# The formation and maintenance of causal beliefs around voice-hearing, within Hearing Voices Network groups

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# ABSTRACT

## Background:

Understanding how acceptable casual beliefs for voice-hearing are formed is relevant to voice-hearers and clinicians due to the apparent impact of causal beliefs on outcome, and the dissonance between views held by clinicians and voice-hearers. Previous research has highlighted social sense-making as a potentially important factor in forming causal attributions for voice-hearing.

This study posed the following questions:

- **1.** How is shared sense-making involved in developing causal models (including in Hearing Voices Network groups (HVGs))?
- 2. How do voice-hearers navigate multiple potential models?

## Method:

10 participants self-identified as voice-hearers, had attended at least three Hearing Voices Network group sessions, and were UK residents. Semistructured interviews were analysed using reflexive Thematic Analysis.

## Results:

Nine themes were developed, encompassing construction and evolution of explanatory models for voice-hearing (seven themes, six with subthemes); and the role of HVGs in the sense-making process (two themes, both with subthemes).

## Conclusions:

This thesis develops understanding of how explanatory models are evaluated by voice-hearers (through weighing up costs and benefits, and appraising different forms of evidence including qualitative aspects of the voices themselves) and how this leads to shifts between preferred explanatory models, with novel insights into the accommodation of multiple explanatory models for different voice-hearing experiences. Social sense-making is enhanced by the HVGs, with important qualities including commonality, authenticity, understanding, and non-judgement, and the freedom to talk about voices without external pressure.

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## **CHAPTER 1. INTRODUCTION**

## 1.1. Chapter Overview

This chapter firstly discusses the importance of causal beliefs for unexpected events in predicting affective and behavioural outcomes, and how attributional theories (processes by which causal beliefs impact outcome) apply to voicehearing. It discusses attribution theory (processes by which attributions are formed and maintained) and the importance of understanding more about this process for voice-hearers.

Secondly discussed is a historical overview of dominant explanatory models for voice-hearing, changes in these over time, and prevalent modern explanatory models. This includes briefly summarised evidence for prevalent models, and highlighting which model tends to be preferred by whom.

Thirdly discussed is support available for voice-hearers from clinical services in the NHS, contrasted with the Hearing Voices Movement and other innovative approaches to voice-hearing.

Fourthly, a literature review is described, collating previous research into development and maintenance of causal attributions for voice-hearing. Nine articles providing relevant background are summarised, and three main articles are reviewed in greater depth.

Finally, a summary of the proposed study is provided, including rationale and research questions. This study broadly aims to explore how voice-hearers develop explanatory models for their experiences, and the role Hearing Voices groups may play in this.

## 1.2. Context

Voice-hearing, while often seen as symptomatic of underlying pathology, is reasonably prevalent in the general population. Beavan et al. (2011), in a review of 17 surveys, found a median of 13.2% of the general population experienced voice-hearing, concluding that voice-hearing did not necessarily co-occur with distress or diagnosed mental illness. This prevalence increases from 30%-60% in amongst widowed subjects (Castelnovo et al., 2015). Comparatively, prevalence of 'schizophrenia' is 0.32% (World Health Organisation, 2022), which suggests that voice-hearing can be understood much more broadly than through this specific pathology. Voice-hearing phenomenologically similar across diagnostic criteria, and with a similar range of beliefs about voices represented across diagnostic groups (Hepworth et al., 2013). Beavan et al. (2011) suggested that interpretations of experiences, or insufficient coping strategies, are more likely to predict pathology than voice-hearing itself. This thesis explores further the interpretation of voice-hearing experiences.

Due to the plurality of possible causal models for these experiences, the term 'voice-hearing / voice-hearers' is preferred throughout to describe this experience and those experiencing it, rather than terminology pre-supposing either abnormality or symptomatology, such as 'auditory hallucination', or a biomedical explanation for voices. An exception is that when discussing previous research within clinical settings, or support available through clinical services, I use terminology associated with a biomedical framework (including 'schizophrenia' and 'psychosis') as this is relevant to service organisation and provision.

<u>1.2.1. Attributional Theories, Attribution Theories, and their relevance for voice-</u> <u>hearing</u>

## Attibutional theories

Causal attributions for voice-hearing are of interest to many voice-hearers for their own sake (Geekie, 2013), but also have relevance due to links with adjustment and subsequent behaviour. Theories regarding influences of causal attributions on behaviour and affect are broadly known as attributional theories (Kelley & Michela, 1980).

People are motivated to make causal attributions for unexpected events, and this appears to happen automatically (Hall et al., 2003). Attributions for unexpected events may aid in reconstructing basic assumptions about the world (such as, the world is benevolent, the self is worthy), and can impact adjustment, coping, and future behaviour (Roesch & Weiner, 2001).

There is no single generally accepted attributional theory describing how different attributions influence outcome. Nonetheless, attributional theories appear relevant for understanding affective outcomes and treatment planning for voice-hearers.

Read et al. (2006) highlight that accepting a diagnosis of 'schizophrenia' and the medical model is associated with lower perceived control and more negative attitudes, identifying this as an impact of 'self-stigma'. This is reinforced by findings from an international review of 21 studies into the impact of causal beliefs for voice-hearing on outcome for voice-hearers engaged with clinical services (Carter, Read, Pyle & Morrison, 2017). Voice-hearers endorsing a biogenetic model potentially experience higher levels of implicit stigma and hold more stigmatising attitudes towards others diagnosed with 'schizophrenia'. This aligns with findings from Roesch and Weiner (2001) that stable, uncontrollable causal attributions are linked with poorer adjustment. Carter et al (2017) also found associations with engagement in clinical services, with those endorsing biological models more likely to adhere to medication than those with a psychosocial model, those with a psychosocial model more likely to engage in psychological therapy, and voice-hearers with a biological model reporting better relationships with keyworkers.

It is unclear how strongly causal attributions predict treatment choices. Carter, Read, Pyle, Law, et al. (2018) surveyed 311 voice-hearers engaged with mental health services in the UK, finding that causal models endorsed for voice-hearing (biogenetic versus psychosocial) did not influence which treatment option voicehearers perceived as most helpful. Endorsement of psychosocial causal models for voice-hearing correlated with uptake of CBT, but direction of causality could not be inferred.

#### Attribution theories

Beyond attributional theories (how causal attribution may influence behaviour and affect), attribution theories (how development of causal attributions is influenced by multiple antecedents, including information, beliefs, and motivation; Kelley & Michela, 1980) are also relevant to voice-hearers.

Coffey and Hewitt (2008) reported that many voice-hearers would like additional opportunities within mental health services to discuss content and meaning of voices ('meaning' was a broad term incorporating causes). Geekie (2013) noted that voice-hearing clients welcomed discussion of causal factors. In a survey of 311 voice-hearers engaged in clinical services, understanding causes of their voices was rated as very important (mean 81% on a scale of 0-100% important; Carter, Read, Pyle, Law, et al., 2018).

Attribution theories suggest that causal attributions are influenced by subjective factors including beliefs and motivations, and by objective evidence (Kelley & Michela, 1980). Weighing up these factors appears to not be an individual process but a familial and social one, with meanings assembled through considering biological processes, cultural significance, and personal significance, within a dialogical process with significant others (Kleinman, 1988). Kleinman viewed causal attributions as unfixed, with possibility for re-evaluating past events and reformulating causal explanations based on current events.

Understanding development of causal attributions may help clinicians to contextualise healthcare choices and engage voice-hearers in personally relevant healthcare. However, despite voice-hearers' interest in discussing voice content and meaning with professionals, professionals were not always

open to these conversations (Coffey & Hewitt, 2008), leaving it unclear how often any causal framework is presented in clinical services. Read et al. (2004), in a review of eight studies from England into causal beliefs endorsed by 'patients' (four studies), their families (one study), and the general public (three studies), found that psychosocial beliefs were the most endorsed model in seven of eight studies. Contrastingly, on a service and individual level, UK psychiatrists are far more likely to endorse biological models of causation for voice-hearing over any other models (Baillie et al., 2009; Kingdon et al., 2004). This suggests that social resources available for assembling meaning differ between services and day-to-day life.

#### 1.2.2. Causal beliefs for voice-hearing

#### Historical conceptualisations of voice-hearing

Voice-hearing experiences are recorded going back millennia, with multiple causal attributions. Supernatural or religious explanatory frameworks for voice-hearing were commonplace through much of recorded history, explaining voice-hearing as the actions of ghosts or spirits (McCarthy-Jones, 2012), ill-wishing from an enemy (human or divine; Read, 2013a), or divine communication (with recorded explanations of voice-hearing as communication from the Greco-Roman pantheon; McCarthy-Jones, 2012). Following Christianity's establishment as official religion over much of Europe, Christianized supernatural and religious explanations proliferated, including hearing the voice of God, being possessed by the Devil, or being affected by witchcraft (Read, 2013a).

Physiological explanations for voice-hearing arose in the 'Classical era', including ideas that voices were caused by interaction between the humours and the brain (McCarthy-Jones, 2012; Read, 2013a). These resurged during the Renaissance, with physicians taking on a scientific role in attempting to differentiate, categorise, theorise on, and treat mental health difficulties, including voice-hearing (Read, 2013a). Theories imputing mental health difficulties or voice-hearing to moral qualities also emerged, with physicians involved as moral authorities rather than scientific experts. Social and psychological explanations for voice-hearing were minority views (Read, 2013a).

The concept of 'psychosis' entered European psychiatric literature in 1841, initially as a disease comprising both psychic and organic features (output of combined organic weakness and psychic vulnerability; Bürgy, 2008). Emphasis on physiological pathology soon predominated. In 1883, Kraepelin labelled a patient group with common presenting features including hallucinations and paranoia as having 'dementia praecox'. In 1911, Bleuler coined the term 'schizophrenia', expanding and subdividing 'dementia praecox'. Kraepelin and Bleuler both focused on determining the anatomical and heritable factors causing these presentations (Read, 2013b). The term psychosis returned in Jaspers' 1923 *General Psychopathology*, as an overarching illness category including schizophrenias. Jaspers viewed psychoses as resulting from organic illnesses and neuroses as having psychological biographical causes (Bürgy, 2008; Jaspers, 1963).

Evidently, a recognisable medical framework for understanding voice-hearing is a historically recent emergence. Dominant causal frameworks did not progress in a straightforward chronological sequence but rather might overlap in an era or rise and fall in popularity in keeping with social and political mores of the day (McCarthy-Jones, 2012; Read, 2013a).

## Modern conceptualisations of voice-hearing

There is debate on what constitutes the most prominent modern causal explanations for voice-hearing. Ritsher et al. (2004) highlighted four main causal models for voice-hearing: a biomedical framework, situational stress (including a traumagenic understanding of voice-hearing), inner voice (from a psychodynamic model of un-integrated thoughts or impulses), and spiritual communication. Geekie (2013), researching voice-hearing clients, identified causes falling into three themes: psychological, social/interpersonal, and biological. A report by the British Psychological Society Division of Clinical Psychology (BPS DCP) highlighted primary causal models as biological (including genetics, neurochemical changes, changes in brain structure and function) and life experiences (including trauma, relationships, inequality including poverty and discrimination). Psychological factors were mentioned primarily as factors moderating why distress may arise in relation to voices. Spiritual crisis was mentioned as a potential causal model, but comparatively briefly (Cooke, 2014).

From this, it appears that major causal frameworks for voice-hearing include biological, psychological, social/interpersonal (including individual life experiences and experiences of living within particular social contexts), and spiritual. Significant attention has been paid in research literature to biological models and a combined psychosocial model. By contrast, spiritual belief frameworks have received less attention from mental health professionals. While acknowledged as a coping strategy for voice-hearing (Carter, Read, Pyle & Morrison, 2017) they are felt to be relatively unimportant as a causal factor by researchers and by clinicians caring for voice-hearers (Carter, Read, Pyle, Law & Morrison, 2017).

Voice-hearers are not accepted as equal partners in attempts to establish causal frameworks for their experiences; in fact their views are systematically marginalised (Geekie, 2013). Marginalisation of voice-hearers and those deemed 'mad' can be understood as an iterative process. Socially labelling someone as 'mad' occurs when behaviour or expression is seen as violating social norms, not making sense within cultural contexts, and lacking a culturally acceptable rationale. This initial lay judgement may be formalised through psychiatric diagnosis. This serves to remove the 'mad' person's credibility in any further sense-making attempts, and absolves witnesses of responsibility to explore social determinants of these difficulties, with increasing likelihood that judgements of 'madness' are reconfirmed (Coles, 2013).

## Causal models for voice-hearing: what is the evidence?

A review of evidence for the dopamine pathway of schizophrenia (Howes & Kapur, 2009) highlights evidence of abnormalities in dopamine systems in the brain, aligning with neuroleptic medication acting through blockade of dopamine receptors. It highlights evidence of genetic causal factors, with multiple genes with small effect sizes associated with schizophrenia, with the most strongly associated genes also linked with functioning of the dopamine system, brain

development, and functioning of other neurotransmitters. It notes elevated dopamine present in those seen as at clinically high risk of psychosis. Howes and Kapur (2009) theorised that due to the 'reward' function of dopamine, elevated firing of dopamine receptors may lead to assignment of salience to innocuous stimuli. Hallucinations and delusions emerge over time through the individual's own explanation for this experience of salience, with explanations moderated through cognitive and sociocultural schemas.

Reviews of evidence for a psychosocial model of causation in voice-hearing (Longden & Read, 2016; Varese & Bentall, 2011) highlight that childhood trauma and adversity rates are several magnitudes higher in people labelled with schizophrenia or psychosis than those without, with a 'dose-response' relationship. Associations remain significant even when controlling for confounders such as family history of psychosis (arguing against theories of genetic vulnerability) and other demographic factors. Trauma and deprivation throughout the lifespan is also associated with increased prevalence of psychosis. Longden and Read (2016) theorise neurological changes in psychosis as responses to environmental adversity (or owing to effects of neuroleptic medication), rather than themselves being centrally causal.

#### Causal models for voice-hearing: what is preferred?

In a review of 84 studies from 25 countries into public views (Read et al., 2013) in 61 psychosocial explanations for psychosis were more commonly endorsed than biogenetic explanations. Six studies had psychosocial explanations endorsed to the same degree as biological explanations, and 17 studies found that biological explanations were most endorsed.

Regarding the preferred causal explanation of voice-hearers' families, in a review of 26 studies from 15 countries (Read et al., 2013), 19 found that psychosocial explanations for voice-hearing were most commonly endorsed.

Regarding the preferred causal explanations of healthcare professionals, a review of four studies from Italy, the USA, and the UK into causal beliefs of clinicians working with voice-hearers found that biological models of causation were endorsed more frequently than any other model (Read et al., 2006). A

more recent UK study asked clinicians from a range of professions working with people with 'psychosis' to rate psychosocial causal models and biogenetic causal models, with psychologists endorsing psychosocial factors more frequently than biogenetic factors, psychiatrists endorsing biogenetic factors more than psychosocial factors, and other professions (community psychiatric nurses, social workers, and occupational therapists) endorsing both models to a similar degree (Carter, Read, Pyle, Law & Morrison, 2017).

Regarding the preferred causal explanations of voice-hearers, Carter, Read, Pyle and Morrison (2017) reviewed 13 studies on causal explanations of voicehearers engaged with clinical services internationally, finding in the majority psychosocial beliefs were most commonly endorsed, then spiritual beliefs, with biological beliefs much less commonly endorsed by voice-hearers. An international survey of 701 voice-hearers found that voice-hearers were 13 times as likely to endorse purely or primarily social explanations for voicehearing than purely or primarily biogenetic explanations (Read, 2020).

As these studies all applied different methods, direct comparison across groups is not definitive. Nonetheless, it appears that biological causal models are endorsed by clinicians and particularly within psychiatry to a degree not matched by the general public, family members of voice-hearers, or voicehearers themselves. This is relevant as dissonance between voice-hearers and clinicians may present significant barriers to engagement.

#### Summarising causal beliefs for voice-hearing

This was a brief overview of a highly contested area, intended to provide context. The predominant causal models for voice-hearing endorsed by the public and services have altered repeatedly over time. Modern clinical conceptions of voice-hearing are relatively recent, only existing in their current form for just over a century.

There is disagreement between many clinicians and voice-hearers on causal explanations for voice-hearing, with voice-hearers more inclined to endorse a psychosocial model and many clinicians more inclined to endorse a biogenetic model. Causes of voice-hearing are seen as important and of interest to voicehearers, however voice-hearers are often excluded from participating in conversations about causal models. Despite this, voice-hearers do engage in their own sense-making, and may have multifactorial accounts of causation (including contradictions), with the majority of clients researched having 'wellformed but flexible' models of causality (Geekie, 2013).

While objective evidence may be one factor in how people form models of causality, this thesis does not take a stance on how voice-hearing actually arises, but instead explores causal models as developed and subjectively experienced by voice-hearers.

## 1.2.3. Voice-hearing and mental health services; psychosis and the NHS

Voice-hearing is often interpreted as a symptom of pathology, and as such it is subject to attention from NHS mental health services. National Institute for Health and Care Excellence (NICE) guidelines for psychosis recommend medication as first-line treatment, in conjunction with psychological interventions. Someone interested only in psychological interventions is advised this is more effective with antipsychotic medication. Contrastingly, someone interested in medication only is not encouraged towards concurrent psychological interventions (NICE, 2014) - privileging biological approaches to psychosis. Notwithstanding, although antipsychotics are effective in reducing hallucinations for some, the effect size is moderate and appears to decrease over time (Leucht et al., 2009), there is significant potential for adverse effects of antipsychotic medication, including tardive dyskinesia (a movement disorder), reduced brain volume, shortened life span, and withdrawal effects, (Moncrieff & Stockmann, 2019), and a proportion of people may be able to achieve good outcomes in social and occupational functioning without use of antipsychotics (Bola & Mosher, 2003; Francey et al., 2020).

Psychological interventions specifically recommended by NICE guidelines include Family Intervention (FI) and individual CBT. Benefits of FI have been identified as including reduced rates of readmission and relapse in serviceusers, improved adherence to pharmacological interventions (Onwumere et al., 2011), and increased insight into and acceptance of 'illness' (Nilsen et al., 2016). Emphasis on these outcomes and the language choices ('illness') indicate a biomedical understanding of voice-hearing implicit within NICE's understanding of FI. While improved social functioning (Onwumere et al., 2011), and improved communication and independence (Nilsen et al., 2016) are also noted, the impression is that these are seen as significant primarily as they support coping with 'illness'.

Modest but beneficial effects have been noted from CBTp (Thomas et al., 2014). CBTp aims to reduce distress rather than reducing symptomatology (Morrison, 2013). A Delphi study of CBTp providers found endorsement that CBTp should allow clients space to discuss their own models first, and that CBTp should take into account the client's perspective and worldview (Morrison & Barratt, 2010). Nonetheless, CBTp providers emphasised understanding behavioural and cognitive maintenance of problems over aetiology (Morrison & Barratt, 2010). One critique of CBT is its focus on the individual as the site of problems and problem maintenance, rather than contextualising problems within unequal social and power structures (Hagan & Donnison, 1999) – emphasising psychological models of aetiology while de-emphasising social models.

It appears that current NICE recommended approaches for psychosis privilege a biological model of causality, with individual psychological models being a distant second, and other causal not seriously considered. This suggests a biobio-bio model for psychosis, or at most a bio-bio-psycho model – not a biopsycho-social model, much less a bio-psycho-social-spiritual model (Saad et al., 2017) that might more flexibly incorporate a plurality of causal attributions.

Beyond NICE guidelines, other forms of psychological therapy have been trialled and shown promise, such as CBTp groups (Dannahy et al., 2011), relating therapy (Hayward et al., 2017), mindfulness- and acceptance-based approaches (Jansen et al., 2020), and avatar therapy (Craig et al., 2017; Leff et al., 2014). These tend to focus primarily on emotional consequences of voice-hearing, rather than closely incorporating causal attributions.

#### 1.2.4. The Hearing Voices Movement

The Hearing Voices Movement (HVM) originated in the 1980s, developing through a partnership between a psychiatrist, Marius Romme, a researcher, Sandra Escher, and a voice-hearer, Patsy Hage, in collaboration with other voice-hearers. They concluded that focus on a medical, pathological model of voice-hearing did not promote coping in many, and that understanding voicehearers' own frames of reference is more helpful (Corstens et al., 2014).

Their work originated the Hearing Voices Network (HVN), an international peerled organisation taking a non-pathologising view of voice-hearing and focusing on expertise-by-experience rather than expertise-by-profession (Corstens et al., 2014; Dillon & Hornstein, 2013). The HVN prioritises personal experience and testimony as important sources of evidence, redefining ownership of power and expertise, creating space for a plurality of causal explanations of voice-hearing alongside biomedical models, and promoting political advocacy for the rights of voice-hearers, alongside their therapeutic goals of developing coping and recovery frameworks (Corstens et al., 2014).

While the social action and political advocacy roots of the HVM inevitably influence their endorsed therapeutic strategies, within this thesis the primary focus is the therapeutic pathways of the HVM. One such has been the development of peer-support groups (Hearing Voices Network Groups, HVGs). These groups provide an accepting space for a range of explanatory models of voices, with the English HVN charter stating that each group must *"Respect each member as an expert; Encourage an ethos of self-determination; Is free to interpret experiences in any way"* (English Hearing Voices Network, n.d.). The ethos of self-determination means that group content is owned and developed by the groups rather than following a centralised model. Therefore, despite an overall philosophy valuing a plurality of models for voice-hearing, in practise particular groups may more strongly endorse one model over another (Corstens et al., 2014). This limits generalisability and makes research within this setting more challenging.

Research into the experience of HVG attendees has identified common positive themes. Ruddle et al. (2011) reviewed 16 group interventions for voice-hearing (including not just user-led HVGs, but also clinical groups). They found an overarching theme that group attendees valued a safe space to share their experience and feel 'normal' (suggesting that group structures or therapeutic modalities were less relevant). Dos Santos and Beavan (2015) used Interpretative Phenomenological Analysis (IPA) to explore experiences of HVG attendees in Australia. Themes identified included social connections (rather than the group being clinical or therapy based), the importance of sharing and willingness to share with others, the importance of feedback (offering reality testing, solutions, or suggestions), the supportive nature of the group, improvements in self-esteem, and changes in relationship to the voices. Oakland and Berry (2015) found, in a study of voice-hearer led, open-ended HVGs, that self-determination and empowerment were significant experiences within the group, with themes emerging of 'no one has power over you' and 'it's our rules'.

Despite limitations imposed by pluralistic models varying across groups, research into clinical and recovery-related outcomes have been conducted for HVGs. In a pilot study of an HVG (Meddings et al., 2004) attendees heard voices less frequently, voices were perceived as less powerful relative to the hearer, and attendees felt better able to cope with voices. Similar findings were reported by Beavan et al. (2017): many participants reported hearing fewer voices, being less afraid of voices, believing voices to be less powerful, experiencing voices as more positive, and feeling more hopeful about the future since attending an HVG, with a small majority reporting fewer hospital admissions and needing less emergency help.

A self-report, quantitative survey of HVGs by Longden et al. (2018) explored participant experiences within groups, the impact of membership on life outside the group (social/occupational and clinical), and the effect of groups on emotional wellbeing. Participants credited groups with helping them improve a range of social, clinical and emotional variables. Participants in this survey reported that HVGs provide support around voice-hearing that is unavailable elsewhere, including within mental health services. Some areas identified as useful within HVGs (such as reality testing, coping strategies, improving self-esteem, or altering relationship with voices) could be targeted by individual therapeutic interventions for voice-hearing. Nonetheless there appear to be important qualities offered by a group approach (normalisation, building social connections and sharing, and generating hope) and particularly HVGs (the ethos of self-determination). Dillon and Hornstein (2013), HVG facilitators, also identify the group as a space where multiple explanations of voice-hearing are shared in order to support attendees in constructing an organised, coherent narrative of their own experience.

#### 1.2.5. Other innovative approaches for voice-hearing

The HVM ethos of questioning, critiquing, and reframing traditional biomedical understandings of voice-hearing is also found in other innovative approaches towards voice-hearing. HVM creators Romme and Escher also developed the 'Maastricht Approach' to hearing voices. This contains three guiding principles: voice-hearing is reasonably prevalent and should not be considered a symptom of illness in and of itself; voice-hearing can be understood as a personal and meaningful reaction to life stresses; and voice-hearing is more accurately considered as a dissociative experience rather than a psychotic symptom. They developed the Maastricht Hearing Voices Interview, an assessment tool aimed at identifying links between life experiences and voice-hearing. The causal model in this approach is that traumatic experiences provoke overwhelming emotions; when coping strategies for these emotions fails, voice-hearing emerges (Corstens et al., 2018).

An approach developed contemporaneously but independently to the HVM is the Soteria paradigm for people diagnosed with schizophrenia, an alternative to hospitalisation and medication as a primary treatment. Core principles include: provision of small, community-based therapeutic spaces with significant layperson staffing; preservation of personal power, social networks, and communal responsibilities; a relational style focusing on 'being with' and 'doing with' clients; an aim of gaining subjective understanding of and giving meaning to the person's experience of psychosis; and no or low-dose antipsychotic medication. A review of three controlled trials of Soteria programs (Calton et al., 2008) found it at least as effective as traditional hospital treatment on factors such as global psychopathology, re-admissions, and life functioning indicators.

