that this at least reflects my interest and orientation towards this process within research.



Motive is certainly important. Involvement in this project was embedded within its ethical stance, rather than as a 'tick box' to meet funding or institutional requirements. I was genuinely invested in taking seriously the views, values and opinions of those I was consulting (Trivedi & Wykes, 2002), built on the genuine belief in the value of survivor involvement. The SURF takes the position that the space offers a two-way relationship where learning can happen on both sides. For service users, there is the chance to understand the purposes and processes of research, while for researchers there are opportunities to receive feedback and guidance from those with lived experience. Empowerment is at the core of service user involvement (Faulkner, 2009) and I hope here that there was room for both sides to be empowered by the other. While there may always be a risk of 'tokenism' with consultation, that service user perspectives and meanings are engaged with superficially (which may mirror the findings of this empirical paper), I hope that this was a mutual and meaningful exchange which genuine belief in the value of involvement. Most importantly, perhaps, I listened to what the group had to say and implemented changes within the project as a result. Comments from the SURF included possible recruitment problems, sample specificity, the inclusion of good practice, and ethical limitations. This led to changes in the design of project materials and scope, including the recruitment advert and interview schedule.

On a practical note, I produced resources for the group which were jargon-free and distributed before the meeting to enable engagement with the project. I first consulted the group so I could understand whether the topic was considered of interest and value to the group. By doing so at the proposal stage of the project I was prepared to be able to make major changes to the study if needed (Wallcraft et al., 2009). Ideological barriers are often a key challenge, as service users can have very different priorities and interests regarding what constitutes valuable research (Telford & Faulkner, 2004; Williamson, 2001). I was fortunate that the forum considered my topic to be of interest and value. I also observed the SURF as they consulted on other projects, so was able to see that not all projects passed this test and

consultees comfortably questioned and critiqued the value or appropriateness of particular topics, approaches and methodologies. I found this reassuring for the value of my proposed topic in their eyes.

It is also valuable to reflect on the role of the organisations to which this study was associated. Despite being a clinical psychology training course funded by the NHS, there was no requirement from UCL for service user involvement in this project. As such there were few guidelines, support structures, or additional resources made available to enable meaningful engagement with service users in research. While there is a risk that mandatory involvement may create a 'tick box' approach by many, funding organisations can nonetheless be "powerful champions" (Telford & Faulkner, 2004, p.555) for encouraging service user involvement in research.

### **Do something that you love**

A key takeaway from the process has been the value of researching a topic that I am so interested in. As I have expressed, this was an idea that had first been ignited in the early days of my own clinical experiences across various psychosis teams, where I began to notice different approaches to conceptualisation and practice. In having this close interest and investment in the topic from the start, I have had the motivation to propel me forward in the busiest days and carry me happily to the end of the project. I am hugely grateful that I pushed to be able to research this topic despite many early hurdles. While I recognise that it is an obvious point to suggest to researchers that they research things in which they are interested, this has perhaps been the most beneficial aspect to me in completing my project. I would encourage others to tap into their own ideas and passions, take them forward with confidence, and see research as the perfect opportunity to get a better grasp of the things that make you tick.

## References

- Aves, W. (2022b, July). Dear Mental Health Professionals, Even 'Good' Formulations Can Harm. *Psychiatry Is Driving Me Mad*. Retrieved from: <https://www.psychiatryisdrivingmemad.co.uk/post/even-good-formulations-can-harm>
- Charmaz, K. (2014). *Constructing Grounded Theory*. London: SAGE.
- Charmaz, K. (2017). The power of constructivist grounded theory for critical inquiry. *Qualitative Inquiry*, 23 (1), 34–45
- Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative research in psychology*, 18(3), 305-327.
- Faulkner, A. (2009) Principles and motives for service user involvement in mental health research, in Wallcraft, J., Schrank, B., & Amering, M. (2009). *Handbook of service user involvement in mental health research*, (pp. 13-25). Chichester: John Wiley & Sons.
- McLean, C. A., & Campbell, C. M. (2003). Locating research informants in a multi-ethnic community: ethnic identities, social networks and recruitment methods. *Ethnicity and health*, 8(1), 41-61.
- Rugkåsa, J., & Canvin, K. (2011). Researching mental health in minority ethnic communities: reflections on recruitment. *Qualitative Health Research*, 21(1), 132-143.
- Syrett, M. (2011). Service user involvement in mental health research: a user's perspective. *Advances in psychiatric treatment*, 17(3), 201-205.

