# An Interpretative Phenomenological study exploring the experience of attending a community Hearing Voices Group

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# Abstract

# **Introduction:**

Voice hearing is increasingly understood through perspectives beyond only medical understandings of the phenomenon, and interventions moving beyond a focus on 'symptom reduction'. The idea of living with voices is increasingly accepted, a principle underpinning Hearing Voices Groups (HVGs). Research suggests HVGs hold clinical potential for voice hearers and may offer new directions for services to move to meet the diverse needs of voice hearers. This project explores the experiences of those attending community HVGs to better understand their benefits and barriers, including how groups may affect relationships with voices. Implications for mental health services are considered.

# Method:

Through consultation and co-production with experts by experience, 6 self-identified voice hearers across two community HVGs participated in semi-structured interviews. Interpretative Phenomenological Analysis was used to elicit individual and group themes.

# **Results:**

Four group themes emerged. Groups facilitate a **secure base** experienced as empowering and flexible, where all perspectives are heard and respected. A shared experience of voice hearing and relational opportunities to facilitate **connecting on a deeper level**, where genuine relationships emerge, making changes to how members view themselves, others and society possible. **Turning toward voices** is supported, leading to a more sustainable and harmonious relationship with voices and an acceptance of their existence. Lastly, **taking a leap of faith** explores the experience of navigating new spaces and pushing through the resistance of voices.

## **Discussion:**

Findings support existing HVG literature and the usefulness of groups as an alternative or addition to existing service provision. Results support the implementation of Trauma Informed Care and other relational approaches to voice hearing. Professionals' confidence when working with voices and the experience of those not attending HVGs are potential areas for future research. Services should consider how they can exist harmoniously alongside HVGs and consider their frameworks in light of these findings.

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#### **CHAPTER ONE - Introduction**

This chapter will explore definitions of voice hearing and associated experiences, reflecting upon the limitations and difficulties of offering any single conceptualisation. The heterogenous nature of the phenomenology and aetiology of voice hearing will be discussed, and consideration given to the relational nature of voices. I will review existing guidance on working with voices in mainstream mental health services in the United Kingdom, critically evaluating the existing evidence base and mainstream services' ability to adequately support all voice hearers equitably. The Recovery Movement and its influence on how mental health is understood and worked with will be explored, including its influence on peer-led support. The Hearing Voices Movement and its contribution towards the development of Hearing Voices Groups will be explored, including a critical review of current literature. The project rationale will then be set out, followed by the research question and project aims.

#### **Epistemological positioning**

I sit within a constructionist position and therefore view the human experience as subjective and that how experiences are constructed is a key part of knowledge acquisition. Whilst I acknowledge there may be commonalities and trends surrounding voice hearing, I do not believe there is any one explanation or 'truth' as to why and how people hear voices. My positioning influences how I have sought to conduct a literature review, striving for a breadth of perspectives and conceptualisations as opposed to ascribing to any one framework of understanding. My epistemological positioning is explored further within the methodology.

#### Use of terminology

I will use the term 'voice hearing' to define a broad range of experiences and phenomena. This is to include understandings and perspectives that may not be commonly accepted or understood within a medicalised framework (e.g., Spirits, Djinns) and to avoid privileging any one single explanation or understanding over another. Where possible, language that may be considered more medicalised in

nature, such as 'schizophrenia', 'hallucinations' or 'psychosis' will be used to reflect concepts and terminology within the literature. However, this is done with full acknowledgement that some individuals partially or fully reject these terms and that such concepts may evoke difficult experiences.

The terms 'clinical' and 'non-clinical' voice hearing will be used in an attempt to distinguish between voice hearing experiences that are distressing to a degree to which an individual may access mainstream mental health services, as opposed to those whose experiences are less distressing, sometimes referred to within literature as 'healthy' voice hearing. It is acknowledged that relationships with voices change over time, and neatly distinguishing into two broad categories does not fully capture the complexity of these experiences. The researcher strongly advocates for those with lived experience, and those who work with them, to accept and respect the language and meaning they themselves make of their experiences.

#### **Defining voice hearing**

The experience of voice hearing has been commonly viewed as a symptom of mental illness since around the 17<sup>th</sup> century (McCarthy-Jones, 2012). Voices are commonly associated with psychiatric diagnoses such as schizophrenia, psychosis, bipolar and major depressive disorder (Bauer et al., 2011; DeVylder, 2017; Toh et al., 2015) and are often described as 'hallucinations' - perceptions occurring without external sensory stimuli (American Psychiatric Association, 2013). Some voice hearing is conceptualised as 'pseudo-hallucinations'' often associated with diagnoses such as PTSD and personality disorder (Clifford et al., 2018). The two main diagnostic classification systems at present are the ICD-11 (2019) and the DSM-5-TR (2022). Both stipulate that an individual must present with more than one co-occurring psychotic symptom to receive a diagnosis of schizophrenia. Schizophrenia as a diagnosis continues to be redefined and criteria for diagnoses altered, with auditory hallucinations a consistent 'symptom'. An associated term, psychosis, refers to experiences thought to occur on a spectrum, typically involving hallucinations and/or delusions (Arciniegas, 2015) or related experiences not shared by the majority of the population. Those who hear voices are typically viewed as having a mental illness and as requiring intervention from mental health services. However, there is a large population of individuals who do not see their voices as the product of a mental illness, and many do not require or want support through mainstream services.

Despite voice hearing presenting in a variety of contexts and being understood differently across different cultures and groups, there remains a dominant narrative within the United Kingdom driven by a westernised perspective. This affects how voices are talked about, researched and understood. A focus on a pathologising view of voice hearing as a symptom associated with negative and debilitating experiences may influence how voice hearing has been researched and understood. Albeit important research, it may lead to a narrow view of how we work with and understand voices, but also how others experience this phenomenon, in turn limiting our ability to adequately support those who may seek help.

The seminal works of Romme and Escher (1989) increased awareness of those who hear voices with little distress and may not present to mental health services or report negative consequences of hearing voices. Research has continued to explore the experience of these voice hearers (Larøi et al., 2012; Johns et al., 2014). It is now more accepted that voice hearing can present trans-diagnostically, and in those without a diagnosis or mental health condition (Baumeister et al., 2017). This opens new ways of conceptualising voices and individuals' relationships with those voices. This has research implications for how we can explore how voices are experienced across different populations or contexts, enriching our understanding of voices. Research exploring the uniqueness of voice hearing experiences, acknowledging the variability of the phenomenon highlights difficulties in offering a single definition of what it is to hear voices.

This highlights the importance of remaining open and developing our understanding of voice hearing, providing novel ways in which to research this phenomenon, and to think critically about how we best support those who hear voices.

#### Epidemiology

Whilst voice hearing can occur in the pre-adolescent period (Steenkamp et al., 2021), adolescence is thought to be when distressing voice hearing experiences are most likely to develop or emerge (Baumeister et al., 2017). There are methodological difficulties in estimating the prevalence of voice hearing. How voices are conceptualised varies depending on a multitude of variables including social and cultural factors, and the country in which the research is conducted (Volpato et al., 2022). Reported figures should therefore be interpreted with this in mind.

Between 0.3 and 0.7% of the general population receive a diagnosis of Schizophrenia during their lifetime (Van Os and Kapur, 2009; World Health Organisation, 2022), with approximately 80% of those diagnosed experiencing at least one form of 'hallucination' such as voice hearing (McCarthy et al., 2017). Leede-Smith et al. (2013) estimate that around 25% of those who do hear voices and would meet criteria for a psychiatric diagnosis still do not experience associated distress. Around 9.8% of those who hear voices do so in the absence of a psychiatric or neurological diagnosis (Maijer et al., 2018). Broadly, it is estimated that between 5 and 13% of the general population experience voices, whether accompanied by a diagnosis or not (Beavan et al., 2011; Krakvil et al., 2015; Linscott and Van Os, 2013).

#### The impact of voice hearing

Those experiencing psychosis or schizophrenia can experience increased anxiety and low mood, in addition to a poorer quality of life (Heinze et al., 2018). Popovic et al. (2019) also found increased rates of cognitive difficulties affecting both working memory and executive functioning. Voice hearing more broadly is associated with poorer concentration and sleep, in addition to negative

external stigma (Vilhauer et al., 2017). Hearing voices may affect voice hearers' ability to communicate with and trust others (Birchwood, 2003; Woods et al., 2015), and may lead to withdrawal from friends, family and society more broadly (Zhuo et al., 2019). Voice hearing experiences are also commonly associated with withdrawal or isolation from friends, family and society more generally (Zhuo et al., 2019). Voices may be socially disruptive through making conversation and connecting with others more difficult (Birchwood, 2003; Woods et al., 2015). They can also have an indirect impact by negatively impacting one's self-esteem, sense of safety or general mood (Woods et al., 2015). These negative experiences can have a significant impact on the families, friends, and carers of voice hearers (Poon et al., 2017).

There is an economic cost of distressing experiences such as voice hearing, including funding services to support individuals, and the impact on someone's ability to earn a reasonable income (Shields et al., 2022), increasing the likelihood of experiencing difficulties associated with poverty and financial challenges. Some voices may be commanding in nature leading someone to engage in more dangerous behaviours in response to their experiences (Sheaves et al., 2023). Higher rates of suicide and self-harm are commonly associated with those who hear distressing voices or experience other related phenomenon (Hielscher et al., 2019; DeVylder et al., 2020). The impact of voices can be bi-directional too. For example, anxiety may make voices more distressing, and the presence of voices simultaneously increasing levels of anxiety. Internalised stigma can lead to young people being less likely to share their difficulties associated with voices, and subsequently withdraw from their peers (Parry et al., 2021; Rammou et al., 2023), and poorer sleep may increase likelihood of difficulties with mood, motivation and anxiety. The negative attitudes towards voice hearing within western societies can lead to other difficulties such as alcohol misuse and inequitable access to housing and employment (Read et al., 2006), although such negative attitudes may exist within non-western societies as well.

Whilst many individuals experience negative and distressing consequences of voice hearing, some who hear voices live harmoniously with them, and have positive associations with their experiences.

Around 40-60% of voice hearers will hear a useful or positive voice at some time (Jenner et al., 2008), with 52% of patients diagnosed with a mental health difficulty reporting some positive effects of voice hearing (Sanjuan et al., 2004). There are voice hearers who report little-to-no distress associated with their voices, and many report having a good quality of life that is enhanced by their voices, increasing their sense of wellbeing, connection, personal growth and companionship (Valvanis et al., 2019). Alderson-day et al. (2021) also found 35% of voice hearers reported positive emotions relating to their voices, and 32.5% reporting that their experiences gave them a sense of companionship in which voices were perceived as helpful. Some young people who experience voices have reported finding them important, and that they could be exciting and comforting (Parry et al., 2021).

Understanding both the experience of those who hear voices positively, and those who experience them negatively, without making broad categories and generalisations around diagnoses or how voices are understood is important. There are many interacting and intersecting factors that make it difficult to be prescriptive as to how voices are and will be experienced. Therefore, ongoing research with those who hear voices across different contexts and who appraise their experiences differently is important in developing our understanding of these experiences.

#### Phenomenology of voice hearing

A medical view of voice hearing may consider voices an abnormality of perception that may be accompanied by other beliefs or 'symptoms' such as paranoia and other delusions. These understandings often derive from clinical observations, interpreting what a person says their experience of voice hearing can change over time (Woods et al., 2015) and are highly heterogeneous across both clinical and non-clinical samples (Wilkinson and Bell, 2016).

Some voices hold pragmatic properties that replicate actual speech (Leudar et al., 1997) and can develop and replicate complex interpersonal relationships with those who hear voices, much like that of another human (Upthegrove, 2016). Large scale studies surveying or interviewing voice hearers

have found a high variability regarding the frequency, intensity (level of distress), tone (e.g. nasty, soft, abrupt), location (internally or externally), loudness, and content (e.g. an utterance, single word, or complex sentences) of voices (Hayward et al., 2014; Woods et al., 2015). This suggests a uniqueness of each voice hearing experience dependent on many different factors. There is also research into less known populations of voice hearers, such as those who are deaf who experience voices through their preferred mode of communication, such as sign language. (Morris et al., 2020). Those who hear voices in the absence of distress or diagnosis also report similar, complex and changing relationships with voices, and variability in how they are experienced (Toh et al., 2020).

Culture has been found to exert an influence on the form and content of experiences such as voice hearing (Jones et al., 2021; Luhrmann et al., 2015). Whilst some communities appraise such experiences as distressing, others may appraise them as a divine spiritual gift, for example (Heffernan et al., 2016). Less distressing voices are also associated less frequent voice hearing experiences in addition to greater perceived control of their experiences (Daalman et al., 2011; Baumeister et al., 2017). Non-clinical voices often have more positive content of speech – sometimes imparting helpful knowledge or reassurance, and voice hearers feel they had a greater sense of who the voice was and what it represented (Moseley et al., 2022). Consideration has been given to attachment styles, with avoidant attachment styles associated with more critical voices (Berry et al., 2017). Individuals who rate their voices as more benevolent also present with more adaptive and positive ways of understanding and living with their experiences (Peters et al., 2012; Tsang et al., 2021).

How voices are experienced and appraised can change over time, therefore we cannot definitively conceptualise how any one individual will experience voice hearing. However, there are common features and factors that may predict the level of distress one may experience as a result of this phenomenon. To build upon our understanding of whether voices are distressing or not, we must consider factors associated with whether people hear voices or not in the first instance.

#### Actiologies of voice hearing

Throughout recorded history, voice hearing has been conceptualised as a supernatural or religious experience, whether that be through ghosts or spirits (McCarthy-Jones, 2012) or communication from a divine or higher being such as God or the devil, for example. Initially termed 'dementia praecox' by Kraeplin at the end of the 19th century (Jablensky, 2010), Schizophrenia was conceptualised as a condition that included voice hearing and other psychotic symptoms, accompanied by severe cognitive and behavioural decline, which was assumed to result in a 'terminal state'. The term Schizophrenia was coined in 1908 by Bleuler, in which a distinction was made between 'basic' and 'accessory' symptoms (Maatz et al., 2015), now referred to broadly as negative/disorganised and positive symptoms, the latter including hearing voices.

As with many phenomena, there is still a lively debate as to what leads someone hear voices, in addition to what factors may mediate how they are experienced. How we talk about and understand voice hearing can have significant consequence for how the experience is perceived societally and how mainstream services may work with those in distress. It is beyond the scope of this thesis to fully explore all potential causes of voice hearing. However, time will be given to more prominent theories that fall loosely under a biopsychosocial approach.

#### **Biological**

A biological understanding of voice hearing is a prominent narrative within both mainstream services and the literature, resulting in significant developments in psychopharmaceutical treatment options for those who may receive a diagnosis of psychosis or schizophrenia. Broadly speaking, those who hear voices are thought to present with biological and neurological differences. This is often identified through comparing brain functionality between those who do and do not hear voices (Arciniegas, 2015). Many different findings have been put forward to identify and isolate differences between the brains and biological makeup of those who do and do not hear voices and tend to focus on those with a diagnosis of schizophrenia. Shao et al. (2021) offer a comprehensive and up-to-date review of biological understandings of voice hearing.

Those with schizophrenia may have enlarged ventricles (DeQuardo et al., 1994), lower connectivity within auditory networks (Guo et al., 2020) and rely more heavily on internal perceptions that are interpreted externally as opposed to actual sensory input (Powers et al., 2017), increasing the likelihood of 'hallucinations'. Studies using functional imaging have reported activation of speech-related areas when voices are present (Richards et al., 2021), Other studies report finding increased activation in language and verbal short-term memory regions of the brain in those who hear voices (Fuentes-Claramonte et al., 2021). More recently, research has explored genetic variants that may be more commonly observed in those with Schizophrenia compared to those without diagnoses (Rajesekaran et al., 2016), and how these variants may interact with psychosocial factors (McCarthy-Jones et al., 2014). Heritability, which estimates the size of genetic effects, is around 80% in twin studies (Hilker et al., 2018) although these estimates vary slightly across studies.

One of the most influential and cited biological theories of schizophrenia is the dopamine hypothesis, first proposed over 50 years ago. This postulates that voice hearing and associated experiences are a result of excess production of striatal dopamine (Deserno et al., 2016). Initial evidence for this hypothesis was thought to be two-fold. Firstly, the therapeutic effects observed with antipsychotic use depend on their ability to block dopamine (Brandl et al., 2019), and secondly, substances that stimulate dopamine, such as amphetamines, appear to produce a state that presents similarly to the positive symptoms of schizophrenia (Connel, 1958), with meta-analyses supporting the idea of increased dopamine synthesis capacity in those with schizophrenia (McCutcheon et al., 2018). Other research proposes that NMDA receptors, and other aspects of the glutamatergic system, have some role in the development of schizophrenia (Catts et al., 2016), including through interaction with the dopamine system. Such hypotheses are still highly debated and contested, and other theories relating to Schizophrenia continue to be explored (Yang and Tsai, 2017).