Open Dialogue (OD) is another approach to voice-hearing, developed since the 1980s in Lapland. OD is not aimed primarily at eliminating symptoms but at understanding their meaning. OD involves creating therapeutic teams operating on guiding principles of immediate provision of help, a social network perspective (with family, friends, potentially employers and educators, and healthcare professionals invited to participate), psychological continuity (with the same team remaining involved throughout treatment), tolerance of uncertainty, and dialogism to support in finding new meanings and new solutions. A five-year study of OD approaches found fewer symptoms at two years and no results poorer at five years compared to traditional approaches (Seikkula et al., 2006). Contrastingly, a review of 23 studies of OD felt that, while promising, the quality of these studies did not allow conclusions to be drawn about its efficacy (Freeman et al., 2019).

Although these approaches hold potential for promoting voice-hearer wellbeing, and may invite more plurality in causal attributions, they are not the focus here. HVGs will be focused on as they offer a strikingly different approach for voicehearers compared to traditional mental health services, while nonetheless being well established and widespread throughout the UK.

#### 1.3. Literature Review

As discussed in the preceding sections, significant previous attention has been given in the research into what different causes for voice-hearing might be (for example outlining theoretical aetiological models and their respective evidence). Also discussed have been which models of voice-hearing are most commonly endorsed, by voice-hearers and by others. Finally, there has been research already discussed as to the impact of which voice-hearing explanation in endorsed on affect and behaviour. However, as noted above, attribution theories and voice-hearing - the manner in which voice-hearers may assemble voice-hearing explanations through individual, familial, and social processes appeared to have been under-researched. Given this and given the potential clinical relevance of this area (noted above) and the interest expressed by voice-hearers in discussing their explanatory models (Geekie, 2013), I felt that a literature review tightly focused on this area would be appropriate in order to more closely understand the extent of the research into this area and any remaining gaps. A literature review was therefore conducted to identify previous research into the causal attributions voice-hearers hold for their experiences, and factors influencing development of these causal attributions.

My approach to this literature review includes elements of a systematic review and elements of a narrative review (Cooper, 1988; Efrat Efron & David, 2018). I draw from systematic approaches in that I attempt through my search procedure to be as exhaustive as possible in identifying literature on this topic, with pre-established inclusion and exclusion criteria for literature items. I prize these systematic elements due to my desire to be transparent about my approaches and mindful of the impact of my own positioning throughout this project. I also draw from narrative approaches in that I aim to provide a holistic background to this topic and summarise key findings in order to present a rationale for research – rather than attempting to answer a specific and focused question. As will be seen, my structuring of this review also follows a more narrative approach, presenting identified articles according to the themes I identified within their findings. I also prized the narrative elements in this literature review as I was keen to remain open to including a range of methodological approaches. In this thesis I wish to wherever possible directly elevate the ideas and words of voice-hearers, in line with the HVM ethos of prizing personal testimony (Corstens et al., 2014), which has influenced me in choosing qualitative methodology for this thesis as a whole. Nonetheless, in reviewing the literature I wished to cast the widest possible net and take a pragmatic stance that all forms of inquiry may have a role in shaping knowledge. In view of this, and in keeping with a narrative approach, I did not place study methodology as an exclusion criteria.

## 1.3.1. Search terms

The search terms used were: ( "Hearing voices" OR "Voice hearing" OR "Voicehearing" OR "Auditory-visual hallucinations" OR "AVH" OR "Auditory Hallucinations" OR "Hallucinat\*" OR "Unshared sensory phenomen\*" OR "Unshared sensory experience" OR "Psychosis" OR "Psychotic" OR "Schizophren\*" ) AND ( "Causal attribution" OR "Causal belief" OR "Causal model" OR "Causal framework" OR "Explanatory model" OR "Explanatory framework" OR "Making sense of" OR "Make sense of" OR "Attribution theory" OR "Attributional theory" ). Title, Abstract, and Keywords were selected as search areas to ensure that subjects of interest were significantly rather than incidentally included.

Despite preferences in this thesis for non-diagnostic terminology, an initial search without the terms "Psychosis" OR "Psychotic" OR "Schizophren\*" produced 158 results, compared to 1295 results when these terms were included. These terms were therefore included.

## 1.3.2. Search procedure

These search terms were used on multiple databases (APA PsycInfo, Academic Search Complete, CINAHL Plus, Web of Science, Cochrane Library, Pubmed, Proquest, Centre for Reviews and Dissemination, and Scopus). The search was conducted on 14/04/2021, and yielded 1295 results. After removal of duplicates, 881 unique results remained.

Inclusion and exclusion criteria for screening were as follows:

- Full articles must be available
- Articles may be from any country but must be available in English
- Focus on causes must be about models subjectively held by voicehearers, and how these models are developed.

e.g. articles were excluded which focused on:

- Gathering or commenting upon evidence for objective causes of voice-hearing
- Identifying causal attributions without attention into how attributions were developed
- How causal attributions impacted on treatment choices or outcomes
- Causal attributions held by others (clinicians, informal caregivers, social contacts, or trends in literature / popular culture)

Academic journals, dissertations, and book chapters were included in searches. Whole books and newspaper articles were excluded (at the initial search where possible, otherwise in subsequent steps).

The references of all final included articles were hand-searched to identify any additional relevant articles. Google Scholar's 'cited by' function was used for all final included articles and the results were hand-searched to identify any additional relevant articles. Additional relevant articles I encountered through parallel research into voice-hearing were added. In total, nine additional items were identified by these means and were screened against inclusion and exclusion criteria.

Screening steps and reasons for removal can be seen in the PRISMA diagram (Figure 1).



Figure 1. PRISMA diagram of the literature search, including reasons for removal

## 1.3.3. Identified articles

Three articles were identified with particular relevance for understanding the formation of causal attributions for voice-hearing held by voice-hearers. Additionally, nine supplementary articles were identified in which formation of causal attributions was a secondary focus. Relevant findings from the supplementary articles are summarised to provide background, followed by more extensive discussion of the three main articles.

Quality of the three main articles was considered using the COREQ checklist for qualitative research (Tong et al., 2007). The 9 supplementary articles included qualitative, quantitative, and mixed-methods designs and therefore the COREQ could not be directly used to compare quality between them, but limitations in study design and analysis and findings have been reported on for each.

## Supplementary articles:

Nine studies were identified (Table 1) from 2004-2020. Due to their disparate aims and outcomes, I have grouped them under broad themes relevant for this thesis, rather than chronologically.

Article Title	Author and Year	Study location	Theme
Assessing the stability of	McCabe &	UK	Stability and alteration
		UN	of causal attributions
schizophrenia patients'	Priebe		or causar altributions
explanatory models of	(2004a).		
illness over time			
Explanatory models of	McCabe &	UK	Influence of culture
illness in schizophrenia:	Priebe		
Comparison of four ethnic	(2004b)		
groups			
Cross-Cultural	Conrad,	Jordan	Influence of culture
Comparison of	Schilling,	and	
Explanatory Models of	Najjar,	Germany	
Illness in Schizophrenic	Geiser,		
	Sharif, &		

Table 1. Nine articles providing grounding in the formation of causal attributions in voice-hearers

Patients in Jordan and Germany	Liedtke (2007)		
Finding meaning in first episode psychosis: Experience, agency, and the cultural repertoire	Larsen (2004)	Denmark	Influence of culture
Narrative insight in psychosis: The relationship with spiritual and religious explanatory frameworks	Marriott, Thompson, Cockshutt, & Rowse (2019)	UK	Negotiating competing explanations
Explanatory model of illness of the patients with schizophrenia and the role of educational intervention	Awan, Jehangir, Irfan, Naeem & Farooq (2017)	Pakistan	Influence of others
"Maybe it's kind of normal to hear voices": The role of spirituality in making sense of voice hearing	Lewis, Sanderson, Gupta, & Klein (2020)	UK	Influence of others
Listening to the Voices We Hear: Clients' understanding of psychotic experiences	Geekie (2013)	New Zealand	Influence of others
Hearing Voices Network groups: experiences of eight voice hearers and the connection to group processes and recovery	Payne, Allen, & Lavender (2017)	UK	Influence of others

## Stability and alteration of causal attributions

## McCabe & Priebe, (2004a)

The study aim was to explore the stability of explanatory models for 'Schizophrenia' for clients receiving long term support through mental health services. This study used quantitative methods to analyse interview data. A modified version of the Short Explanatory Model Interview (SEMI; Lloyd et al., 1998) measured explanatory models with 8 participants from four ethnic groups on two occasions, approximately 1 year apart. Answers to questions from the SEMI about 'concept of illness' (e.g. 'What do you call your problem?') and 'cause of illness' (e.g. 'What do you think caused your problem?') at the two time points were analysed, coded as 'identical', 'similar', or 'different', and were found to be unstable over time.

There were significant limitations to the study. Factors that might influence the alteration of explanatory model were not considered. There was a very small sample size which limits wider applicability. However, this study does indicate that explanatory models of voice-hearing are dynamic and subject to ongoing revision over time.

#### Influence of culture

#### McCabe & Priebe (2004b)

The study aim was to compare explanatory models among people with 'Schizophrenia' from different cultural backgrounds, and explore any relationships with clinical and psychological characteristics. 30 White participants, 30 Bangladeshi participants, 30 African-Caribbean participants, and 29 West African participants, with a diagnosis of 'Schizophrenia' and in contact with mental health services, were administered the SEMI. Qualitative methods were used to identify explanatory models from the interview data; the method was not named but it was noted that explanatory model categories were identified *a posteriori*. Results for 'explanatory model' were coded into four categories: biological; social; supernatural; and non-specific (do not know/mental illness/other). Qualitative methods were then used to compare mapping of explanatory models onto the participant groups.

White participants' preferred explanatory models were, in order of most to least preference, biological, then social, then supernatural. Bangladeshi participants' preferred explanatory models were, in order of most to least preference, supernatural, then social, then biological. African Carribeans participants' preferred explanatory models were, in order of most to least preference, supernatural and social (with no significant differences in preference), then biological. West African participants' preferred explanatory models were, in order of most to least preference, supernatural, then biological and social (with no significant differences in preference).

One limitation is that although all non-White participants were second generation immigrants there were no measurements of identification with their culture of origin, which could have provided more insight into the role of culture in developing explanatory models for voice-hearing. However, it does appear that preferred explanatory models for voice-hearing differ according to cultural background.

## Conrad et al (2007)

The aim of the study was to gain cross-cultural insight into explanatory models for 'Schizophrenia', and attitudes towards treatment options. There were 24 Jordanian and 23 German participants, all with a diagnosis of 'Schizophrenia'. Participants were asked 'What do you think are the main causes of your illness?' with the results coded using content analysis.

The German participant group endorsed 'biological/hereditary' causes significantly more than the Jordanian group. The Jordanian group endorsed 'Society/Environment' and 'Esoteric' (including supernatural) causes significantly more than the German group. As well as broad differences there were examples of more culturally specific differences, for example several German but no Jordanian participants mentioning loneliness in their responses; and several Jordanian but no German participants mentioning social and political conditions in their responses.

This suggests that causal attributions for voice-hearing differ according to cultural background, in ways that may be both broad (informed by wider cultural norms) and specific (informed by the day-to-day experiences of living within a culture).

## Larsen (2004)

The study aim was to trial an analytic approach that integrates the experiential reality of the individual suffering from mental illness with their individual attempts to find meaning in these experiences. 15 participants were all service-

users in an intensive 2 year early intervention for psychosis program; the author conducted interviews with them (including some but not all participants providing repeat interviews, up to twice yearly) for two years. He also drew from field notes (criteria for inclusion in his field notes was unclear). He used a person-centred ethnographic approach. This included some coding of interviews into themes, but the methodology used was unclear.

The main outcomes relevant for this study were that explanatory models of voice-hearing appear to emerge through constant and active processes of negotiation between systems of explanation. Different explanatory models might be drawn on in different settings in order to serve different functions. Systems of explanation are formed from the cultural repertoire. New systems of explanation may become available to be drawn upon as voice-hearers enter the mental health system. The role of media is potentially significant; it is created within but also can serve to reinforce concepts that are part of a cultural repertoire, and increase the availability of these to voice-hearers.

The main limitation of this study was that its unsystematic analysis of interviews made it difficult to establish how much these represented themes across participants rather than the remarks of one participant or indeed the author's own reflections. The author does not systematically explore what contexts led to a participant selecting one explanatory model over another.

However, the concepts of systems of explanation forming from the cultural repertoire, including the significant role of the media and the concept that new systems of explanation may become available to be drawn upon as voice-hearers enter the mental health system, are useful for understanding how culture may influence the development of causal explanations for voice-hearers.

#### Negotiating competing explanations

#### Marriott et al (2019)

The study aim was to explore personal accounts of psychosis in order to consider whether 'narrative insight' (in which the awareness of experiences is contextualized within the individual's world view) offers a useful alternative to 'clinical insight' (acceptance of an illness model). Eight participants selfidentified as hearing voices or having other unusual experiences, and also as having religious or spiritual beliefs that were important to them. Semi-structured interviews were conducted and coded using IPA.

When examples of unusual experiences were volunteered, often participants offered both spiritual and biological explanations as potential models that could be held, with implications that different situations might prompt them to favour one over the other, or that both might concurrently be held as valid. Participants were able to name origins for their explanations, such as read material, contact with others, a 'felt reality' of their experience that linked them to a spiritual explanation, or a result of the framework for life and the world that they already held. Participants were able to identify that they engaged in a process of evidence-gathering and testing for their beliefs, with a sense that their explanations for their experiences were not held in a fixed and rigid way.

Limitations of this study were the small number of participants, and the fact that participants were specifically selected for significant religious or spiritual beliefs that might limit applicability to voice-hearers without such beliefs. However, the study suggests that multiple contradictory explanations can be held, with an ongoing evaluative process allowing for alteration in explanatory models, and the possibility of altered circumstances leading to changes.

#### Influence of others

## Awan et al (2017)

The study aim was to examine if a brief educational intervention delivered by healthcare assistants (which specifically included education on a biological model of 'Schizophrenia') altered causal attributions for clients with a diagnosis of 'Schizophrenia' in contact with mental health services. 103 participants were randomly allocated to a control or an experimental group. A SEMI was carried out at baseline and at 3 month follow up. Content analysis was used to generate categories for explanatory models, which were then subject to quantitative analyses.

At baseline, there was no significant difference between the intervention group and the control group in endorsement of biological causes for their difficulties. At the follow up, significantly more participants in the intervention group than the control group endorsed biological causes for their difficulties.

There were some methodological limitations: there were significant betweengroup differences at baseline (for example significantly fewer people in the intervention group than the control group endorsed 'the supernatural' as a causal factor, and these between-group differences were not controlled for in calculating difference at follow up. However, it does seem that the causal models endorsed and taught by clinical staff influence explanatory models used by voice-hearers in contact with mental health services.

## Lewis et al (2020)

The study aim was to explore the role of spirituality in the sense-making process of hearing voices. The 5 participants were described as 'voice hearers', recruited from mental health services. Semi-structured interviews were coded using IPA. Themes identified were 'Need for a connection'; 'Values about self and identity'; and 'Making sense'.

The theme 'Making sense' contained subthemes 'Difficult to express'; 'External to self'; and 'Influence of others'. The subtheme 'influence of others' is relevant to understanding how causal attributions are developed. Participants named several ways others were influential to their own explanatory models, including how they had seen others make sense of mental health difficulties, particularly in early life, and how mental health services influenced explanatory models.

While the study was limited by small numbers of participants, it appears that the beliefs held by others and contact with others influence voice-hearers in their making sense of voices.

## Geekie, (2013)

The study aim was to gain a greater understanding of how voice-hearers describe and relate to their causal explanations for voices. 15 participants, already receiving psychotherapy with the primary author within which causal explanations had emerged as relevant, agreed to participate and a total of 51 sessions were recorded and analysed using grounded theory (though findings reported in this chapter were descriptive rather than inferential).

Key findings were that participants tended to have "flexible but well-formed ideas of causation", which were often multifactorial and could accommodate apparently contradictory factors; that there were themes in causal factors identified corresponding to social / interpersonal, psychological, or biological models; and the importance of 'narrating experience'.

Within the theme of 'narrating experience', subthemes were 'attitude to storytelling' (including the importance of having agency in this narration, rather than accepting another's explanation) and 'experiences of invalidation' (with comments on how this narrating of experience has been undermined, undervalued, or overlooked by others). The role of the listener is discussed explicitly with the potential for the listener to be undermining; the potential impact of an accepting listener on the formation of causal explanations does not explicitly emerge from these identified themes.

The conclusion relevant for this thesis is that voice-hearers desired to have agency in the development of causal explanations for voices; a space to narrate one's own story is a means by which this can be accomplished, though with risk of the 'audience' being undermining to this process.

## Payne, Allen, & Lavender (2017)

The study aim was to investigate how attendees of HVGs experienced a Hearing Voices group. Participants were 8 voice-hearers. Semi-structured interviews were conducted on changes in understanding of their voice-hearing, and its impact on their lives. These were analysed using IPA. Four main themes emerged: Healing (connecting with humanity; Group as an emotional container; Making sense of the voices and me; Freedom to be myself and grow.

The theme 'Making sense of the voices and me' has relevance for understanding the development of causal attributions for voice-hearing. Subthemes within this included: an opportunity to explore safely; gaining wisdom; and "clearer in myself"/personal growth. It appears that the safety of the group reduced shame and catastrophising in a way which made it easier to engage in sense-making; that the group provided voice-hearers with an experienced audience who could support one another to gain insight; and that this meaning-making was associated with increased coping.

While the applicability is limited by small numbers of participants, Hearing Voices Network groups appear to be a useful environment for making sense of voices, with safety and shared wisdom being important elements of this.

#### Conclusions from supplementary articles

Explanatory models of voice-hearing are dynamic and subject to ongoing revision over time (McCabe & Priebe, 2004a). Explanatory models for voicehearing may differ according to cultural background (McCabe & Priebe, 2004b). The influence of cultural background may be both broad (informed by wider cultural norms) and specific (informed by day-to-day experiences of living within a culture; Conrad et al, 2007). Explanatory systems form from the cultural repertoire, with a significant role of the media and new systems of explanation potentially becoming available as voice-hearers enter mental health services (Larsen, 2004). Multiple contradictory explanations can be held, with an ongoing evaluative process allowing for alteration in explanatory models, and the possibility of altered circumstances leading to a change in preferred model (Marriott et al, 2019). The causal models endorsed and taught by clinical staff can influence models used by voice-hearers (Awan et al, 2017). The beliefs held by others and contact with others influence voice-hearers in their sensemaking (Lewis et al, 2020). Voice-hearers desired to have agency in developing causal explanations for voices. A space to narrate one's own story is one

means for accomplishing this, though with risks of 'audiences' undermining this process (Geekie, 2013). HVGs appear to be a useful environment for sense-making, with safety and shared wisdom being important elements of this (Payne, Allen, & Lavender, 2017)

## Main articles:

Three articles identified as specifically exploring the development of causal beliefs for voice-hearing are listed in Table 2, with in-depth analysis for each below.

# Table 2. Three main identified articles in understanding the development of causal beliefs for voice-hearing

Title	Author and Year	Study Location
"I'm not telling an illness story. I'm	Clements (2015)	Australia
telling a story of opportunity": Making		
sense of voice hearing experiences		
"Opening the curtains": How do voice	Holt & Tickle	UK
hearers make sense of their voices?	(2015)	
"I believe I know better even than the	Carter,	UK
psychiatrists what caused it": Exploring	Read, Pyle, &	
the development of causal beliefs in	Morrison (2018)	
people experiencing psychosis		

Clements (2015): "I'm not telling an illness story. I'm telling a story of opportunity": Making sense of voice hearing experiences

<u>The study</u> aim was to explore how adults with lived experiences of voicehearing understand and make sense of these experiences.

The participants were five self-identified voice-hearers, attending a Hearing Voices Recovery Support Group (HVRSG). Participant ethnicity was not reported. This was a nine-week group series, co-facilitated by an expert-byexperience and a mental health clinician, based on a Hearing Voices Movement model. The researcher was not involved in facilitating or evaluating any clinical outcome of the group series. Semi-structured interviews were conducted, with questions including: "Tell me the story of your experience of voice-hearing from the beginning," "How did you make sense of your first voice-hearing experience at the time?" and "What contributed to this?" The interviews were coded using thematic analysis, with a phenomenological approach.

An overarching theme was identified of *'tension and recalibration'* – a recurrent cycle of exploration and re-adjustment with regards to voice-hearing experiences. Five sub-themes included *'beliefs about voices'*, *'navigating the relationship with my voices'*, *'learning to live with my voices'*, *'rediscovering myself with my voices'*, and *'influences to understanding my voices'*.

*'Beliefs about voices'* incorporated beliefs about voice origin, voice identity, and power and control of voices. A period of confusion was highlighted when voice-hearing first emerged, characterised by difficulties in sense-making, generation of multiple theories, and learning of alternative perspectives as potentially challenging previously held theories.

*'Navigating the relationship with voices'* highlighted that a relationship with voices evolved over time, with a need to acknowledge voices and voices' needs, balanced against a need for boundaries.

*'Learning to live with my voices'* incorporated factors of acceptance and discovering the meaning and purpose of voices – which appeared important for integrating voices into voice-hearers' lives.

*'Rediscovering myself with my voices'* highlighted that voice-hearing interacted with self-identity, with choices to accept or reject illness identities, and voice-hearing experiences providing opportunities for personal growth.

*'Influences to understanding my voices'* highlighted that initial responses from others (including mental health services) profoundly influenced how participants understood voices. Initial responses from services often supported beliefs that voices were abnormal, with illness models often provided by services and invalidating other perspectives. Contrastingly, the HVRSG offered new
perspectives (including a traumagenic model), which was valued by participants. Social support from family and friends was also mentioned, with potential to help or hinder understanding.

There are several findings relevant to this thesis. Understanding the meaning and purpose of voices was identified as an important part of *'Learning to Live with Voices'* – as this allowed voices to become more integrated into voicehearers' lives. Plausibly, understanding meaning and purpose of voices could be connected to ability to acknowledge voices' needs, which was also highlighted as part of navigating the relationship with voices. Understanding voices is a non-linear process, and meaning-making may not have a defined end-point.

Other people (mental health services, HVGs, family and friends) were important in developing understanding of voice-hearing. Services could be influential in sense-making, but illness models presented by services were experienced as invalidating and unhelpful for sense of self. Family and friends were at times helpful and at times unhelpful in supporting understanding, and did not always allow free expression of experiences. HVGs may provide a venue where it is easier to speak up and where new perspectives become available.

The COREQ checklist (Tong et al., 2007) was used to appraise quality of this study. Of the 32 items on this checklist, the author provided information on 22 items. Notably absent was information about the author, including their and their co-researchers' own positioning and biases, and how these might have impacted on information gathering and analysis. The participants of this study were also not invited to comment on transcripts or comment on analyses prior to study completion.

A further limitation of this study is that the low participant number limits applicability. Ethnicity was not reported. Additionally, although the HVRSG drew upon ideas from the HVM, it was not a prototypical HVG in that it was time limited, with a clinician co-facilitator. This, in conjunction with references to outcome measures (Self-Identified Stages of Recovery Assessment, Beliefs About Voices Questionnaire) leaves it unclear if the group intended to engender measurable clinical change, rather than the group being owned and steered by attendees. Further, despite providing useful information on the importance of personal meaning-making for voices, information about the role of others in meaning-making was more limited. For example, there was no exploration of what qualities or content within a social exchange make this helpful or unhelpful for meaning-making.

Holt & Tickle (2015): "Opening the curtains": How do voice hearers make sense of their voices?

The study explored and developed a tentative theory of how voice-hearers made sense of the origin and maintenance of distressing voices.

This study used grounded theory to analyse semi-structured interviews of eight participants, self-identified as hearing distressing voices. Interview questions included "What is your understanding of why you started to hear voices?", "What is your understanding of why you continue to hear voices?", and "What do you think has influenced your view about why you hear voices?"

Three over-arching themes were reported: '*search for meaning*', '*view of self*', and '*explanations for voices*'.

'Search for meaning' included subthemes 'personal meaning-making', 'shared sense-making', and 'mental health services'. 'Personal meaning-making' included voice-hearers asking questions of themselves and the voices, and developing a theory of understanding. 'Shared sense-making' included seeking information from others (such as the internet or peer support groups) due to inability to complete sense-making processes alone. 'Mental health services' were referred to by all participants as significant in sense-making, though not always positively. They did not always offer acceptable explanatory models, might not ask about experiences in a way which supported sense-making, and sometimes responded to concerns about meaning by increasing medication. Not all participants felt that sense-making was complete despite efforts made.

*'View of self'* considered how beliefs held by individuals about themselves impacted on ability to make sense of voices. Subthemes included *'blocking agents'*, and *'role of the voices'*. Blocking agents were factors impeding ability to make sense, and included not seeing explanation of voices as relevant, hopelessness regarding changing voice-hearing experiences, and fear of judgement from others impeding shared sense-making.

*Explanations for voices*' highlighted that participants drew on multiple frameworks, without necessarily settling on one explanation. Most participants reported actively rejecting theories imposed upon them by others.

Grounded theory aims to move beyond identification of themes and consider underlying processes at work. Accordingly, participants were theorised to draw on interpersonal, intrapersonal, and parapersonal frameworks when exploring explanations for voices, with their ability to engage with this hypothesised to be affected by sense of agency and stigma experienced.