- Telford, R., & Faulkner, A. (2004). Learning about service user involvement in mental health research. *Journal of Mental Health, 13*(6), 549-559.
- Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners: qualitative review of user involvement in research. *The British Journal of Psychiatry, 181*(6), 468-472.
- Underwood, M., Satterthwait, L. D., & Bartlett, H. P. (2010). Reflexivity and minimization of the impact of age-cohort differences between researcher and research participants. *Qualitative Health Research, 20*, 1585–1595
- Veseth, M., Binder, P. E., Borg, M., & Davidson, L. (2017). Collaborating to stay open and aware: service user involvement in mental health research as an aid in reflexivity. *Nordic Psychology, 69*(4), 256-263.
- Wallcraft, J., Schrank, B., & Amering, M. (2009). *Handbook of service user involvement in mental health research*. Chichester: John Wiley & Sons.
- Williams, M., Tellawi, G., Wetterneck, C. T., & Chapman, L. K. (2013). Recruitment of ethnoracial minorities for mental health research. *Drugs, 67*(2), 236-244.
- Williamson, C. (2001). What does involving consumers in research mean?. *Qjm, 94*(12), 661-664.

## Appendices

### Appendix 1: Public recruitment advertisement



UCL Ethics ID  
22121.001

**UCL Research Project**  
**How do we  
make sense  
of psychosis?**

Are you a  
**mental health  
professional**  
with experience of  
working with  
**first-episode  
psychosis?**

There are many **different perspectives** on how we **understand psychosis**. This research project is interested in **hearing yours**.

We are looking for mental health professionals to take part in an hour long interview (remotely or at UCL). We will ask you about working with service users experiencing psychosis, and how you and they make sense of it.

**£15 VOUCHER FOR TAKING PART**

If you are interested in taking part or for more information please contact James via email: [\[redacted\]](#)

**\*\*Please share this advert with others who may be interested\*\***

## Appendix 2: Interview schedule

### Initial interview schedule

*<Later questions and prompts added in italics as the interviews progressed and the schedule developed>*

- Can we begin by taking a few details about you? What is/how would you describe your: age; gender; ethnicity; professional role; and the service you work(ed) in?
- Can you tell me a little bit about your role within the team?
- Thinking about your own work of supporting people towards recovery in first-episode psychosis, what aspects stand out to you as the most meaningful or important? *<If you're sitting in a room with someone, what's your mission? How does your 'mission' compare with the clinical reality of your work? >*
- How do you (and your service?) support your clients' understanding of what they are experiencing & why it's happening? *<Is this similar in the rest of the service, or different?>*
- Psychosis is a complex category. What does it mean to you? (Follow up: why does it happen?)
  - Could you say a little about the factors that have informed your perspective on this? *<What shaped that view, did it change over time? What changed it? Is that different to people in your team?>*
  - Are there any other meanings or ways of making sense that feel relevant or important to you?
  - How does this range of perspectives inform your clinical work?
- What are some of the different ways that clients explain and make sense of their experiences? *< What are the factors in your experience that help them? Do SUs come with an idea of what's going on for them and why? Does that change over time? What impacts it?>*
- Could you say a little about how you think clients develop an understanding of what they're experiencing & why it's happening?
- I wonder if there are times when yourself and a client have held differing views on how their experience might be understood/why it's happening?
  - What does that feel like for you as a clinician?
  - Do you have a sense of what that is like for clients in those situations *(disagreement, differing views)?*
  - In your experience, how - if at all - should differences in perspective be managed or resolved?