Whilst biological understandings of voice hearing are an important piece of the puzzle and have greatly contributed toward the development of less invasive interventions, the area is not without its criticisms. Such theories are complicated by voice hearing presenting across a vast range of diagnoses such as Parkinson's, strokes, migraines (Vreeburg et al., 2016), tumours in specific areas of the brain (Braun et al., 2003), and sleep disorders (Fortuyn et al., 2009), in addition to those without diagnoses. How these experiences are observed, treated and understood is therefore variable, dependent on further contextual information and influences beyond distinct diagnoses. Many biological theories of voice hearing operate on the assumption of diagnostic criteria to compare those with and without diagnoses, whereas we now know voice hearing to exist in both populations, limiting generalisability to all voice hearers. Secondly, the concept of schizophrenia is questioned by many (Van Os, 2016), as are diagnoses more broadly. There are concerns that biological explanations of voice hearing, or mental health difficulties more generally, may perpetuate ideas of chronicity, illness and stigma (Kyalle et al., 2013). This debate is large and very much alive today, a more comprehensive review of the Schizophrenia research critique can be seen in St. Clair and Lang (2021).

### **Psychosocial**

Biological understandings of voices are often critiqued for their lack of consideration of both social and psychological factors (Lonergan, 2017). The Division of Clinical Psychology (2013) call for human experience to be seen within the context it exists, including the context of the wider systems and influences of any given individual. Psychological understandings of voice hearing therefore tend to focus more on a formulation of experiences, allowing for a plurality of ways to make sense of voices. These aetiologies are often a blend of both psychological theory and acknowledgement of social contexts. The British Psychological Society Division of Clinical Psychology (BPS DCP) proposes that biological and life experience factors (including trauma, inequality and discrimination) are important considerations for how voices come to exist and how they are experienced. Psychological factors may moderate levels of distress associated with voice hearing too. Early Freudian theories of voice hearing postulated that voices are a result of ego disintegration – an individual unable to accept and assimilate a voice as part of themselves. More recent theories of voice hearing consider cognitive models in which associations are made between schizophrenia and cognitive deficits implicated with voice hearing (Waters et al., 2012) and that inner speech is misattributed to external sources in those who hear voices, perhaps as a result of source monitoring difficulties (Moseley et al., 2013). Some research suggests voices are the result of faulty intrusions from memories, in which working internal and external representations of oneself become fragmented (Waters et al., 2006). These theories suggest that voices hearing sits within a wider cognitive experience, and that how voices are appraised and managed may be predictive of distress and the need for additional support (Mewson et al., 2010; Peters et al., 2016).

Strong associations exist between trauma and voice hearing (Moskowitz et al., 2009). This notion has been supported through cross-cultural studies too (Fung et al., 2020). An abundance of research shows that traumatic experiences, bereavement, loss and adverse childhood events can all increase the likelihood of experiencing both clinical and non-clinical voice hearing, or other unusual experiences by up to 7.6 times (Gibson et al., 2016, McGrath et al., 2017; Varese et al., 2012). These adverse experiences/traumas are also risk factors for diagnosis of psychotic disorders including schizophrenia (Morgan and Fischer, 2007). Research has found the content of voices to often be thematically or symbolically linked to past traumas too (Shinn et al., 2020). It has also been speculated that the psychological effects of loneliness, for example, may lead to voice hearing as a means of meeting a communicative need (Hoffman, 2007). Negative voices are also thought to be associated with both negative self-schema, and insecure attachment (Scott et al., 2020).

Socioeconomic factors may also increase the likelihood of voice hearing experiences, such as the chronic stress of living in under resourced communities (Hastings et al., 2019). There has been extensive research into those who might be considered 'at risk' of experiencing voice hearing or other experiences, often termed At-Risk Mental State (ARMS) or those who have only recently begun hearing voices that are impacting their lives. Research has found factors such as past traumatic events,

bullying, poverty, immigration, and cannabis use may increase the risk of developing psychosis (Cornblatt et al., 2012; Addington et al., 2020).

Psychological factors may have both causal and modifying effects on if and how voices are experienced. Perceived social power or a lack thereof may influence levels of distress caused by voices, as well as an increased sense of disempowerment by the voice hearer. Longden et al. (2012) proposes that those who have experienced perceived or actual powerlessness may therefore experience more powerful voices. Some research suggests that in young voice hearers, voice hearing may emerge as a consequence of loneliness and isolation, or a sense of not belonging socially in attempt to fulfil subjective social needs not otherwise met (Mawson et al., 2011).

Like other risk factors, psychological risk factors and theories/models should be considered cautiously, as research is ongoing. There is likely to be a variety of interacting factors that may increase the likelihood of such experiences, and many individuals who are identified as 'ARMS' or prodromal do not go on to experience clinical voice hearing or associated experiences long term. Acknowledgement must be given to epistemic harm caused by social injustice, systemic racism, inequality and both societal and political influence on the likelihood of receiving diagnoses, ill-treatment within mental health systems and predicted poorer outcomes as a result (Crichton et al., 2017; Brandt et al., 2019; Tibber et al., 2019), in addition to the effects of intersectionality on these factors. Fricker (2007) defines epistemic injustice as a form of discrimination in which an individual's expertise or abilities are undermined due to belonging to a marginalised group. Research has found that voice-hearing continues to be associated with negative stereotypes and attitudes in society (Huggett et al., 2018), which has significant impact on both emotional wellbeing and recovery (Burke et al., 2016).

It is difficult to disentangle the aetiology and phenomenology of voice hearing. Voice hearing may increase the likelihood of experiencing psychosis in some individuals. Both secondary intersecting factors and mechanisms which maintain clinical voice hearing may mediate or protect against this,

such as the presence of social support (Laroi et al., 2012). The potential cumulative effects of these factors make this area of research particularly complex. Attempts are being made to isolate and identify subtypes of voices, in attempt to develop more effective ways of drawing broader conclusions to inform intervention and understanding of voice hearing (Corona-Herandez et al., 2022). Acknowledging the interaction between different aetiologies of voice hearing is imperative in fully appreciating the complexities of this phenomenon, its onset and maintaining factors. What is clear is that the relationship an individual has with themselves, their voices, and wider society can have an impact on how voices are experienced, and how others understand and speak about voices can influence how in turn voices are experienced and understood by voice hearers.

#### **Recommended interventions for voice hearers**

The World Health Organisation (WHO) recommend a rehabilitation model for those who are experiencing a 'serious mental illness', which commonly includes distressing voice hearing or associated experiences. It is recommended that individuals have access to the use of psychiatric medications, and to psychosocial interventions. Such interventions include being supported within the community, access to talking therapies, and practical support around employment, housing etc (WHO, 2016). Early Intervention in Psychosis Teams within the UK are commissioned with the intent of providing support to those experiencing a first episode of psychosis.

Within the UK, the National Institute of Clinical Excellence (NICE, 2014) sets out recommendations and guidance for professionals working with those who may experience a first episode of psychosis, including voice hearing experiences. Such recommendations are derived through evaluating existing research. The language used within this guidance tends to reflect psychiatric diagnoses and the medical model of mental health that remains dominant within the UK. NICE propose three main interventions for working with those who have received diagnoses associated with Schizophrenia and Psychosis. Each will be discussed in turn, and related research critically evaluated.

#### Cognitive Behavioural Therapy for psychosis (CBTp)

Cognitive Behavioural Therapy is a heavily researched psychological intervention. CBTp was developed with a focus on unshared experiences such as voices and visions, and broadly aims to shift negative or 'maladaptive' appraisals of voices with hopes to reduce the intensity and impact of the voices (Birchwood et al., 2018). Models such as the Morrison model work to explore how voices are made sense of and related to, in addition to considering historical relationships and events, and how these influence the interpretation of voices (Morrison and Renton, 2001). CBTp is also used for other commonly associated experiences such as paranoia and unshared visual experiences. Therapeutic alliance is seen as important within CBT practice and acknowledged as a mediator of outcomes in both CBT and CBTp (Dobson, 2022; Newman-Taylor and Bentall, 2023), with Beck (1979) considering this as a foundation of CBT necessary for change.

There is an acknowledgement that one's relationship with voices can often mirror other social relationships (Birchwood et al., 2004), and CBTp approaches increasingly consider the importance of relational elements of voice hearing (Chadwick, 2006). This is also reflected in third-wave CBT-based therapies such as Compassion Focussed therapy, of which explicitly consider how individuals relate to themselves, others, and their voice hearing experiences (Heriot-Maitland et al., 2019). Large scale meta-analyses have found small-to-moderate effect sizes for CBT in reducing distress associated with voices, as a 1:1 intervention (Jauhar et al., 2014; Lincoln and Peter, 2019), and in group settings (Smailes et al., 2015). Other studies have also found CBTp to be an effective intervention for experiences associated with psychosis, with reported improvements remaining at follow-up (Peters et al., 2015).

Whilst CBTp presents a strong evidence base within the literature, exactly what aspects are useful and are not is thought to remain unclear due to variability in its delivery (Thomas, 2015). It is questioned whether CBT adequately addresses the other potential consequences or difficulties associated with voice hearing, such as social withdrawal, stigma, or a lack of opportunity to make sense of experiences (Hall et al., 2022). Accessing CBTp typically requires someone to be under a mental health service such as an Early Intervention team (Prytys et al., 2011), limiting accessibility. Self-guided CBT for voices resources have been evaluated, showing encouraging results when compared to treatment as usual (Hazell et al., 2018). These may offer more accessibility but may miss out on key relational aspects of therapeutic work such as the therapeutic alliance.

There are calls for newer more personalised approaches to CBTp both in research and practice to improve outcomes further, leaning into this variability in delivery to be more flexible and attuned to the needs of the individual and their specific experiences (Newman-taylor and Bentall, 2024). Johnstone and Boyle (2018) also query how much space is given for social, cultural and political contexts within more standardised interventions like CBTp. Whilst focussing on sense making, CBTp may not be flexible enough in allowing for all meaningful narratives and interpretations that voices hearers may express and may potentially neglect more positive elements of voice hearing, or interpretations outside of more westernised perspectives of voice hearing (Sinha and Ranganathan, 2020). Lastly, whilst holding in mind relational aspects of voice hearing, CBT does not explicitly advocate for direct interactions with the voice hearing experience, therefore not focussing on broader relationships of voice hearing beyond cognitive appraisal. This contrasts newer approaches such as Talking With Voices (Longden et al., 2021) of which seeks to conscientiously but intentionally engage with voices.

#### Family interventions (FI)

Potentially distressing experiences, such as voice hearing, can have implications for those close to a person. Many families and/or carers can experience carer strain, high expressed emotion and increased anxiety (Shiraischi and Reilly, 2019). Such factors can lead to critical comments, over-

involvement and other detrimental relational difficulties associated with poorer outcomes for those experiencing psychosis (Cechnicki et al., 2013). It is therefore imperative that support and interventions for family or support systems are available and implemented. Family interventions for psychosis may vary in their delivery, but typically focusses on the relationships within which an individual's difficulties present, including thinking about all of those involved in the system (Burbach, 2018). FI works to utilise existing strengths and expertise within support networks to develop new understandings of an individual's difficulties and experiences (Onwumere et al., 2018).

With regards to evidence of efficacy, FI has been found to reduce carer strain (Lobban et al., 2013), reducing hospital admission rates (Pharoah et al., 2010) and improving social functioning for the individual (Hahlweg and Baucom, 2022). There have been observed changes in carer empathy and engagement styles too (Giron et al., 2015). FI has also been evaluated as a cost-effective resource (Bird, 2010). However, FI benefits are not typically sustained post-intervention follow-up, nor does it reduce the frequency of voice hearing (Claxton et al., 2017). Also, such intervention depends on an individual having a social network present, and mental health services having the available resources to engage in such intensive intervention. There are also known difficulties with resources and accessibility, as is the case for many mental health interventions.

#### Antipsychotic medication

Antipsychotic medications are often considered the first-line intervention for various severe mental illnesses, including schizophrenia and psychosis. Antipsychotics vary slightly in their mechanisms of action, but broadly speaking, they work to affect dopamine D2 receptors, blocking or acting as a partial agonist (Aringhiere et al., 2018). Many consider antipsychotics to have revolutionised treatment and intervention in those diagnosed with schizophrenia, with continued antipsychotic treatment found to significantly reduce risk of relapse (Leutch et al., 2012). There has been extensive research on the efficacy of antipsychotic medication, with large scale systematic reviews suggest that compared to placebo, antipsychotics are efficacious in reducing rates of both relapse and hospitalisation, as well as some evidence of reduction in voice hearing (Zhu et al., 2017). There is

little difference between second-generation antipsychotics with respects to their efficacy, but the risk relating to adverse effects appear to differ across treatment options, often being the primary factor in deciding which antipsychotic to provide (Leutch et al., 2012; Haddadd and Correll, 2018).

However, caution should be given to antipsychotic efficacy research due to conflicts of interest and financial influences of large pharmacological organisations and the potential for bias (Heres et al., 2006) and that antipsychotics are less effective than suggested, and that placebo is sometimes just as effective (Leucht et al., 2017). Antipsychotics have most efficacy in reducing positive symptoms, but up to a third of those prescribed antipsychotics also continue to have distressing experiences, such as voice hearing (Hasan et al., 2012). The detrimental side effects of antipsychotics are also well documented (Stroup and Gray, 2018) leading to high rates of unplanned cessation, bringing about difficult withdrawal symptoms (Kaar et al., 2020). Some find antipsychotics beneficial to varying degrees, and others very unhelpful (Read and Williams, 2019). What is consistent is the prevalence of reported adverse effects such as sedation, emotional numbing and slowed thoughts. Outcomes for people who experience voice hearing have hardly changed over the years (Lee et al., 2018), and many would argue that long-term anti-psychotic use has serious health consequences such as weight gain and drowsiness (Harrow and Jobe, 2018). Antipsychotic prescribing has increased sharply over 20 years in young people and adolescents (Radojčić et al., 2023) highlighting a need for more research into the long-term efficacy and dangers of antipsychotic use. Furthermore, there is limited evidence as to the effectiveness and safety of antipsychotic medication for this population (Krause et al., 2018; Parry et al., 2021, p716).

NICE recommended interventions have positive outcomes for those distressed by their voice hearing experiences in many instances. However, these recommendations are evaluated for their use on those who receive diagnoses, meeting set criteria that is not without its criticisms. Diagnosis tells us very little about the reasons behind the experiences, and it is argued that the DSM pays insufficient attention to the subjective human experience and sense making (Zisman-Ilani et al., 2013), undermining the scientific basis of diagnoses as well as their potential accuracy. It may also exclude

those who do not make sense of their experiences through the dominant medical model in western societies, excluding many individuals from receiving meaningful and effective support. Retraumatisation is commonly reported in mainstream mental health services and having one's voice not heard or beliefs questioned may contribute to increased distress (Grossman et al., 2021). Research has found that voice-hearers who receive care through mental health services commonly report having to explain their voices through means that do not truly align with their experiences or perspectives, such as adopting medicalised terminology, leading to a sense of disempowerment as well as perceiving themselves as 'not normal' (Oakland and Berry, 2015; Lee et al., 2019). Furthermore, the efficacy of both medication and psychotherapies appears to be beneficial but only to a point, and their efficacy overestimated due to methodological limitations such as bias (Leichsenring et al., 2022).

It therefore feels important that we think critically about viable alternatives as to how to work with voices and voice hearers. Current NICE recommended approaches appear to privilege a biological understanding of voice hearing first and foremost, with more psychologically informed models being secondary. This leaves little room to incorporate an individual's understandings and beliefs around their experiences. Those who do not identify fully with a medicalised understanding of their experiences commonly feel unheard, stigmatised and in some cases, retraumatised (Harrison et al., 2022). In turn, this can lead to their views and experiences of hearing voices being misrepresented and unhelpful narratives around voices being a symptom reinforced. This can lead to more distressing voice hearing experiences (Barlati et al., 2022; Reddyhough et al., 2021). Those who use mental health services have shared that they would want assistance in exploring and making sense of their voices (McCarthy-Jones et al., 2015; Sapey and Bullimore, 2013).

I will now discuss further perspectives and ways of both viewing and working with those who hear voices.