Voice-hearers' sense of agency was identified as their perceived ability to seek out and draw upon different meaning-making processes. The authors felt that influential factors here included dominant discourses of pathology, mental illness, and Western cultural assumptions of autonomy versus help-seeking, placing voice-hearers in a 'double bind' between personal responsibility and a perceived incompetence to act, limiting agency in making sense of voices. The authors highlight that meaning-making occurs within the context of stigma towards voice-hearing, potentially affecting frameworks available to make meaning within.

The authors concluded that participants attempted to construct an understanding of voices through drawing on three main frameworks (inter-, intra-, and para-personal), but the relative success of this, and potential usefulness of understandings developed, is affected by the sense of agency, stigma, and hope/hopelessness perceived by voice-hearers.

Relevant for this thesis, all participants engaged in a search for meaning. This search for meaning was both individual and shared, with contact with mental

health services being a significant, though not necessarily helpful, experience. The wider social context of voice-hearing experiences (for example experiences of stigma) had implications for how free voice-hearers felt to engage in meaning-making.

The COREQ checklist (Tong et al., 2007) was used to appraise quality of this study. Of the 32 items on this checklist, the authors provided information on 15 items. Notably absent was information about the author, including their and their co-researchers' own positioning and biases, and how these might have impacted on information gathering and analysis. It was also unclear how participants were recruited (e.g. through mental health services, HVGs, or other sources) and whether this might impact on results. The participants of this study were also not invited to comment on transcripts or comment on analyses prior to study completion. The small number of participants, who were also all White British, limits applicability.

It was highlighted that participants actively rejected theories imposed upon them by others, but questions still remained. For example - is it what the model is, where it comes from, or purely its externality that renders it unacceptable? It could potentially be useful to know more about different sources voice-hearers can draw on for theories, and how these compare to each other.

Carter, Read, Pyle, & Morrison (2018): "I Believe I Know Better Even than the Psychiatrists What Caused It": Exploring the Development of Causal Beliefs in People Experiencing Psychosis

The study explored the explanatory models of individuals with experience of psychosis, and what factors contributed to their development and maintenance. Thematic analysis was used to analyse semi-structured interviews with 15 White British users of NHS mental health services in England. Participants were required to either have a diagnosis of 'Schizophrenia', 'Schizo-affective disorder', psychosis or psychotic-like experiences, or be in contact with early intervention for psychosis services. The interviews asked about perceived

causes of participants' experiences and how these beliefs developed and changed.

The study's theoretical backdrop was that understanding causal beliefs is relevant for treatment choices, and people will process information and form attributions using logical (temporal precedence) and selective (most noticeable factors) processes. Causal attributions may be influenced by an individual's subjective needs as well as objective evidence, suggesting that individuals will develop attributions based on errors, bias and incomplete data gathering, to promote a favourable self-view.

A minority of participants ultimately did not endorse any aetiological beliefs, however all participants seemed to welcome conversation regarding their voicehearing. Causal models were often sophisticated and personally meaningful. These might include a 'main cause' but with multiple factors being considered relevant, and participants suggesting potential additive effects.

Several themes emerged around developing and maintaining causal beliefs. *'Moving from believing experiences are real perceptions to needing a causal explanation*' highlights that initially experiences are received as 'real' and don't need a causal explanation, and there may be specific times when this changed and the search for meaning began. *'The cause is not immediately obvious'* referred to a time period, potentially ongoing, where they are unsure of causes.

Themes emerged suggesting processes by which causal beliefs were formed. In *'evaluate psychosocial causes and make a decision about their relevance,'* there is a deliberate search for meaning in environment and context, with acceptance or rejection of explanations generated. In *'understand experiences based on their preconceptions of psychosis,'* previous knowledge influenced conclusions reached. *'Attribute to factors that have a positive impact on how they feel'* highlighted that spirituality or a positively viewed sensitivity to others might be preferred as explanations. Similarly, *'reluctance to attribute cause to drug-use'* might relate to favouring positively viewed explanations. The role of others in meaning-making was discussed. In *'discuss with others and evaluate their opinions,'* participants referred to models of aetiology provided by family, friends and professionals, including seeking out the opinions of others, but differing in degree to which they endorsed these views. In *'professionals do not offer a causal model,'* most participants said their healthcare teams offered no model beyond a diagnosis.

The unfixed nature of beliefs was discussed, including *'differing conviction in beliefs*,' and *'awareness of a discrepancy between contradictory beliefs*,' whereby beliefs may be flexible, with possibilities for holding more than one belief simultaneously.

There are several findings relevant to this thesis. This study highlights a search for meaning as a process with deliberate and less deliberate elements *('evaluate psychosocial causes and make a decision about their relevance'* contrasted with *'understand experiences based on their preconceptions of psychosis'*), and including intentionally involving others in meaning-making processes. It also highlights that beliefs are unfixed, potentially contradictory, and with potential fluidity in how differing beliefs are weighted at different times – something which was not deeply explored.

The COREQ checklist (Tong et al., 2007) was used to appraise quality of this study. Of the 32 items on this checklist, the author provided information on 19 items. For example, there was no information on whether participants of this study were invited to comment on transcripts or comment on analyses prior to study completion.

There were also additional limitations. Despite having more participants than the other two main studies, this was still a small study, with only White British participants, limiting applicability. All participants were in contact with mental health services, with this apparently the primary 'venue' considered for social meaning-making. There is significant scope for understanding more about how voice-hearers access and make use of other venues for social meaning-making, particularly given the identified theme *'professionals do not offer a causal model'*.

#### Conclusions from the main articles

Voice-hearers actively seek out others' views when forming explanatory models (Carter, Read, Pyle, & Morrison, 2018; Holt & Tickle, 2015), with the ideas of others sometimes accepted but sometimes rejected (Holt & Tickle, 2015). Family and friends have potential to help or hinder meaning-making processes (Clements, 2015).

Mental health services seem to be influential but not always helpful in meaningmaking processes (Clements, 2015; Holt & Tickle, 2015), sometimes providing illness models that invalidated other perspectives (Clements, 2015) or undermining discussions of causal beliefs (Holt & Tickle, 2015). Contrastingly, Carter, Read, Pyle, and Morrison (2018) found that mental health services did not provide much in the way of causal explanations. Overall, this suggests that mental health services do not support voice-hearers in considering multiple potential explanatory models for voices, and that when they do offer input it is influential but often narrowly focused on an illness model.

Peer support groups offer venues where it may be easier to speak up and where new explanatory models may become available (Clements, 2015). It was unclear if participants in the latter two studies had made significant use of peer support, and if so how this compared to the utility of other social venues for sense-making.

Holt and Tickle (2015) highlight stigma as a socially contextualised experience that may impede sense-making (connectedly, in the supplementary articles Payne et al., 2017, highlight a sense of safety as important in enabling discussion of causal beliefs). Aside from 'safety' it was not explored within these three studies what qualities make a social venue helpful in discussing causal beliefs for voice-hearing. It is also unclear whether qualities of peer support groups originating from the HVM – including being self-owned and directed, open-ended, without focusing on any particular outcome – would impact on meaning-making. Many voice-hearers do succeed in developing sophisticated, fluid, multifactorial causal explanations for their voice-hearing (Carter, Read, Pyle, & Morrison, 2018), but this might be an ongoing rather than completed process (Carter, Read, Pyle, & Morrison, 2018; Holt & Tickle, 2015). Besides being unfixed, beliefs are potentially contradictory (Carter, Read, Pyle, & Morrison, 2018). There could be value in exploring further how contradictory beliefs are accommodated, and how and when a switch in preference between plural beliefs occurs.

### 1.4. The Current Project

#### 1.4.1. Study rationale

Limitations in the previous research conducted, and the conclusions that can be drawn from them, were identified in the literature review. The review indicates that the search for causal explanations for voices is a common, if not universal, experience, and one that occurs both singly (with evaluations based on preexisting beliefs) and socially. HVGs appear, for some people, to be useful venues for sense-making in terms of offering acceptable new perspectives on voice-hearing. Comparatively, mental health services are influential but often received as offering only a biological model or no explanation at all. If HVGs offer discussion of causal beliefs where mental health services do not, this could be considered a particular benefit of HVGs. Research into sense-making centred on HVGs seems appropriate in order to explore this further. Although studies on experiences within HVGs have been conducted previously in the UK, I was unable to identify any previous studies in the UK focused around the role of HVGs specifically in making sense of voices.

We lack in-depth information on the role of others in meaning-making, such as what qualities in an interaction contribute to acceptance or rejection of novel information presented, and how this shows itself in HVGs compared with other venues accessed by voice-hearers.

The literature review also highlighted that the search for meaning is potentially open-ended, with causal attributions appearing to be flexible and open to adaptation over time, and possibilities for multiple contradictory beliefs to be held simultaneously. More could be explored regarding what promotes a shift between causal models and how this shift is experienced by voice-hearers.

#### 1.4.2. Relevance to clinical psychology

Understanding causal attributions for voice-hearing can provide context for understanding affective outcome and treatment decisions made by voicehearers. Understanding how such causal attributions develop and continue to alter can help us shed further light on this process. This may better position clinicians to support voice-hearers in identifying and incorporating causal models they find preferable and relevant for obtaining personally meaningful outcomes.

Understanding development of causal attributions may also be helpful in cognitive or trauma-based formulations for voice-hearing, where attributions about experiences play a role in understanding distress associated with voice-hearing.

# 1.4.3. Research questions

This research broadly aims to explore how voice-hearers develop causal models for their voice-hearing experience. Questions within this are:

- **1.** How is shared sense-making involved in the development of causal models?
  - i) How do voice-hearers experience HVGs as a venue for developing causal attributions for voices?
  - ii) How does this venue compare to other opportunities for shared sense-making?
  - iii) What qualities in a social interaction support or detract from shared sense-making?
- 2. How do voice-hearers navigate multiple potential models?
  - i) Are concurrent models held?
  - ii) What circumstances prompt a shift between preferred models?
  - iii) How is such a shift experienced by voice-hearers?

# **CHAPTER 2: METHODOLOGY**

# 2.1. Chapter Overview

This chapter firstly discusses the rationale for thematic analysis (TA). This includes my epistemological stance of critical realism and how my stance and values relate to a history of epistemic injustice and voice-hearer exclusion in positivist research in this field, with discussion of TA as a method congruent to these.

Next discussed is the research procedure. This includes ethical approval, creating the interview schedule, selecting participant inclusion and exclusion criteria, recruitment, and data collection. Additionally summarised is the participant information.

I then discuss my analytic approach, reflexive TA. This includes discussion of reflexive TA in comparison to other subtypes of TA, and how analysis was conducted with reference to six stages recommended by Braun and Clarke (2006).

Finally included are personal reflections on how my experiences and valuesbase may impact on analysis.

### 2.2. Rationale for chosen research method

### 2.2.1. Epistemology and Ontology

Ontology is the study into the nature of reality - what there is that can be known, what entities exist, and what the relationships are between them. Epistemology is the study into the nature of knowledge and how we possess knowledge – how is it that we know what we know (Cruickshank, 2012). The ontological and epistemological assumptions underpinning research delimit what areas of study are seen as valid and open to inquiry, what elements of experience are 'taken for granted' and which are seen as worthy of investigation, and how research is usefully conducted. Ontological and epistemological positions include but are not limited to realist/positivist, social constructionist, and critical realist (Cruickshank, 2012).

An epistemological position of realism sits within ontological realism - assuming there are processes existing independently of observers, which can be examined (a 'real world'). Realist positions exist on a continuum of naïve to critical (Willig, 2012). A naïve realist epistemological position holds that knowledge can be directly gathered through observation and experimentation (positivist methods; Willig, 2012). This stance requires the assumption that observers can be neutral and can avoid influencing data-gathering.

An epistemological position of critical realism sits between a naïve realist and a social constructionist viewpoint (Pilgrim & Bentall, 1999). This takes a position of ontological realism – there is a 'real world' – however, perception of facts is based on interpretation, not observation, and is subject to social, historical, and cultural forces (Cruickshank, 2012).

A social constructionist epistemological position is grounded in ontological relativism – that 'reality', if it exists, is not accessible to us; only representations of the world are accessible, with no means of comparing the accuracy of these against 'reality' (Burr, 2015). As such, psychological phenomena are not 'real' but are socially constructed. How we come to socially constitute meanings, and

the social consequences of these meanings, is the key area of study (Cruickshank, 2012).

Epistemological positioning and connected methodological choices can have marked impacts on participant experience, which I aimed to bear in mind throughout.

#### 2.2.2. Epistemic injustice and voice-hearer marginalisation in positivist research

Epistemic injustice – a wrong done to someone in their position as a 'knower' – includes testimonial injustice, where prejudice leads to listeners not endowing speakers with credibility, and hermeneutical injustice, where the social and cultural knowledge set available to persons or groups is insufficient for making sense of and communicating experiences (Kidd & Carel, 2017). Both forms can apply to voice-hearers. The presence or potential of diagnostic labels may strip voice-hearers of credibility and absolve witnesses of responsibility to explore voice-hearers' personal meanings (Coles, 2013). Voice-hearers have also been excluded from participating in the process of categorisation of experiences that underpins realist biomedical assumptions of voice-hearing as an illness symptom (Wallcraft, 2013). This has created a set of shared meanings used by positivist researchers and biomedical clinicians which may not correspond to many voice-hearers' own experiences.

Engaging in positivist research may position research subjects as passive objects who experience an external intervention, with questions of meaning determined by researchers, not the researched (Wallcraft, 2013). While this includes highly respected and valuable forms of research (such as randomised controlled trials), a focus on trends across large numbers, statistical outcomes, and generalisability excludes individual testimony. Such methods risk replicating epistemic injustice and the exclusion of voice-hearers from research.

Qualitative research has the capacity to 'give voice' to participants and allow communication of personal meaning. Nonetheless, qualitative research can also marginalise participant experience. Waddingham (2015) noted that in some qualitative research the voice of participants is present early on, but as

conclusions are drawn participants are discoursed about rather than participating in conversation. Waddingham advises researchers to acknowledge interpretations as subjective and tentative, to ensure participants retain ownership of their own words and meanings. Further, she advises researchers to approach qualitative information with a mind open to complexity, rather than allowing their own research aims to override complexity or contradictions (Waddingham, 2015).

### 2.2.3. Critical realism

Taking a purely realist/positivist stance risks replicating voice-hearer marginalisation and limits incorporation of voice-hearers' personal meanings. Taking a social constructionist stance offers space personal meanings and considering social and contextual factors as integral for sense-making, however taken to its logical conclusions a social constructionist stance places the stated beliefs of voice-hearers as themselves a valid area for interrogation and discourse, rather than respecting these as accounts of experience.

#### Therefore, a critical realist stance was taken. Critica

xdl realism acknowledges that statements made by participants are inevitably affected by the historical, social, and situational context in which they are made. Nonetheless, critical realism holds that it is possible to investigate the 'real world', and that participant statements contain valuable information about the 'real world', although this information is filtered through the lens of participants' contexts (Cruickshank, 2012). A critical realist stance required me to bear in mind social and contextual influence son how voice-hearing experiences and causal attributions for these are constructed, while also honouring participants' ability to give reliable accounts of themselves and their experiences.

# 2.2.4. Thematic Analysis

Aiming to avoid voice-hearer marginalisation has also influenced my chosen methodology. Aligning with the BPS code of human research ethics (being respectful of insights, expertise and experiences of participants; BPS, 2021) and the HVM prioritisation of personal testimony as important evidence (Corstens et al., 2014), I determined to use a qualitative approach focusing on personal narratives of voice-hearers. I aimed for my findings to draw directly from, and as far as is possible to be in conversation with, participant contributions, rather than introducing further researcher subjectivity by discoursing about them.

Different qualitative methods were evaluated on their ability to answer the research questions from a critical realist positioning. Grounded theory is aimed towards theory development and towards considering interventions requiring a theoretical rationale (Braun & Clarke, 2006; Starks & Brown Trinidad, 2007). I felt that grounded theory would therefore be liable to the 'discoursing about' that I wished to avoid. Phenomenological analyses, while aligning closely with my aim of prioritising personal testimony and individual experiences within this research, are theoretically bounded by close consideration of embodied, individual experiences that are explored for common essences (Starks & Brown Trinidad, 2007). Contrastingly, my research includes interpersonal sense-making.

Thematic analysis (TA) seemed well positioned as a flexible analytic method fitting within a critical realist epistemology, which would allow interview data to be explored in relation to the research questions. This methodology will hopefully allow experiences of voice-hearers to 'speak through', without using them to infer a deeper layer of meaning.

TA refers not to one specific procedure but to a collection of methods (Braun et al., 2018). I have detailed below the analytic approach used here.

#### 2.2.5. Limitations

Logistical constraints placed upon a thesis have limited participant-led practise and the embodiment of values foundational to this research.

The research questions were not developed by or in significant consultation with voice-hearers. The interview schedule, aimed to elicit conversations regarding these research questions, inevitably limited participants' opportunities to guide

the conversation. Although commentary was sought on research questions and interview schedule from experts-by-experience (discussed below), this was a consultative process rather than a collaboration, co-production, or user-led research (National Institute for Health Research, NIHR, 2021a).

Waddingham (2015) recommended consulting with participants on identified themes, to ensure these reflect participants' own experiences, however timedemands made this unfeasible. This would also have required further time commitment from participants; as funding was not available to pay research contributors it seemed inappropriate to request this (NIHR, 2021b).

### 2.3. Procedure

### 2.3.1. Ethical Approval

Ethical approval for this research project was granted by the Research Ethics Committee for The UEL School of Psychology. The Ethics Review Decision Letter, an Ethics Amendment Request, and the finalised ethics application form (incorporating all amendments) are in Appendices A-C.

Legal and ethical considerations for conducting research during the COVID-19 pandemic were considered from inception. Given the potential of social distancing being required either by law or by participant preference, and given BPS guidance on research with human participants during Covid-19 (BPS, 2020), I planned to conduct all interviews remotely. This unfortunately carried the unavoidable possibility of excluding voice-hearers experiencing digital poverty or lacking confidence with technology.

Addressing information security concerns, Microsoft Teams (held under license from UEL) was selected as a secure program for conducting remote interviews. A data management plan was approved by UEL's Research Data Management Team (Appendix D).

The standard ethics approval process required me to consider whether potential participants were 'vulnerable' and therefore potentially less able to freely give or withdraw consent to participate. I understood this concern to arise from institutional understandings of voice-hearing as symptomatic of underlying pathology. The stance taken here is that voice-hearing can be understood as separate to pathology. Nonetheless, some voice-hearers may have additional difficulties that leave them vulnerable to exploitation, or experience significant distress related to their experiences which would increase risk of harm from participation. Therefore, it was agreed that while diagnostic labels were immaterial to this research project, currently being under the Mental Health Act would be an exclusion criteria, as a proxy for greater risk of vulnerability or distress. The risk of participant distress was otherwise addressed through openly discussing this possibility at initial contact and encouraging participants

to selectively answer interview questions if preferred. Participant information and debrief letters, including information on accessing further support (see Appendix E and F), were also provided for harm mitigation.

The BPS Code of Human Research Ethics (BPS, 2021) states that offering incentives for research can be ethically problematic if they compromise a person's freely made decision to participate in research, but that payment should be given if participants are giving up substantial amounts of time, and other costs reimbursed. It was judged that participation should not entail additional costs or extraordinary time commitment. Therefore payment was not provided to participants. Ethically, this must be balanced against this research's use of participants including experts-by-experience being expected to share expertise without reimbursement. It must also be acknowledged that this decision was primarily logistical; funding was not available to pay research participants. I was transparent throughout recruitment that participation would be unpaid.

# 2.3.2. Creating the interview schedule

No previous standardised approach to exploring explanatory models was identified which explored aetiology of causal models. Therefore, I determined to use semi-structured interviews, with questions specific to this study. While a schedule inherently delimits which conversations are possible, the semistructured format hopefully permitted meaningful and contextualised exploration.

A representative from the UEL Doctorate of Clinical Psychology Service User and Carer panel was consulted about the research questions and interview schedule. Further consultations were conducted with Rachel Waddingham, the Chair of the English Hearing Voices Network and expert-by-experience in voicehearing, who provided substantial feedback on an initial draft interview schedule, resulting in removal of questions about content and nature of voices. As identified by Waddingham, it is unethical to enquire about sensitive areas not directly relating to the research questions, aligning with the BPS code of human research ethics on scientific integrity (ensuring that the time contribution of participants is used well) and maximising benefit and minimising potential harm (BPS, 2021).

The finalised interview schedule (Appendix G) includes questions into experiences at HVGs, how the participant makes sense of their voices, any alteration of sense-making over time, the impact of current and historical subjective explanations for voice-hearing, experiences of HVGs as venues for sharing and developing explanations for voices, and the role of people outside HVGs in making sense of voices.

# 2.3.3. Establishing inclusion and exclusion criteria

Participants required first-hand experience of HVGs. Longden et al. (2018) found that positive changes from HVG attendance occured quickly, rather than being affected by duration of membership. It is unclear if group influences on development of explanatory models would likewise occur quickly, however based on this finding and to widen the recruitment pool, having attended a minimum of three HVG sessions was established as an inclusion criteria.

Participants were not asked about diagnoses. This aligned with the HVM ethos of not focusing on a medicalised, pathologised view of voices (Corstens et al., 2014), and with research highlighting that voice-hearing manifests in both clinical and non-clinical populations (Beavan et al., 2011), and across people with a range of diagnoses (Waters & Fernyhough, 2017).

Given the potential of cultural influences on causal attributions for voice-hearing (Conrad et al., 2007; Larsen, 2004; McCabe & Priebe, 2004b), I confined recruitment to UK residents, to allow more specific focus on the influence of HVGs.

In order to understand whose voices might be accessible when recruiting specifically with regards to HVG attendance, and whose voices might not, I attempted to find survey data on the demographics of HVG attenders in the UK, or demographics of England HVN members. Unfortunately, I could not find

published records of this data. On 31/07/2022 I contacted the chair of the England HVN to inquire about any records they held regarding their members' demographics, but I have not yet received any response. As a result, it may be that the HVGs are seen as less accessible or less relevant to some demographic groups, who will therefore be less likely to be represented in this research, but I do not have the available information to draw clear conclusions about this or to compensate for it.

# 2.3.4. Recruitment

Publicly available lists of HVGs in the UK (from the England HVN's website, and from resource lists curated by Mind) were used to generate a contact list of HVG facilitators. 66 facilitators were contacted by email, provided with information about this research, and invited to share information about the research project with their groups. Seven group facilitators responded saying they intended to include information on the research project in a newsletter or social media page, discuss it as a group, or share it with specific group members.

The England HVN also shared information about this research as a news post on their website on 29/06/2021, and in their newsletter in the first week of October 2021. Members of the England HVN Board were asked to disseminate the research advert among their own networks. The London HVN also shared information on this research in their newsletter.

A visual flyer advertising the research project was shared on Twitter and Instagram, and in the Intervoice group on Facebook. Text and visual flyers used for recruitment are included in Appendix H and I.

# 2.3.5. Participants

Inclusion and exclusion criteria for this research project were that participants must:

- Be over the age of 18
- Currently reside within the UK

- Self-identify as hearing voices or having other unshared sensory experiences
- Have attended at least three HVG sessions, in-person or online
- Not be currently under the Mental Health Act 2007

Participants could have any psychiatric diagnosis or none, and might or might not be involved with mental health services. Participants had to be able to organise and communicate their thoughts over a relatively sustained period of time (up to an hour). They had to be able to hear potentially sensitive questions and selectively answer if necessary for managing distress. These subjective criteria were assessed through initial email exchanges and through conversation prior to interview.

Participants contacted me by email, by direct message on social media, or by responding to a participant information letter available on Microsoft Forms (Appendix E). Of 14 initial contacts expressing interest in taking part, 10 completed interviews. No participants withdrew from the study.

Ages of the 10 participants ranged from 25-74 years, with a mean age of 51.1 years. Six described their gender as female, and four as male. Seven participants identified as White British, two as British Pakistani, and one as White Jewish.

The participants had attended HVGs for varying lengths of time (ranging from a few months to over a decade). Five were currently active attenders. Five had also facilitated HVGs (including three still actively attending and facilitating, and two not currently actively attending or facilitating).

Pseudonyms were selected for each participant, and are used throughout the Results and Discussion chapters.

# 2.3.4. Data collection

Participants were provided with an information sheet (Appendix E) and given opportunities to ask any initial questions via email or through an initial phone or

video call. Consent forms were completed and returned by email or electronically completed through Microsoft Forms.

A video call was arranged over Microsoft Teams. Screening questions were asked to ensure participants met inclusion and exclusion criteria. Participants were given further opportunity to ask questions. As failure to engage research participants in my own sense-making process may alter the data I receive and my ability to accurately interpret it (Waddingham, 2015), I was transparent throughout about the research aims and how they informed the interview questions.

Participants were invited to either continue immediately with the interview or to delay and consider further. All 10 participants chose to continue immediately. They were informed that interview recording would begin. At this point the interview schedule was used to guide conversation. After a question was asked, the participant was allowed to speak freely, with prompt questions (such as those on the interview schedule), reflective summaries, and my authentic responses and expressions of interest used to encourage participants to continue exploring the topic. Interview schedule questions were asked out of order if naturally invited by the conversation, but I aimed in each interview to include every main question.

Following interview, participants were given further opportunities to ask questions. A debrief sheet (Appendix F) was sent to each participant.