- Could you say a little about what the dominant model for understanding psychosis is within your team? *<Are there any other models that come up? Are there different professional opinions, differences of view, does it come up? Discussions? Where does the power tend to sit? >*
  - What is your sense of what these models/understandings are informed by?
- Previously we've touched on a few other perspectives for making sense of psychosis (for example...). What kinds of influence, if any, do these perspectives have on how the team conceptualise clients' problems?
  - Could you say a little about why you think that is the case?
- Imagining what services could look like in the future, what would need to change for you/your team to be better able to work towards recovery with first-episode psychosis?

### **Key prompts**

Could you say a little more about that?

Where did that come from? What shaped that?

Has that changed over time?

Why are you different to that person in the team?

What was it about that environment that was conducive to X? How is that similar/different to the team you might be working in now?

### **Further questions added in later interviews**

- *Whose responsibility in the team is it to do that 'making sense' work?*
- *If you have an insight-rich discussion with someone, what do you do next? How do you take it to the team?*
- *If there is emergent meaning about a person comes up, what process is it given weight (held onto and used in the team, beyond just a conversation)*
- *How do you balance structural pressures (KPIs, audits, monitoring of care, getting processes done) with more person-centred work (getting to know them, recovery focus, meaning-making)? How are you able to engage in meaning-making*

### Appendix 3: Example of coded transcript

<p>Disagreement on whether that person has 'psychosis'</p> <p>Different understandings of what that means</p> <p>Psychosis is imprecise, but system treats it like a precise label</p> <p>Different approaches: e.g. taking medication might help vs please leave me along</p> <p>Negotiating differences of opinion (sometimes including navigating delusional ideas in here too)</p> <p>Trying to be in their shoes</p> <p>Connecting with client's own framework</p> <p>Impact of crisis on approach</p> <p>Clinical uncertainty about whether their POV is valid, whether to challenge...</p> <p>Different understandings = different interventions</p> <p>Crisis means prioritise safety over thinking?</p> <p>System can't support many things people want, e.g. getting safe housing</p> <p>Limits of role</p>	<p><a href="#">00:04:36.20</a> Question: The point you made about sometimes there can be different ideas, could you say a bit more about that?</p> <p><a href="#">[00:04:58.16]</a> Marlene: Yeah I think quite often there's an initial conflict where someone may or may not think that they have psychosis, and you're offering a service because you or the service think that they have psychosis, or you might have just different understandings of what that might be. And I think that, I think psychosis is sometimes really hard to talk about because I don't think it's like, we'd like to think it's a really precise, like it's the system that operates as if it's like a precise label, this is what you have. But I don't think that it's that precise really. And I think, yeah people have different interpretations of what's going on. I guess like, sometimes I might think, well I actually think if you took some tablets for a week you would feel a lot better, and a lot of your experiences would be really reduced and you'd be feeling better. And the person might think that they need people to leave them alone, and need to be listened to and taken seriously, and they need a new mattress to get the stuff out of the mattress or whatever. And then you're kind of trying to maybe negotiate, or trying to sort of think if you were in their framework is there, how much, I don't know if that makes sense, if you, how much you challenge their framework, how much do you try to say well maybe their framework's valid, but then when you're at the crisis side it feels like maybe there isn't the space to do that when someone's not very safe. You said when they want different things to what you want, and I think that often in psychosis comes down to your different understandings of what might be going on for a person and so the different things that might help with that. Also sometimes people really want to keep using drugs and you wonder if that's the best thing, people are really angry and want to tell someone how angry they are, and you wonder how helpful that is. Or people want things that just aren't possible, like lots of people want a council flat, nobody really gets a council flat, and trying to say, well yeah we can apply to be on the housing register but it's a seven year wait so maybe we should also accept the private accommodation which isn't good and isn't secure and isn't a nice place to live, but that's the only option we have. I don't like that conversation but it also comes up all the time I guess. So that's another time when you have different perspectives, on what's realistic I guess.</p>
---	---