#### The recovery movement

The Recovery Movement gained momentum in the early 70s and saw individuals who had received diagnoses such as Schizophrenia wanting more of a voice in mental health services and interventions. Fundamentally, the movement emphasised the importance of seeing recovery outside of 'symptom' reduction, and rather support people to live with their experiences (Davison, 2016). Historically, those who heard voices were placed in asylums and given little hope for the future (Chow and Priebe, 2013). Emerging research highlighting improved outcomes in those initially thought to be 'chronically' unwell served as a catalyst for change (Harding et al., 1987), with the notion of 'recovery' being challenged. Rather than viewing symptom reduction alone as a measure of recovery, functional recovery (Harvey and Bellack, 2009) considered the importance of social functioning, and personal recovery (Slade, 2009) considered the subjective experience of an individual, viewing recovery as a dynamic and fluctuating process in which hope, and personal choice were important factors (Davidson and Roe, 2007).

Changing conceptualisations of recovery led to systematic changes within legislation and service provision, including an enhanced focus on the importance of self-determination and choice for those with mental health difficulties - both in how they define themselves and their experiences, and the conceptualisation of recovery (Davison, 2016). Fundamentally, the movement argues for a focus on building resilience and supporting emotional distress, not just symptom reduction (Jacob, 2015). There is still some difference in definition and application of recovery by those with lived experience and those in mental health services, as seen by recommended interventions for voice hearers in mainstream services, compared to a growing popularity of peer support groups and interventions led by those with lived experience. The recovery movement is often praised for contributing toward a growing acceptance of self-help and peer support, within mental health services and independently (Ostrow and Adams, 2012).

#### Peer support groups

It could be argued that an increase in peer support groups reflects the growing recognition of the value of lived experiences as a means of sense making and intervention (Myrick and Del Vecchio, 2016). Peer support is not a new concept, with the Alleged Lunatics' Friends Society offering an example from the 19th century, in which former patients of an asylum worked together to engage in mutual support, and advocate for protection against improper treatment and law reforms. Peer support groups are becoming increasingly commonplace within the National Health Service (NHS) and third sector organisations (NHS England, 2017) and form part of the NHS long-term plan (NHS, 2016, p25). Peer support can be broadly defined as a group of individuals who share a similar experience can both give and receive support (Hardy et al., 2019). Their function is underpinned by principles of self-help, mutual support, mentoring, recovery and open dialogue. There is a distinct focus on empowering members, with a focus on both a strengths and recovery model, typically not an illness model (Repper and Carter, 2011). Peer support works on the assumption that those with similar experiences have an enhanced ability to relate to one another and are therefore able to offer authentic empathy and validation that mental health professionals or others without the shared experience may not fully achieve (Mead and MacNeil, 2004).

Peer-support provision can vary greatly in their structure and delivery. Groups may be owned and facilitated by all members of the group or may be 'professionally' led by a mental health worker who may or may not have lived experience (Doull et al., 2017). Groups such as Hearing Voices Groups (HVGs) exist both within existing NHS services, and externally through voluntary and third sector organisations (Bellamy et al., 2017). To help those with lived experience navigate and locate such groups, organisations such as Mind (2019) have developed directories and signposting resources.

#### Psychological theories of groups

To understand and evaluate the potential value of peer-support groups, it is important to review existing literature on how and why groups might work, and the psychological theory underpinning them. Maslow's hierarchy of needs (1943) may suggest how groups offer a sense of belonging and psychological safety. It may be that being within a group in which there is a common or shared identity or experience may provide a greater sense of belonging for those with more commonly unshared experiences such as voice hearing. Yalom's therapeutic factors in groups (Yalom and Lesczc, 2005) also provides a helpful framework for thinking about the functionality of peer support. Existing research assimilated into direct clinical observations were synthesised into eleven mechanisms considered the 'ingredients' of group psychotherapy, summarised in Table 1.

#### Table 1.

Therapeutic Factors	Definition
Universality	Members recognise that other members share similar feelings, thoughts, and problems.
Altruism	Members boost self-esteem through extending help to other group members.
Instillation of hope	Members recognise other members improvement, and they develop optimism for their own improvement
Imparting information	Education or advice provided by the therapist or group members
Corrective recapitulation of primary family experience	Opportunity to re-enact critical family dynamics with group members but in a corrective manner
Development of socialising techniques	The group provides members with an environment that fosters adaptive and effective communication
Imitative behaviour	Members expand their personal knowledge and skills through the observation of group members' self-exploration, working through, and personal development
Group cohesiveness	Feelings of trust, belonging, and togetherness experienced by the group members
Existential factors	Members accept responsibility for life decisions
Catharsis	Members release of strong feelings about past or present events
Interpersonal learning	Members gain personal insight about their interpersonal impact through feedback provided by other members, and allows members to interact in a more adaptive manner

Each of these mechanisms may present within in peer-support groups. Universality is a core feature of peer-support, as all members of a group share similar experiences. Many of these mechanisms may complement literature around voice hearing and distress. Romme and Escher (1989) found supportive social environments to be protective in reducing rates of relapse, with social isolation known to increase voice-related distress (Garety et al., 2001). Therefore, Yalom's therapeutic factors are important in considering the functionality and efficacy of peer-support groups, including HVGs.

#### Theories of peer support groups

Research into psychological theories underpinning peer support groups often mentions both experiential knowledge and social comparison theory (Solomon, 2004; Deci and Ryan, 2008). Borkman's theory of experiential knowledge (1976) makes distinction between theoretical knowledge, such as that perhaps held by a mental health professional, and knowledge acquired through direct experiences, such as those with lived experience of voice hearing. This theory acknowledges the specialised knowledge acquired through direct experience, and how individuals with a shared common experience may be able to relate on a much deeper level. This may play a role in the validation, normalisation and sense of belonging often reported in peer support groups. Furthermore, Bandura (1977) proposed that being able to personally relate to and identify with another individual who has more adaptive means of coping can promote recovery, enhanced by exchange of experiential knowledge. Group conversations in which members relate may influence how individuals think, feel, view and speak about themselves and others. This makes room for new, potentially more adaptive and helpful narratives to develop. Being able to identify within a group may also facilitate individuals more readily embracing relational meanings of safety. This in turn can nurture more compassionate relationships with themselves and others.

Social Comparison Theory (Festinger, 1954) stipulates that developing a sense of shared identity within a group can facilitate upward or downward comparison, with varying effects. A member of the group may feel more hopeful and see how their experiences and coping strategies may improve if there are group members who appraise their experiences more positively, demonstrating upward

comparison. Additionally, if a member of the group presents as more distressed with their experiences, or presenting with more severe experiences, an individual may appraise their own experiences more positively, demonstrating downward comparison. Both forms of comparison allow for members of a group to both give and receive support and share knowledge. Other psychological theories thought to explain change in peer-support groups include self-determination theory. This proposes that people need autonomy (control of their own behaviours), competence, and connection or relatedness (a sense of belonging and attachment to others) to achieve 'psychological growth' or to facilitate change (Ryan and Deci, 2000).

These theories may explain observed shifts in the perception of self-leading to higher self-worth, social power, and improved resilience (Lan and Wang, 2019) within peer support groups. Within mental health, this may facilitate a move away from the identity of a passive 'patient' toward a more autonomous and valued member of society. Peer support groups may also facilitate a space where different views can be held more equally, with equal importance and space, creating a sense of acceptance of not knowing, and no single individual holding the expertise of an experience. This moves away from absolute truths and certainty, instead allowing for individuals to be validated and own their own perceptions of their experiences and the notion of recovery (Faulkner, 2017).

Whilst this literature highlights the potential benefits of peer support groups, the theories are not without their critique. Helgeson and Gottieb (2000) highlight that when opportunity for validation arises, there is a risk of invalidation, or feeling unheard in a group. With the heterogeneity of voice hearing for example, someone may still feel isolated and like no one else fully appreciates their difficulties, which could go on to further isolate them. Both upward and downward comparison may lead individuals to view their situation more negatively if they are not coping as well as others, or equally become anxious that they may experience more distress in the future.

To summarise, whilst potentially limited and still developing, theories of both groups and peersupport potentially foster opportunities for the unique benefits of experiential knowledge and shared

experiences. Such environments may facilitate a validating environment in which uncertainty is more tolerated, and support becomes a didactic process. There is a clear importance regarding the relational nature of groups, which may underpin present peer support group literature. There is a continued need for high quality research into peer support, to further built upon theories as to how peer support works and fosters change (Cronise et al., 2016), including exploration of relational processes given psychological theories of peer support commonly consider the effects of being with others.

#### Current evidence for peer support groups

While important in their own right, theories of peer support are limited in their ability to explain the psychological mechanisms by which complex psychological transformation occurs. Peer support groups have been researched across a wide range of contexts. In doing so, themes and potential mechanisms of change have emerged.

Research has identified many different potential mechanisms that underpin peer support, including the role of lived experienced and providing the provision of strengths focussed, social and practical support (Watson, 2019). Psychosocial benefits of peer support include increased hope and motivation likely as a result of feeling less alone and being able to relate to others within the group (Joo et al., 2022). Opportunity to relate with others who have achieved or are doing better with similar experiences and learning practical ways of coping and being able to then support others to do so, highlights the importance of relational factors and processes within peer-support. Rogers (1959) argues that the 'core conditions' of a helpful relationship include empathy, congruence, and unconditional positive regard, all highly relevant to peer support. Relationships and shared identities are also highly valued and viewed as important by peer support workers in one-to-one work (Walker et al., 2024).

Peer support groups appear to be effective in various areas of mental and physical health, including bereavement (Ali and Luckock, 2020), Psychosis (Castelein et al., 2008), Spinal cord injuries

(Barclay and Lalor, 2022), people living with HIV (Berg et al., 2021), and dementia (Harding et al., 2023). Peer support groups may not show improvements on clinical outcome measures commonly used to evaluate mainstream services or interventions, such as a reduction in 'symptoms' or hospitalisation (Fuhr et al., 2014) but show potential improvements in measures of personal recovery (Lyons et al., 2021).

A systematic review of randomised controlled trials of peer support groups for those with significant mental health difficulties found self-reported improvements across areas of hope, recovery and empowerment (Lloyd-evans et al., 2014). Furthermore, individuals report increased treatment satisfaction (Chinman et al., 2014), improved quality of life (Cabassa et al., 2017) and an increased sense of empowerment, and ability to develop new ways of coping (Burke et al., 2018; Ali and Lucock, 2020). Attendees of peer support groups report having a sense of shared identity, improved self-acceptance, and shifting perspectives of self and their experiences (Davis et al., 2014; Klarare et al., 2022). Individuals reported feeling able to speak freely about their beliefs and experiences, without fear of shocking or upsetting others or being judged, due to the shared experiences within the group (Hardy et al., 2019). Interestingly, peer support has found to show similar outcomes even if delivered online, which can allow for greater flexibility and accessibility (Banbury et al., 2019) and have been found to be of benefit to carers and those close to an individual experiencing difficulty (e.g. Nicula et al., 2023). Overall, peer-support groups appear to benefit those who attend - not necessarily on measures of symptom reduction for example, but on measures that may lack more objective outcome measures such as hope and empowerment, making it difficult to effectively evaluate peersupport group efficacy (Watson, 2019).

#### **The Hearing Voices Movement**

The seminal work of Romme and Escher (1989), in collaboration with voice hearers, brought to light the notion of non-clinical voice hearing and led to a movement aligned with the broader recovery movement – The Hearing Voices Movement (HVM). A focus on medical models of voice hearing

was seen as reductionist and viewing recovery as indicated by symptom reduction, as opposed to focussing on the individuals' own understandings and hopes (Corstens et al., 2014). Eventually becoming the Hearing Voices Network, voices are understood as meaningful reactions that may relate to life events, and actively encourage meaningful engagement and sense making (Romme and Escher, 2000). They strongly focus on the relational element of voice hearing, and advocate for voice hearers being acknowledged as the experts of their own experiences. This network has led to important shifts in voice hearing narratives, and from it, publications, research and new ways of working with voices have surfaced.

Several key principles are held by the HVN, which guide the ethos of HVGs. Voices are seen as a meaningful and valuable response to human experience, moving away from western-dominant perspectives to make room for societies in which voices may be celebrated (Al-Issa, 1995). All possible explanations for voices should be valued equally, including different cultural or religious beliefs (McCarthy Jones et al., 2013). This approach may be perceived by some as unconventional in supporting voice hearers to be empowered by their experiences and seek out meaning as opposed to suppressing the existence of voices. Voice hearers should have ownership over their experiences and define it as they see fit, moving away from spiritual beliefs and ideologies being pathologised (McCarthy Jones, 2012, p201). Acceptance of voices is viewed as more helpful than attempts to suppress or eradicate them, and finally peer support and collaboration is empowering and an important part of recovery. There appear to be few available published papers criticising this approach, however some have expressed a need for 'science-based advice' for voice hearing and that the movement may undermine trust in medical help (Epperson, 2013).

These principles have led to a shift toward a more dialogical and relational understanding of voice hearing, and subsequently led to new ways of working with voices away from traditional interventions. Dialogical approaches are a product of shifts in our understanding of voice hearing. However, these are yet to be commonplace in mainstream services. These can be clustered into two overlapping strands. Avatar Therapy (Ward et al., 2022) and Relating Therapy (Hayward et al., 2017) focus on supporting a voice hearer develop assertive communications with dominant or persecutory voices, sitting more closely with CBT-p, for example. Compassion focussed therapy for psychosis (CFTp; Heriot-Maitland et al., 2019) and HVM-led approaches such as the Talking with Voices approach (Longden et al., 2021) hold a more relational focus, helping the voice-hearer develop a more harmonious relationship with their voices (Longden et al., 2021). A shift toward direct communication and dialogue with voices has become well established within the HVM both in the UK and internationally (Longden et al., 2021), including the use of tools such as the Maastricht Interview (Moskowitz, 2008) that helps voice hearers to develop an understanding of their voices in the context of their own lives. These emerging interventions may present with their own criticism and limitations.

The HVN has led to the development of HVGs – a move away from professional-led interventions. These groups do not explicitly exclude those who do not hear voices but have other related experiences (e.g. visions, unusual thoughts) (Hearing Voices Network, 2022).

#### **Hearing Voices Groups**

The first HVG began in Manchester in 1988, with over 180 different groups existing in the United Kingdom alone (Branitsky et al., 2020), and similar trends seen internationally. Their only criteria are typically an acceptance of the HVN principles. Some HVGs are within NHS funded services, such as Early Intervention in Psychosis Teams, Community Mental Health Teams, and Inpatient facilities. Whilst they are often run very similar to community-based groups, these may have specific criteria for attendance such as diagnoses or being supported by their service, for example. Some may also require a referral from a healthcare professional to access this group, presenting as a potential barrier. HVGs hold a distinct focus on group ownership, with all members collaboratively deciding how to work together and what will be discussed (Dillon and Hornstein, 2013).

The emergence and continual growth of HVGs internationally continues to provide an important alternative or addition to the existing support for voice hearers. There are calls for further research to understand the distinct mechanism of change HVGs hold to develop a strong 'evidence-base'. The main critique of HVGs comes from those fearful of the effects of actively discouraging 'science-based advice' (Inman, 2013), perceiving the HVNs distancing away from the medical model as setting a dangerous precedent. Pierre (2017) offers a more balanced perspective where HVGs offer alternative or additional perspectives for working with and understanding voices. These perspectives may complement existing ways of working with voices, increasing the plurality of approaches to voice hearing. Equally, they may not fit some individuals ways of working, who may prefer to engage with more biological interventions such as antipsychotic treatment.

Whilst HVGs share some of the key features of peer support groups, such as people being able to attend the groups for as long as they feel appropriate and being for those with shared lived experience, they are distinct in other ways. HVGs accept all frameworks and explanations for an individual's difficulties or experiences with no referral or diagnostic criteria is required to attend. Similarly, HVGs share some key features of psychotherapy groups, which aims to develop new ways of making sense of experiences to develop new narratives. However, HVGs do not require diagnoses, attendance is not mandatory, group discussion is actively encouraged inside and out of the group, and HVGs try to foster authentic relationships that exist beyond the group.

#### Current literature around HVGs

There are ongoing efforts to better understand the efficacy and outcomes of HVGs, in addition to the mechanisms of change and clinical potential. Many studies have found HVGs help to provide a basic human need of feeling connected and developing interpersonal relationships with others (Payne et al., 2017; Schaefer et al., 2021). This may be particularly significant for those who hear voices due to the well documented stigma and societal marginalisation they commonly experience, that can affect one's confidence and social skills.

Hendry (2011) found HVGs are experienced as places of acceptance, where members felt safe and could engage with their own personal journeys of recovery with both voices and reconnecting with others. More recent literature suggests that HVGs may develop and facilitate a sense of improved hope and inspiration for voice hearers (Longden et al., 2018). 79% of participants in Beaven et al.'s (2017) study reported feeling more hopeful after attending HVGs, and that this helped them to feel safer. More specifically, that hearing positive stories of living with voces from other voice hearers can improve a sense of hope. (Nkouth et al., 2010). Both Oakland and Berry (2015) and Schaefer et al. (2021) capture how participants feel inspired and hopeful through hearing others' experiences and stories of things improving, which can come from both attendees and group facilitators.