Interview recordings and automatically generated transcriptions were downloaded from Microsoft Stream onto a secure computer system, then deleted from Microsoft Stream. All recordings and transcriptions were stored, password protected, on UEL's secure OneDrive for Business.

### 2.4. Analytic Approach

Braun and Clarke (2021b) discuss TA as having three versions: 'Coding reliability' TA, 'Codebook' TA, and 'Reflexive' TA, used here. Coding reliability TA aligns with positivist frameworks, using a clearly defined codebook to focus on replicability and reliability, with initially identified themes driving the ongoing coding process (Braun et al., 2018). Codebook TA provides a pragmatic compromise between this method and the more open and organic reflexive TA (Braun et al., 2018). With no pre-determined information needs and with no compelling need for a coding team (Braun & Clarke, 2021a), this compromise between efficiency and my value of openness and flexibility was unnecessary.

Reflexive TA centres on researcher subjectivity, organic and recursive coding processes, and deeply reflective engagement with data (Braun & Clarke, 2019). As such, reflexive TA matches my epistemological stance and values around letting participants 'speak for themselves' as much as possible.

I aimed for my approach to be inductive (analysis grounded in the data) rather than deductive (using existing theory and research as a lens through which data is analysed and interpreted; Braun & Clarke, 2021b). Although it is unrealistic to undertake analysis from a fully naïve standpoint, I intended to keep my impact as researcher 'visible' within this process (discussed in Personal Reflexivity, below). Accordingly, throughout this research I invited stakeholders (research participants, HVG facilitators, others who provided advice or support at any stage) to receive a research summary on completion. I intended that this accountability would remind me to hold interpretations tentatively and note my influence within the research.

In analysing the data, I used six stages of analysis recommended by Braun and Clarke (2006, 2021a).

# Familiarisation

In this stage, the researcher shifts from data generation to immersion in the data.

Interviews were conducted over the course of 19 weeks. I was concerned that if I began analysis of early interviews, my initial theme construction might alter my manner when carrying out later interviews, introducing new subjectivity and potentially influencing the information I received. Therefore, in accordance with the idea that data familiarisation begins during transcription (Braun & Clarke, 2006) I delayed transcription until all interviews were completed.

Transcriptions automatically generated by Microsoft Teams were closely reviewed and edited to ensure accuracy. I then re-read each interview again. During transcription and initial re-reading, I made casual notes, including on any points of personal resonance or anything that struck me as interesting or curious, aiming to focus both on the research questions and also to be broadly curious about overarching trends.

### Generating codes

This stage requires more detailed and systematic engagement with the data. Content is collated into chunks of text, with codes identifying chunks holding similar meanings. Codes are expected to evolve throughout this process in an organic way as insight develops, for example being split, combined, or renamed (Braun et al., 2018; Braun & Clarke, 2021a). Braun and Clarke caution against identifying themes too early, as this risks underdeveloped themes (Braun & Clarke, 2021a).

I used NVivo 12 to code the data. I regularly reviewed each code, often removing data into other codes as they branched off from each other or as my understanding of the data shifted. I often found participants' phrases resonant and meaningful, and as coding progressed I sometimes used such phrases as codes (including *'just diagnose and drug', 'services don't listen', 'everyone has their own stories'*, and *'you have to play the game'*). Through gathering more data under these codes I often found myself developing new understanding of the collected extracts, and accordingly finding a more cohesive name.

#### Generating initial themes

Themes are patterns of shared meaning underpinned by a central organizing concept, aiming to tell a coherent and insightful story in relation to the research

question (Braun et al., 2018; Braun & Clarke, 2019). Themes do not 'emerge' but are *"built, molded, and given meaning at the intersection of data, researcher experience and subjectivity, and research question(s)"* (Braun et al., 2018, p854). 'Candidate themes' are developed through the phases above and are 'tested out' for fit with the data set as a whole. Constructing themes might involve using codes as 'building blocks' or 'promoting' a substantial code.

As my codes combined I initially found myself drawn to a wide number of themes and 'stories' in the data, with significant overlap in the themes. At this stage, ideas were emerging about HVGs contrasted with traditional mental health services, about freedom versus constriction, safety versus risk, listening versus dismissal, and about power.

#### Reviewing and developing themes

Braun and Clarke emphasise the importance of not getting too attached to themes at the initial stage, as this can lead to 'thin' or overlapping themes (Braun et al., 2018).

Attempting to bear this in mind, and aware of my overlapping and chaotic data, I created a thematic map (normally recommended in the next stage; Braun et al., 2018). This map initially contained four areas: starting and stopping the HVG, experience and impact of attending the HVG, experience of contact with mental health services, and construction of explanatory models for voice-hearing. Standing back and observing, I drew new connections across these four areas, linking services who don't listen, healthcare professionals who provided transformative care, HVG attendees who shared their stories, and fear of disclosing voice-hearing into more developed themes about the kinds of conversations available to voice-hearers, and their impact. Appendix J contains a photograph of this thematic map.

At this stage, sharing candidate themes with my supervisor helpfully reminding me of a pragmatic need in the face of such rich data to focus closely on the research questions. I also removed from further consideration any items that only appeared relevant to one participant – setting a minimum of contributions from two participants as necessary to constitute a theme.

### Refining, defining, and naming themes

Theme naming is highlighted as a means of ensuring themes are usefully rich and nuanced. Themes that can be named with single words are unlikely to capture a story or pattern of shared meaning, and may be better understood as domain summaries or codes (Braun & Clarke, 2019, 2021b; Connelly & Peltzer, 2016). Similarly recommended is avoidance of too many subthemes – as themes should be rich, complex, and multifaceted, rather than brief or dry (Braun & Clarke, 2019). Defining each theme means delineating the theme's boundaries and central organising concept, to clarify the essence and scope of each theme, and reduce likelihood of theme overlap. This requires compiling all coded data for each theme and reviewing it to ensure that all data relates to a central organising concept, and checking themes against the whole data set (Braun et al., 2018).

This stage required a radical re-organisation of my themes in order to increase their distinctiveness from each other and to improve readability. I ultimately developed a theme 'order' such that each theme can be understood as building a new layer of understanding onto those previous. Although this may be seen as implying linearity to the construction of explanatory models, in actuality this should be read as linearity in this researcher.

At this stage, I and my research supervisor each reviewed sections of transcripts to explore whether my theme names and definitions seemed adequate for parsing the data, and to discuss any coding disagreements. The aim was not to ensure fidelity to an established codebook, but to enhance an ongoing reflexive process, and identify areas where my subjectivity might colour theme development. This process is further discussed in the Results chapter.

#### Producing the report

Braun et al., (2018) encourage researchers to view this as a final stage of analysis, as it can serve as a test of how well themes work individually, in relation to the dataset, and overall – approaching with a willingness to return to earlier stages of analysis if new insights occur. Indeed, at this stage, I identified a subtheme ('*comparing and rejecting explanatory models'*) that seemed wholly

connected to processes already encompassed within other subthemes. Resultantly, this was removed and the remaining subthemes re-checked to ensure distinctiveness.

#### 2.5 Personal Reflexivity

Within qualitative research the researcher is the instrument through which information is obtained (Pezalla et al., 2012). It is unfeasible to undertake qualitative research without changing the examined situation by my questions or my presence (Becker, 1996). Further, themes do not exist within the data, but emerge through researcher interpretation of the data (Braun & Clarke, 2019). It was therefore vital to be mindful of my presence and influence within this research. In keeping with Braun and Clarke's (2021b) framing of the researcher as resource for knowledge production, rather than threat to credibility, my aim was not limiting subjectivity at all costs, but rather remaining conscious of my inevitable shaping of the research, and endeavouring to articulate this impact.

My social context will influence my attitudes and beliefs around voice-hearing and its causation. Influential personal and social experiences include spending my early life within a Christian tradition where ecstatic religious experiences were accepted and respected, although I hold no religious faith now, and my early life and continuing familial connections in Aotearoa New Zealand. Despite systematic marginalisation of Māori people by Pākehā (White settlers) such as myself, Māori language, concepts, and culture remain woven into broader New Zealand culture. Māori conceptualisations of 'schizophrenia' may include psychiatric, biomedical explanations, but also include cultural and spiritual explanations, with potential for voice-hearing to be seen as commonplace (Taitimu et al., 2018).

Additionally, I have multiple family members who have experiences of voicehearing, including a voice-hearer who was not distressed and whose experiences were incorporated into an existing spiritual framework, and a voicehearer who initially found their experiences extremely distressing and upon whom illness frameworks were imposed. The second voice-hearer has over several years considered multiple causal models for voice-hearing, now holding multiple frameworks in a non-exclusionary way, including biological (heritable neurobiological sensitivity), spiritual (ancestral, heritable damage to *wairua,* spiritual self, through acts of aggression within the family, and to indigenous people and the land through colonisation, resulting in vulnerability to spiritual disturbance), psychological (viewing ancestral experiences through theories of moral injury and disrupted attachment), and traumagenic (with trauma implicated in the spiritual and psychological damage, and with further trauma activating potential for voice-hearing).

I am critical of psychiatric diagnosis as being flawed scientifically (Boyle, 1999) and as potentially damaging to the self-identity of those who receive a diagnostic label, and critical of reductive biomedical models. I approached analysis mindful of the risk of projecting my views onto the data, interpreting participants' experiences with biomedical models more negatively, and psychosocial models more positively. Since this research is not into what causal model is most evidenced or preferred, but rather how a model *comes to be* preferred, I hoped any impact of my biases would be limited. Throughout analysis I also aimed to hold centrally my values that voice-hearers are experts of their own experiences, with a right to interpret experiences in any way or multiple ways.

In the Discussion I reflect, retrospectively but using my reflective journal, on the extent to which my subjectivity did influence the study and its findings.

# **CHAPTER 3: RESULTS**

# 3.1. Chapter Overview

This chapter firstly discusses an Independent Coding Validation exercise. This was carried out to assess the face validity of themes, and to contribute to theme refinement and finalisation.

Themes were developed on the construction and evolution of explanatory models for voice-hearing (seven themes, six with subthemes) and the role of HVGs in a sense-making process (two themes, both with subthemes). In each area, themes and subthemes are discussed in depth and illustrated with extracts from participant interviews.

# 3.2. Independent Coding Validation

In refining and finalising themes, face validity was evaluated through discussion with my research supervisor. Discussions were structured around an independent coding process.

34 distinct extracts from the interviews were selected randomly across all themes and subthemes. Initial theme names and theme definitions were shared and used to independently code the extracts. The data was rich, with a total of 48 themes coded onto the 34 extracts. The nature of disagreements was discussed in each case.

# 3.3.1 Independent coding at the main theme level

At the main theme level, we agreed on 27 occasions, disagreeing on 24.

Reasons for disagreement included 19 cases of rater error by either coder (e.g. the wrong code was applied due to incomplete reading or misunderstanding of the theme definition or extract, all resolved by subsequent discussion), and five cases of context lacking from the extract which altered interpretation.

An example of an error due to an extract lacking context was the following: "They all thought I was imagining it. I suppose I was, really, in a funny sort of way. That's really a bit what the psychiatrists say, they'd say it was a hallucination. I suppose that's what it was, in a way, but I had to experience that to accept it sort of thing."

I coded this within 'Different explanatory models are held sequentially or switched between' (specifically here that a model can be 'outgrown' or 'grown into'). On discussion with my supervisor it was apparent that contextual knowledge of the full interview was required for this conclusion. Therefore, the extract was edited to include "[Having initially understood voices as telepathy, and later having come to understand them as internally generated]". I reviewed all other extracts to ensure that they were presented with appropriate context. Of 27 occasions where we agreed on main themes, 25 included subthemes (potentially multiple subthemes per extract). We agreed on 28 cases, disagreeing on 8. Reasons for disagreement included three cases of rater error, and five cases where it was concluded that theme names or definitions were inadequate. An example of this was *'The role of others in advancing a sense-making process'*, with three subthemes:

- Subtheme a: Holding space for the ideas of influential others Significant people in the voice-hearer's life (including healthcare workers, family, friends) offer their own explanations for voice-hearing, which the voice-hearer gives consideration to (whether or not it aligns fully with their own explanatory models so far).
- Subtheme b: Explorative conversations
   Specific explorative conversations or conversational partners are
   discussed, where the conversation served to introduce or expand upon
   explanatory models.
- Subtheme c: Exposure to ideas from multiple people Ideas from multiple people or from group conversations are referenced as meaningful in introducing new perspectives

This led to disagreement regarding the following extract:

"I think about 10 years ago, when I started to evolve the idea that I've created my voices – before that - I think that came from listening to other people making that connection. Uhm, I mean it always crossed my mind, but I've never made a firm connection. And that, but listening to other people saying that I, I thought, yeah, I think there's something in that. And then when I went to see my psychotherapist, which is about, I think it's about six years ago, and you know, we we made that connection strong, more strongly, but it got triggered by going to the hearing voices group."

My research supervisor coded this as fitting subthemes a, b, and c, whereas I coded it as subtheme b and c. I subsequently significantly refined these three subthemes to more clearly delineate them from each other (updated definitions in Table 3).

# 3.3. Overview of theme construction

I focused theme construction on two areas.

Firstly, construction and evolution of explanatory models for voice-hearing. This included the means by which voice-hearers begin a process of sense-making, independent and interpersonal components to sense-making and developing explanatory models, and barriers to sense-making processes. There were seven themes, six with subthemes.

Secondly, the role of HVGs in enabling these sense-making processes, for example through enabling positive interpersonal exchanges and discussions that support the construction of explanatory models. There were two themes, both with subthemes.

Theme names and definitions can be seen in Table 3.

### Table 3: Themes and subthemes

	Theme name	Theme definition	Subtheme names and definitions	Number of extracts in this theme	Number of participants contributing to this theme
1	Starting a search for meaning	Factors causing voice-hearers to consider explanations for voices and engage in sense-making processes	<b>1a. Voices invite questioning</b> Voice-hearing itself is seen as inviting questioning / voices are seen as having important meaning	7	5
			<b>1b. Representation</b> Encountering others with similar experiences leads to increased engagement in sense-making	2	2
2	The role of others in advancing a sense-making process	Interpersonal exchanges about voice-hearing influence how voice-hearers come to make sense of their voices. Note: Includes interpersonal exchanges in HVGs and elsewhere. Does not include self-initiated reading/research into understanding voice-hearing (see <b>Theme 3a</b> .)	2a. Ideas expressed by someone with a particular expertise on voice- hearing or on the voice-hearer Voice-hearers are predisposed to listen to, respect, and trust the other, due to their presumed knowledge about voice-hearing (e.g. a healthcare professional) or due to their presumed knowledge of, and good intentions towards, the voice-hearer (e.g. a close friend or family member).	13	7

			<ul> <li>2b. Many ideas from many people</li> <li>Voice-hearers encountered explanatory models from multiple people (multiple individuals over time and/or multiple people within a group)</li> <li>These people did not hold any special status predisposing voice- hearers to be influenced by their views</li> <li>These conversations influenced introduction, reinforcement, or rejection of explanatory models.</li> <li>2c. Explorative conversations One-to-one conversations which both parties approached with an explicitly curious or explorative intent, AND which led to a memorable moment in introduction, reinforcement, or rejection of explanatory models.</li> </ul>	7	7
3	Independent work towards sense-making	Self-initiated, largely independent work gathering information about explanatory models and considering relevance for the self.	<b>3a. Researching explanations</b> Reading and researching about voice- hearing provides new potential explanations, or normalises/strengthens current models.	12	7

			<b>3b. Personal reflection</b> Time is spent reflecting on voice- hearing experiences, linking this to different parts of self and world – synthesising different ideas and testing 'fit' against self.	9	6
4	Evaluating explanatory models	Voice-hearers engage in multiple forms of evaluation of explanatory model(s), which can lead to models becoming preferred or	<b>4a. Weighing up evidence</b> Various different experiences/observations are used as evidence, including:	38	10
		being rejected.	<ul> <li><u>Nature of the voices:</u> Qualities and characteristics of voices, or qualitative experiences of hearing voices, are seen as evidence</li> </ul>	23	9
			<ul> <li><u>External signs</u>: Observations of the external world contradict or reinforce an explanatory model</li> <li>Character and behaviour:</li> </ul>	13	5
			Knowledge of self is used to assess 'fit' of a model	4	2
			<b>4b. Balancing costs and benefits</b> Positive or negative impacts on wellbeing and functioning (past, present, predicted future) of accepting an explanatory model are considered.	36	10
5	Multiple valid	More than one explanatory model	5a. Different explanatory models	13	6
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	models might	is/was accepted/endorsed by the	are held sequentially or switched		
	be used	voice-hearer (models endorsed	between		
		sequentially AND/OR	Different factors influence change		
		concurrently).	between preferred models, including:		
			<u>Models are 'outgrown' or 'grown</u>	6	4
			<u>into':</u> Voice-hearers may be		
			aware of different potential		
			explanatory models but unable		
			to consider them as personally		
			applicable until their		
			circumstances (mental and		
			emotional state, life stage, etc.)		
			alter.	6	3
			Internal state as determinant for		
			which model is accepted:		
			Emotional states, cognitions,		
			and whether someone is		
			'stressed' or 'well' influence	•	
			which model is most	3	3
			persuasive/most endorsed		
			Deliberately endorsing the most		
			beneficial model for the context:		
			Attempts are made to accept,		
			internalise, and seek		
			confirmatory evidence for a		
			model predicted to give most		
			benefits and least costs		

			<b>5b. Models are held concurrently</b> Two or more explanatory models are reasonably consistently accepted for the voice-hearer's experience. <i>Note: this is differentiated from model</i> <i>switching. Although voice-hearers may</i> <i>discuss one model preferentially in a</i> <i>particular context, there is continued</i> <i>internal acceptance of other model(s).</i>	11	6
			<b>5c. Different voices, different</b> <b>explanations</b> Voice-hearers with multiple voices/types of voices may have differing and reasonably consistent explanations for the origins of the different voices/types of voice.	5	3
6	Barriers to sense-making	Factors impeding sense-making processes include lacking access to relevant personal and interpersonal resources.	<b>6a. Disclosure is seen as risky</b> Voice-hearers deliberately avoid(ed) disclosing their voice-hearing or their explanatory models to others, due to predicting stigma or negative consequences (i.e. unwanted clinical intervention, social rejection). Note: this theme is about imagined/predicted risk of disclosure. Actual occasions upon which disclosure has led to negative	22	7

7	Accenting	Fither instead of reaching a	<ul> <li>consequences may be better understood under Theme 6b.</li> <li>6b. Conversations that limit exploration Voice-hearers have experienced conversations in which another's explanation for voice-hearing was presented with no option for disagreement or discussion, or in which it is made clear that conversation about explanatory models would be unwelcome.</li> <li>6c. Sense-making is a privileged activity Sense-making processes are understood as requiring an investment of time, money, energy, and/or academic expertise, which may limit some voice-hearers in engaging in these.</li> </ul>	16	7
7	Accepting uncertainty and doubt	Either instead of reaching a preferred explanatory model(s), or alongside preferred `model(s), there is an acknowledgement of doubt and the impossibility of total certainty.		7	3

8	HVGs offer a particular and special social experience	HVGs provide a social experience in which attendees feel particularly safe and accepted.	<b>1a. Points of commonality</b> HVGs are spaces where voice-hearers are with others like themselves	20	8
			<b>1b. People who attend HVGs are</b> <b>particularly qualified to understand</b> HVG attendees are seen as more understanding and supportive than people met in other areas of life.	8	5
			<b>1c. Allowing authenticity and</b> <b>unmasking</b> Voice-hearers are more able to be authentically themselves at HVGs than in other areas of life.	11	6
			<b>1d. Explicitly non-judgemental:</b> HVGs are safe because they are contracted as non-critical and non- judgemental.	4	4
9	HVGs offer particular and special freedoms for discussion of voice-hearing	HVGs offer opportunities to discuss ideas about voice-hearing more freely than other spaces do, with less concern about unwanted consequence and opportunities to develop one's own ideas more	<b>1a. Freedom from intellectual</b> <b>intervention</b> Ability to develop own ideas and frame narratives in own ways, without pressure to reach a particular conclusion.	11	4
	and explanatory	fully.	1b. Freedom from clinical intervention	3	3

models for	Ability to discuss ideas without need to	
voice-hearing	consider what might elicit concern	
	from clinicians or have implications for	
	healthcare provision.	

# 3.4. Construction and evolution of explanatory models for voice-hearing

Seven themes, six with subthemes, explore construction and evolution of explanatory models for voice-hearing.

I have attempted to order these such that a journey of sense-making can be followed through the themes. This is to support readability, not because linearity was always suggested by participant interviews.

I have illustrated these themes with quotes from the participant interviews. In the interests of parsimony, I have selected quotes that most clearly illustrate or encapsulate the theme. This has led to some participants being quoted here more extensively (for example, Sarah is quoted here on 17 occasions, and Jane and Austin are each quoted here three times); however, quotes from other participants were essential for developing and thickening themes even if they have not been extensively quoted (for example, 16 extracts were identified in Jane's interview, supporting the construction of eight separate themes.)

# 3.4.1. Theme 1: Starting a search for meaning

There was potential for a search for voice-hearing explanations to be selfinitiated. Two subthemes appeared influential.

# Subtheme a: Voices invite questioning

This subtheme was constructed from a total seven quotes across five participants. These seven participants spoke about questioning the origin and nature of their voices as a natural response, with curiosity either inspired by the voices themselves or by the confusion when voices were first experienced:

... to me they always were meaningful. ...even though they were very distressing for a very long time and very overwhelming, there was something that was, you know. I had a hard time believing that they meant absolutely nothing. -Sarah ...in the very early days it was, 'What is this? Where is it coming from? You know these are not me imaginary friends' - although I'd grown out of that state by then, I were in my late teens - but I I I questioned 'oh am I imagining that?' But that's the only way I can explain it, it was something completely different. -Helen

Subtheme b: Representation

This subtheme was constructed from a total of two quotes across two participants. Meeting or hearing from other voice-hearers was mentioned by these two participants as making them feel more normal, inspiring interest in understanding their own experiences more, or inspiring them to seek out more information about voice-hearing experiences.

[Regarding attending a public talk by a voice-hearer] I ended up going and it was, you know, really really a life-changing experience. ...you know it was the first time in my life I'd ever really had any sort of representation. And to see someone sort of speak to the experiences that were so similar to what I had experienced in my life, in a way that was so eloquent, but also seeing her in person made it very clear that, you know, like this was a person. Not someone who had this very perfect life that was absent of any sort of struggle. And it it was from there that it really catalysed me wanting to try to understand my experiences a lot more. -Sarah

I, I think it – it helps to understand. I've watched, um, I forgot, um, Eleanor [Longden]... I enjoy watching her YouTube videos and everything, and what she says makes so much...I don't know, they they make me feel normalized, they make me feel normal because you do - I think you do think that it's just you... These feelings that I have and you know they're not terrible, they are quite normal thing to feel these things. -Helen These subthemes suggest that a catalyst for seeking to understand more about voices may be internal (questioning one's own experience) or external (hearing about experiences of similar others in a way which encourages new perspectives of self and voice-hearing experiences).

# 3.4.2: Theme 2: The role of others in advancing a sense-making process

Interpersonal exchanges about voice-hearing were relevant for voice-hearers' sense-making processes. Three different kinds of conversation are discussed as subthemes.

# Subtheme a: Ideas expressed by someone with a particular expertise on voicehearing or on the voice-hearer

This subtheme was constructed from 13 quotes across seven participants. The beliefs and ideas of others often noticeably impacted on explanatory models drawn upon by voice-hearers. These seven participants mentioned explanatory models spoken of by significant figures in their lives.

For example, when asked about explanations for voice-hearing, one answered with a belief held primarily by her family:

The second rational explanation is I was smoking cannabis, uh, fairly regularly, fairly heavily around that time. Uh, so initially my family I think had their fingers crossed that it was just a drug induced psychosis and it wouldn't be a long lasting or chronic condition. -Aisha

One also spoke explicitly of accepting a family member's view of voice-hearing and acting on this, despite it contradicting her own understanding at the time:

[Regarding her sister recommending she see a doctor about voicehearing]

I think because my sister suggested it and I I trusted my sister more than anything in the world, that I, you know, I just, I think I went along to please her because at that time I I didn't really... I think because [the voices] was so abusive to me and I've been used to abuse... abuse becomes natural to you, and because these voices were so abusive and so nasty and so aggressive, and... I just thought it was just another form of abuse, and I'd become accustomed to it, if you like. So to me it didn't seem a problem. I just accepted it for what it was. But obviously, my sister said, you know 'it is a problem'. -Helen

It seemed that close family members might be highly trusted and influential in developing explanatory models. Even when the voice-hearer has a different understanding, views of these important others may be considered.

Voice-hearers might also be influenced by professionals:

I think in in later life when I first went into services, I didn't know what schizophrenia was.... And when I was given this diagnosis of chronic schizophrenia and I was also told by a psychiatrist, and a forensic psychiatrist said - I remember his words clearly – 'You are a chronic schizophrenic. You will never ever work again. Go away and enjoy your life... And and that's what I believed for 10 years. That I'd got this diagnosis, I could never recover. -Andrew

I was not raised to question authority. And you know, if you're nine years old and someone in a white coat is telling you there's something wrong with your brain, why would you, how could you say that they're not right? -Sarah

Offering serious consideration to the views of important others was complex. Some recalled important others expressing views in conflict with each other.