# Appendix 4: Coding through visual representation – hypothesised categories, sub-categories and connections



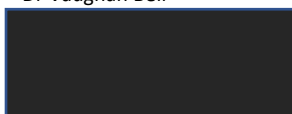
## Appendix 5: UCL Ethics Approval

UCL RESEARCH ETHICS COMMITTEE  
OFFICE FOR THE VICE PROVOST RESEARCH



3<sup>rd</sup> March 2022

Dr Vaughan Bell



Dear Dr Bell

**Notification of Ethics Approval**

**Project ID: 22121.001**

**Title: Narrative insight in psychosis: How EIP clinicians and services respond to personal meaning-making.**

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm that your study has been ethically approved by the UCL Research Ethics Committee until **30<sup>th</sup> June 2023.**

Ethical approval is subject to the following conditions:

**Notification of Amendments to the Research**

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

**Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol.

The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.



**Final Report**

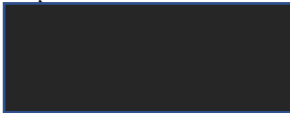
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

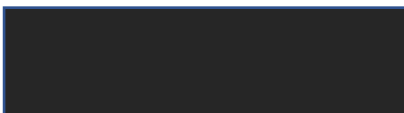
- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <https://www.ucl.ac.uk/srs/file/579>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



**Research Ethics Officer, on behalf of the Co-Chairs of the UCL Research Ethics Committee**



## Appendix 6: Participant Information Sheet

UCL Ethics ID:  
22121.001



### **PARTICIPANT INFORMATION SHEET** Division of Psychology and Language Sciences

#### **Study title:**

How do clinicians and service users make sense of psychosis?

**Researcher:** James Kiely [REDACTED]

**Principal Researcher:** Dr Vaughan Bell [REDACTED]

**UCL Data Protection Officer:** Alexandra Potts [REDACTED]

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read through the follow information and ask us if you have any questions or would like further clarification.

#### **The research topic**

This research is looking into the complex issue of how we make sense of psychosis. It will explore, from the perspective of clinicians, how mental health professionals and service users come to understand psychosis within clinical settings.

The research will be speaking with clinicians who have experience of working with first-episode psychosis to hear their perspective on this topic. This is why you have been asked to participate.

#### **What will participation involve?**

You will take part in an interview lasting around an hour, where you will be asked questions on the topic above. This will happen either via video (Microsoft Teams or Zoom) or in-person at UCL, depending on your preference and current coronavirus restrictions at the time of interview. Some people may be asked for a follow-up or extended interview, for example if we run out of time and you feel that you have more you want to say.

You will receive a £15 shopping voucher as compensation for your time.

#### **Audio recording**

The interviews will be audio-recorded so that they can be transcribed. The researcher will then transcribe and anonymise the interviews within a week of the interview, after which the original recordings will be permanently deleted. Nobody else outside of the research team will hear or have access to the audio recordings.

### **Voluntary participation**

Participation is entirely voluntary, so it is your decision whether you would like to take part. You can decide not to take part at any time before your interview if you change your mind. There will be no consequences for this.

After completing your interview, you may withdraw your data from the study for up to a week after the interview date. This means that your data will be deleted from the study. If you choose to withdraw post-interview, you will still receive your £15 shopping voucher.

### **Risk and benefits of taking part**

Participants will be compensated a £15 shopping voucher for taking part, as a way of saying thank you for your time. You will also be contributing to the broader understanding of how psychosis is made sense of within clinical settings.

As with general conversations about clinical or professional experiences, it is possible that content may be raised in interview which is upsetting. If this happens, we will signpost you towards appropriate support, such as the Samaritans (telephone 116 123; [www.samaritans.org](http://www.samaritans.org)) or NHS Practitioner Health (text 85258; [www.practitionerhealth.nhs.uk](http://www.practitionerhealth.nhs.uk)).

There are no other anticipated risks or disadvantages of taking part, beyond those that may be experienced in everyday life. The project has been approved by the UCL Research Ethics Committee.