For some, HVGs meet their needs in ways they feel mental health services cannot. 95% of respondents in Longden et al.'s (2018) study reported using mental health services, but that HVGs provided them with a service otherwise not available. Similarly, Shaefer et al. (2021) found that participants really valued the peer-led aspect of the group and being able to share and hear experiences with those who have lived experiences, more uncommonly feasible in mainstream services.

HVG literature suggests that these groups can facilitate the development of new knowledge and improved coping skills. Participants commonly begin to question their own beliefs about voices and say that the groups have helped them to identify and better understand potential triggers for distressing experiences (Dos Santos and Beavan, 2015). Those who better understand their voices also appear to be less fearful of their experiences, with up to 82% of participants in Beavan et al.'s (2017) study agreeing that HVGs had improved their ability to cope with voices. Similarly, a qualitative study by Longden et al. (2018) found that 59 of 101 respondents felt HVG attendance led to improved coping through sharing knowledge and better understanding their experiences, in turn reducing stress. Similar findings were also reported by Nkouth et al., 2010, Oakland and Berry, (2015), Schaefer et al. (2021) and Payne et al. (2017). Perhaps what this area of research lacks are the views and experiences of those who have attended HVGs and have subsequently stopped going, and therefore dissatisfaction

of groups is often missed. Often it is unclear how long people have attended groups and it is often hard to assess whether there are subtle differences across groups as a result of geography or other factors.

These studies propose that the sharing of experiences between voice hearers allowed for the mutual exchange of knowledge and support, and a greater understanding of voice hearing experiences. Such exchange of knowledge by those with similar experiences provided extra credibility and value for participants, allowing for changed perception of self and one's ability to cope, in addition to participants reporting feeling good through being able to help others (Oakland and Berry, 2015). The studies suggest that such information was more valued than advice given by mental health professionals, but that knowledge of mental health professionals was still seen as valuable (Schaefer et al., 2021). Research from Payne et al. (2017) found that as voice hearers develop a better understanding of their voices, they can experience a shift from passively experiencing voices, to being more in control. Similar findings were reported by Rácz et al. (2017) and Ruddle et al. (2014). This process was found to give more control to voice hearers and shifted the voice from mainly negative to more supportive and positive.

Some HVG attendees reported that the HVG was the only place they socially connected with others, and that the social aspect of the groups were very important. Attendees reported that the non-clinical nature of the group fosters a more communal and informal environment where genuine friendships can develop (Dos Santos and Beaven, 2015; Tomlins and Cawley, 2016). Nkouth et al. (2010) report similar findings, in addition to participants feeling less alone or isolated, and having a real sense of belonging. Oakland and Berry (2015) found that HVG attendees often felt less viewed purely for their experiences, but more so for who they were more broadly, making people feel more valued. Longden et al. (2018) report that this nurturing environment leads to participants feeling more socially confident, and several studies find improvements in outcomes such as social skills, increased self-esteem, and social connectedness (Abram et al., 2020; Beavan et al., 2017). Rufato et al. (2023) found

that this togetherness and acceptance is often key in reducing social isolation, in turn reducing distress and making space for new ways of thinking.

HVGs have been adapted for other populations such as Veterans who hear voices or have visions, in which members report a sense of comradery, reduced social isolation and a significant reduction in distress related to their experiences (Kalofonos et al., 2024). Furthermore, whilst presenting with different challenges, groups facilitated online are found to have similar benefits in addition to being more accessible to those who may struggle to attend in person (Branitsky et al., 2024). They have also been researched and found to provide voice hearers with strategies of coping cross culturally (Rufato et al., 2023).

Hornstein et al. (2020) also utilised surveys but with those who attend HVGs within the USA. They found that attendees of these groups felt less perceived pressure to change than experienced in mental health services, and that self-determination and volition was highly prioritised both within the group, and externally. Respondents also reported that the groups allowed for multiple understandings of voice hearing to be held simultaneously, and that dialogue within the group felt organic, non-judgemental and collaborative. This in turn appeared to foster genuine relationships that continued outside of the groups.

Rufato et al. (2023) explores the voice management strategies shared in a hearing voices peer support group in Brazil, who more commonly utilise peer-support in their mainstream mental health services. They identified five main strategies used to broadly cope with voice hearing, social connectedness and spirituality or religion. These strategies were found to help voice hearers feel less isolated, in turn reducing distress related to their experiences and feel able to better accept and cope with their experiences. Their findings also highlight the importance of space to accept beliefs other than biomedical explanations of voice hearing, such as spiritual or religious explanations (Corradi-Webster et al., 2018).

A large systematic review by Corentin et al. (2023) synthesises much of the findings to date. The review found that those who attend HVGs or associated groups report several benefits consistently across the literature, including reduced isolation, development of coping skills, improved knowledge around their experiences, and improved hope and inspiration. Our understanding of this area continues to grow as researchers utilise a mixture of both qualitative and quantitative methodologies. These factors potentially position HVGs as a valuable source of support for voice hearers, both as a standalone resource, or having potential to complement more traditional mental health settings. HVGs may hold potential in equipping those who hear voices to feel more empowered and have more volition within mainstream services, holding onto their understanding of their own experiences and personal perceptions of recovery.

Moving towards an acceptance of voices as a wider society, as experienced within HVGs, can reduce voice-related distress (Luhrmann et al., 2015; Powers et al., 2017). Furthermore, emerging research appears to find HVGs being accessible and efficacious across cultures and with different populations (e.g., those with a learning disability) (Roche-morris et al., 2019) further supporting their flexible use. However, healthcare professionals remain sceptical and uncertain about integrating peer support due to a perceived lack of 'real' evidence (Hornstein et al., 2020; McCluskey et al., 2022). Groups embedded in services may be limited in who and how people are informed about HVGs according to studies exploring the beliefs of professionals around HVGs (Kilpatrick et al., 2017; Waller and Turner, 2016). This means that service users may not be routinely offered this type of support, and professionals may place an over emphasis or reliance on symptom reduction (van Os et al., 2019).

#### **Rationale for current project**

There is growing evidence supporting the efficacy and value of HVGs. However, more research is required to expand how we understand these groups and their clinical potential. I will now set out rationale for this project.

Firstly, existing guidance within UK mental health services may fall short of meeting the needs of all voice hearers due to the heterogeneous nature of their experiences and how those experiences are understood. These services and interventions may be culturally inflexible and do not facilitate an acceptance of voices within society, and there are known barriers to accessing mainstream support for certain populations or demographics. It is therefore essential that research into this area is ongoing, to allow for us to better understand and explore the implementation of HVGs as an alternative or addition to current clinical practice, especially with the knowledge that existing provisions may not be equitable in their accessibility and may perpetuate distress.

Second, both national and international policy is turning towards the utilisation of peer support and adopting a recovery approach towards mental health difficulties (World Health Organisation, 2013). An increased evidence base is needed to help mental health professionals feel more confident about the clinical potential of HVGs as standalone support as well as their potential integration into mainstream services. A focus on medication or biology alone is not in line with the current evidence base and has impact on how nurses and other healthcare professionals feel they can work and adequately support voice hearers (McCluskey and Vries, 2021). There is a distinct lack of research into the implementation of HVN frameworks within specialised community mental health services. Research is required to be able to identify, describe and evaluate the efficacy of peer-supported interventions and interactions (Styron et al., 2017).

Traditional measures of efficacy have focussed on factors such as symptom reduction, or reduced hospitalisation. Both factors are important considerations but fail to capture the diverse benefits of HVGs (de Jager et al., 2016), nor do they allow for subjective conceptualisations of recovery. Exploration of the experiences of those attending HVGs is a foundational step in evaluating their efficacy, which can contribute towards the development of more robust and valid measures. It is essential that evaluation of peer-support is conducted to ensure policy and practice are based on evidence about what works, for who, and how, to avoid low-value care in which interventions waste already limited resources and cause more harm than good. Ongoing research hearing different Voice

Hearers perspectives, combined with a synthesis of evidence may help to shift the attitudes of healthcare professionals, highlighting the potential benefits of peer-support and HVGs.

This project considers the influence and importance of relational processes and their potential role on change and growth within HVGs. There is an increasing acknowledgement of relational factors in seen within individual therapies such as CBT (Dobson, 2022) and more recently Talking with Voices (Longden et al., 2021). The aim of relational therapies is to facilitate a change of attitude with voices and explore new and improved ways of building relationships and communication between voice and voice hearer (Steel et al., 2020), with the outcomes of these therapies appear promising (Dellazizzo et al. (2022). In these interventions, change may not be explicitly intended but often observed. Relational processes are highlighted within peer support literature more broadly too, and their influence on mechanisms of change questioned. Recent research from Allison (2024) identifies the importance of relationships between voice, voice hearer and professionals. However, more research is required to understand the relational influences and mechanisms of change within HVGs, with regards to both voices and others. This project aims to explore how HVGs might facilitate such changes and if so, how relational processes emerge, develop and affect the groups.

Third, this study aims to build upon limitations of previous studies and consider recommendations made for future research. A similar study was conducted by Hendry (2011), exploring the experiences of attendees of HVGs. However, Hendry (2011) identified methodological limitations in having actively participated in the HVGs they interviewed, with the potential for participants to censor findings based on a pre-existing relationship with the researcher or assume the researcher may have held similar views and assumptions about the group as themselves. Over 13 years have passed since this study, and our understanding of both voice hearing and HVGs has vastly developed. Emerging literature proposing a framework around relational aspects of voice hearing (Allison et al., 2024) and informed the areas this project wished to explore and helped to situate the findings of this project within existing understandings and frameworks of voice hearing and peer support literature. This includes considering how HVGs may relate to and offer additional support for more contemporary

dialogical and relational approaches to voice hearing. Such new frameworks are important to incorporate into any research findings. The current study has also been designed through consultation and collaboration with HVG facilitators, with two facilitators who have direct lived experience of voice hearing and experience of mental health systems. Their input into the design of this project will be discussed in the methodology. Such co-produced designs appear lacking in the current literature, risking studies being biased towards researcher and professional assumptions and perceptions of HVGs. This project will address that gap.

Finally, this study can contribute toward HVG literature and offer novel findings with real world clinical implications. Providing up-to-date information on HVGs allows for discussion around their positives and potential shortcomings and allows for alternative perspectives and potential new interventions for voice hearers. Developing an understanding of the experience of attending HVGs can shed light on how to adapt existing practices within the NHS, develop more accurate measures of outcomes in a recovery framework, and consider how core features of the HVG may be integrated into national policy and practice, and offer more choice for those who hear voices.

The aims of this project were to explore the following questions:

What are the experiences of those attending a community Hearing Voices Group and the sense made of these experiences?

- Why do participants attend Hearing Voices Groups?
- What do participants find beneficial about Hearing Voices Groups?
- What do participants find less helpful about Hearing Voices Groups?
- How might participants relationship with voices change from attending Hearing Voices Groups?

#### **CHAPTER TWO - Methodology**

This chapter will outline and provide rationale for the design and methodology of this project, in addition to how these decisions were developed. I will outline my epistemological and ontological stance. I will then outline the process of recruitment, data collection and analysis, followed by ethical considerations. Lastly a reflective summary will be provided.

### Design

A homogenous convenience sample of 6 participants was recruited from two community HVGs based in Yorkshire. Semi-structured interviews were used to explore the experience of attending community HVGs. All participants had experience of both hearing voices and attending HVGs. Interpretative Phenomenological Analysis (IPA) was used to analyse transcribed interviews to explore the experience of participants and the sense they made of these experiences.

## **Theoretical underpinnings**

Exploring and making explicit my philosophical perspectives is important in capturing my own assumptions about this research project. These assumptions based on knowledge, affect how I view the world and the acquisition of knowledge and affect all aspects of this project including the development of its research questions, design and interpretation of findings.

# **Ontological position**

Ontology concerns itself with the nature of being and as to what constitutes reality (Smith, 2004). Broadly speaking, they are realist, relativist and anti-realist positions. This helps position as a researcher how I navigate different and conflicting ideas of reality. I align with a relativist position in which I believe reality is constructed by each individual, being relative to how individuals experience the world at any given time. This project does not aim to produce a true objective account or generalise the experience of one individual to all individuals, but rather understand how individuals

make sense of their experiences of attending a HVG from a subjective perspective. The very nature of this project stipulates that there is no one single reality or truth.

#### Epistemological position

Epistemological positions exist on a continuum, with each position broadly defining how the acquisition of knowledge occurs, and how we assess and measure reality. An objectivist position views reality as objective and existing regardless of an individual's knowledge or experience. A subjectivist perspective sits at the other end of the continuum. This position views knowledge as existing within an individual and created by perceptions and understandings of reality completely. I align with certain elements of both objectivism and subjectivism. I reject the idea of objective reality and believe a subject constructs the reality of the object; therefore no pre-existing real world exists independently of human interaction. In this context, a constructionist position would argue that knowledge is not passively received but actively constructed through our experiences, suggesting toward there being no single objective reality. I position myself within the constructionist position and argue that reality is socially constructed. I believe that it is important to understand the subjective experiences of individuals and to explore how they make sense of their experiences (Smith et al., 2022).

This is in keeping with the current aims of the project in exploring the experience of attending community HVGs. I see subjective lived experiences and constructs of said experiences as imperative in knowledge acquisition and how voices and HVGs are understood and experienced. I believe that individuals, such as those who hear voices, construct knowledge through their interpretations and interactions with HVGs and the world more broadly. This project aims to obtain insights on an individual level as well as explore the commonly shared experiences across all participants as determined through the constructionist lens. A constructionist epistemology allows me to explore and develop contextual understandings of the experience of attending HVGs – the reality experienced by attendees and how knowledge is constructed as a result of this. This allows for acknowledgement of other contextually relevant influences from how members interact with the world outside of groups

too. My epistemological stance influences how I frame and develop this project in the pursuit of discovering knowledge. I reject the idea of objective truth existing and that my interest lies in how members of groups engage with their realities. This is also in keeping with my methodological choice of Interpretative Phenomenological Analysis.

Both my epistemological and ontological position derive from my own experiences and interpretations of the world and reality. The reflexive passages throughout this project help to contextualise my perspectives and decision making.

### **Methodological orientation**

This project aimed to explore the subjective experiences of attending HVGs and the sense made of these experiences. A qualitative methodology was chosen. Quantitative methods have been effectively surveyed attendees of HVGs (Longden et al., 2017) and have contributed greatly towards this area. However, quantitative research can often miss out on exploration of deeper meanings and understandings of a given phenomenon (Rahman, 2016). There are known limitations associated with qualitative research, such the influence of the experiences, values and views of the researcher (Onwuegbuzie, 2004). However, qualitative research can provide deeper insights into real-world experiences (Moser and Korstjens., 2017) and can be effective in developing new hypotheses and theories in lesser established areas, as well as providing rich, subjective information (Verhoef and Casebeer, 1997).

#### **Ethical approval**

This project received ethical approval (Appendix A) by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (DClinREC MREC 22-076). Recruitment was conducted through community HVGs which did not come under NHS organisations or services. As such, NHS ethical approval was not required.

#### Recruitment

The Hearing Voices Network website (www.hearingvoices.org/groups) was consulted to identify UK HVGs. Four HVGs in Yorkshire were initially contacted via email as potential recruitment sources. One HVG did not respond, and another initially responded but no participants were recruited. This left two HVG. Only HVGs that did not operate criteria for attendance based around accessing mainstream services were approached. This was to be in keeping with the HVG ethos which seeks an intentional separation from mainstream services. Both groups had been operating for at least 5 years and were facilitated in person, either weekly or fortnightly. Both groups aligned with the Hearing Voices Network Group Charter (https://www.hearing-voices.org/hearing-voices-groups/charter) indicated by their presence on the hearingvoices.org website and followed a similar flexible and open structure. One group had had recently changed locations. The other had been established for many more years with a more consistent group facilitator. It was acknowledged and of interest within the project to understand how participants may experience and make sense of the groups differently.

HVG facilitators shared a recruitment poster (Appendix B) within group meetings on several occasions over the course of the project, to ensure existing and new members had opportunity to receive information about the project. This was accompanied by an information sheet (Appendix C). I attended one HVG meeting in person to share information about the project. I was welcomed as an active participant as opposed to a passive observer, becoming involved in conversations held during the meeting. This was a one-off attendance to establish links with the group without being too immersed and risking influencing findings.