For example family members offering contradictory views:

[When asked who had been helpful for making sense of voices] Um. Not my family, because my mum thinks it's demons and my dad thinks it's an illness. -Laila

Or a family member offering views that contradicted a psychiatrist:

[My mother] could see what I've achieved in my life, you know, I'd built things up from nothing, and come and see old gouges by the psychiatrist's words, and she never really believed in the concept of schizophrenia, never really wild for it anyway, and I think that was just her final words. You know, 'it's not schizophrenia, you've got a gift.' -Andrew

Another recalled not being immediately swayed from his own preferred explanatory model even by agreement between a friend and a psychiatrist:

[Having initially understood voices as telepathy, and later having come to understand them as internally generated] I mentioned something to one good friend and she said 'oh that's rubbish.' She said 'you're imagining.' They all thought I was imagining it. I suppose I was, really, in a funny sort of way. That's really a bit what the psychiatrists say, they'd say it was a hallucination. I suppose that's what it was, in a way, but I had to experience that to accept it sort of thing. -Thomas

This suggests that while views of family members and professionals potentially influence construction of explanatory models, this is a complex area. Potentially relevant may be the voice-hearer's predisposition to trust this source of information (*"I was not raised to question authority,"*), what views they already hold, if any (*"I didn't know what schizophrenia was,"*), what views are encountered from other trusted sources, and their own receptivity to offered ideas (*"I had to experience that to accept it."*)

#### Subtheme b: Many ideas from many people

This subtheme was constructed from 13 quotes across seven participants. These seven participants discussed the impact of hearing multiple views about voice-hearing from different people. This included having a series of conversations with different individuals over time, as well as hearing from multiple people within a group setting (for example HVGs.) Those expressing views to or around participants did not initially hold any special status predisposing participants to take their words into account. Participants spoke about how hearing the stories and ideas of others helped them start to consider new explanations, or to build up new explanatory models in a more connected way:

[Regarding coming to reject a diagnosis of schizophrenia] I think that's how it was with me when I first went to group, hearing different stories from different people. But they did these similarities, but lots of differences. But the similarities still. Then you think maybe there is another explanation for all this.

-Andrew

When I started to evolve the idea that I've created my voices – before that - I think that came from listening to other people making that connection. Uhm, I mean it always crossed my mind, but I'd never made a firm connection. And that, but listening to other people saying that I, I thought, yeah, I think there's something in that... it got triggered by going to the Hearing Voices group. -Samantha

The beliefs of others were also spoken of in the context of one's own beliefs: I'm more inclined to believe it's, it's trauma. And in fact in fact everybody that goes to the group has got some kind of reason for, you know having trauma. And I don't think anybody really believes that it's dopamine. -Jane

Access to multiple ideas was also explicitly seen as enabling deeper and more personalised exploration of one's own ideas:

[Regarding the experience of listening to the ideas of HVG attendees:] ...when you only have one narrative to work with, I think I've found it very easy to just sort of try to match my experiences onto that, rather than maybe you try to understand some of the places where it diverged, or some of the nuances that I had. -Sarah

It appears there are several potential impacts of hearing multiple people's ideas about voices. Where the voice-hearer's ideas differ from others' ideas, this can introduce new explanations for voice-hearing and provide opportunities to make new connections. Where the voice-hearer's ideas align with the others' ideas, it might be felt as reassuring and normalising. When multiple ideas are present, this may enable the voice-hearer to revisit their own explanatory models and develop them in personally relevant ways.

#### Subtheme c: Explorative conversations

This subtheme was constructed from seven quotes across four participants. These four participants named memorable conversations that led to new explanatory models being introduced or reinforced. I defined an 'explorative' conversation here as one in which both parties appeared to approach with an explicitly curious or explorative intent, as well as containing a striking moment of learning or consolidation.

For some, the context was a therapeutic relationship:

I think about 10 years ago, when I started to evolve the idea that I've created my voices ... I went to see my psychotherapist, which is about, I think it's about six years ago, and you know, we we made that connection strong, more strongly. -Samantha

For others, one-off conversations were potentially powerful:

[Regarding a voice which had dictated a children's book, which was ultimately published] But what always confused me and this is what I learned from somebody in Ireland, that voice was female, and I thought, why? Why is it female? Then somebody says to me, 'I can explain this to you.' She said 'This, this is a part of you. This is your creative side.' ... She said 'Artists, poets, authors, musicians, everybody got a creative side. And predominantly, they're heard as a female. It is a part of you.' And it just made - and I looked it up and it's true and made so much sense.

-Andrew

#### 3.4.3. Theme 3: Independent work towards sense-making

The theme around independent information gathering and reflective work had two subthemes:

## Subtheme a: Researching explanations

This subtheme was constructed from 12 quotes across seven participants. These seven participants spoke about multiple forms of independent research they undertook about voice-hearing and explanatory models, including academic research papers, popular science works, and accounts from other voice-hearers.

This included using social media to access accounts from other voice-hearers: [Having previously mentioned following the social media of voicehearers] I've learned a lot myself. I I like, I enjoy reading. I find solace in reading so I have read a lot of literature and books and a lot of things about around schizophrenia. And I think that's why I went on Twitter because I found it quite interesting. You know, there's some really interesting people on there. I do like to learn. -Helen

Some directly linked the development of explanatory models to research: *Uhm, the believing that they come from here from the trauma has been for the last sort of about 10 years. Yeah, so that that sort of came - I I read stuff about it and and thought, yeah, that that sounds likely, you know.* 

-Samantha

Others might use research to provide evidence supporting a preferred explanatory model or supporting rejection of an undesirable model:

...it's much harder for people to dismiss you as being crazy when you can back yourself up with science, and when you know. And sometimes I wonder like you know ... did I read every single research paper that existed on this so that way I could prove to other people that I wasn't crazy? -Sarah

There's a woman in Canada who's written a book about it. You know, and all her schizophrenia came from childhood abuse and trauma. And she was able to lift herself out of schizophrenia without any medication. ... people get the diagnosis for life. But there is proof, there is proof out there that recovery is possible. -Austin

#### Subtheme b: Personal reflection

This subtheme was constructed from nine quotes across six participants. These six participants mentioned time spent reflecting on voice-hearing experiences.

Reflection was mentioned as being important to make sense of what had already occurred before further work of recovery and sense-making was possible:

I had kind of 13 years or so where I just wasn't able to function in society... And I kind of look at it now, and that period of time was a time of sort of deep reflection on what I've been through. And I think having come out of it - this is, you know, when I started to write, the book – was suddenly that that time of remission or whatever you might call it, of um recovery, was had more meaning to it. -Austin

Reflection was used to make connections between one's own experiences and what was being learned elsewhere:

Interviewer:

*OK, so it was reading that you did that helped you develop that belief. Participant:* 

Yeah, I think so. That and and thinking back a bit more to the past, and thinking when did the voices start? And they started after one particular trauma. So I made that connection and about 10 years ago that it felt more likely that I had created it in my brain, you know? -Samantha Or introspection was in itself what allowed a new explanatory model to develop: *I was hearing the voice from a friend who was about five miles away - I used to think that I could read minds, and they could read my mind, you know 'cause a sort of, yeah, a sort of a mental exchange with the with the voice, with people, and these were the voices. So this woman was, um, radiating a voice to me, uh, and I radiated a voice back. And then I realized it was the same, had the same flavour sort of thing. It was identical. And that tended me, that caused me to believe that uhm I created her voice. Uhm, yeah. I created her voice, and that then made me believe that all the voices I created with my mind, all the voices came from my mind. -Thomas* 

3.4.4. Theme 4: Evaluating explanatory models

Beyond these different means of discovering models, I was struck by multiple complex ways participants evaluated explanatory models, separated here into four subthemes.

#### Subtheme a: Weighing up evidence

This subtheme was constructed from 38 quotes across 10 participants. All participants spoke about considering various forms of evidence.

The evidence I identified as most frequently used (nine participants) was the nature of the voices themselves.

Voice content was often seen as supporting a particular explanation for voices. For example, when voices were felt to provide information the voice-hearer would not otherwise have been able to access, this might support a supernatural explanatory model:

I have two internal voices. One is my mum, who's dead. Now I see that as being mediumistic. ...Now there are things I have asked my mum's voice and every prediction comes true. -Andrew ...especially at times when I hear back in a voice something that I didn't know, or something I feel I didn't know, or wasn't thinking of, and it's it's an adequate and like appropriate contribution to to my thought conversation. Like it's kind of surprising, but like I take it as dialogue with angelic beings. So there's my irrational explanation. -Aisha

Voice content was also used as evidence against a supernatural explanatory model, when it was considered insufficiently accurate:

I now recognise that you know, they don't tell me things about the future. Maybe on the odd occasion they they're right, when they they say something about the future, but the amount of things they tell me on a day-by-day, week-by-week basis - anybody if they gave you that many responses, they would be truthful in some you know percentage. -Laila

Voice content was also used to support a trauma explanatory model, when this content seemed to 'fit' a specific distressing experience:

[Regarding a theory that voices were caused by trauma related to a breakup]

...it's the obvious explanation given the content of the voices I was experiencing. ...they were extremely complex, like each voice had its own personality, had its own tonality had their own own geospatial direction, so for example, the father figure would come from here and had a particular tonality. The mother figure would come from here. The ex would come from here. The younger brother would come from here. ... So given the content and the and the extremity and the consistency of of it being those personalities, I think it was the obvious conclusion to make that it was a traumatic response to the break up. -Aisha

In addition to voice content, qualitative experience of voice-hearing was often considered persuasive evidence:

[Regarding a trauma/psychological model for some voices alongside a supernatural explanatory model for other voices]

But there are certainly others, some that I've heard more than once and some that I only hear at a particular time or place, that just don't feel like they're coming from me in quite the same way, and feel much more... Yeah, they just feel like they're not mine, and that I didn't generate them, and that it would almost be very, very egotistical to say that I generated these voices, which are usually very like, they're just very beautiful, and very... it feels like a gift to be able to hear them. ... they certainly have just like a phenomenologically different experience, so a qualitatively different experience to actually experiencing them. It's very, very different.

-Sarah

[When discussing a psychological explanatory model for voices] But you see, even as I say that I find myself thinking, 'They can't come from me because they're too real.' -Samantha

Beyond the consideration of voice quality/characteristics as evidence, five reported appraising events around them as either supporting or undermining an explanatory model:

[Regarding her family's explanation that this was a drug-induced psychosis] I think... I knew it to be wrong. Because I didn't touch cannabis for a good 6-7 years after that and it, you know my condition didn't improve any. -Aisha

[Regarding voices, initially perceived as being of supernatural origin, which were encouraging suicide]

Yep, and I said ... 'if if you're what you're saying is true, if everybody in the world knows who I am, knows where I live now, I'll get some cyanide through the post and if I get any tablets through the post I'll take them.' ... Nothing came through the post. Um, they said then 'Slit your wrists in the bath.' I was like, 'I'm not going to slit my wrists in the bath, based on a voice that's in my head that might not be real.' -Laila

Well I know it's connected with dopamine levels, isn't it. Um. But presumably if it if it's dop - is caused by dopamine levels, then presumably, you know, I would have had it - I mean, I was diagnosed in [when] I'm 29, 30, roughly? So presumably if it was dopamine levels, I would have got it before. -Jane

Two mentioned using their own character and behaviour as useful evidence: Interviewer: Was there something in particular about the idea of paranoid schizophrenia that really made sense to you? Participant: I I don't know I. I think as I was reading things and I thought 'I feel that, I say that, I do that, that's me.' -Helen

Some of them say it's the work of the Devil. I've been told that before by some person I confided in that I heard voices – he said 'oh well you're the Devil's disciple then,' were his words. And I thought how silly, 'cause I've always tried to be reasonably pleasant to people. I've never borne any grudges against anybody, and I've never wanted to take people to task or anything like that. Um, I used to give up three lunch hours a week while I [volunteered] just to listen to people's problems. You know. So, so to be told that I was the Devil's disciple, just because I heard voices? -Philip

The fact that all participants made reference to considering some form of evidence for explanatory models felt important. It seems that for explanatory models to be applicable they may need to fit with observations the voice-hearer makes about themselves, the world, and the voices.

#### Subtheme b: Balancing costs and benefits

This subtheme was constructed from 36 quotes across 10 participants. All participants spoke of positive or negative impacts that accepting a particular explanatory model has had or was predicted to have on wellbeing and functioning, in a way that was relevant for whether this explanatory model came to be preferred or rejected.

Four spoke about potential costs of endorsing a model:

I was also told by a psychiatrist, and a forensic psychiatrist said - I remember his words clearly – 'You are a chronic schizophrenic. You will never ever work again. Go away and enjoy your life.' ...And and that's what I believed for 10 years. That I'd got this diagnosis, I could never recover. And it is so impacting. ... I remember my eldest child, he'd got a basketball net. 'Dad, can you drill the wall and put me that up please?' I could have done it easily, but I didn't do it. 'You'll never ever work again.' That's how powerful those words are. I wouldn't pick a drill up and drill the wall, drill the wall, because of what that psychiatrist says, became so disempowering. -Andrew

[Regarding previous use of a supernatural explanatory model in which she was hearing the voice of her ex] That kind of led to a combustion situation with with that romantic relationship being constantly very present in my life. ... Just basically like doing like post-analysis on steroids of that relationship - which lasted three years, but then the the voices made it last a lot longer, like another seven years on top of that. So I'm exhausted with that relationship. -Aisha

Nine spoke about different benefits from accepting/endorsing a model.

Avoiding aversive experiences:

[Regarding previous acceptance of an illness explanatory model] I was, you know, in hospital for like almost you know well over three years, and just being told you know every day, like you know 'you don't have a choice into what you think' and it's a survival mechanism to agree with what's being said to you, so that way you're not put on more medication, or you're not secluded, or not restrained, so that way you can eventually leave. I mean, so it's like, you just have to play the game. -Sarah

Providing hope for a positive resolution:

I don't know, was I invested in it being a drug induced psychosis? Uhm, no I wasn't. I wasn't. I mean, maybe in the sense that I wanted it to be over, and so I was looking for an explanation that would mean that it wasn't a chronic condition. -Aisha

Interviewer: And when you first started to think about as being an illness rather than taking the voices at face value, what was it like to come to that realisation? Participant: I I think it was a bit of a relief. Um. A bit more a bit of a 'right, how do we get this fixed? If it's an illness, how do we fix it?' -Laila

Supporting coping with voices / with mental health:

Yeah, so like the voices that I hear on a day to day basis ... I think certainly arise from trauma... and I and I found that to be a very, very useful explanation, and something that's enabled me to actually really like change my relationship with my voices by understanding them in that way.

-Sarah

...I approached him at the end of the training and just said, 'I like what you've had to say about voices, mate. But you're talking about voices with identities. Mine have no identity. They have no agenda, they're demonic.' ... he just said 'address the demons of your past,' and walked off. And that's – his words were powerful because subconsciously, I knew who my voices were. But because I still felt like that child, which is what [a friend] pointed out years later, I wouldn't let them become their voices, 'cause they would overwhelm me and I didn't think I had the power and control to deal with them now. -Andrew

Providing comfort / safety / good feelings:

[Regarding a supernatural explanatory model for voices] It's like being uhm in harmony with the universe... to feel that I have angelic companions and to to be invested in this kind of task makes me feel like I have a special vantage point of of assuming knowledge at this point in my life. Which not many people get. -Aisha

Hearing it, you could imagine someone saying, 'oh, you're paranoid Schizophrenic,' that being a terrible thing, but actually ...I wasn't appalled by them saying it, I was actually, I think I think I was quite relieved. ...Where I'd just thought - I think before I just went 'I'm just this barmy woman, this completely mental nutcase of a woman ... just a freak of nature.'

-Helen

There was no consistent sense that one model was more costly or beneficial than another. An illness model was costly to Andrew ("*what that psychiatrist says, became so disempowering*") but experienced as a relief by Helen (a positive alternative to being *"a freak of nature"*). A psychological model was useful to Sarah, quoted above, but for Andrew, accepting a supernatural model (voices as demonic) was preferred at one point to accepting a traumagenic/psychological model (voices as the demons of the past), which would have felt overwhelming.

Having accepted a model at one point and received benefits from it did not imply continued acceptance of the model. Some costs and benefits were contextual: for example, Sarah experienced benefits of accepting an illness model within a hospital setting (not medicated, restrained, or secluded) which would be less relevant outside this setting.

## 3.4.5. Theme 5: Multiple valid models might be used

Nine had accepted more than one explanatory model of voice-hearing at some point in their lives. I constructed three subthemes:

# Subtheme a: Different explanatory models are held sequentially or switched between

This subtheme was constructed from 13 quotes across six participants. These six participants held different explanatory models in sequence or in turn. Rather than identifying specific sequences, I focused on factors influencing shifts between endorsed explanatory models. Three factors were identified.

Four spoke in a way I constructed as 'outgrowing' or 'growing into' models. In this understanding, the voice-hearer might be aware of different potential explanations for their voice-hearing but not see them as personally applicable until they experience changes in external context (such as altered costs and benefits to a model), or changes to self (such as life stage, or emotional growth).

But uhm now that, I mean now that I'm coming to the end of this CAT therapy where we've examined uhm the reasons for, the causes of things, what I've found is I'm ready now to move away from the narrative that it was based on a romantic traumatic experience. I I find that explanation is no longer serving me. -Aisha

So from a 2011 till about 2012, I did think it was real. I had a relapse in 2013. And then after that is when I realized or when I kind of consciously was aware that it's an illness, I think. So it did take a while to get my head around it at first. It took a second episode for me to do that. -Laila

Three also spoke of model switching as being brought about by internal states (for example emotional states or being 'stressed' or 'unwell') in a way that was not necessarily voluntary, and might be distressing:

I'd be stable. Uh, happy angelic mode and then. It's a really, it's a really horrible thing, but uhm. If I thought about my ex... even if it was just about me remembering my own life in the past during my psychosis... But what would happen in those situations is the angelic reality would dissipate and the the the witch reality would immediately lock on. -Aisha

I know I hear voices because of childhood trauma, and something happened to my brain that made me split bits off, and uhm, they became voices. ... So I know they're from me in that sense, but when I'm not very well and when I'm hearing them a lot ... when I'm really being bothered by them and when they're very insistent I sometimes feel as if they are external. Obviously they sound external, but I mean I, I believe that they are external and in some way, something outside that's influencing me. -Samantha

Three spoke of deliberative elements to model selection, accepting/endorsing the most beneficial model within a context.

This included taking steps to enhance a preferred but tentative explanatory model:

I'm ready now to move away from the narrative that it was based on a romantic traumatic experience. I I find that explanation is no longer serving me. So the next set of therapy that I'm looking to do is going to be psychodynamic, maybe, hopefully Jungian therapy, to look out earlier experiences in life and see if there was any indication in earlier experiences, rather than it being, 'you got broken up with, you got dumped and then you started hearing voices.' So yeah, so that's that. -Aisha

This also included moving deliberately towards a model that was felt as more hopeful:

[Regarding a currently endorsed supernatural explanatory model:] That was just [my mother's] final words. You know, 'it's not Schizophrenia, you've got a gift.' It's like move beyond this you you you can you can find a way out of this by finding a different explanation. -Andrew

Finally, this also included selecting a model that was seen as most useful in avoiding aversive experiences:

I was, you know, in hospital for like almost you know well over three years, and just being told you know every day, like you know 'you don't have a choice into what you think' and it's a survival mechanism to agree with what's being said to you, so that way you're not put on more medication, or you're not secluded, or not restrained, so that way you can eventually leave. I mean, so it's like, you just have to play the game. -Sarah

#### Subtheme b: Explanatory models held concurrently

This subtheme was constructed from 11 quotes across six participants. These six participants mentioned multiple different explanations for voices which they held reasonably consistently over time (rather than switching sequentially between explanatory models).

There's two rational explanations and one irrational explanation. -Aisha

It's pretty strange you can sort of hold two positions at once. I feel like I've got these people in my life who are having a go at me, and yet I do firmly believe that they they are from me as well. -Samantha

#### Subtheme c: Different voices, different explanations

This subtheme was constructed from six quotes across three participants. In investigating concurrently held models, I identified that these three participants, who each heard multiple voices, consistently held different explanations for their different voices.

For me I have I have three different explanations, to be honest. The three external voices that I hear... they're the three people, the two women

and man that raped me for eight years. Now, I know it's their voices 'cause I started to hear them when I was a child. But they're the external voices. I have two internal voices. One is my mum, who's dead. Now I see that as being mediumistic. That's a gift I got from my Mum. Because my mum's dying words to me were, 'You're not a schizophrenic, you've got a gift.' Now there are things I have asked my mum's voice and every prediction comes true. Now, I've probably got a better relationship with my mum now she's dead than when she was alive. ... I had another voice from 2009 to 2012 and that voice helped me write a children's book. It dictated the book to me. But when that book got published that voice disappeared. I've not heard it since. Now I think that was my creative side, that I had as a child, got crushed with abuse. -Andrew

*Um, well, some people say it's caused by trauma. I mean, in my case my bad voices all started when the sexual abuse started when I was six years old. Before that, I'd only heard that one good voice, [VOICE NAME].* 

[VOICE NAME] was a good voice, clearly. I don't know where that came from. Um, I have heard theories that maybe she was a previous incarnation. Whether I believe in that - well, the door's open. I, I'd like to believe in that, it's quite interesting, but uh, so the theory is that [VOICE NAME] was a previous incarnation of mine, who died of the Spanish flu in 1918.

In later life my grandmother ... after she died, I got her voice, the second good voice of my life. And she told me she was in the Resting Place, 'cause she died and she was somewhere called the Resting Place ... Yeah, interesting, so part of that helped me with the [VOICE NAME] areas as well because I put the two things together, my two good voices. -Philip

... the voices that I hear on a day to day basis certainly have sort of a trauma, like I think certainly arise from trauma... the things that they say and the things that they have said historically, are just like almost textbook in terms of how much they they could match onto sort of like a

trauma, dissociative explanation for things .... And then there's other voices that I hear on a less common basis that I certainly feel are much more spiritual, that don't feel like mine in quite the same way, if that makes sense. -Sarah

Explanatory models used for different voices can be evaluated separately, with their own evidence, costs, and benefits. This is particularly relevant for using voices as evidence; two voices with highly distinct characteristics and phenomenological experiences may be more likely to invite different explanations.

# 3.4.6. Theme 6: Barriers to sense-making

Participants referred to not only what supported the creation of explanatory models, but what interfered with this process. I constructed this as three subthemes.

# Subtheme a: Disclosure is seen as risky

This subtheme was constructed from 22 quotes across seven participants. Discussion with others was seen as potentially helpful for a sense-making process (Theme 2). Contrastingly, these seven participants mentioned times when they hesitated to disclose voice-hearing or explanations about voicehearing due to predicting stigma or negative consequences (i.e. unwanted clinical intervention, social rejection).

It is difficult when people you know find out that you're paranoid schizophrenic, because as I say, I live in a small town. And people read the headlines, all 'paranoid schizophrenic goes on spree and kills someone.' So for a small town you know it's there's a lot of ignorance around mental illness. So when people - I I I keep myself to myself and... But then people finding that out and then you add on top 'Oh, and I hear voices' - it's very difficult, you know, in in in my environment, to be able to share that. -Helen And most of the time you have to hide it, and even my family and my close friends who are really supportive, can't understand it 'cause they've not been there. And so I wouldn't feel happy talking about my ideas behind the voices with them, particularly. It's, sometimes it's arisen, but I don't feel particularly happy about it. -Samantha

This suggests that access to spaces where they can openly discuss voices and access support from others in connection with developing exploratory models may be limited for voice-hearers.

#### Subtheme b: Conversations that limit exploration

This subtheme was constructed from 16 quotes across seven participants. Contrasting with explorative conversations as relevant for introducing or reinforcing new explanatory models (Theme 2), these seven participants mentioned conversations with the opposite effect of causing withdrawal from sense-making processes including social sense-making.

I think a lot of what was stopping me from going [to the Hearing Voices group] was this real fear of of repercussions and for negative consequences, which had been, you know, with - 'cause I had a very long history with the mental health system and that was very much sort of the the MO with them, was you know. I think there's a lot of it feeling like I was trying to be lured into self-disclosure, then any type of selfdisclosure was met with what felt like punishment, and was really not met with any type of acceptance, or validation, or real support. -Sarah

I remember talking to my uncle, who was quite supportive. ... I told him I heard voices. He said 'keep that to yourself, don't tell anyone' so I didn't. He said 'or or you'll be joining those queues of people wandering around for walks outside the asylums.' ...So I took his advice. No, I didn't tell anyone until I met my wife. -Philip I've talked to my son a bit... And he, like anybody who's in my life... is supportive. But almost all of them seem to think, if they're a construct of my brain, then surely it's easy to resist them. ...That's their their shortcut answer to that, and they certainly don't hold with the Devil and the demons and all that. ... to them that's a simple answer. You started it, you stop it, you know. So it's not very helpful. -Samantha

#### Subtheme c: Sense-making is a privileged activity

This subtheme was constructed from seven quotes across three participants. These three participants identified sense-making as requiring investment of time, money, energy, and/or academic expertise, potentially limiting ability to engage fully in this.