### **Publishing and results**

Results of the research will be published around September 2023. Data will be anonymised so that you or your service cannot be identified in any report or publication. Once it is released, you can access a copy of the publication at: [REDACTED] or using this QR code:



### **What if something goes wrong?**

If you have any complaints about the project, in the first instance you can contact the Vaughan Bell, the Principle Researcher for the project [REDACTED]. If you feel your complaint has not been handled satisfactorily, you can contact the Chair of the UCL Research Ethics Committee [REDACTED].

### **Data and confidentiality**

All information that we collect about you during the course of the research will be kept strictly confidential. You or your service will not be able to be identified in any publications that may come out of the research. Any data collected about you will be stored securely online using UCL password-protected systems. Only the members of the research team will have access to your information and data.

Once your interview has been transcribed, this will be anonymised. Your contact details will be stored securely on UCL password-protected systems until the interviews are completed, after which they will be permanently deleted.

As in our clinical work, the limits of confidentiality also apply here. If information arises suggesting that you or someone else is at risk of harm, this may need to be shared with others. You will be informed if this had to happen.

#### **Local Data Protection Privacy Notice**

**Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice for participants in research studies: Click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Name; Gender; Ethnicity; Occupation; Email address; Telephone number

In accordance with data protection legislation, 'public task' will be the lawful basis for processing your personal data (e.g. name, gender, contact details). The lawful basis for processing special category data (e.g. ethnicity) will be 'research purposes'.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact the UCL Data Protection Officer, Alexandra Potts, in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

**Thank you for reading this information sheet and considering to participate.**

If you have decided to take part in the study, please initial and sign the attached consent form.

## Appendix 7: Informed Consent Form

UCL Ethics ID:  
22121.001



### PARTICIPANT CONSENT FORM

Division of Psychology and Language Sciences

#### Study title:

How do clinicians and service users make sense of psychosis?

**Researcher:** James Kiely [REDACTED]  
**Principal Researcher:** Dr Vaughan Bell [REDACTED]  
**UCL Data Protection Officer:** Alexandra Potts [REDACTED]

Thank you for reading the information sheet and considering to take part in this research. James, who is organising the research, will explain the project to you before you agree to take part. If you have any questions, please ask James before you decide whether to take part. You will be given a copy of this consent form to hold onto.

I understand that:		
<ul style="list-style-type: none"><li>• by ticking each box below I am consenting to this element of the study.</li><li>• unticked boxes mean that I do not consent to that part of the study.</li><li>• by not giving consent for any one element that I may be deemed ineligible for the study.</li></ul>		
		Tick
1	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction.	
2	I understand that I will be able to withdraw my data up to one week following the interview, when interviews will be transcribed and anonymised.	
3	I consent to participate in the study. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing my personal information (e.g. name, gender, contact details) and 'research purposes' will be the lawful basis for processing my special category data (e.g. ethnicity).	
4	I understand that all personal information will remain confidential and will be deleted when it is no longer needed. I understand that if there are compelling and legitimate reasons for this to be breached, such as danger of harm, the researchers might have to inform relevant agencies of this and would inform me of any decisions that might limit my confidentiality.	



		Tick
5	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without penalty or prejudice as a result.	
6	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
7	I understand that I will be compensated for the portion of time spent in the study with a £15 shopping voucher, even if I choose to withdraw.	
8	I understand that the information I have submitted will be published as a report and I will be able to access a copy of this using the URL provided after [date].	
9	I consent to my interview being audio recorded. I understand that the recordings will be destroyed immediately following transcription by the researcher.. The transcriptions will be anonymised by removing any references to identifiable people and personal details and the pre-anonymisation transcripts will be deleted. I understand that if I do not consent to being audio recorded in the interview, I cannot take part in the study.	
10	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
11	I am aware of who I should contact if I wish to lodge a complaint.	
12	I voluntarily agree to take part in this study.	

Name of participant	Date	Signature
Name of researcher	Date	Signature