### **Participants**

Between six to ten participants is considered appropriate for IPA projects (Smith et al., 2022). This is consistent with studies using other methodological approaches to explore HVGs (e.g., Dos Santos and Beavan, 2015; Payne et al., 2017). Participants did not need identify with 'hearing voices' specifically to participate. All understandings and conceptualisations of their experiences were accepted (for

example spirits, angels, psychosis) with the focus being on them having attended HVGs. This project aimed to be accessible to all those who attended the HVGs, aligning with the HVN principles, including that there is no formal referral process or definitive criteria on who can and cannot attend their groups. Participants were eligible to participate regardless of the presence or absence of diagnoses, distressing voices, other experiences or difficulties, involvement with mainstream mental health services, or receiving any intervention or support for their experiences whether through medication or otherwise.

There were several identified inclusion and exclusion criteria established prior to recruiting. I explored participant eligibility at the point of obtaining informed consent for participation as well as these criteria being set out in the information sheet.

# Inclusion criteria

- Attend a HVG at least twice within the past 6 months so that participants had recent experiences to draw upon.
- To have or currently be having voice hearing experiences.
- Be over the age of 18 at the time of consenting to participate in line with the ethical approval obtained for the project.
- Be either confident or fluent in the use of spoken English as the method of analysis relies on a shared understanding of language to capture and interpret experiences.

## Exclusion criteria

• Individuals who were actively distressed to a degree in which taking part in the project may have affected their wellbeing negatively were asked not to participate. See ethical considerations for further clarification of how risk of harm to participants and myself were managed.

#### **Interview setting**

Participants had a choice of face-to-face, video or telephone interviews. Video interviews were completed via MS Teams using their built-in facilities to record the interview in line with university data policy. Participants were asked to be in a confidential space for video interviews to be able to speak freely with minimum distraction, and I was also in a confidential space. One face-to-face interview was conducted in a confidential room and the interview was recorded using MS Teams. Participants emailed through signed consent forms or signed a physical consent from after talking through the form and inviting any questions.

#### Methodological approach

## Interpretative Phenomenological Analysis (Smith et al., 2022).

Interpretative Phenomenological Analysis (IPA) is an idiographic and qualitative method of analysis that is considered effective in exploring how individuals relate to a given experience or experiences. It uses an inducive approach in which the subjective lived experience of participants is central – not prescribing pre-defined or pre-existing concepts and frameworks. It allows for the development of strong connections with participants through interactive interactions (Alase, 2017).

IPA is underpinned by three core theoretical underpinnings: phenomenology, hermeneutics and ideography. Phenomenology concerns itself with the exploration and understanding of lived experience, including utilising self-reflexivity to transparently acknowledge my own views and experiences and their influence on the research. Hermeneutics refers to the consideration of interactions existing between participant interpretation of experiences and my own interpretation of those experiences – a double hermeneutic. Acknowledging double hermeneutics considers how my own views and experiences may influence how the project unfolds, and data is understood and interacted with.

Reflexive statements will be offered throughout the project text to capture my own processes and the potential influence of my own experiences and perspectives. Ideography refers to the detailed and indepth analysis conducted for each case (Larkin et al., 2006), focusing less on seeking generalisable findings. Smith et al. (2022) refer to this as capturing existence as opposed to incidence of experiences through using direct extracts from transcripts to ground any findings within the data. IPA then takes each individual analysis and develops master themes across all participants.

### Data collection

Qualitative methods of data collection commonly utilise focus groups and semi-structured interviews. Focus groups allow for rich data collection from a group of participants simultaneously and for group dynamics to potentially generate new ideas otherwise not observed at individual interview. This method can also be more time efficient. However focus groups can experience 'group think' in which the views of participants are shaped by the group dynamics. Sharing distressing or more personal experiences may also feel more difficult in a group setting. Disentangling what is the groups' experience and what is an individual experience would prove difficult with this method and therefore was considered inappropriate in exploring the research question.

Semi-structured interviews use open-ended questions to explore any given phenomenon. This allows a level of flexibility for participants to guide conversations toward areas more pertinent to their own experiences whilst maintaining a focus around the research question (Smith et al., 2022). The individual nature of the interview can attempt to overcome the limitations of focus groups. It is well documented that voice-hearing can be a highly stigmatised experience societally, therefore optimising a sense of safety and ability to speak freely about ones experiences felt important. Furthermore, semi-structured interviews have been used effectively to explore the experience of attending other peer support groups such as for bereaved children (Metel and Barnes, 2011) and bereaved family members (Ali and Lucock, 2020).

A semi-structured interview schedule (Appendix D) was developed as a 'virtual map' to guide the interview process (Smith et al., 2022). Semi-structured interviews are at risk of presenting leading questions that are of interest to the interviewer and the project. Therefore, the schedule was developed through several sources. My existing interest and knowledge in the area guided initial review of existing literature. This happened alongside conversations with supervisors, peers and consultation with two individuals with lived experience of voice-hearing and attending HVGs (see consultancy and collaboration). Probes and prompts were given to some questions and used flexibly if felt relevant at interview.

## Justification of approach

In deciding the most appropriate methodology for this research project, I focussed on seeking how to most effectively answer the research questions (Kelle, 2006). IPA holds a particular interest in the experience of individuals, and how they make sense of those experiences. This fits well with the aims of exploring the experience of attending community HVGs. Smith et al. (2022) support the use of IPA when exploring topics that may be considered complex or novel. HVG research is of increasing interest within the literature but remains limited in understanding how groups are experienced. Furthermore, IPA has been used to explore other areas of lived experience such as pain (Smith and Osborn, 2015).

### Two other qualitative methodologies were considered:

## Thematic Analysis (Braun and Clarke, 2006)

Thematic analysis provides a flexible method of analysis to establish codes and overarching themes within datasets. It is a popular qualitative method and has been applied widely within the literature. Thematic analysis often goes beyond the personal experience to consider more broad experiences and structures. However, this project sought to specifically focus on the personal lived experience and the meaning of such experiences.

#### Discourse Analysis (Potter and Wetherell, 1987)

Discourse analysis concerns itself more with the nuance and use of language, and how it can construct our reality. This approach could effectively explore how language is used to construct meaning for those who hear voices and attend HVGs, and if this changes over time as a result of attending. This would be particularly useful in considering the well-established associations with voice hearing and negative self-stigma. This project was more interested in the experience of attending the group and how participants made sense of this experience, therefore making IPA more appropriate.

### Pen Portraits

Pen portraits are beneficial for both capturing qualitative information about a participant and incorporating themes simultaneously (Hollway and Jefferson, 2013). Individual Pen Portraits were developed with the intention of providing both a descriptive and interpretative summary combining information obtained at interview in addition to individual themes developed through analysis (Blundell and Oakley, 2023). These individual themes formed the basis of the group analysis. At interview, questions exploring the length of time hearing voices, past mental health involvement, gender and religion were asked to develop these Pen Portraits. This process was made explicit to the participants in the consent form and information sheet, and at interview.

### Procedure

Interested individuals contacted myself via email or requested a telephone call to discuss the project. Those still interested were offered an interview via their preferred method (in-person, online or by telephone) and provided both the information sheet and consent form. Prior to interview, I gave participants opportunities to ask any questions and talked through the consent form together. Once consent was obtained, the recording was started, and the interview began– guided by the interview schedule. The interview started by collecting contextual information aiming to capture the participants history of voice hearing, attendance of HVGs, mental health services and ways of coping. Questions then focused on exploring the experience of attending community HVGs followed by a more open space for participants to add other thoughts and reflections. Lastly, demographic information was

collected including age, ethnicity and other important aspects of identity. Participants were then offered space to ask any questions before the recording was stopped. Time was then offered to checkin on how participants felt post-interview and provided with signposting resources dependent on where their group was based (Appendix E). Audio and Video recordings of interviews were saved securely onto the Leeds University One Drive as per ethical protocol, along with automatically generated transcripts.

## **Transcriptions**

Transcriptions were automatically generated live through Microsoft Teams. I used these automatically generated transcripts to refer to when manually transcribing interviews verbatim. I listened to each interview, accompanied by video, and transcribed the contents of the conversation whilst pausing intermittently. When I had difficulty deciphering what was being said, I would refer to the automatically generated transcript, in addition to relistening to the audio recording at both full and half speed. If the audio was still inaudible, this was denoted in the transcription. At the point of transcription, potentially identifiable information (e.g. names of services, names of places and people) were anonymised either using pseudonyms or by denoting that this information had been redacted from the transcript. All data, including transcriptions were stored on Leeds University One Drive, as per conditions of ethical approval.

## Involving those with lived experience(s)

This project sought to engage at the top end of the ladder of co-production where feasible (Think Local Act Personal, 2021 – Appendix F). Co-production with those with lived experience allows for a coming together of different agendas and experiences and embodies the Hearing Voices Network charter. Consultancy involved me actively engaging with those who have unique perspectives and experiences of a given topic, asking questions to explore and guide the development and implimentation of research, and allows for a better understanding of the contexts in which the research may touch upon (Jacobson et al., 2005). Experts by experience were consulted numerous

times throughout the project. Conversations were held with facilitators of HVGs, who also heard voices, to explore what areas of research they felt were most pertinent through their experiences. Utilising co-production where possible aims to enhance the quality of research by increasing the my understanding of a given area through the lens of those more aware of an issue or context (Oliver et al., 2019) Whilst co-designing the project from these conversations would have been optimal, I had to hold in mind the nature of this project being for a Doctoral degree and consider feasibility for example. Consultancy was also sought regarding both the consent form and the information sheet. HVGs facilitators offered feedback on an appropriate length of information sheet as well as key information those who attend groups may want to hear, helping to develop this document from the beginning. Drafts were also shared in which facilitators offered more consultancy as to its contents. Whilst co-produced at the beginning, consultancy was more feasible later in the project as I had to ensure certain criteria were met and that my documentation met university standards.

A pilot interview was conducted with an individual who identified as a voice hearer, but also facilitated a HVG that was not involved in this project. The interview was not recorded nor transcribed. It was intended to explore the flow of the interview schedule and for consultancy on the phrasing of questions. This led to several changes to the interview schedule. Firstly, demographic information felt more appropriate to ask toward the end of the interview as it was experienced as tokenistic and as a tick-box exercise when placed at the beginning. Terms such as 'power' in relation to voices or self-empowerment were changed in favour of more neutral terminology asking how relationships with voices may have changed, after discussion of how power may be interpreted or experienced by some voice hearers.

### Analysis

Data analysis was guided by steps proposed by the IPA protocol set out by Smith et al. (2022), summarised in Table 2.

#### Table 2.

A

summary of the IPA protocol	(Smith et al.,	2022).

Stage	Brief description				
1	Reading and re-reading the original data and				
	audio-recordings.				
2	Initial noting to produce comprehensive and				
	detailed set of notes about transcripts.				
3	Developing emergent themes to produce concise				
	statement about what was important in chunks of				
	transcripts.				
4	Searching for connections across emergent themes,				
	mapping how themes relate to one another.				
5	Repeat the process above with remaining				
	transcripts.				
6	Looking for patterns and connections across cases.				

## Individual Case Analysis

To align with the idiographic commitment of IPA, in-depth analysis of each interview was carried out. I began by reading each individual transcript accompanied by video recordings, only making notes if anything pertinent presented itself. This was to aide my immersion into what was being said and the general flow of the data without delving too quickly into interpretation. At this stage I noted interviews that felt particularly disrupted by internet connectivity issues, for example.

Transcripts were then read again, and initial notes were made in the left-hand margin. These notes included any initial observations or thoughts of what had been said by participants. This was followed by a more meticulous line-by-line review of the transcript. This captured any remarks around the content of what was said and the linguistics of what was said (including discourse used, how it was

said). At this stage I also made note of any tentative interpretations or reflections I had. This captured a shift from exploring the participants meaning making toward my own experiences and knowledge.

The transcript was then read again with consideration of comments in the left-hand margin, and tentative and emergent themes were noted in the right-hand margin. These themes were noted and synthesised with other related themes to develop subordinate themes. Following recommendations by Smith et al. (2022, p100), Personal Experiential Themes (PETs) were reviewed for each individual to think about similarities and differences broadly. PETs that appeared similar or using similar terms were examined further to explore how each participant made sense of the PET and how these may connect across cases. Any possible convergences and divergences of PETs were noted across cases, and those converging were grouped together and at times, the theme name altered to capture the essence of the experiences captured within it. This process was then repeated for each individual interview. Previous transcripts were revisited as my confidence in the analysis process grew, allowing for themes and coding to be refined. Excerpts of a transcription including annotations can be seen in Appendix G.

## Group analysis

Upon completing individual analysis, connections and themes across cases were examined. I created a spreadsheet to capture the frequency of similar themes across participants and to note any themes that were merged. This process was iterative in nature, involving existing themes being shaped, reallocated and re-titled into sub-ordinate and super-ordinate themes. Again, throughout this process supervisory meetings were used to explore the development of themes across individual data sets. A thematic map of Group Experiential Themes and subordinate themes can be found in the results section.

#### **Credibility checks**

To strive towards a high standard of qualitative research, and that both the analysis and findings are credible and present as true as possible picture of the phenomenon being explored, credibility checks were used. I sought out several different recommendations and guidelines to further enhance the credibility of this research.

Ahmed (2024) proposes strategies for ensuring trustworthiness in qualitative work. These include ongoing reflexivity of one's own biases to allow for a bracketing of such biases throughout the research process and providing detailed contextual information so readers can evaluate the applicability and relevance of interpretations and findings. Similarly, Nizza et al. (2021) provide four markers of high-quality IPA research which includes a close analytic reading of participants' words, providing quotes alongside interpretations to remain grounded in the data, and the construction of a compelling and unfolding narrative in which analysis tells a coherent story of experiences. Informed by these guidelines and recommendations, the following steps were taken throughout this research project:

- Reflexive passages are offered throughout this thesis. These passages capture reflections and acknowledgement of my own experiences and biases at different stages of the project. These passages establish my own positioning and relationship with the project and allow the reader to also be aware of how this position may influence or affect the project.
- Several other peers and I on the Doctoral programme met periodically from the beginning of project development to explore our own assumptions and pulls toward our own projects.
- I attended several sessions set up by a researcher specialising in Interpretative
   Phenomenological Analysis, who shared their knowledge and expertise on various aspects of the methodology, including developing research questions and the interview schedule.
- Routine supervision with the project supervisors allowed for the sharing of participant transcripts and my ongoing analysis, allowing for ongoing verification and feedback of

emerging coding and themes. Supervision also allowed for ongoing discussion throughout the development and implementation of this project, including study design, analysis and writeup of results.

- Pen portraits have been provided to offer the reader a contextual background of each participant and the themes that emerged throughout individual interviews.
- Appendices H offers a snapshot of transcription and subsequent analysis (both coding and interpretation) to offer transparency around the process of analysis. Extracts from the data, including quotations, will accompany master and super-ordinate themes to provide transparency around findings.

## **Ethical Considerations**

#### Nature of participation

Participants were made explicitly aware that their participation in this project was completely voluntary. Informed consent was obtained through providing participants with an information sheet and consent form (Appendix H). The information sheet outlined the nature of the project and what would be expected from participants. Participants were given opportunity to ask any further questions or discuss any queries regarding this information. At interview, questions could be answered in as much or as little detail as felt comfortable or could be unanswered in their entirety. Additionally, participants were able to take a break or terminate the interview at any time. Participants were able to withdraw their data to 14 days after interviews were completed. It was made clear that withdrawal or partial participation in the project would not result in a loss of payment.

## **Confidentiality**

Participants were aware that I was not directly affiliated with any HVG, and that any details which identified the individual and which group they attended would be removed or anonymised to encourage participants to speak freely about their experiences. Participants were made aware of times where confidentiality would be breached, and the rationale behind this. It was made explicit within the

information sheet and in discussion prior to interview that confidentiality would be breached should concerns emerge regarding risk to self or others, this information would be disclosed to the HVG facilitator, and that this would be discussed with the participant directly should this occur. Demographic information such as age has been made more anonymous, as has the amount of time of attending HVGs and hearing voices to protect confidentiality. This was achieved through offering vaguer time frames.

## Participant wellbeing

Several steps were taken to safeguard the wellbeing of participants throughout the research project. The information sheet stated that should there be concerns regarding a participants safety, I would share concerns with the HVG facilitator. This was also mentioned at the start of the interview. Participants were invited to bring another person with them at interview as a means of support. Documents offering signposting to local services and resources were also provided for each participant, varying dependant on the location of their HVG. Participants were advised that they could answer questions at interview in as much or little detail as felt comfortable, and they were free to not answer questions. Participants could also take a break at any time during the interview. I am also a Psychologist in Clinical Training, with experience of risk management and working with distress.