I I need to concentrate on getting through another day. Being well. And that's hard enough, you know. So should I really put all my resources now as I'm getting older into trying to keep myself well, rather than, you know, thrashing about, wondering why, where they're coming from. -Helen

I also know that a lot of the things that I've... but you know, I've been able to access a lot of knowledge because I was able to, you know, go to college. And a lot of people in the group do not have that kind of privilege. And I've been able to do a lot of self exploration. I don't know. I don't know why, but it feels very like there's a lot of privilege that stopped up in it. -Sarah

This suggests that personal resources are relevant for being able to successfully engage in sense-making processes and come to a beneficial and personally relevant explanatory model.

# 3.4.7. Theme 7: Accepting uncertainty and doubt

This theme was constructed from seven quotes across three participants. While some participants seemed confident explaining their voice-hearing, continuing doubt and uncertainty was apparent for these three.

For one, the experience of doubt and uncertainty was primary:

I don't know. I I think. I think there's so much out there, you know. I I can grasp onto 'Well, my dad was a paranoid schizophrenic so so am I.' You know but is that actually the explanation? You know? Is there more to it? You know you can then say, well, I was abused as a child, did I – is that part of that created these voices? There's numerous things you know, and I'm I'm very open minded and I don't want to be closed minded on it. And I don't - but then again, I don't think I'll ever know, but then again, I don't think I I really need to know. I think I've got to my age now where I think well, 'Perhaps I'll never know, and does it really matter if I don't know', you know.

-Helen

For another, the experience of doubt was linked to the concurrent holding of two contrasting explanatory models:

It's pretty strange you can sort of hold two positions at once. I feel like I've got these people in my life who are having a go at me, and yet I do firmly believe that they they are from me as well. So there is that disconnect and I've never really resolved that. ... I I definitely have my doubts.

-Samantha

For another, an explanatory model that was deeply personally meaningful, was complexly developed and had been reflected on in depth, and was felt to have significant areas of evidence and significant benefits, was nonetheless presented as having room for doubt:

[Regarding a supernatural explanatory model] Whether I believe in that - well, the door's open. I, I'd like to believe in that, it's quite interesting... But that's just an interesting theory. But you know, nobody has to believe, I certainly don't expect you to believe it, but... -Philip

# 3.5. The role of HVGs in the sense-making process

Two themes, both with subthemes, explored the role of HVGs in enabling sense-making processes. Expanding on '*the role of others in advancing a sense-making process*,' HVGs are constructed as supporting positive interpersonal exchanges around voice-hearing and explanatory models. These themes do not include specific social exchanges within HVGs, but rather what qualities HVGs have that support social exchanges.

# 3.5.1. Theme 8: HVGs offer a particular and special social experience

It appeared that participants experienced HVGs as particularly safe and accepting. For readability I constructed this as four subthemes, though in practise they significantly interlock and engender each other.

# Subtheme a: Points of commonality

This subtheme was constructed from 20 quotes across eight participants. These eight participants identified that at HVGs they were with others like themselves. This was experienced as novel and powerful.

I connected with them straight away. I think you're do in that kind of environment, you think 'Wow, I'm with my my people' is is the sort of thing.... you sometimes meet after and have a chat and you think 'wow, that's me. That's me like that.' And you've got so much in common with those guys that it's, I connected straight away and so I kept on coming. -Helen

Points of commonality were felt as making HVGs attendees particularly understanding (linking this subtheme to subtheme b, below):

I think it's, it's being around people who don't have to explain what's going on, because there's a an understanding. Though everybody's experiences are different, we have enough in common that you can just, there's just an understanding that it of of what it what it feels like. -Samantha Points of commonality, felt powerfully in themselves, also invited authenticity and openness (linking to subtheme c):

... it's a very strange thing to say, I know, but when you walked in, it's like I knew that every person in that room had been sexually abused, and you could talk about it in a way that was very, very open to the extent that it almost became funny. I mean not funny, but like you know how when you're with a group of people and you've all had the same experience, and then sometimes like it becomes funny because you're much more uninhibited, because you can speak really authentically. -Sarah

# Subtheme b: People who attend HVGs are particularly qualified to understand

This subtheme was constructed from eight quotes across five participants. These five participants made comments about HVG attendees being particularly understanding or tolerant, either as personal qualities, due to having experienced their own difficulties, or due to common experiences:

I think basically everyone in that group's kind of got got a level of tolerance beyond your average person, because they they have suffered and suffer um in terms of their condition. So you know, I, I think you know people are, people are tolerant in the in the groups. -Austin

[Regarding talking to family members about experiences] You know they're busy and I yeah, I don't really don't really waste their time. 'Cause they don't, I don't think they really.. So I I don't know that they can... Yeah, I don't know that they have the time. Well, no, I I suppose I just it's just more appropriate that I talked to the [Hearing Voices group] really. I think 'cause, they um they could provide understanding...

-Jane

# Subtheme c: Allowing authenticity and unmasking

This subtheme was constructed from 11 quotes across six participants. These six participants commented on having authentic and open experiences at HVGs

that were not considered possible elsewhere. This was seen as enabled by commonality group attendees. This was also explicitly linked to the space being felt as non-judgemental, interlinking with subtheme d.

It be nice to have that space where you can go and relax and be yourself and be talk about what you want to not be judged. I think that that's that's the important thing for me. -Andrew

Um in in my day-to-day life, I have to hide that I hear voices. Not from my family now, but from my wider acquaintances and from my work. And um going to the group is a place where I don't have to hide it and you can talk about it.

-Samantha

An experience of authenticity was linked to an ability to hold more explorative conversations:

It was just much more authentic, and I think it allowed people to actually really get into what each other's experiences were, really ask questions, and explore, and reflect back. -Sarah

# Subtheme d: Explicitly non-judgemental

This subtheme was constructed from four quotes across four participants. These four participants experienced the group as a space where they would not encounter judgement, criticism, or invalidation. In some cases this was explicitly linked to contracting and ground rules.

People listened, and they heard, they didn't judge, didn't pass comment unless I said as, would anybody give me some support with that. -Andrew

But you know, there's a general - we have a rule that you're not allowed to criticize anybody's beliefs. So obviously that gives us uhm a security blanket and, and you know. I feel very safe there.

#### -Samantha

This sense of safety was seen as relevant in enabling conversations about voice-hearing that were not otherwise possible, and in supporting sense-making:

Before I came to a group, I had never spoken about my voices before, ever in my life and it was really helpful to have a space that was very non-threatening, in a way, to sort of work a lot of stuff out. -Sarah

To summarise this theme: HVGs are felt as spaces where participants were with others like them. This fostered a sense that at the group they would be better understood than in other parts of their lives, and in turn invited participants to be more authentic and open. The HVG's explicitly nonjudgemental stance also invited authenticity.

# <u>3.5.2. Theme 9: HVGs offer a particular and special freedoms for the discussion</u> of voice-hearing and explanatory models

This theme contrasts with *'barriers to sense-making'*, where conversations that limit exploration was constructed as a barrier. Contrastingly, HVGs were understood as spaces where conversations happened differently. I constructed this as two subthemes.

#### Subtheme a: Freedom from intellectual intervention

This subtheme was constructed from 11 quotes across four participants. These four participants commented on HVGs as offering a space where they could develop ideas and frame their own narratives, without external pressure:

...there was no sense that there was a topic that was gonna be like too triggering to talk about, or that you had to sort of couch a narrative in a certain way, so that way it's always about how I overcame or where the hope was at the end. -Sarah What it did was it made me think more about voices. It's, yeah, it really made it, made me think what they were and everything you know, let me think about them.

-Thomas

In addition to encouraging conversations, this freedom might also encourage personal reflection (*'Independent work towards sense-making'*).

# Subtheme b: Freedom from clinical intervention

This subtheme was constructed from three quotes across three participants. These three participants commented on HVGs as offering a space where talking freely about voice-hearing and explanatory models would not lead to unwanted interventions:

...there was other people I could talk to and share my experience, and I wasn't gonna be judged or overmedicated or sectioned. -Andrew

I think that's important to everybody to open up, knowing that they're not going to be risk-assessed, and written down and recorded, and all that, and so they're they're very good from that point of view. -Samantha

Yeah yeah, when they were interested in the voices, they weren't sort of saying 'oh yeah, if you're hearing voices you should up your medication.' I wouldn't, you know, I didn't see that at all. -Thomas

# **CHAPTER 4: DISCUSSION AND CONCLUSIONS**

#### 4.1. Chapter Overview

The main themes identified in the Results chapter are summarised, then commented on in relation to previous research – what previous findings are matched or expanded, and where this thesis has presented new ideas about the construction of explanatory models for voice-hearing. Clinical and research implications of these findings are also considered.

The impact of my critical realist epistemology on data gathering and analysis is discussed. How my values and biases may have shaped this work is revisited in a personal reflexivity section. Other limitations which potentially delimited or slanted the findings are also noted.
### 4.2. Summary of Main Findings

The complexity, richness, and individuality of these 10 accounts was notable, and should be considered a finding in itself. Despite the marginalisation of voice-hearers from academic and clinical literature, when offered an opportunity to speak about their experiences they did so with depth and nuance.

The themes constructed in the Results chapter are not considered exhaustive, but as a pragmatic compromise between the data's richness and the need to focus on the research aims. Given the complex and interwoven nature of the themes, the main findings are briefly summarised here.

A search for meaning could be initiated either by seeing others who hear voices who live differently or explain voices differently, presenting new possibilities, or by a sense that voice-hearing experiences are intrinsically meaningful and invite questioning.

Interpersonal exchanges can provide new explanatory models, or expand, reinforce, or reduce belief in a model. Conversations with an 'expert' on voice-hearing or the voice-hearer, conversations approached with mutually explorative intent, or conversations with multiple people, were each considered. The voice-hearer's current knowledge, receptivity to new ideas, and trust in the speaker, all potentially affected how influential these conversations were. Voice-hearers also engaged in personal research and reflection, which might inform them of new potential models, or reinforce or weaken conviction about current models.

Models are evaluated through considering evidence and considering costs and benefits. Evidence considered included the voice-hearer's character and behaviour, external events, and the nature of the voices. Potential benefits included offering hope, providing positive feelings, and supporting desired life functioning. Costs and benefits could be context-specific, and experiencing benefits from one model at one time did not mean this model would continue to be endorsed. Different means of negotiating multiple potential models were identified. Switching between models might be influenced by altered internal states. Holding models sequentially might involve a deliberate change if the model was felt to serve poorly, or through models being 'outgrown' or 'grown into'. Additionally, some voice-hearers concurrently held conviction in multiple models. This included different models being used for the same voice, or different voices being explained using different models.

Barriers to sense-making were identified, including lacking social resources for useful exchange, previous negative responses which inhibited new sensemaking attempts, or lacking personal resources. Alongside the construction of explanatory models there may be continued doubt and uncertainty.

HVGs offer a particular kind of social experience, in which common experiences, a sense that attendees are particularly understanding and nonjudgemental, and a sense that it is safe to be authentic, all support attendees in disclosing voice-hearing experiences and engaging in potentially constructive conversations. HVGs offer space for discussions in which there is no concern about unwanted clinical interventions. Attendees are able to construct and frame their own narratives without outside pressure.

### 4.3. Commentary On Main Findings

#### 4.3.1. The construction and evolution of explanatory models for voice-hearing

The subtheme '*Voices invite questioning*' is consistent with findings that voicehearers are interested in opportunities to discuss causes and meanings of voice-hearing, viewing this as important (Carter, Read, Pyle, Law et al., 2018; Coffey & Hewitt, 2008; Geekie, 2013). The process named by participants here – asking questions of the self about voice-hearing prompted by the nature of the experience (felt as meaningful, or felt as confusing) is reminiscent of Clements' (2015) finding of a period of confusion following voice-hearing onset, including making multiple theories and finding new perspectives.

Themes constructed regarding interpersonal aspects of sense-making are in keeping with Kleinman's (1988) theory of explanations for unexpected events being generated through dialogue with important others. The subtheme '*Ideas expressed by someone with a particular expertise on voice-hearing or on the voice-hearer*' connects with previous findings that healthcare professionals were influential to the formation of explanatory models (Clements, 2015; Lewis et al., 2020). This theme, alongside '*Conversations that limit exploration*', also connect with previous findings that family and friends might potentially help or hinder sense-making (Clements, 2015). Overall, themes around interpersonal sense-making echoed findings by Carter, Read, Pyle, & Morrison (2018): voice-hearers '*discuss with others and evaluate their opinions*', with varying levels of endorsement of others' suggestions. I suggested prior knowledge and receptivity as potentially important to whether an externally suggested model is endorsed; this echoes Carter et al.'s theme that voice-hearers '*understand experiences based on their preconceptions of psychosis*'.

My construction of subthemes around evaluation of models ('*Weighing up evidence*' and '*Balancing costs and benefits*') matches previous findings. Carter, Read, Pyle, and Morrison (2018) identified that voice-hearers '*evaluate psychosocial causes and make a decision about their relevance*' (including a deliberate search for meaning in environment and context, with acceptance or rejection of these explanations) and '*attribute to factors that have a positive* 

*impact on how they feel*' (for example spirituality or a positively viewed sensitivity to others being preferred as explanations).

When weighing evidence, many participants referred to the 'felt' experience of voices. This felt sense was persuasive even in the presence of other readily accessible explanatory models. This connects with Marriott et al's (2019) finding 'felt reality' used as evidence for spiritual explanations alongside other evidence-gathering and evidence testing.

The theme '*Multiple valid models might be used*' echoes previous findings that explanatory models for voice-hearing were unfixed (Carter, Read, Pyle, & Morrison, 2018), and were potentially multifactorial and able to incorporate internal contradictions (Geekie, 2013; Read, 2020). Contrastingly, I was unable to identify previous research identifying different explanations being stably held by one voice-hearer for different voices. Plausibly, this is not a novel finding but a novel construction, previously being held under multifactorial explanations of voice-hearing. With both research questions into and a personal interest in concurrently held models, I may have been particularly inclined to construct themes in this area.

The theme 'barriers to sense-making' is partially similar to Holt and Tickle's (2015) 'blocking agents', which included fear of judgement from others. Contrastingly, lacking access to privileged resources has not previously been identified as a barrier to sense-making. Identifying privilege as a factor may be due to all participants being HVG attendees and having exposure to the HVN political ethos, which specifically examines inequality and oppression ("We focus on helping to create respectful and empowering spaces, whilst challenging the inequalities & oppressive practices that hold people back"; English Hearing Voices Network, n.d.). Additionally, my own interest power, privilege, and social justice may have attuned me to relevant aspects of the data.

### 4.3.2. The role of HVGs in the sense-making process

Themes constructed here are broadly aligned with previous findings that a space to share, to experience social connection and social support, and to feel 'normal' are highly valued (Beavan et al., 2017; Dos Santos & Beavan, 2015; Ruddle et al., 2011). More specifically, the theme *'HVGs offer a particular and special social experience'* echoes Clements (2015), who highlighted that HVGs may enable voice-hearers to speak up and express themselves freely in a way that supported developing understanding of voice-hearing experiences. The themes constructed build on Clements' by explicating in more detail elements of HVGs that support this freer expression (commonality, understanding, authenticity, lack of judgement).

The theme 'HVGs offer particular and special freedoms for discussion of voicehearing and explanatory models' is consistent with previous findings that selfdetermination was a significant and meaningful experience in HVGs (Oakland and Berry, 2015). My naming of the theme – specifying that a venue for discussion offering these freedoms is both particular and special – was connected to Geekie (2013) identifying that voice-hearers wished to actively participate in narrating their own experiences and making sense of them, and that invalidation of voice-hearers' narration of experience was both common and painful.

Collectively, the themes 'HVGs offer a particular and special social experience' and 'HVGs offer particular and special freedoms for discussion of voice-hearing and explanatory models' are reminiscent of findings from Payne, Allen, & Lavender (2017). My subtheme constructed around commonality appears similar to their theme of connection, their identifying the group as a safe space for exploration seems to include authenticity, and their theme 'freedom to be myself and grow' appears similar to my subtheme 'freedom from intellectual intervention'. As I have, they posited this sense of connection, safety, and freedom as useful in supporting sense-making and interpersonal learning.

### 4.4. Clinical Implications

For these findings to be translated into clinical practise, mental health services would need to remodel around three core assumptions:

- Voice-hearers possess the capacity to evaluate new models, move away from models they recognise as not serving them, and assemble complex individual models from multiple sources
- Understanding causal models currently used by voice-hearers is useful for providing information about how they experience voices and what costs and benefits they may encounter
- No model is necessarily better or worse than any other, but has the capacity to be more or less useful, at specific times or contexts, for the attainment of specific goals

This would require services to ask about the voice-hearer's sense-making, and to provide genuinely explorative and respectful spaces to discuss this further – for example, offering information on different explanations without an agenda of persuading the voice-hearer towards one model over another. It would require a de-emphasising of medicalised treatment plans, with medical management of voice-hearing considered as one option among many rather than first-line.

There would potentially be tension if a clinician feels strongly that a voicehearer's conviction in a particular explanatory model is leading to significant costs. Nonetheless it feels important to be respectful of voice-hearers' current models – respect here not meaning necessarily joining the voice-hearer's endorsement, but taking an interest in how this idea arose, and exploring why it feels persuasive.

This would also require reconsideration of psychological therapy offered to voice-hearers. The current recommended psychological input is FI or CBTp (NICE, 2014). Given the emphasis in increasing understanding of psychosis as an 'illness' as outcome for FI (Nilsen et al., 2016), the illness model appears implicit in this approach and it would require extensive review.

Regarding CBTp, weighing up costs and benefits, and weighing up external events to test the fit of explanatory models, are consistent with CBTp approaches. Contrastingly, using the nature of the voices themselves and the 'felt sense' of hearing a voice as evidence is not aligned with CBTp (practitioners are encouraged to reject 'gut feeling' as a valid source of evidence; Morrison et al., 2004). Nonetheless, given how persuasive these 'gut feelings' appeared, it seems important to discuss them openly and incorporate them into clinical practise. The risk of not doing so is that ideas agreed upon in CBTp may feel logically convincing and even preferred, without being emotionally convincing. If the voice-hearer in future finds their analytic ability decreased through increased demands or stress, they may be less able to access the 'logical' model while still experiencing the 'felt truth' of another model. Engaging with 'felt truth' in CBTp might invite multifactorial models. While potentially leading to more complex therapy this might also provide more options for accessing benefits.

Another potential consideration is whether it would benefit service-users for HVGs to integrate with services. This is a complex issue, with significant concerns about what HVGs might lose through integration. Further, as noted in the Methodology chapter, it is not clear in what ways, if any, HVG attendees systematically vary from the UK voice-hearing population at large and what might be the nature of any barriers to attendance. These areas would need to be clearly understood prior to any attempt at integrating HVGs into services, in order to ensure a choice of acceptable and accessible options to all potential service-users.

There are significant barriers to implementing these ideas. Clinicians may have sincere reservations about whether voice-hearers' models will provide the same benefits as models offered by clinicians. Anxiety might be evoked in services particularly regarding risk management if medication was de-emphasised. Professionals might also have complicated motivations around protecting professional domains.

Nonetheless, there are potential benefits from such a shift. This might invite in models that are more complex, but which also offer a broader range of benefits,

and are more flexible in the presence of distress. Further, creating more respectful spaces for voice-hearers not only feels ethically imperative, it holds potential to shift engagement patterns. Voice-hearers might feel more able to discuss personally held models with services and receive support in balancing inherent costs and benefits – rather than withholding information out of concern about invalidation. Although these findings, and therefore the clinical implications, are based on a limited sample that does not represent the full diversity of those who hear voice-hearers across the UK, the approach I suggest here is respectful, flexible, and individual, and should be able to accommodate the views and needs of voice-hearers from a range of backgrounds and perspectives.

Given the clinical implications, disseminating this work is important. On completion, this thesis will be publically accessible through the UEL research depository. I intend to submit this research to peer-reviewed journals. I will send a summary of my findings to stakeholders who supported this work, including HVG facilitators who supported recruitment and participants who expressed an interest in this. I will also offer this summary to the English HVN and the London HVN, for dissemination through their networks.

#### 4.5. Research Implications

Regarding the impact of others' views, I constructed the subtheme 'Many ideas from many people', highlighting that these might allow normalisation and reinforcement of beliefs. This could be explored further. How do voice-hearers negotiate discussing or withholding voice-hearing explanations when they predict these will not be socially validated? What is the experience of social dissonance, and what allows this to be tolerated versus leading to voice-hearers either re-constructing their models or seeking different social groups? This could lead to insights into what internal processes encourage voice-hearers to re-negotiate their explanatory models of voices, or into what causes them to engage or disengage with clinical services or with HVGs.

Although I constructed HVGs as a particular and special social space, with positive qualities inviting sense-making, individual participants also commented on times HVGs felt difficult – either feeling it was unhelpful for them, or worrying it was unhelpful for others. Clearly, the experience of HVGs as positive and safe is not the case for all attendees, all the time. It would be interesting to explore further for consistent patterns - for whom are HVGs transformative? For whom are they neutral? For whom are they unhelpful? – and to consider also how this aligned or not with who feels helped or not helped by traditional mental health services. This could explore - is there a cadre of voice-hearers who is helped by either approach, a cadre helped by one and not both, or a cadre helped by neither? What sort of approaches are helpful for that final cadre if so?

Beyond the causal beliefs of voice-hearers, another area of research would be on how the people around them – family, friends, and healthcare professionals – develop their own explanatory models for voice-hearing. Previous research by Carter, Read, Pyle, Law and Morrison (2017) highlighted what the common causal beliefs were within different healthcare professions, and speculated that these differences might connect to differential emphasis in training. It could be interesting to explore with different professionals what their current models are and how these developed.

### 4.6. Impact of Epistemology

My epistemological positioning of critical realism has influenced my data collection and analysis at multiple levels. My focus in this thesis has been on how an individual voice-hearer interprets and makes sense of their experiences, with an understanding of the social forces that shape this interpretation, rather than a focus on the social forces themselves and how they operate at a wider level. Similarly, my focus in analysis has been primarily on how the sense-making of these participants impacts or is enacted on an individual and level – not on how they may contribute to the construction or re-construction of these ideas socially and culturally. My application of this epistemological position in this way may also be influenced by my role as a clinician – where immediately interpersonal interaction is the medium of my work, and individual sense-making and application of this is the influenced area.

This influenced choice of data collection through individual interviews (as opposed to focus groups or conversation analysis, where available content might be less richly detailed on an individual level but inclined to identify common themes on a broader social and cultural level). In analysis, it has also influenced my themes towards a focus on sense-making at an individual and immediately interpersonal level – for example, a focus on how an individual voice-hearer weighs up different forms of evidence for their theories of voicehearing, and what is considered persuasive evidence. This means I have by contrast attended less to ideas about what the cultural repertoire or social discourses might offer a voice-hearer as tools or barriers for sense-making.

### 4.7. Personal Reflexivity

Using my reflective journal, I reflect here on how my values and biases may have shaped this project and the themes constructed. I noted above that my subjectivity may have impacted on my constructing sense-making as a privileged activity, and on my identification of different voices heard by a voicehearer as holding the potential to be explained by different stable explanatory models. I expand here on how my non-neutral stance may have altered the course of the interviews, and on how my personal interest in explanatory models for voice-hearing may have altered the selection of research questions and construction of themes.

While carrying out interviews, I was aware of being moved and empathically engaged. I imagine my non-neutral stance was evident to participants. This was in some ways a deliberate choice on my part, linked with my awareness that my subjectivity could not be fully neutralised (and attempting to do so might paradoxically interfere with my awareness of my subjectivity), and moreover that my subjectivity might enable connections with participants and support open conversations. Indeed, several participants said they had felt able to talk openly with me, or found it a pleasant or interesting experience. It is possible that my warm and encouraging tone encouraged sharing of socially invalidated models or ideas - for example, supernatural models that might normally be undisclosed, the 'felt evidence' of models, or evidence that might not be socially endorsed. A potential concern is that it may have encouraged participants to 'oversell' their interest or conviction towards a model, where in other contexts it is downplayed. If so, I will have been given a slanted picture of participants' stances. Nonetheless, this stance might still be interestingly distinct from presentations in other contexts. Another potential concern is that I may also have shown if I lacked interest in a model, potentially discouraging voicehearers from speaking freely. In actuality, the models I have least personal resonance with (supernatural and biogenetic models) were both mentioned and endorsed by multiple participants, suggesting this has not greatly altered my findings.

While my construction of research questions and the interview schedule were based on previous research and on expressed interest from voice-hearers (e.g. findings from previous studies that space to discuss explanatory models was seen as valuable and under-provided; Coffey & Hewitt, 2008; Geekie, 2013), my focus on this area was also guided by my own interests. These interests are rooted in my personal context, including my experience of having multiple family members with voice-hearing experience. The question *'why do you hear voices?'* particularly resonates when it may provide insight into a second question – *'does this mean I also will come to hear voices?'* 

This personal interest in explanatory models may also have shaped theme construction. I constructing themes in relation to models being discussed or evaluated, but it might have been equally possible to construct themes around a lack of prioritisation of explanatory models. Multiple participants noted that explanations for voice-hearing were not often discussed explicitly within HVGs, or that this might be of secondary interest to coping with voices.

It's not like, it's not like someone was sitting and asking, 'How do you interpret this experience?' It was well, I guess more organic than that, and you could just sort of get a sense based on how people were talking about their experiences -Sarah

It's not a common theme to discuss the origin, uhm, or ideas about what they are, but it sometimes comes up in discussing dealing with them dayto-day. -Samantha.