# **Researcher wellbeing**

With regards to my own wellbeing, interviews not carried out virtually were planned for, with a risk assessment developed in line with the University lone working policy. This stipulated that face-to-face interview took place in an NHS registered building and their lone-working procedures were followed including reception being aware of the room booking and nature of the appointment. All interviews were carried out during standard working hours, when supervisors were contactable should concerns arise.

#### Payment

All participants received a £15 Love2Shop voucher for their participation. They were aware that a voucher would still be provided even if they chose to withdraw after interview. All participants accepted a voucher. These were provided through emailing a unique code that was redeemed online at https://www.love2shoprewards.co.uk/login.php

## **Reflexive statement**

Reflexivity is an important part of qualitative research, specifically in IPA as my own interpretations and the sense made of the data is central to the analysis process (Smith et al., 2022).

I do not have lived experiences of hearing voices or of using mainstream mental health services outside of my occupation. I have met and worked alongside many people who identify with the experience of voice hearing amongst other experiences some may describe as unshared, unusual or understood through a psychiatric lens. My interactions with those individuals in combination with my own experiences within academia and personal life have influenced how I view the current climate surrounding voice hearing and supporting those in distress.

I have both witnessed and heard from those who hear voices how beneficial they have found mainstream services, whether this be through antipsychotic medications, talking therapies or other means, and I view these options as important in giving voice hearers choice. I have also seen the negative and sometimes disempowering ways services can operate and the detrimental effects of overprescribing of antipsychotic medications and an under resourced and outdated framework for mental health. I hold a critical view of the legislation and frameworks surrounding mental health within the United Kingdom more broadly as a result of seeing how it can lead to traumatisation and distress, whilst acknowledging the good it also does each day and my own role within this system.

My personal views align closely with both the Hearing Voices Network approach and principles of the recovery movement more broadly. I view voices as meaningful experiences that exist in a context of people's lives and am open to all perspectives and ideas as to what that meaning may be – with people having a right to define their own experiences. I also strongly believe that those who hear voices should be given choice as to what support or interventions they find beneficial in managing more distressing experiences. I advocate for more autonomy and power to be given to those with lived experience and their input to lead to meaningful changes within mainstream mental health services.

Awareness of my own values and beliefs has prompted me to seek out a more balanced discourse and wide evidence base both supporting and critiquing all literature. This was aided by ongoing conversations within supervisory meetings, in which multiple perspectives are held and considered. Co-producing large parts of the project where feasible may address the potential for interview questions to be developed through the lens of my own experiences. Ongoing reflexivity has been important in data analysis, ensuring that my own knowledge and experiences are not overly prescribed and represented, and instead the words of participants were closely kept to. Whenever my own beliefs and knowledge may influence or have shaped any aspect of the project, effort was made to make this explicit through reflexive statements and clear connections made to the contents of this project.

### **Reflective/bracketing interview**

Before finalising the interview schedule, I took part in a reflective/bracketing interview. This was conducted by another Trainee Clinical Psychologist and aimed to explore my interest in the research area. I was able to explore my assumptions as to what this project may find and consider how these may lead to a bias in how I develop the interview schedule and subsequent analyses. It helped me to think carefully about assumptions around HVG being experienced positively and led to the addition of more neutral questions seeking both good and bad experiences of the groups. I was able to reflect on my views and assumptions about what I may hear at interview and what findings may emerge as a result of this project. I held assumptions that HVGs would be experienced positively and that many members would hold sceptical or cynical views of mainstream mental health services. Without this

bracketing interview, these assumptions may have lain dormant and heavily influenced the direction of the interview schedule and analysis after interview. My awareness allowed me to remain vigilant that I was exploring the experience of attending HVGs more openly, with an intentional ear for any negative or more critical perspectives of the groups in addition to making space for positive experiences of mainstream mental health services too.

#### Conversations with supervisors

From the earliest stages of this project, I openly spoke with supervisors to critically evaluate my decision making and consider the influence of my world views. At the point of beginning a scoping literature review supervisory discussions captured my personal beliefs around antipsychotic medications and the risk of me not representing a balanced review of the available literature. With this in the forefront I was able to ensure a balanced evaluation of all interventions for voice hearing were presented.

### **Professional identity**

Through self-reflexivity and conversations with HVG facilitators I have considered my role as a 'professional', 'researcher', and Trainee Clinical Psychologist. This made me more aware of the common language and discourse used within professional environments that often differ from that used by those with lived experience. I used these reflections to guide the language used throughout my conversations and any documentation relating to this project. I was conscious of the Hearing Voices Movement and my understanding of how it related to mainstream mental health. The movement appears to almost reject the ways in which mainstream systems operate and view experiences such as voice hearing. I am unavoidably a part of this system and may represent something unpleasant or difficult for some attendees of HVGs. I therefore wanted to own this position very clearly and pin down why I am passionate about voice hearing and shifting discourse to reflect more closely words used by those with lived experience. Reflecting on my professional identity was helpful in remaining focussed on completing academic research to a high standard, but also holding

onto the topic area and the passion I hold for better understanding the experience of those who hear voices.

#### **CHAPTER THREE - Results**

This chapter presents the results of the Interpretative Phenomenological Analysis carried out on 6 interviews. The analysis aimed to explore the following research questions:

What are the experiences of those attending a community Hearing Voices Group and the sense made of these experiences?

- Why do participants attend Hearing Voices Groups?
- What do participants find beneficial about Hearing Voices Groups?
- What do participants find less helpful about Hearing Voices Groups?
- How might participants relationship with voices change from attending Hearing Voices Groups?

I will begin by presenting demographic information of the participants, summarised in Table 3. I will present a pen portrait for each participant, describing the context of each participant whilst preserving anonymity. This will be followed by a narrative account of the individual themes that emerged through interview. I will conclude with a reflective statement, capturing reflections made throughout the process of analysis and at reflective interview.

# Table 3.

Table of demographics

Pseudonym	Age	Gender	Ethnicity	Time attending HVGs	Current contact with MH services	Medication	Length of time hearing voices
Daniel	30s	М	White- British	5+ years	Y	Y	10+ years
Jane	50s	F	White- British	10+ years	Y	Y	10+ years
Simon	50s	М	White- British	15+ years	Y	Y	30+ years
Elen	20s	F	White- British	2+ years	Y	Y	2+ years
Michael	60s	М	White- British	10+ years	Y	Y	30+ years
Oscar	50s	М	White- British	7+ years	Y	Y	30+ years

N.B. Age, time attending HVGs and time hearing voices has been rounded to protect confidentiality.

#### **Summary of information**

In total, 6 individuals expressed interest and 6 agreed to take part in the project. No participants withdrew nor were any interviews omitted from the final analysis. All of those interviewed had attended HVGs at least twice in the past 6 months, were prescribed and taking antipsychotic medication and had some involvement with mainstream services. All participants heard about the groups through mental health professionals they were working with at the time. As the table shows, a majority of participants have heard voices for 10+ years, with one younger participant having heard voices and attended groups for a much shorter period of time. 4 males and 2 females completed interviews, and all identified as white British. Participants were asked if there were other important aspects of their identity they wanted to share (spirituality, sexuality, religion), however none were identified.

## **Pen Portraits**

### Daniel

Daniel first attended a HVG several years ago, upon the recommendation and support of a mental health worker. He has heard voices for over a decade now and at interview reflected on his experience of HVGs in addition to other experiences such as hospital admissions. Daniel's **experience of mental health services** captured experiencing feeling unheard by mental health professionals and that services tend to offer a 'one-size fits all' approach to those who hear voices. He compares this with HVGs in which he feels empowered to use language that makes sense to him and can take what he needs from the group and leave what does not work – viewing it as less prescriptive and more flexible. Daniel has found **connecting with others** a large part of his experience of groups, having made friendships that may have begun within the group, but now extend beyond weekly meetings. Others also hearing voices has given opportunity to connect on a deeper level. He describes experiencing a sense of hope when seeing others succeed and believing in him. His close connection to others can lead to feeling responsible for others wellbeing and worrying about the welfare of others which can feel difficult at times. The group offers a **safe space** in which Daniel feels able to speak

openly about his experiences without fear of judgement, which he has received in the past when speaking about beliefs others perceive as unusual or risky. This safety is in part due to the shared experience of voice hearing but also the longevity of the groups – being able to attend for many years and having opportunity to develop meaningful relationships. Daniel spoke of opportunity for **reframing the experience of voice hearing.** Society may give a message that voices are not 'normal' and should be avoided, a battle that led Daniel to feeling more distressed. The group encourages the acceptance of voices and supports members to do so. This acceptance has led to significant positive change in Daniel's life, and he has learned to negotiate and live alongside his voices. There are **barriers of attending** HVGs, including the discomfort and anxiety that comes with the first attendance. For Daniel, groups were a daunting prospect and even when he arrived, he felt a defensiveness and need to protect himself, needing time to assimilate into the group given how radical the group's ethos and way of speaking about voices was for Daniel. Daniel's voices can react negatively to his attendance and responses. However, he appraises this as the voices reminding him to take care of himself. Overall, Daniel values the groups and attends meetings as often as he can.

## Reflections

This being my first interview led to some initial nerves and apprehension as to how it would be received by Daniel. I felt the conversation flowed well and the interview schedule could be held close enough to maintain a consistency in future interviews, but loosely enough for Daniel to bring in his own thoughts and experiences around mental health services for example. I was particularly struck by Daniels recollection of how harrowing and negatively impactful voices once were on his life compared to where he finds himself today. This came through in interview, but also throughout the analysis in which a narrative of isolation, darkness and fear had shifted toward feeling socially connected, empowered and safe. I also noticed my pull toward exploring Daniel's experiences of being described as 'risky' and 'dangerous' but noticed how he aligned himself with these words at that time in his life and did not want to use our conversation to assert my own opinions of his experiences. Although I maintained a curiosity without offering too much of my own views of mental

health provision, our similar perspectives may have affected the level of interpretation I was able to draw from what Daniel shared.

#### Jane

Jane has attended HVGs for over 5 years now and began hearing voices over 10 years ago. She first heard about groups through a mental health worker she was being supported by. Jane had experienced other forms of support for her voice hearing experiences too. Jane has found connecting with others an integral part of groups, having made lifelong friendships that now exist outside of meetings. They connect on the level of voice hearers but also as human beings, developing genuine connections with other members. As a result, Jane feels supported in different aspects of her life, not only with her voices. Groups offer a safe space where Jane feels able to speak about the good and the bad days. A sense of safety has allowed her to experience personal growth, able to assert herself more with others through being given a voice at groups. The consistent space of the group offers a sense of security in knowing you have a place to go. Jane has experienced a reframing of voice hearing experiences. For her, this has been encouragement and experience in turning toward her voices and developing meaningful relationships with them, understanding their purpose and role in her life. This has been a welcome change and has led to a more harmonious relationship with herself and her voices. For Jane, barriers of attending HVGs come from struggling when there are lots of people at meetings – which is not every meeting. Jane's voices can also be reluctant to attend groups, but she experiences this as opportunities to negotiate with the voices and meet their needs as well as her own. Despite these factors, Jane described meetings being an important part of her life and that she prioritises attendance.

#### Reflections

My interview with Jane felt very light, with her regularly using humour throughout our conversations. Jane had taken part in research before, and I felt this came through in her reflections on group attendance. I wonder if her clear responses and use of humour affected how deeply I probed and sought to explore her experiences at times. Her view of HVGs were very positive, and at times I suspect I took her views very much on face value, potentially closing opportunity to think more

critically about the groups, such as when there are lots of people at a meeting. This interview also closely followed Daniel's, with the contents of his interview still fresh in my mind. Perhaps some of the more emotive content of that interview made me lean more into the humour and lightness of my interview with Jane as it felt more comfortable and safer. I was interested in how through exploring her voices, she had made sense of the voices negative comments as attempts to make her more assertive with others and how unlikely she would be to discover this had she not had opportunity to explore and build up a relationship with her voices.

### Simon

Simon has heard voices for over 30 years and first attended a HVG around 20 years ago. Simon heard about HVGs through a mental health professional. The group provides a secure base for Simon as a result of it offering a consistent space he can attend. He compares this to mainstream services in which limited resources change what is on offer and for how long. Members can also be realistic about the ups and downs of life and the group does not pretend to be a fix all or magic bullet. Connecting with others is achieved through the shared experience of being a voice hearer. Simon describes a sense of 'comradery' within the group, a shared purpose that helped them connect on a level different to connections made with those who do not hear voices. Simon's reframing of voice hearing experiences is a result of the group encouraging a place of acceptance of voices, which is experienced as leading to a more harmonious and peaceful life alongside the voices. He would no longer get rid of his voices even given the choice, as they are part of who he is now. Simon did share some barriers of attending HVGs. Simon was apprehensive prior to his first attendance due to the thought of meeting lots of new people. Upon first attending, there was a period of assimilation. At first, the friendliness and openness of the group was overwhelming and uncomfortable, a big change from Simons experience of people. However, over time this became one of the things he valued about the group. He prioritises attending the group each meeting, even whilst his voices may not like him attending the group.

### Reflections

Simon's interview again shortly followed my interview with Jane, and I had begun the process of analysis on my earlier interviews. Simon's stories of attempting to manage his voice hearing early on in his life really struck me. The ways of coping were difficult to hear, and I felt a sense of injustice that there was not enough available and accessible support at this time. Simon identified that mental health services have changed significantly since he first accessed them, and I wondered if this was one small part of why he found HVGs such a formative experience. When Simon shared of his difficulties in first attending the group, feeling overwhelmed by the kindness and informal nature of the group, I realised my assumptions that voice hearers would instantly find this a pleasant experience. This realisation helped me to delve deeper into making sense of the experience of attendance, considering how being in such a radically different environment, even if positive, may feel difficult.

# Elen

Elen heard voices for several years and began attending HVGs two years afterwards. At interview Elen shared of her experiences of mainstream mental health services in addition to the HVGs. She attended the HVGs most infrequently out of all the participants but has remained at the same group. Elen shared finding the group a space of **acceptance of all views**. All ideas about voices are held equally and responded to with respect, which helped Elen to feel heard within the group. This came at a cost of sometimes feeling frustrated when people shared views that felt too different or offensive, but Elen saw this as valuable in not censoring or alienating others. It also allowed Elen to hear new perspectives that helped her shape her own understanding of her voices. Elen also made **Comparisons with mainstream mental health services**, reflecting on the beneficial nature of diagnoses for her, but also its limitations in fully capturing the nuances of her beliefs and experiences. For Elen, things like hospitalisation and psychiatry can be beneficial if done correctly but can also be hindering too. She draws parallels to HVGs too in which it is beneficial but is just one part of a much-needed area of support. Elen views the group as opportunity for **connecting with others**, helping her rebuild her

confidence to reintegrate into wider society and develop relationships and support external to the group. Members being able to connect on the level of hearing voices and associated experiences helps to foster deeper connections – something that was difficult in the past. Elen also found the group a **flexible and accessible space.** Elen felt able to engage with the group how she found most helpful, whether this be actively talking or adopting a more listening position, allowing her to feel more comfortable and get the most from the group. Elen also reflected on attending the group much less now she feels more confident engaging in hobbies and activities again because of the group, but also because she knows the group is always there if and when she needs it, without having to go through a referral process making it much quicker to re-attend.

## Reflections

Elen was my first and only interview with someone who did not attend groups consistently (but still met criteria for participation). I felt that this knowledge carried through to interview and conversations around the limitations of groups felt easier to delve into and explore compared to other interviews. I was drawn toward how Elen made sense of diagnoses, seeing it as a way of communicating in shorthand about her experiences, even though she does not agree with the diagnosis necessarily. At analysis, I resisted getting too drawn into my views on power and diagnoses and balanced this by holding onto how diagnosis has helped Elen access what she views as helpful support.

#### Michael

Michael has heard voices for over 30 years, first attending a HVG around 10 years ago upon the recommendation of a mental health worker. He has remained at the same group over this period of time. Michael shared his experience of **reframing voice hearing** from attending the group. He has learned how to turn toward and listen to his voices even when the content may be distressing. Through acceptance of his experiences, he is also more confident in communicating his experiences to others whereas in the past felt uncomfortable in doing so due to feelings of shame. Michael spoke of the **difficulties with mental health services** in comparison to HVGs. He shared his experience of increasingly reduced options of support like day centres and support from community teams, and how

the groups offer a consistent space in which members can attend as long as they want. He shared views on medications and psychiatry that spoke to their usefulness in his life, but a need for other options and ideas to be on offer too. Michael has found **connecting with others** an important part of his experience of groups. He spoke of striking strong friendships with other member and how important it is for him to ensure others feel heard and can share their experiences. He holds others' perspectives in high regard, believing that hearing other perspectives can lead and has led to profound change in his life. This has also given him opportunity to develop an identity outside of being a 'voice hearer'. For Michael, **barriers to attendance** captured his initial anxieties and apprehension about meeting new people – something he had struggled with in the past. However, after getting used to the groups, he now feels he is quite chatty but also contentious about speaking too much, which can take up headspace when in meetings.

### Reflections

Michael's interview was the only interview completed face-to-face, upon his request. I felt that our conversation flowed more naturally and there were less technical issues interfering. However, I found that the interview schedule felt lost at several points during our meeting. At times our conversation appeared to deviate from the initial question asked and it felt more difficult to interrupt to gain both clarity and guide us back to the initial question. Michael had spent a long time in and out of mental health services and I felt he was able to draw upon a lot of experiences, and that his experiences of services and different groups at times merged into one. I found it difficult to tease apart what experiences related to what support and which were specific to his attendance of an HVG. Difficulties in following the conversation also came through at the point of transcription, in which it was hard to decipher at times what was being said. This made analysis feel much more tentative and perhaps relying more on my own assumptions and interpretations than other interviews.

## Oscar

Oscar has heard voices for over 30 years, and first attended a HVG over 5 years ago. He first heard about groups through a mental health professional and has since attended several different groups

over the years. Oscar spoke of **connecting with others** through the group, finding their shared experiences of voice hearing as a key factor in quickly building trust and feeling a sense of belonging. He has forged friendships that extend beyond the group and across groups he has attended over the years. Oscar experienced meeting other voice hearers as very powerful after feeling he was one of the few who had these experiences, helping him to overcome aspects of shame and stigma he had experienced in the past. The group provided **unconditional acceptance** of Oscar's perspectives and views around his experiences. He shares that this is a key feature of HVGs, where all members can feel safe and listened to no matter what their beliefs are. This has allowed Oscar to not only make sense of his own experiences but help others to do the same. His experience of **mainstream services** captured feeling unheard and that he had little autonomy over what support was on offer, which he feels the HVG provides. He also captures his views of mental health professionals occasionally perpetuating unhelpful and untrue stereotypes about mental health. Oscar experiences a focus or given privilege to any one explanation for voices as unhelpful and can be experienced as a **barrier to attendance.** He also captures an apprehension and fear of first attending groups due to fear of stigma and judgement in line with his past experiences.

### Reflections

Oscar's interview was the longest of all the interviews. I was struck by his coherent account of his life thus far and the sense of acceptance around some of the injustices he had faced. Oscar was extremely passionate about HVGs and a need for reform within mental health services. I found myself captivated by his stories, which may have led to me being less curious about the stories not told. Aspects of his story were quite difficult to hear and evoked a strong sense of injustice within me. Being drawn in like this likely led to a strong alignment to what he was saying and may have neglected a more balanced stance that would allow other narratives or more positive experiences to be elicited.

#### **Overall reflections**

Interviewing was a humbling and enlightening experience and reminded me of why I am passionate about this area. Each participant held a unique story that superseded the experience of attending HVGs, sharing narratives often not given opportunity to be voiced. Writing the pen portraits was a difficult process as a result. I decided to keep information to a minimum due to difficulties in holding power to decide what aspects of identity or narratives should be privileged for each Pen Portrait. In retrospect, offering the participants to share what they may want included would have helped.

Whilst this made the interviews and analysis a pleasurable experience, it also led to feeling emotionally connected to the data. Whilst acknowledging the need for anonymity I felt a pressure to give time and justice to each individual story and the lives behind the participants. I also found prioritising and focussing on experiences relating to HVGs only brought about a sense of dismissing other important experiences in participants lives. At times, I reminded myself of the purpose of the project and the research questions to remain focussed. Hearing stories about the failures of services stuck with me more than stories of success. I held this in mind at analysis to ensure my interpretations and themes were grounded in the data and represented an accurate narrative.

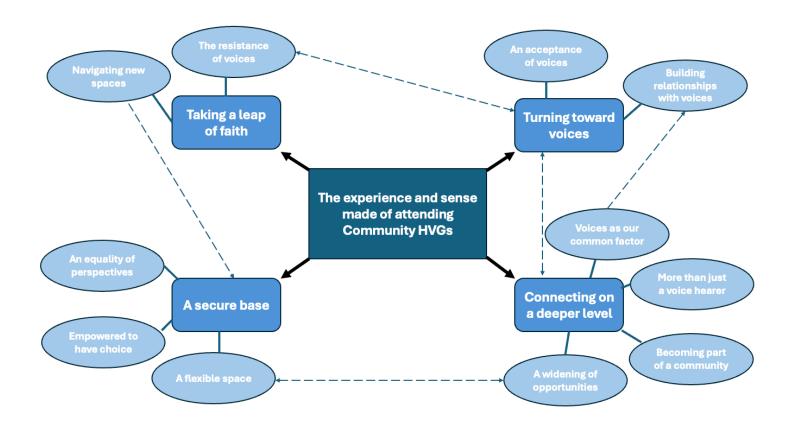
At analysis I was aware of wearing multiple hats at the same time. My psychologist identity drew me toward the importance of social connections and the negative impact of stigma that keeps people isolated and afraid to explore their experience. My personal identity linked to values around justice drew me toward interpreting the offerings of HVGs as overcoming limitations of current service structure, reflecting upon my own frustrations with the perceived failings of mental health services and wider political issues. My identity as a researcher for this project was drawn to the complex juxtaposition that occurs to new members who find initial discomfort in experiencing warmth and kindness due to past experiences. I engaged in intentional reflexivity throughout analysis to ensure I considered interpretations through these multiple selves and was mindful of how this interacted with the data.

## **Group analysis**

As a result of group analysis using IPA, four Group Experiential Themes (GETs) were identified, each with subthemes (See figure 1.). I will offer a summary of each GET in turn, followed by exploration of each subtheme with quotations to support my interpretations. Throughout the results, occasional reflections will be offered to capture my experience of exploring the data. Dashed lines indicate where GETs and subthemes interacted or related to one another.

## Figure 1.

Thematic Map capturing master themes and sub-themes of group analysis, illustrating where themes may interact.



A table capturing the frequency of each theme and sub-theme for each individual participant can be

seen below.

## Table 4.

Frequency of master and superordinate themes across participants

Group Experiential Theme		Participant					
	Sub-theme	Daniel	Jane	Simon	Elen	Michael	Oscar
Taking a leap of faith	Navigating new spaces	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
	The resistance of voices	$\checkmark$	$\checkmark$	$\checkmark$	Х	Х	Х
Connecting on a deeper level	Voices as our common factor	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
	More than just a voice hearer	Х	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
	Becoming part of a community	$\checkmark$	$\checkmark$	$\checkmark$	Х	$\checkmark$	$\checkmark$
	A widening of opportunities	Х	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Turning toward voices	An acceptance of voices	$\checkmark$	$\checkmark$	$\checkmark$	Х	X	$\checkmark$
	Building relationships with voices	$\checkmark$	$\checkmark$	$\checkmark$	Х	$\checkmark$	$\checkmark$
A secure base	A flexible space	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
	An equality of perspectives	$\checkmark$	$\checkmark$	Х	$\checkmark$	$\checkmark$	$\checkmark$
	Empowered to have choice	$\checkmark$	Х	Х	$\checkmark$	$\checkmark$	$\checkmark$

## 1. Taking a leap of faith

This theme captures the emotional and practical barriers of attending HVGs, and the leap of faith members must take if they are to attend the group both initially and ongoing. Whilst groups are generally valued by those who attend, the first step toward attending groups can be a difficult and overwhelming journey. New members have to challenge their own preconceptions and past experiences, in addition to facing uncertainty as to what the group is and is not. Once there, members navigate new ways of relating to others, being related to and relating with their voices, requiring a period of assimilation that can at times feel too much. Ongoing attendance requires a constant renegotiation of other priorities in life that differ for each individual, including how their voices respond to the group.

## a. Navigating new spaces

Elen shares of her initial anxieties to attend the HVG, perpetuated by an uncertainty as to what the group entails and what would be expected of her. Without knowing the parameters of what the group is and is not may lead to members filling in the blanks themselves, drawing upon previous experiences of group work or interactions with others that may have been negative. A lack of clarity as to what to expect therefore leads to feelings of apprehension and may impact new members' willingness to attend.

# "I was very anxious as I am before anything... I didn't know what to expect. I I didn't know if it was structured kind of format, or we talk about this or whatever." (Elen)

For other new members, there may be an anxiety around meeting new people specifically. Michael's anxieties are in part based on past experiences of navigating mental health systems and becoming increasingly isolated. Attending the group may feel like an all-or-nothing scenario in which one must fully commit to opening up to daunting and anxiety provoking scenarios that they may have actively avoided in the past.

"It was hard to get to the group in the first place, to even face breaking ice with people" (Michael)

Oscar captures similar anxieties based on past experiences and his own assumptions as to how attending such a group would play out. There is a real sense of disbelief that other voice hearers exist and if they do, he will still find himself being judged and laughed at. He has learned that voice hearing brings with it stigma and judgement from others, and the thought of others – especially someone who knows him – finding out he hears voices made the thought of attending groups a potentially exposing and unsafe leap to take.

"And, and then your thoughts are, well if I join this group, people gonna sit there laughing at us... people are not gonna believe us. People are gonna yeah laugh at us and and then the fear is, that you walk into a room and there might be somebody that knows you and then it'll get spread around. And erm, mental health problems, if you've got mental health problems, people are very very very cruel. And erm, yeah. The, they pick on you." (Oscar)

As Daniel captures, initial attendance requires a period of preparation to overcome or feel able to manage the initial anxieties. This may give space for more worry and fears to emerge, but also provides opportunity for new members to seek support from existing trusting relationships, such as Jane being supported by her support worker and daughter. Despite these worries, fears and preconceptions of groups, people often still take that leap of faith. Simon attended, even whilst feeling vulnerable. Past experiences of trying new ways of understanding and coping with voices may set potential new members up to sit more with the uncertainty and trepidation, allowing them to try out something new. For others, there may be a desperation or hope for things to be different in their lives, and the group a potential space for that to happen that outweighs the fears and anxieties of attendance.

"It did take me a while to to build up to actually going though." (Daniel)

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## "Went along full of trepidation, scared." (Simon)

"and the support worker said, I'll drive you there. So that's the only reason why we got there in the first place. And erm, because my daughter came with me. And then the support worker. Or else I don't think I'd have got there" (Jane)

That first meeting can be overwhelming and destabilising, especially for those whose past experiences of services or of others do not align with what they experience within the group. Jane captures the overwhelming experience of being around so many people again, something she had shared finding hard in the past. Daniel and Simon both share how jarring it might feel for new members being in what might be experienced as a radically new environment. Hearing others speak openly about voices is a new experience for many members, as few other spaces offer such opportunities or exposure. Many voice hearers learn to hide their experiences due to fears of shame and judgement.

"... I I remember going into the group one day and they were like, there must have been about 16 people, and I just felt so overwhelmed..." (Jane)

"I was exhausted erm. I was overwhelmed erm. Not used to hearing people talk about voices." (Daniel)

"the people started giving me their phone numbers, email addresses and I thought hang on what's going on here, this is getting a bit too familiar. I feel very very uncomfortable about this, and I didn't go back the following week." (Simon)

Similarly, members being familiar and friendly may not fit with past experiences of new members and lead to suspiciousness or a guardedness as to what the intentions of other members are. Some suspiciousness or worry may come from other associated beliefs with voices, like in Oscar's experience of believing others can communicate with his mind. Whilst members may have hoped internally that such a space could exist, their past experiences do not neatly fit or allow for an immediate assimilation into new ways of being. Micheal's distrust of others came from fears others could read his mind.

"Erm will they be in my head. Will they be in my head? Sometimes I feel like people can communicate with me in my mind as well with my illness." (Michael)

Some members prioritise attendance more so when things feel difficult, viewing the group as a place that can be of benefit regardless of how positive or negative things may feel. However, others may find that during more difficult days, practical aspects of attendance such as public transport can present as barriers. For others, different priorities can surface over time such as family commitments. These barriers are fluctuating, and the groups' flexible structure of attendance allows members to determine what they must prioritise for their own wellbeing. There is a real sense of knowing the group is there regardless of if other things come up, and members are empowered to choose what feels most important for them each time.

"Erm... I've gone in bad weather. I've gone when I've been feeling down and really needed the group support." (Simon)

"The only time I don't go is when I, I, I can't cope. I can't mentally comprehend getting on a bus." (Daniel)

"Yeah you've got to navigate other things yeah. And I would like to go to the group tomorrow I really would but I go every week and don't see [name] often he doesn't see his mum often." (Michael)

## b. The resistance of voices

The voices of members also have important perspectives and experiences of attending the groups. Some voices view the group as threatening or unsafe and therefore discourage members from

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attending, as is the case for Daniel and Jane. For members who still want to attend and find benefits from the group, there is a possibility that attendance results in more distressing and negative voices – something that understandably may serve as a barrier to attendance during more difficult days. There is a sense that over time, voices may change or lessen in their reluctance to attend meetings, almost a parallel of how the early meetings might be experienced by members.

"like if I'm having a day, where I'm not, I'm not brilliant, but I still want to go. They're like, no, don't go. You're not going. And that's for me to stay home and look after myself, not because they want to spoil things for me, you know?" (Daniel)

"Er, well, because my voices weren't allowing me to go in, they were creating every, every Wednesday when there were a group on." (Jane)

For Simon, the voices have a particular difficulty with the facilitator of the group, which can affect how directly the facilitator can interact or support both Simon and his voices. However, the opinions of the voices are not dismissed but embraced and given space within the group. Simon's use of humour around the voices response suggests that through attending the group, he has come to a place of acknowledgement with his voices views rather than ignoring them. Attending the HVG whilst a flexible space can bring about internal tensions in which members feel obliged to negotiate each member needs on that day. This includes consideration of their past and ongoing experiences of interacting with others, and the responses of the voices.

"Sometimes when I smile, the voices don't like it because I I smile, smile a lot in group over the last few years. The voices haven't appreciated it very much because I've got to give back a lot more before I can smile." (Daniel)

"Erm, he was negative, both of them. Erm, I did get a very hard time, of of them from what I can remember cos it's quite a few years ago... My voices on the other hand were not so supportive. They were very dismissive of the facilitator, my voice was, who's the bad voice, even after all this time still doesn't like the facilitator... He wants me to tell him frequently that he doesn't like the facilitator [laughs], which is a bit embarrassing. (Simon)

Reflections: Whilst it did not come out in interview, I did wonder how voices had responded during my interviews and whether asking for their perspectives of groups specifically would have helped to capture a more diverse range of responses from voices toward Hearing Voices Groups.

## 2. Connecting on a deeper level

HVG members have developed many different meaningful and trusting relationships with professionals and non-professionals over their lifetime. However, the group offers something unique in the opportunity to connect on a deeper level. Members connect on the level of being voice hearers, able to relate and empathise on a level unmatched by others – not purely on the experience of hearing voices, but associated experiences too whether good or bad. The group is also experienced as helping members find other aspects of themselves outside of the identity of being a voice hearer, moving away from limiting and stigmatising narratives and rediscovering themselves. These deeper connections also facilitate relationships within the group moving beyond both the parameters of meetings and being members of a group. Lastly, this theme explores how connecting on a deeper level facilitates opportunities to integrate or reintegrate back into wider society, with the group actively working to expand the worlds of those who attend, not keeping them reliant on the groups.

#### a. Voices as our common factor

The realisation that others hear voices too is extremely powerful and transformative. Both Oscar and Simon capture an immediate realisation that they are not alone and that the stigma and prejudice they had faced or internalised did not hold true – their experienced validated as real and of importance. This began a process in which they were able to start to deconstruct and make sense of their experiences. This offers an immediate sense of belonging that many members had not experienced for

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many years or ever. The use of the phrase 'sanctuary' captures the day-to-day difficulties of voice hearing that many experience and the power of finding yourself surrounded by others who truly get it. These factors nurture a psychological safety.

"Yeah I suddenly, something clicked inside me [gestures toward head] and suddenly realised well, there's all these other people who hear voices. I'm not the only one. I can't be going crazy. I rationed it out." (Simon)

"But I felt like I was floating because, I couldn't believe, there was 15 other people in the same room that could hear voices. I wasn't that freak on my own." (Oscar)

Micheal's reflection of it being 'different' for everybody else nurtures an identity of togetherness in the room – no one else can fully get it like we can. New and existing members alike immediately feel a sense of connectedness and togetherness on the basis of their voice hearing experiences. To a degree, this togetherness is not bound by how long they have known one another nor how many meetings they have been to. This unconditional togetherness provides a strong foundation for developing a sense of safety and meaningful connection. Jane captures how she can relate directly to how others have felt at different points in their lives. The group brings together people who have both positive and negative experiences of childhood, diagnoses, medications, hospitalisations and mental health services more broadly, allowing members to connect on many different levels.