I reflect on this work in connection to critiques made of qualitative research articles by Waddingham (2015):

"I sometimes felt like the authors were sifting through a complex landscape looking for their version of Gold. It was as if intensely personal and meaningful narratives just fell through the net, unheard and unexplored."

Have I been deceptively selective as I panned through data? It is inevitably the case that a researcher with less interest in explanatory models for voice-hearing could have found an entirely different set of themes in these rich accounts – for example a theme-set around a journey into, through, and potentially out of HVGs, or how safety, expertise, power, and freedom is negotiated at HVGs compared to other contexts.

Despite this, I do think the topic of explanatory models was felt as relevant by participants. All participants referred to models having potential costs or benefits – potentially highly relevant for day-to-day functioning. This indicates this area is

indeed important - though perhaps alongside, rather than dominant over, other important conversations around voice-hearing.

### 4.8. Study Limitations

The small sample size, and the individual nature of these accounts, means that these findings cannot be incautiously generalised. However, in reflexive TA, sample size is considered less significant than data richness (Braun & Clarke, 2021c).

A further limitation is that an inclusion criteria was having attended at least three HVG sessions, and recruitment was substantially conducted through HVN newsletters, HVN social media, or direct communication with HVG facilitators. Therefore I was unlikely to attract participants who had more negative experience with HVGs – who might not have returned after initial sessions, or still be receiving HVN communications. Resultantly, HVGs supporting sensemaking through felt safety and commonality cannot be considered a universal experience. Indeed, even among participants of this study, there were occasional critical comments about HVGs, with some groups or some facilitators seen as less helpful than others. The construction of themes about safety at HVGs is based on consideration that on balance this experience seemed common, rather than universal or unequivocal.

More broadly, this study openly advertised the aim of exploring how voicehearers share and grow their ideas. Voice-hearers with little interest in sensemaking might not respond. This makes it impossible to assume that interest in explanatory models for voice-hearing, or factors constructed here as relevant in their development and maintenance, are universal across voice-hearers.

## 4.9. Concluding Remarks

The research questions were:

- **1.** How is shared sense-making involved in the development of causal models?
  - i) How do voice-hearers experience HVGs as a venue for developing causal attributions for voices?
  - ii) How does this venue compare to other opportunities for shared sense-making?
  - iii) What qualities in a social interaction support or detract from shared sense-making?
- 2. How do voice-hearers navigate multiple potential models?
  - i) Are concurrent models held?
  - ii) What circumstances prompt a shift between preferred models?
  - iii) How is such a shift experienced by voice-hearers?

I have made progress towards answering all of these questions over the Results and Discussion chapters, though in practise the answers were not discrete packages that could be applied to each question, but were significantly interwoven with each other.

In moving towards answers, this study also expands from previous work in this field. By focusing this research within HVGs, this thesis was able to confirm and build on previous research about the social sense-making process, identifying different factors for model development offered by interpersonal exchange (new models, more nuanced models, reinforcement of preferred models, and potentially a sense of normalisation). Further, this thesis builds on previous research by explicating in more depth the ways in with HVGs may support social sense-making, through felt commonality, understanding, authenticity, and lack of judgement – apparently differentiating it from other spaces accessed by voice-hearers.

While previous research has identified that voice-hearers engage in a deliberate evaluation of explanatory models, and this influences model development, this thesis provides deeper information on how a model may be evaluated (what is counted as evidence, and the type of benefits considered). Previous work acknowledged fluidity and potential for change in models; this thesis provides insights into factors behind a model shifting (e.g. contextual costs and benefits altering, contextual changes allowing models to be re-evaluated). Further, this thesis has the novel theme that different voices heard by a voice-hearer can be explained with different models, including different evidence, costs, and benefits for each.

There may be a belief within traditional mental health services that a voicehearer will or should accept the model (the 'insight') provided by clinicians. This expectation is overly simplistic. While voice-hearers may be receptive to clinicians' ideas, this occurs in the context of multiple evaluative strategies and with the possibility of multiple other models available for consideration.

Finding that causal models for voice-hearing are developed through a mixture of external and internal processes is in many ways uncontroversial. Indeed, this aligns with attribution theory (Kelley & Michela, 1980) which identifies relatively similar internal and external factors in how people make attributions about many kinds of events.

The controversy is not in my findings but in the context. From its early conceptualisations, being identified as having 'Schizophrenia' has caused people to be viewed as un-understandable (*Jaspers, 1963*), and lacking in understanding of themselves. This is seen in the inclusion of lack of 'insight' as an associated feature of the 'schizophrenia' diagnosis in the Diagnostic and Statistical Manual (DSM-5; American Psychiatric Association, 2013). This sense that any explanatory model not endorsed by clinicians must be due to illness or flawed reasoning does not align with the ways in which voice-hearers actually evaluated their explanatory models – thoughtfully and thoroughly.

As I noted at the opening of this chapter, a key finding beyond the themes lay in the complexity, richness, and nuance in these accounts. The models used by voice-hearers, and their means of evaluating them, were often insightful, creative, resourceful, and engaged with flexibly and persistently over years or decades. When mental health services fail to ask about explanatory models for voice-hearing they may miss vital information about the person sitting in the room with them – not just about their ideas about voice-hearing, but their potential to apply creativity, intuition, flexibility, and persistence to many aspects of their lives.

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### APPENDIX

### Appendix A: Ethics Review Decision Letter

# School of Psychology Research Ethics Committee

# NOTICE OF ETHICS REVIEW DECISION

#### For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

#### **REVIEWER:** Jeeda Alhakim

#### SUPERVISOR: John Read

**STUDENT: Joanna Brett** 

Course: Doctorate in Clinical Psychology

**Title of proposed study**: The formation and maintenance of causal beliefs around voice-hearing, within Hearing Voices Network groups

#### **DECISION OPTIONS:**

- **1. APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
- 2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE</u> THE RESEARCH COMMENCES (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
- **3.** NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

### DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES

#### Minor amendments required (for reviewer):

Trainee should consider completing the following sections in the ethics application and clarify how data will be stored and who will have access -

- 4.4 How will the data be securely stored?
- 4.5 Who will have access to the data?

Trainee indicates that they are not going to be working with vulnerable adults, however depending on their inclusion/ exclusion criteria which the trainee does not specific in the form it maybe that their participant group fall under this criterion. This is particularly the case if they have been given a psychiatric diagnosis.

7.1 Does your research involve working with children (aged 16 or under) or vulnerable adults (\*see below for definition)?

It would be helpful if the trainee were to indicate more explicitly their inclusion and exclusion criteria.

It would be helpful to consider additional risk reducing measures, perhaps a screening call prior to the interview.

Major amendments required (for reviewer):

**Confirmation of making the above minor amendments** (for students):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*): Joanna Brett Student number: u1945411

Date: 26/02/2021

(*Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required*)

#### ASSESSMENT OF RISK TO RESEACHER (for reviewer)

Has an adequate risk assessment been offered in the application form?

YES / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:



HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.



MEDIUM (Please approve but with appropriate recommendations)



Reviewer comments in relation to researcher risk (if any).

Reviewer (*Typed name to act as signature*): Dr Jeeda Alhakim Date: 25<sup>th</sup> February 2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

### **RESEARCHER PLEASE NOTE:**

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

### UNIVERSITY OF EAST LONDON School of Psychology

# **REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION**

### FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

# Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Trishna Patel (Deputy Research Director/Chair of School Research Ethics Committee).

### HOW TO COMPLETE & SUBMIT THE REQUEST

- 1. Complete the request form electronically and accurately.
- 2. Type your name in the 'student's signature' section (page 2).
- 3. When submitting this request form, ensure that all necessary documents are attached (see below).
- 4. Using your UEL email address, email the completed request form along with associated documents to: Dr Trishna Patel at <u>t.patel@uel.ac.uk</u>
- 5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
- 6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

### **REQUIRED DOCUMENTS**

- 1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
- 2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
- 3. A copy of the approval of your initial ethics application.

Name	of	ap	olic	ant <sup>.</sup>
Name		ap	piic	απ.

#### Joanna Brett

Programme of study:Doctorate in Clinical PsychologyTitle of research:The formation and maintenance of causal beliefsaround voice-hearing, within Hearing Voices Network groupsName of supervisor:John Read

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale		
Using electronic information letter through Microsoft Forms. This will retains all the content of the original information letter approved by the ethics application This will have a separate additional section where potential participants can directly express interest rather than needing to email <u>https://forms.office.com/r/5e8JmPXXFh</u>	This will allow participants to access the full information about the research project without needing to contact me directly: -this may make participants more likely to proceed if they find initiating email contact challenging -this may reduce a potential sense of obligation to continue after reading the information letter that might be present if they have initiated an email exchange. -the original information letter as already cleared can also be shared by email if participants prefer and in order to give them a copy to retain Microsoft Forms is held through UEL licensing		
Using an electronic consent form through Microsoft Forms This retains content from the original with minor alterations due to it requiring an electronic rather than physical signature. Completed electronic consent forms would be downloaded for safe storage <u>https://forms.office.com/r/Yx8CVXce1M</u>	The study is taking place remotely: -physical consent forms are not practical (would require postage) -scanning a signature to create a proxy of a physical signature on an electronic form may not be possible for all participants -an internet-based form is faster and more intuitive for participants than exchanging electronic forms by email (requires downloading, altering, and attaching to email again in order to return, or downloading, printing, signing, and photographing for return) Microsoft Forms is held through UEL licensing		

An updated participant advert aimed to be more visual and eye catching. This does not contain materially different information from the original approved advert.	Recruitment through social media was approved in the original ethical approval, however the original advert was text-based rather than poster- based and therefore less suitable for sharing via social media.

Please tick		NO
Is your supervisor aware of your proposed amendment(s)	Yes	
and agree to them?		

Student's signature (please type your name):

Joanna Brett

Date:

23/08/2021

TO BE COMPLETED BY REVIEWER				
Amendment(s) approved	YES			
	Comments			

Date: 02/09/2021
#### UNIVERSITY OF EAST LONDON School of Psychology

#### APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS (Updated October 2019)

#### FOR BSc RESEARCH FOR MSc/MA RESEARCH FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

#### 1. Completing the application

- 1.1 Before completing this application please familiarise yourself with the British Psychological Society's <u>Code of Ethics and Conduct (2018)</u> and the <u>UEL Code</u> <u>of Practice for Research Ethics (2015-16)</u>. Please tick to confirm that you have read and understood these codes:
- 1.2 Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.
- 1.3 When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.
- 1.4 Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).
- 1.5 Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

-	The participant invitation letter	$\checkmark$
_	The participant consent form	(

- The participant debrief letter



1.6 The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.	
<ul> <li>A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.</li> <li>Included  or</li> <li>Not required (because no participation adverts will be used)</li> </ul>	
<ul> <li>A general risk assessment form for research conducted off campus (see section 6).</li> <li>Included  or  Not required (because the research takes place solely on campus or  online)</li> </ul>	
<ul> <li>A country-specific risk assessment form for research conducted abroad (see section 6).</li> <li>Included or</li> </ul>	
Not required (because the researcher will be based solely in the UK)     A Disclosure and Barring Service (DBS) certificate (see section 7).     Included or	]
Not required (because the research does not involve children aged 16 or under or vulnerable adults) - Ethical clearance or permission from an external organisation (see section 8). Included or	,
Not required (because no external organisations are involved in the research) - Original and/or pre-existing questionnaire(s) and test(s) you intend to use. Included or	
Not required (because you are not using pre-existing questionnaires or tests) - Interview questions for qualitative studies. Included or	
Not required (because you are not conducting qualitative interviews) - Visual material(s) you intend showing participants. Included or	
Not required (because you are not using any visual materials) 2. Your details	$\checkmark$
2.1 Your name: Joanna Brett	

2.2 Your supervisor's name: John Read

#### 2.3 Title of your programme: Doctorate of Clinical Psychology

2.4 UEL assignment submission date (stating both the initial date and the resit date):May 2022

3. Your research

Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.

3.1 The title of your study:

The formation and maintenance of causal beliefs around voice-hearing, within Hearing Voices Network groups

3.2 Your research question:

The proposed study will use Thematic Analysis to explore causal beliefs related to voice-hearing. It will specifically consider the development and potential for both evolution and maintenance of causal beliefs within the context of Hearing Voices Network groups, and the impact of causal beliefs on lived experience.

3.3 Design of the research: Qualitative, using Thematic Analysis

#### 3.4 Participants:

Participants will--Be over the age of 18 -Currently reside within the UK -Self-identify as hearing voices or having other unshared sensory experiences -Have attended at least 3 sessions of a Hearing Voices group, either inperson or online -Not be currently under the Mental Health Act 2007 Participants may have any psychiatric diagnosis or none (this is not an exclusion criteria) Participants may or may not be involved with mental health services (this is not an exclusion criteria) In order to participate in the interview, participants must be able to organise their thoughts in order to communicate them, and must be able to do so over a relatively sustained period of time (up to an hour). Participants must also be able to hear potentially sensitive questions and make choices about whether or not they can answer them while still managing their distress. These subjective criteria will be assessed through initial email exchanges and by a screening call prior to the initial interview.

3.5 Recruitment:

Recruitment will be carried out through social media and newsletters associated with the Hearing Voices Network.

3.6 Measures, materials or equipment:

The study will require access to a password protected computer and separate digital storage for backing up data (e.g. the UEL H drive). It will require access to MS Teams and to audio-transcribing programmes. As participants will be interviewed remotely there will be no expenses related to travel, but a secure private space will be needed in which to carry out interviews.

3.7 Data collection:

Interviews will be carried out one-to-one via MS Teams, and recorded through MS Teams.

3.8 Data analysis:

Thematic Analysis will be used.

4. Confidentiality and security

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the <u>UEL guidance on data protection</u>, and also the <u>UK government guide to data protection</u> regulations.

4.1 Will participants' data be gathered anonymously? No – qualitative interviews will not allow for this.

If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)? Transcripts will be anonymised (all references to names, locations, or identifiable details, removed during transcription). Extracts of the interviews will be used in the published work to illustrate themes but the complete interviews will not be disseminated.

4.2 How will you ensure participants details will be kept confidential?

Consent forms (which will contain identifiable participant data) will be stored in a separately folder from interview recordings and interview transcripts. In the event of a security breach, this will reduce the likelihood of interview recordings or transcripts being identifiable to a specific person.

Where electronic consent forms through Microsoft Forms are used, the response will be downloaded and stored alongside other consent forms. The response will then be deleted from Microsoft Forms so only the stored copy remains.

A spreadsheet containing a 'data key' for identifying which interview transcript corresponds with which interview recording would be retained, to allow for verification of transcript accuracy if needed. Within the 'data key', participant names and contact details will be retained for the minimum possible length of time that would still allow interviews to be identified and withdrawn from the study at the participant's request (3 weeks post-interview); while any identifiable details are still included this data-key will be stored in a separate folder from interview recordings and transcripts. Following September 2022, the interview recordings and the key will be destroyed, and only the anonymised transcripts will remain.

4.3 How will the data be securely stored?

Completed consent forms will be stored on UEL's One Drive for Business.

Interview recordings will be created on Microsoft Stream Library (as this is default for recording via Microsoft Teams). However, immediately following the interview these will be moved to UEL's OneDrive for Business. Any local copies that are created during this transfer will be deleted immediately following the upload to UEL's OneDrive for Business.

Separate folders on UEL's OneDrive for Business will be used to store: -Documentation containing identifiable patient details (the completed consent forms; the spreadsheet data key while this retains any participant contact details or reference to consent forms) -Potentially identifiable and sensitive data, which will be deleted in September 2022 (Interview recordings; the spreadsheet data key that allows these to be linked to the interview transcripts, once this has had all participant details removed) -Anonymised data for thematic analysis (anonymised interview

transcripts; codebooks)

Data will be backed up on the UEL H Drive.

4.4 Who will have access to the data?

Aside from the primary researcher (J Brett), access to data will be granted to the Director of Studies and examiners on a need-to-know basis. This would be shared by using a secure link to the relevant data item on UEL's OneDrive for Business.

4.5 How long will data be retained for?

Audio recordings of interviews will be retained until September 2022. The anonymised interview transcripts will be retained for 10 years.

5. Informing participants

Please confirm that your information letter includes the following details:

5.1 Your research title:

/		
	$\checkmark$	/

5.2 Your research question:5.3 The purpose of the research:

5.4 The exact nature of their participation. This includes location, duration, and the tasks etc. involved:

5.5 That participation is strictly voluntary:  $\sqrt{}$ 

5.6 What are the potential risks to taking part:

5.7 What are the potential advantages to taking part:

- 5.8 Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked):
- 5.9 Their right to withdraw data (usually within a three-week window from the time of their participation):

5.10	How long their data will be retained for:
5.11	How their information will be kept confidential: $\checkmark$
5.12	How their data will be securely stored:
5.13	What will happen to the results/analysis:
5.14	Your UEL contact details:
5.15	The UEL contact details of your supervisor:

Please also confirm whether:

- 5.16 Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature. **NO.**
- 5.17 Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants? Qualitative interviews means it is not possible to gather data anonymously. Transcribed data will have all identifiable details removed (names, locations, etc). During dissemination, while extracts of the interviews will be included the full transcript of interviews will not be included.
- 5.18 Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it

be worth? NO.

#### 6. Risk Assessment

Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

- 6.1 Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised? **YES.**
- 6.2 Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised? NO.
- 6.3 Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?
  - Samaritans (open at all times, and can provide ad hoc support)
  - HVN groups (this is a source of ongoing support that the participant has access to and has used before) Local mental health services (they may already be engaged with these services, and if so will have allocated workers who they can contact)
  - Their GP (if they are not already in contact with mental health services, their GP would be able to support them with a referral)
- 6.4 Does the research take place outside the UEL campus? If so, where?
   NO however an risk assessment was requested at another stage and therefore has been included here as Appendix 8

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this has been completed:

6.5 Does the research take place outside the UK? If so, where? NO.

If so, in addition to the 'general risk assessment form', a 'country-specific risk assessment form' must be also completed (available in the <u>Ethics folder in the</u> <u>Psychology Noticeboard</u>), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a 'country-specific risk assessment form' *is* needed, please tick to confirm that this has been included:

However, please also note:

- For assistance in completing the risk assessment, please use the <u>AIG Travel Guard</u> website to ascertain risk levels. Click on 'sign in' and then 'register here' using policy # 0015865161. Please also consult the <u>Foreign Office travel advice website</u> for further guidance.
- For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
- For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

#### 7. Disclosure and Barring Service (DBS) certificates

7.1 Does your research involve working with children (aged 16 or under) or vulnerable adults (\*see below for definition)?

#### NO

Although the definition of vulnerable people in this form advises that people with psychiatric illnesses may be considered vulnerable, I feel that my inclusion criteria, exclusion criteria, and screening will ensure that potentially vulnerable people are not selected as participants. This is in line with a Department of Health definition of a vulnerable adult as someone "who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation".

- While people who hear voices / experience unshared sensory phenomena are more likely than the general population to receive a psychiatric diagnosis, participant recruitment will not be aimed specifically at those who have a diagnostic label.
- Being currently under the Mental Health Act is an exclusion criteria as people currently under the Mental Health Act may be more likely to be vulnerable.
- In order to meet the inclusion criteria, participants must be functioning sufficiently well that they are able to attend community-based groups.

- Each client will have a screening call prior to their interview to assess for less specific indicators of vulnerability (e.g. inability to organise their thoughts, poor understanding of the nature of the commitment required, or the participant predicting they would respond poorly to sensitive questions.)
- 7.2 If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this:

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead:

Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead:

- 7.3 If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these:
- 7.4 If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this

\* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children click here.

#### 8. Other permissions

8.1 Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

#### NO If yes, please note:

- You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see <u>further details here</u>).
- However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
- If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged).
   If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.
- IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
- IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.
- 8.2 Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

#### N/A

8.3 If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

#### N/A

8.4 Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.

## Recruitment will take place with support from the Hearing Voices Network.

Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here to confirm that you have included this written permission as an appendix:

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'l' with 'our organisation,' or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

#### 9. Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature): Joanna Brett

Student's number: 1945411

Date: 21/10/2020

As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.

#### **Ethics Form Appendices**

#### Ethics Form Appendix 1: Participant information letter



#### PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

#### Who am I?

I am a Trainee Clinical Psychologist studying in the School of Psychology at the University of East London, and am studying for a Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

#### What is the research?

The beliefs people have about the causes of their mental health experiences and conditions can affect how they feel about them, and the decisions they make about them. Similarly, the beliefs people have about the causes of their voice-hearing or other unusual experiences can impact on how they feel and decisions they make. As a result, we're interested in learning more about how these beliefs develop, and how Hearing Voices Network groups may play a role in this.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

#### Why have you been asked to participate?

You have been invited to participate in my research as someone who has had an experience of hearing voices, or other unusual experiences, and who has attended a Hearing Voices Network group.

I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way, and you will be treated with respect. You are free to decide whether or not to participate.

#### What will your participation involve?

If you agree to participate you will be asked to attend a one-to-one interview, in which you'll be asked about your experiences of voice-hearing (or other unusual experiences), your experience with the Hearing Voices Network, and beliefs you have about the cause of your experiences. While we call it an interview it will be very informal – more like a conversation!

The interview will take place online; you will need an internet connection and a device you can use to access the internet, and a place that is private enough that you can speak freely. You will not need to download any special programme for the interview. You are welcome to use video as well as audio, or just audio; it is your choice. The interviews will be recorded.

We expect the interview will take up to an hour, though how much you want to speak is up to you and the interview can end sooner if you prefer.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic

#### Your taking part will be safe and confidential

During the interview, you would not have to answer all questions asked, and can stop your participation at any time.

Your privacy and safety will be respected at all times. The interview recording will be typed out, and at this point all identifying details (like names and places) will be removed. While quotes from the interviews may be included in the write-up of the research, these quotes would not contain any identifiable information.

#### What will happen to the information that you provide?

All the data gathered during this project will be kept on a password-protected computer, that only I will be able to access.

Recordings of the interviews will be kept until September 2022, when the write-up will be complete. These recordings will be kept only for the unlikely event that the anonymised interview transcripts need to be verified; if this was to happen, sections of them would be viewed by examiners from the School of Psychology. Contact details of participants will also be destroyed at this time.

The anonymised interview transcripts may be viewed by my supervisor to assist in developing the data. Quotes from the interviews may be included in the write-up and if so these could be published in academic journals, but these would not include personal details. The interview transcripts will be retained for 10 years, in line with Research Councils UK (RCUK) guidance, after which data will be destroyed and all files deleted. If you wish to withdraw your interview from the study, you will have three weeks following the interview in which to do so; after this time analysis will already have begun.

#### What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw the content of your interview, provided that this request is made within 3 weeks of the interview.

#### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Joanna Brett u1945411@uel.ac.uk If you have any questions or concerns about how the research has been conducted please contact the research supervisor John Read, School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: john.read2@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

# Ethics Form Appendix 2: Participant Information Letter (Microsoft Forms version)

The letter below is a replica of the version made on Microsoft Forms. It can also be viewed via Microsoft Forms at



You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

#### Who am I?

I am a Trainee Clinical Psychologist studying in the School of Psychology at the University of East London, and am studying for a Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

#### 1. What is the research?

How people understand the causes of their voice-hearing or other unusual experiences can impact on how they feel and decisions they make. As a result, we're interested in learning more about how these beliefs develop, and how Hearing Voices Network groups may play a role in this.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

#### 2. Why have you been asked to participate?

You have been invited to participate in my research as someone who has had an experience of hearing voices, or other unusual experiences, and who has attended a Hearing Voices Network group.

I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way, and you will be treated with respect. You are free to decide whether or not to participate.

#### 3. What will your participation involve?

If you agree to participate you will be asked to attend a one-to-one interview, in which you'll be asked about your experiences of voice-hearing (or other unusual

experiences), your experience with the Hearing Voices groups, and beliefs you have about the cause of your experiences.

While we call it an interview it will be very informal – more like a conversation! The interview will take place online; you will need an internet connection and a device you can use to access the internet, and a place that is private enough that you can speak freely. You will not need to download any special programme for the interview. You are welcome to use video as well as audio, or just audio; it is your choice. The interviews will be recorded.

We expect the interview could take up to an hour if needed, though how much you want to speak is up to you and the interview can end sooner if you prefer.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic.

#### 4. Your taking part will be safe and confidential

During the interview, you would not have to answer all questions asked, and can stop your participation at any time. Your privacy and safety will be respected at all times. The interview recording will be typed out, and at this point all identifying details (like names and places) will be removed. While quotes from the interviews may be included in the write-up of the research, these quotes would not contain any identifiable information.

#### 5. What will happen to the information that you provide?

All the data gathered during this project will be kept on a password-protected computer, that only I will be able to access. Recordings of the interviews will be kept until September 2022, when the write-up will be complete. These recordings will be kept only for the unlikely event that the anonymised interview transcripts need to be verified; if this was to happen, sections of them would be viewed by examiners from the School of Psychology. Contact details of participants will also be destroyed at this time.

The anonymised interview transcripts may be viewed by my supervisor to assist in developing the data. Quotes from the interviews maybe included in the write-up and if so these could be published in academic journals, but these would not include personal details. The interview transcripts will be retained for 10 years, in line with Research Councils UK(RCUK) guidance, after which data will be destroyed and all files deleted.

If you wish to withdraw your interview from the study, you will have three weeks following the interview in which to do so; after this time analysis will already have begun.

#### 6. Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

#### Joanna Brett

u1945411@uel.ac.uk (mailto:u1945411@uel.ac.uk)

If you have any questions orconcerns about how the research has been conducted please contact the research supervisor John Read, School of Psychology, University of East London, WaterLane, London E15 4LZ,

Email: john.read2@uel.ac.uk (mailto:john.read2@uel.ac.uk)

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: t.patel@uel.ac.uk (http://uel.ac.uk)

#### 7. Thank you for reading.

If you are interested in taking part in this research, please press 'Next' below.

[Next] [Page break]

#### 8. What happens next?

If you would like to take part in the project, the next step is to set up an initial call. This call gives us a chance to meet. You will have a chance to ask any questions you might have. It also gives me a chance to check in with you about our inclusion criteria.

If you want more time to think after the initial call, that's fine. Otherwise, we could carry on and have our conversation right away.

For Covid safety reasons, these conversations are arranged remotely.

For data security reasons, these conversations are arranged through Microsoft Teams. You don't need to download a special program to use Microsoft Teams. You will get an email invitation that you can open in the usual program you use to access the internet.

If you would like to arrange a conversation, please fill in the form below. I will be in touch as soon as possible with an invitation to talk.

#### 9. What is your name?

10. What is an email address I can use to contact you?

#### 11. What times of day or days of the week would suit you for a conversation?

You can always say no if a time I suggest doesn't work for you; I will be happy to reschedule for a better time.

Monday mornings
 Monday afternoons
 Monday evenings
 Tuesday evenings
 Wednesday evenings
 Thursday evenings
 Friday mornings
 Friday afternoons
 Friday evenings

12. If you are interested in taking part but aren't sure this will work for you (for example if you aren't available at these times), I'm happy to contact you to see if we can arrange something different.

Please leave a contact number or email and I will be in touch.

You are also welcome to email me with any questions or concerns at u1945411@uel.ac.uk

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#### Ethics Form Appendix 3: Participant consent form



#### UNIVERSITY OF EAST LONDON

#### Consent to participate in a research study

## The formation and maintenance of causal beliefs around voice-hearing, within Hearing Voices Network groups

- 1. I have the read the information page relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.
  - Please tick box
- 2. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.
  - Please tick box
- **3.** I hereby freely and fully consent to participate in the study which has been fully explained to me.
  - Please tick box
- 4. Having given this consent, I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw more than 3 weeks after the time of my interview, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher
  - Please tick box

# By only ticking all of the above boxes this be taken as consent to participant in the research study

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

JOANNA BRETT

Researcher's Signature

.....

Date: .....

Ethics Form Appendix 4: Participant Consent Form (Microsoft Forms version) The letter below is a replica of the version made on Microsoft Forms. It can also be viewed via Microsoft Forms at <u>https://forms.office.com/r/Yx8CVXce1M</u>



# Consent to participate in a research study

1. I have the read the information page (*https://forms.office.com/r/5e8JmPXXFh*) relating to the above research study and have been allowed to make a copy to retain. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

Please tick the box to confirm

2. I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

Please tick the box to confirm

3. I hereby freely and fully consent to participate in the study which has been fully explained to me.

Please tick the box to confirm

4. Having given this consent, I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw more than 3 weeks after the time of my interview, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Please tick the box to confirm

5. If you are unsure if you wish to consent or have more questions, please contact the researcher.

Name: Joanna Brett Email address: <u>u1945411@uel.ac.uk</u>

If you are happy to consent to take part in this research, please type your full name as an electronic signature.

6. Please fill in the date of signing

\_\_\_\_\_

\_

#### Ethics Form Appendix 5: Participant debrief letter



#### PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on the development and maintenance of causal beliefs for voice-hearing and other unusual experiences, within the context of Hearing Voices Network groups. This letter offers information that may be relevant in light of you having now taken part.

#### What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

All the data gathered during this project will be kept on a password-protected computer, that only I will be able to access.

Recordings of the interviews will be kept until September 2022, when the write-up will be complete. These recordings will be kept only for the unlikely event that the anonymised interview transcripts need to be verified; if this was to happen, sections of them would be viewed by examiners from the School of Psychology. Contact details of participants will also be destroyed at this time.

The anonymised interview transcripts may be viewed by my supervisor to assist in developing the data. Quotes from the interviews may be included in the write-up and if so these could be published in academic journals, but these would not include personal details. The interview transcripts will be retained for 10 years, in line with Research Councils UK (RCUK) guidance, after which data will be destroyed and all files deleted. If you wish to withdraw your interview from the study, you will have three weeks following the interview in which to do so; after this time analysis will already have begun and it will no longer be possible to remove your data.

#### What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

#### <u>Samaritans</u>

Their helpline is open 24/7, and can be reached on 116 123 for non-judgemental listening support.

#### Hearing Voices Network groups

You can attend your local group session for support.

#### Mental Health Services

If you're already engaged with mental health services, you can contact them to

talk about feeling distressed; they may have provided you with numbers to contact for support in between appointments.

#### Your GP

If you're not currently engaged with mental health services, you can make an appointment with your GP to discuss your current needs; they will be able to talk with you about what support may be available to you from local mental health services, and to make a referral for you.

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

#### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

#### Joanna Brett u1945411@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor John Read. School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: john.read2@uel.ac.uk

#### or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

#### Ethics Form Appendix 6: Participant advert (original)

#### Interested in taking part in research about hearing voices?

What do you think caused your voice-hearing? How did you come to believe that?

My study, undertaken as part of my Doctoral of Clinical Psychology degree at the University of East London, explores how people who attend Hearing Voices groups make sense of their own experiences, and how the Hearing Voices group has affected this. We hope to learn more about how the ways people make sense of their voicehearing can impact on other parts of their lives, and what kind of group spaces help people who hear voices in feeling heard and supported.

This research involves an anonymous interview where you'd be asked about your experiences with the Hearing Voices group, and about how you make sense of your voice-hearing or other unusual experiences. This interview will last for up to an hour.

You are eligible to participate in this study if you've attended at least three Hearing Voices group sessions, whether or not you still attend regularly. Unfortunately no payment is available for attending.

To ask questions or to express interest, please contact Joanna Brett at <u>u1945411@uel.ac.uk</u>.

If you have any concerns please contact the Chair of the School of Psychology Ethics Committee,

#### Do you hear voices?

#### Do you attend Hearing Voices groups?

# Would you like to take part in research about your experiences?

Do you think there's a cause of your voice-hearing?
Has anything helped you to make sense of your experiences?
Do you talk about this at the Hearing Voices groups?

I would like to invite you to have a one-to-one conversation with me to share your ideas.

#### My research keeps your words and ideas at the centre.

- > My aim is to better understand how people who hear voices can be best heard and supported.
- Anything you share with me will be used to develop an indepth account of how people who hear voices share and grow their ideas, and specifically how spaces like Hearing Voices groups may be a part of that.

Who can take part?



Anyone who... ...hears voices or has other unusual experiences ...has attended three or more Hearing Voices group sessions (at any time) ...is over the age of 18 ...lives in the UK ...might be able to take part!

This research is being carried out as part of a Clinical Psychology doctorate at the University of East London. For more information, please contact Jo Brett (Trainee Clinical Psychologist) E: <u>u1945411@uel.ac.uk</u> W: <u>https://forms.office.com/r/5e8JmPXXFh</u>

If you have any concerns about this research please contact the School of Psychology Ethics Committee, via Dr Trishna Patel at <u>t.patel@uel.ac.uk</u>

Name of Assessor:	Joanna Brett	Date of Assessment	12/02/2021
Activity title:	Interviews with voice-hearers	Location of activity:	Remote interviews over MS Teams – fro interviewer's home work space and a sp the interviewee's choosing.
Signed off by	Dr John Read (Director of Studies)	Date and time (if applicable)	Dates not fixed but planned for June-Oc 2021
Manager (Print Name)	e the activity/event in as much detail as possible		nated number of participants, etc)
Manager (Print Name) Please describe If the activity to Remotely condu- interviews are p can be conduct	e the activity/event in as much detail as possible o be assessed is part of a fieldtrip or event plea ucted interviews on the subject of voice-hearing planned, each with a separate interviewee. Date ed from a place of the interviewee's choosing.	e (include nature of activity, estir se add an overview of this below g, lasting up to an hour, between and time of the interview will be	: Joanna Brett and an interviewee. Betweer agreed with the interviewee in advance. In
Manager (Print Name) Please describe If the activity to Remotely condu- interviews are p can be conduct present.	b be assessed is part of a fieldtrip or event plea ucted interviews on the subject of voice-hearing planned, each with a separate interviewee. Date	e (include nature of activity, estir se add an overview of this below g, lasting up to an hour, between and time of the interview will be	: Joanna Brett and an interviewee. Betwee agreed with the interviewee in advance. I

Guide to risk ratings:

a) Likelihood of Risk	b) Hazard Severity	c) Risk Rating (a x b = c)
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

			Hazaro	ls atta	ached t	o the activity	
Hazards identified	Who is at risk?	Existing Controls	Likelihood	Severity	Residual Risk Rating (Likelihood x Severity)	Additional control measures required (if any)	Final risk rating

#### Ethics form Appendix 9: Clearance from external organisation

chair@hearing-voices.org Tue 05/01/2021 12:20 To:

Joanna BRETT

•

Cc:

John Read

Dear Joanna,

This is just a quick email to confirm that the English National Hearing Voices Network agree to assist you with the recruitment of participants for your doctoral thesis.

With best wishes

Rai,

Rachel Waddingham

Chair, Hearing Voices Network www.hearing-voices.org

Charity No. 1094021

#### UEL Data Management Plan Completed plans <u>must</u> be sent to researchdata@uel.ac.uk for review



Pioneering Futures Since 1898

### If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Joanna Brett
PI/Researcher ID (e.g. ORCiD)	0000-0002-0176-6353
PI/Researcher email	u1945411@uel.ac.uk
Research Title	The formation and maintenance of causal beliefs around voice- hearing, within Hearing Voices Network groups
Project ID	
Research start date and duration	January 2021-May 2022
Research Description	Qualitative interviews will be carried out with 10-20 adults who have experienced hearing voices or similar anomalous sensory experiences, and who have attended a Hearing Voices Network group. They will be invited to talk about their experience of voice hearing, their experiences of the group, what causal beliefs they have about the origin of their voices, the role of the Hearing Voices Network and other social environments in reinforcing particular beliefs, and the impact of holding different beliefs on their lives. The interviews will be transcribed, and will be coded to identify patterns and themes within the data, using Thematic Analysis.

	N/A
Funder	
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	25/10/2020
Date of last update (of DMP)	19/01/2021
Related Policies	e.g. <u>Research Data Management Policy</u>
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
What data will you collect or create?	Completed consent forms (these will be sent as email attachments, with the request to complete and return them. As physical copies cannot be shared, it may not be possible to receive a copy containing a participant signature; therefore completion and return of the consent form will be used to signify consent) Interview data -Audio or video recordings (based on participant preference for audio-only or video interviews) .mp4 -Transcripts of recordings (to be stored as Word documents) Data from analysis -Code books for thematic analysis (to be stored as Word documents)
How will the data be collected or created?	One-to-one interviews, carried out and recorded through MS Teams. MS Teams transcription software will also be used. NVivo will be used to support analysis of the interview transcripts and the creation of codebooks.
Documentation and Metadata	

What documentation and metadata will accompany the data?	Support documents (not confidential) -Advert for the study -Participant information letter -Participant consent form (blank) -Participant debrief letter - An interview schedule (containing core questions that will be asked of every participant, and potential prompt questions to expand upon the core questions as needed) Completed participant consent forms Excel spreadsheet containing a key connecting: -Participant contact details (for correspondence – this will only be retained in the spreadsheet for 3 weeks following the interview) -Randomly generated reference number for the participant's interview recording -Randomly generated reference number for the participant's interview transcript Interview recordings will be saved with the relevant interview recording reference number in the document name. This will allow an interview to be identified and removed from further study (if this is requested by the participant within 3 weeks of the interview). Interview transcripts will be saved with the relevant interview transcript reference number in the document name. This will allow the transcript to be verified against the original recording if necessary (through use of the spreadsheet as a key). Codebooks
Ethics and Intellectual Property	
Identify any ethical issues and how these will be managed	<ul> <li>Participants will be fully informed of the purpose of the interview and how their interview data will be used prior to the interview itself (the participant information letter).</li> <li>During the interview, participants will be reminded that they can answer each question as briefly or fully as they like, including refusing to answer a question they find distressing, and are allowed to end the interview at any time for any reason.</li> <li>Following the interview, participants will be provided with a list of resources to contact if distressed by the content of the interview (the participant debrief letter).</li> <li>If participants wish for their interviews to not be included in the study, they have the right to withdraw these; however in practical terms it would be challenging to do this after analysis of the data has begun and as a result participants are told that any withdrawal from the study must happen in the first 3 weeks following the interview.</li> </ul>

	Consent forms (which will contain identifiable participant data) will be stored in a separately folder from interview recordings and interview transcripts. Within the spreadsheet 'data key', participant names and contact details will be retained for the minimum possible length of time (3 weeks post-interview); while any identifiable details are still included this will also be stored in a separate folder from interview recordings and transcripts. In the event of a security breach, this will reduce the likelihood of interview recordings or transcripts being identifiable to a specific person. Transcripts will be anonymised (all references to names, locations, or identifiable details, removed during transcription). A spreadsheet containing a 'data key' for identifying which interview transcript corresponds with which interview recording would be retained, to allow for verification of transcript accuracy if needed. Following September 2022, the interview recordings and the key will be destroyed, and only the anonymised transcripts will remain.
Identify any copyright and Intellectual Property Rights issues and how these will be managed	No copyrighted measures, tools, or texts will be used in this research project.
Storage and	
Backup	Completed consent forms will be stored on UEL's One Drive for
How will the data be stored and backed up during the research?	Business. Interview recordings will be created on Microsoft Stream Library (as this is default for recording via Microsoft Teams). However, immediately following the interview these will be moved to UEL's OneDrive for Business. Any local copies that are created during this transfer will be deleted immediately following the upload to UEL's OneDrive for Business. Separate folders on UEL's OneDrive for Business will be used to store: -Documentation containing identifiable patient details (the completed consent forms; the spreadsheet data key while this retains any participant contact details or reference to consent forms) -Potentially identifiable and sensitive data, which will be deleted in September 2022 (Interview recordings; the spreadsheet data key that allows these to be linked to the interview transcripts, once this has had all participant details removed) -Anonymised data for thematic analysis (anonymised interview transcripts; codebooks) Data will be backed up on the UEL H Drive.

How will you manage access and security?	Access to data will be granted to the Director of Studies and examiners on a need-to-know basis. This would be shared by using a secure link to the relevant data item on UEL's OneDrive for Business.
Data Sharing	
How will you share the data?	It is not anticipated that there will be any need to share the original recordings, which will be retained as a failsafe until the write-up is complete. Anonymised transcription data will be shared with the Director of Studies as needed, shared by secure link to the relevant data item on UEL's OneDrive for Business.
	Interview transcripts and codebooks will not be shared on UEL's Research Repository as even with anonymization the information included is too personal and potentially identifiable if whole interviews are posted. The completed thesis will be shared on UEL's Research Repository.
Are any restrictions on data sharing required?	None
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	The interview recordings will be retained until September 2022, until completion of the research project, and then destroyed. The anonymised transcription data and code books will be retained for 10 years (the minimum time recommended by UK Research and Innovation guidelines), but will not be shared after the research project is completed as the interviews are too personal and potentially identifiable if whole interviews are shared.
What is the long-term preservation plan for the data?	The anonymised transcription data will be preserved on a secure hard drive for 10 years and then destroyed.
Responsibilities and Resources	
Who will be responsible for data management?	Joanna Brett
---	---
What resources will you require to deliver your plan?	Remote access to UEL IT services including OneDrive for Business and the UEL H drive for backing up data (this is standardly available and should not require any additional outlay).
Review	
Review	Please send your plan to <u>researchdata@uel.ac.uk</u> We will review within 5 working days and request further information or amendments as required before signing



# PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

# Who am I?

I am a Trainee Clinical Psychologist studying in the School of Psychology at the University of East London, and am studying for a Doctorate in Clinical Psychology. As part of my studies I am conducting the research you are being invited to participate in.

### What is the research?

How people understand the causes of their voice-hearing or other unusual experiences can impact on how they feel and decisions they make. As a result, we're interested in learning more about how these beliefs develop, and how Hearing Voices Network groups may play a role in this.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

# Why have you been asked to participate?

You have been invited to participate in my research as someone who has had an experience of hearing voices, or other unusual experiences, and who has attended a Hearing Voices Network group.

I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way, and you will be treated with respect. You are free to decide whether or not to participate.

# What will your participation involve?

If you agree to participate you will be asked to attend a one-to-one interview, in which you'll be asked about your experiences of voice-hearing (or other unusual experiences), your experience with the Hearing Voices groups, and beliefs you have about the cause of your experiences. While we call it an interview it will be very informal – more like a conversation!

The interview will take place online; you will need an internet connection and a device you can use to access the internet, and a place that is private enough that you can speak freely. You will not need to download any special programme for the interview. You are welcome to use video as well as audio, or just audio; it is your choice. The interviews will be recorded.

We expect the interview could take up to an hour if needed, though how much you want to speak is up to you and the interview can end sooner if you prefer. I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of my research topic.

#### Your taking part will be safe and confidential

During the interview, you would not have to answer all questions asked, and can stop your participation at any time.

Your privacy and safety will be respected at all times. The interview recording will be typed out, and at this point all identifying details (like names and places) will be removed. While quotes from the interviews may be included in the write-up of the research, these quotes would not contain any identifiable information.

#### What will happen to the information that you provide?

All the data gathered during this project will be kept on a password-protected computer, that only I will be able to access.

Recordings of the interviews will be kept until September 2022, when the write-up will be complete. These recordings will be kept only for the unlikely event that the anonymised interview transcripts need to be verified; if this was to happen, sections of them would be viewed by examiners from the School of Psychology. Contact details of participants will also be destroyed at this time.

The anonymised interview transcripts may be viewed by my supervisor to assist in developing the data. Quotes from the interviews may be included in the write-up and if so these could be published in academic journals, but these would not include personal details. The interview transcripts will be retained for 10 years, in line with Research Councils UK (RCUK) guidance, after which data will be destroyed and all files deleted. If you wish to withdraw your interview from the study, you will have three weeks following the interview in which to do so; after this time analysis will already have begun.

#### What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw the content of your interview, provided that this request is made within 3 weeks of the interview.

### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

# Joanna Brett u1945411@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor John Read, School of Psychology, University of East London, Water Lane, London E15 4LZ,

# Email: john.read2@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)



# PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study on the development and maintenance of causal beliefs for voice-hearing and other unusual experiences, within the context of Hearing Voices Network groups. This letter offers information that may be relevant in light of you having now taken part.

#### What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided.

All the data gathered during this project will be kept on a password-protected computer, that only I will be able to access.

Recordings of the interviews will be kept until September 2022, when the write-up will be complete. These recordings will be kept only for the unlikely event that the anonymised interview transcripts need to be verified; if this was to happen, sections of them would be viewed by examiners from the School of Psychology. Contact details of participants will also be destroyed at this time.

The anonymised interview transcripts may be viewed by my supervisor to assist in developing the data. Quotes from the interviews may be included in the write-up and if so these could be published in academic journals, but these would not include personal details. The interview transcripts will be retained for 10 years, in line with Research Councils UK (RCUK) guidance, after which data will be destroyed and all files deleted. If you wish to withdraw your interview from the study, you will have three weeks following the interview in which to do so; after this time analysis will already have begun and it will no longer be possible to remove your data.

### What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

#### Samaritans

Their helpline is open 24/7, and can be reached on 116 123 for non-judgemental listening support.

#### **Hearing Voices Network groups**

You can attend your local group session for support.

### Mental Health Services

If you're already engaged with mental health services, you can contact them to talk about feeling distressed; they may have provided you with numbers to contact for support in between appointments.

#### Your GP

If you're not currently engaged with mental health services, you can make an appointment with your GP to discuss your current needs; they will be able to talk with you about what support may be available to you from local mental health services, and to make a referral for you.

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

#### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

# Joanna Brett u1945411@uel.ac.uk

If you have any questions or concerns about how the research has been conducted please contact the research supervisor John Read. School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: john.read2@uel.ac.uk

#### or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

- How did you first come to attend a Hearing Voices group? *Potential prompt questions:* 
  - When did you start going to the Hearing Voices group?
  - What led to you attending the Hearing Voices group?
- What has attending the Hearing Voices group been like for you?
  - Do you still attend the group?
  - What sort of things make you decide to go to a group session, or not?
  - Why did you choose to stop going?
  - Are there things you do / did enjoy about the group?
  - Are there things you don't / didn't enjoy about the group?
  - Are there things you find / found helpful about the group?
  - Are there things you find / found unhelpful about the group?
  - Since you stopped going to the group, are there things about it that you miss?
  - Since you stopped going to the group, are there things about it that you don't miss?
- What sense do you make of why you hear voices / have these experiences?

Potential prompt questions:

- Is there anything which seemed to lead to you hearing voices / having these experiences?
- Has the way you've made sense of your experiences changed over time?

Potential prompt questions:

- Have there been times when you've made sense of your experiences in a different way?
- What ideas about sense-making have stuck with you?
- Why do you think those ideas have stuck with you?
- What's it like for you to have made sense of your experiences in this way?

Potential prompt questions:

- How did you feel when you made sense of your experiences in the previous way?
- How do you feel now that you make sense of your experiences in this new way?

I'm going to ask shortly about how this making sense of your voices might have been talked about at the Hearing Voices group. However, I'm also interested in knowing about any other people you might have spoken about this with, for example friends or family, or professionals who've been involved in your care. You're welcome to choose what experiences you talk about, and we can skip past this question if you prefer.

• Have other people (not from the Hearing Voices group) influenced the way you make sense of your experiences?

Potential prompt questions:

- Who is it that's influenced how you make sense of your experiences?
- What conversations have you had with other people that have helped you in making sense of your experiences?
- Have there been times you've agreed with the ideas of other people about how to make sense of your experiences?
- Have there been times you've disagreed with the ideas of other people about how to make sense of your experiences?
- At a Hearing Voices group you've gone to, have other people shared their ideas about the causes of their voices / experiences? Would you tell me about that?

Potential prompt questions:

- What beliefs about the cause of their experiences do other people talk about?
- What was it like for you to hear other people talk about that?
- Did hearing other people talk about that help you in making sense of your voice-hearing / other experiences?
- At a Hearing Voices group you've gone to, have you ever shared your own ideas about the origin of your voices / other experiences? *Potential prompt questions:* 
  - Are there any specific times you've talked about those ideas that have really stuck with you?
  - Can you tell me about a specific time that talking about that went well? What was it that made that a good experience?
  - Can you tell me about a specific time that talking about that didn't go so well? What was it that made that a bad experience?
  - Did sharing in that way help you in making sense of your voices / other experiences?
- If you could design a space where people felt comfortable to talk about their reasons for hearing voices what would it look like?

- Was there something you were expecting me to ask that I didn't?
- How do you feel about the conversation we've had today?

# Appendix H: Text advert for research project

# Interested in taking part in research about hearing voices?

What do you think caused your voice-hearing? How did you come to believe that?

My study, undertaken as part of my Doctoral of Clinical Psychology degree at the University of East London, explores how people who attend Hearing Voices groups make sense of their own experiences, and how the Hearing Voices group has affected this. We hope to learn more about what kind of group spaces help people who hear voices in feeling heard and supported.

This research involves an anonymous interview where you'd be asked about your experiences with the Hearing Voices group, and about how you make sense of your voice-hearing or other unusual experiences. This interview will last for up to an hour.

You are eligible to participate in this study if you've attended at least three Hearing Voices group sessions, whether or not you still attend regularly. Unfortunately no payment is available for participating.

To ask questions or to express interest, please contact Joanna Brett at <u>u1945411@uel.ac.uk</u>.

If you have any concerns please contact the Chair of the School of Psychology Ethics Committee, Dr Trishna Patel at t.patel@uel.ac.uk

# Do you hear voices?

# Do you attend Hearing Voices groups?

# Would you like to take part in research about your experiences?

Do you think there's a cause of your voice-hearing?
Has anything helped you to make sense of your experiences?
Do you talk about this at the Hearing Voices groups?

I would like to invite you to have a one-to-one conversation with me to share your ideas.

#### My research keeps your words and ideas at the centre.

- > My aim is to better understand how people who hear voices can be best heard and supported.
- Anything you share with me will be used to develop an indepth account of how people who hear voices share and grow their ideas, and specifically how spaces like Hearing Voices groups may be a part of that.



#### Who can take part?

...hears voices or has other unusual experiences ...has attended three or more Hearing Voices group sessions (at any time) ...is over the age of 18 ...lives in the UK

...might be able to take part!

This research is being carried out as part of a Clinical Psychology doctorate at the University of East London. For more information, please contact Jo Brett (Trainee Clinical Psychologist) E: <u>u1945411@uel.ac.uk</u> W: <u>https://forms.office.com/r/5e8JmPXXFh</u>

If you have any concerns about this research please contact the School of Psychology Ethics Committee, via Dr Trishna Patel at <u>t.patel@uel.ac.uk</u>

# Appendix J: Early Thematic Map