"The other people in the group. and telling me because their stories were very, very similar to mine. You know like lot before they started getting help or or medication or both. They just felt like they were just isolated and and very vulnerable. And and that's how I felt. Erm, I just remember thinking, is this me for the rest of my life. Uh, but er yeah, it it were... It just changed everything." (Jane)

"And then you're comfortable then cos you're all talking on a different level if you know what I mean... That's what I'm saying everyone's in the same boat." (Michael) Members feel less judged and able to be vulnerable because others have been through similar. This again brings about a togetherness that does not occur elsewhere. Some members may be working and living with voices more harmoniously, offering hope and strength to members who may be struggling with their experiences or other aspects of life. Members can offer each other messages of hope and compassion that are heard differently from others who may not hear voices or be able to truly relate. Daniel views this as seeing others succeed that perhaps normally you do not believe can, and that instilling hope within him that he too should be hopeful. Elen reflects on how there is value hearing from members who still hear voices and those who may not, both are seen as valuable positions in which learning, and connection can form. Outside of the group, members rarely get opportunity to meet other voice hearers or speak so openly and frankly about their experiences due to fear of judgement and stigma.

"Cos its watching people succeed but wouldn't normally you wouldn't normally see succeed. Cos, you hear about how people are slipping through their life. Learn compassion, learn understanding and you learn patience and you learn... strength. You learn how to be strong by seeing others be strong."

(Daniel)

"Basically seeing different people, the spectrum of the experiences and not so much how they manage their experiences. But it's just interesting to see other people, and what their voices are like, some people who come don't hear the voices anymore." (Elen)

Having experiences in common helps facilitate a sense of safety and acceptance. Michael shares how the group will accept what society may not accept or fully understand. The group's identity as a group for voice hearers brings with it a group of people who have likely some common experiences of societies' view of their experiences. If these are negative, the group offers a space to feel supported and heard. If members have positive experiences of societal responses, these are shared too and can inspire and instil hope in other members. Those not in the group might not fully get it, nor are they expected to for Simon. Those who do not hear voices can and do offer support, but they cannot relate in quite the same way.

"If you're hearing voices it's acceptance of what society may not accept you for." (Michael)

"So... if I told my friends, I wouldn't expect them to understand and I wouldn't expect that level of trust, like we have, as group members." (Simon)

Michael speaks to the group being experienced as more than just a crowd of people, or a group of people who might look like you. In contexts such as hospital, those who hear voices may meet others who share this experience. However, conversations appear to distance from acknowledgement or exploration of voices – voices are not communicated about in the same way, if at all. Acknowledgement of voices in some contexts may be seen as a barrier to progression toward discharge and professionals may view voices as a sign of illness. The experience of meeting voice hearers outside of the group is therefore very different. Those who do not hear voices may be quick to judge or panic at the content of voices. Speaking openly about voices to non-voice hearers can feel like an 'unleashing' that can be overwhelming and instil fear or worry in others. Professional responses may be quick to utilise restrictive practices such as detention under the Mental Health Act, for example. This can deter voice hearers speaking openly about their contents outside of group.

"I'd met people who'd heard voices before. Who haven't talked as much about it. Or they've talked as, people who are hearing voices just talking are you having a good day are you having a bad day things like that. And asking me how I am and me asking them how they are and understanding you know like, no communicating in a way. But when you go to hearing voices group you communicate more about it." (Michael) "You always know to hold something back from therapists, or care workers. If you unleash the full dialogue that's going on and you're terrified of getting sectioned then if you are sectioned, then it makes you wary." (Daniel)

## b. More than just a voice hearer

The group offers opportunity to explore an identity outside of voice-hearing, in which other aspects of members are valued and developed. For Simon, this can be experienced as loosening the secrecy or dominance of narratives surrounding voice hearing and feel more 'normal'. This may take time to 'realise' and is an ongoing journey through attendance of groups and having space to explore identities away from voices.

"So like I'm starting to realize now that I can... be a, as normal as possible around people and not that person that's got that secret illness or whatever." (Simon)

Space is made to think about members outside of their voice hearing experiences. Members can view themselves outside of solely being a voice hearer allowing for new opportunities to connect with other aspects of themselves that may have been lost as a result of more limiting narratives and discourses. Hearing voices becomes second to being a human being.

"We sort of just talking about your day-to-day life and stuff and then it might, might be relevant, might not, yeah. So it wasn't, wasn't like a big shock or anything because it was just people who you talked to, who happened to hear voices. It was more that was more, the thing really. Yeah." (Michael)

"You're seen for the person you are and then your experiences come with that rather than you've seen as somebody who has this experience. And then who you are as secondary to that. (Elen)

Opportunity to talk about friends, families and general life does not take away from hearing voices or talking about living with voices but offers a loosening of voice hearing being such a dominant part of

one's life. For some members, this is experienced as having conversations that others who do not hear voices have, a human conversation that appears to have been absent prior to attending the groups. Others in society may view members as 'voice hearers' first and foremost and neglect to acknowledge or explore the rich and multi-layered lives those who hear voices have.

"I might talk about my wife or my family or other things, and then like conversation there, you still know you're hearing voices but you're breaking away from voices a bit. You're having a normal conversation like normal pe- not normal but every day people do. Who've never heard voices or heard about voices." (Michael)

Reflections: I found this subtheme quite moving. Hearing how many participants had at one point viewed themselves only as voice hearers, and the negative connotations they attributed toward not only themselves but others who also hear voices. I was mindful of my own critical views of medicalised perspectives of unshared experiences and to ensure my interpretations remained grounded in the data.

## c. Becoming part of a community

Daniel shares of living a 'sheltered life' for many years, isolating himself from others and viewing relationships as toxic. The group has allowed him to reevaluate his relationships with others. The group provides members opportunity to rebuild social connections. For some members, their attempts to rid themselves of voices and their experience of support for voice hearing prior to groups had led to further isolation and moved them further away from opportunities to develop friendships and social connections. Those who have struggled for a long time with their experiences may have never experienced close friendships or connections or know how to navigate meeting others. The group offers a safe space in which this can occur. Members become friends within the context of the group, and this grows and begins to exist outside of the group. The group is therefore transformative for some members in providing the foundations of building trusting and safe relationships, becoming a community, more than just surface level friendships. Both Oscar and Simon reflect on the close nature of their relationships with other group members both past and present. Members can really get to know one another due to the open-ended nature of the groups, meaning members can attend over long

periods of time. Such connections may be difficult to form in other contexts such as mainstream service group programmes as these are often time limited or gatekept by referral criteria such as being open to the service. Whether it is sending Christmas cards or visiting each other even when members may no longer attend the group or move away, the group does not discourage this. These relationships more than emulate those that exist outside of groups but develop into actual relations that are not contingent on group membership.

"I didn't have many people in my life because I lead quite a sheltered life. And I just thought well if they can be kind to me, I can be kind to them." (Daniel)

"I've been friends with group members for... years... Erm, I think the oldest one now, the oldest friendship I've got now is 20 years with [name]. Er, we go out and we socialise. We support each other on messenger or a phone call when we're feeling down or the voices are getting a bit too much for us. It's that camaraderie, in a group friendship, a group support what you can't get anywhere else. What you can't get in a clinic for instance." (Simon)

"We turned into a little family. We still keep in touch." (Oscar)

Whilst these strong friendships are held in high regard and experienced as opening up members worlds, for Daniel it also brings with it a sense of responsibility for the wellbeing of other members. Feeling so connected and mutually responsible for one another as occurs in friendships can lead to increased anxiety and worry when a member may not attend or may be going through a difficult period of time. Whilst this may occur in any friendship, there is a sense of members holding a collective responsibility for one another's wellbeing. Experiencing others struggle is also experienced as transformative too. The strong relationship within the group motivates members to do well for one another, wanting to make other members proud and to support others to feel proud of themselves too. In a sense, members hold one another to account but in a positive and supportive way, there for one another through the good and the bad.

"I have a lot of memories of people just talking about suicide. Like "why won't no one let me jump in the road and jump in the road" and you never see them again. And you always worry about them and you always hear about... worry about their voices." (Daniel)

"I'm trying to learn off this gentleman that struggles to come a lot of the time who communicates with his voice. I keep telling myself I want to be like him. I want to do it for him, to want to make him proud with me the way I am of him." (Daniel)

## d. A widening of opportunities

As captured in other themes, the experience of voice hearing is commonly associated with withdrawal from society, whether this be due to fears around stigma, a lack of self-confidence or a sense of hopelessness. Elen shares how factors such as hospital admissions limit opportunities to integrate into society once more and over time, people lose confidence in their ability to do so. People may feel institutionalised or distrusting of others. Feeling detached from society can then lead to a vicious cycle in which an individual feels unable to reconnect or have the opportunity to reintegrate. The group offers a safe space to test out communicating with others and socialising again. It allows members to rebuild confidence in interacting with others. This does not feel like a forced process but rather a result of the organic and genuine friendships and connections that are experienced within the group. There is also opportunity to develop oneself and explore how people want to interact with society.

"But being in hospital, well, being in active addiction, then basically going into a lockdown, then going into hospital like everything, there's not much time. There's not much opportunity in all that time to become a part of society." (Elen)

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"So its let me kind of reintegrate into society and where you re learn how to socialize and and talk to people and just be a person. You know umm. So I feel it's helped. It's benefited with my relationship with myself and others." (Elen)

Jane and Simon capture a journey of self-discovery in which they have opportunity to explore who they are and how they relate to others. Jane feels able to almost try out different ways of relating and communicating with others, whilst Simon feels he has both rediscovered parts of himself that were 'bashed away', but also gaining new experiences of wanting to meet others and have a voice.

"I've started to, erm realize that I could erm, get back into erm communicating with people, socializing with people, not not on the same level that I used to, but I'd try a couple of hours out and stuff like that. And that's gradually grown." (Jane)

"Um, I think the groups are my friends, and the groups drew my personality out of me. Once more that had been bashed away, that had been hidden for so long. Made me more confident and easy going with people." (Simon)

"And I learned that from groups, or from group. Erm... I learned to talk to people which I hadn't done before. Even at university I was the one at the back. Please don't pay attention to me please don't pay attention to me, don't look at me. Just let me get on with my work. Er, get home as fast as I can, lock the door and do what I had to do." (Simon)

Members of groups can come from all walks of life – something Michael has found valuable. This is experienced as opportunity to learn from others, and to break down barriers. Exposure to others views and experiences allows a realisation that even those who you may have not crossed paths with outside of the group can be well intended and friendly. There is an acknowledgement that not everyone is 'good' or 'bad' but that this can be navigated relationally. Jane shares how the group allows for disagreement and relational challenges, and nurtures prosocial ways of navigating such difficulties as a collective.

"It breaks a lot of barriers down cos you see people are friendly. People of all different parts of life can be very friendly even in nasty things they can still be very friendly in some of it do you know what I mean? Which comes back to what my dad used to say there's good and bad in all people." (Michael)

"And, you know you can sort of like, be a bit disgruntled by something somebody said or what the voices have said and and it's like I've never been able to sort of like speak out and say "you really upset me when you said that" bla-di-bla-di-bla and like I can say that in the group, you know when we socialize and stuff like that because I feel so comfortable with them. And I feel so safe there you know." (Jane)

Jane feels more confident in going places outside of the group because of better communicating with both her voices and others. Oscar shares a similar narrative of his world opening up as a result of attending the groups and having more trust in both him and others, a similar experience to Elen's. Developing new meaningful friendships facilitates a new or renewed confidence in members. This further benefits life and relationships outside of the group. New relationships may be forged outside of the group, or members may feel empowered to engage with their voices more relationally and advocate more for what they need as individuals. The journey of attending the groups and being less isolated can encourage members to then access other groups or public places. These changes expand the worlds of members, whereas experiences of other support such as medical interventions are experienced as potentially limiting opportunities to interact with others and leave the house for example.

"I've got more confidence to go places, whereas like before, if I was stood, like at the train station, the voices were telling me to jump off and, and stuff like that, you know, like telling me to kill myself and

yeah erm. So it's just been... so helpful for me. I've been able to get about and I didn't communicate with people either because there's just so much going off in my mind in my head." (Jane)

"Groups have been absolutely amazing for me, they've opened my world up so much erm. I didn't go out of the house for three, four years because I thought other people could hear my voices, I thought I was gonna get picked on. And the groups, hearing voices groups have got me out of that. I can go out when I want, do what I want." (Oscar)

"for a long time, erm my mum would take me there, but sometimes I'd I'd have to get the bus and that helps build up my confidence. And I knew I was going to a destination, so it wasn't like, get on the bus just because I I in my head, it helped motivate me knowing I was going on the bus to get somewhere."

(Elen)

#### 3. Turning toward voices

The ethos of the HVN is clear – that voices are meaningful experiences that can and should be accepted. This message is experienced within groups and over time, is embodied by all members. This theme explores how the group facilitates a turning toward voices and empowers members to accept the presence of voices. The experiences of those who had previously rejected their voices are also explored. Groups are experienced as working with voices, not against, intentionally developing relationships with voices. This can be a difficult and jarring journey but is ultimately experienced as opening new possibilities for change without necessarily reducing the frequency of voices.

#### a. An acceptance of voices

Michael reflects on his own early assumptions and reactions to those with psychiatric diagnoses who may hear voices. Upon being diagnosed, these assumptions became about himself too. Societal narratives around voice hearing are often associated with risk and danger – voices should not be experienced and are indicative of a mental illness. Voice hearers may internalise these messages and see to repress and get rid of their voices as a result, perpetuated by messages often conveyed within

mainstream mental health services. Accepting voices if these narratives were to be true would mean an acceptance of a difficult and isolated life.

"At first I was in hospital and there was a girl who came up to me and she says am, and she says my name is so and so yeah what's wrong with you? I've got Schizophrenia. And I ran a mile from her." (Michael)

Oscar shares similar internalised narratives. For many members accepting the existence of voices is a radical idea. Oscar had to mask and hide away from his experiences in order to have a career and reflects on how society may want to keep voice hearers away. Outside of HVGs, the recurring message is to hide or reject voices. He had learned to survive and move forward in life by hiding the existence of voices.

"Erm, so then after that I kept the voices really quiet. Didn't tell anyone, I wouldn't have been able to join the army if they knew I'd had voices. Who trusts anyone with voices [laughs]. Keep away, keep away." (Oscar)

HVGs offer a new way of viewing voices, and a narrative of acceptance as opposed to rejection. This offers an alternative from a 'textbook' understanding of voice hearing and leads to new opportunities of how to manage or live with voice hearing experiences. As Daniel shares, the group aims to make life more comfortable for both the voice hearer and voices, making space for a more harmonious relationship to exist. In welcoming voices, internalised stigma can be shifted too as members begin to feel humanised and that their voices do not mean they are necessarily dangerous.

"Erm... [facilitator] ... will say I don't want to get rid of your voices, where as a clinician would say, take these pills, keep on the medication and your voices will go. I think clinicians tend to be, oh what's the word for it. Not inhumane, but textbook understanding." (Simon) "Erm, the groups aims is to not get rid of the voices, but make it more comfortable for everybody to live with their voices, and the voices to live with that person." (Daniel)

For Oscar, meeting other voice hearers who are now turning toward an acceptance of voices and being empowered to do so has helped come to new conclusions about how voices may be there whether you want them to be or not, and resisting this may lead to more distress not less.

"The voices are, see, I try to explain to people. People that come in the group and that, you talk to your voices after what they've put you through? You know but. What I say to them is, you're stuck with one another." (Oscar)

The distressing nature of the voices and desperation felt is reflected in Simon's consideration of cutting off his ears to no longer hear them. Societal narratives around voice hearing being something 'normal' people do not have and being indicative of a problematic and stigmatised mental health issue perpetuates a damaging narrative that can lead voice hearers to extreme action. In the pursuit of avoiding or rejecting voices, members have experienced intense feelings of hate both toward themselves and toward voices. Mental, physical and emotional distress accompanies this with some individuals resorting to self-harm – a war against the voices is tiring.

"Yeah, erm a few years my voices were very very negative. Erm, they used to hate me as much as I hated them, and it was real hate. I resented them. I thought about cutting my ears off. I've got scars behind my ears that's why my hairs long. I thought about cutting my ears off so I wouldn't have to hear them anymore. I thought they would stop..." (Simon)

"I was sick and fed up of fighting a war every morning. And, going to bed at night knowing you were going to wake up to this awful darkness. It was you know, nothing you did was right. Everything you did was, you was making a mess of things. This that, the other. Once we started working with the cause of the voices, once I got that into my head, then we started working with the voices." (Oscar) With acknowledgement of how distressing and impactful voices can be, attempts to avoid or reject these experiences also comes at a cost for individuals, including an impact on relationships and engaging meaningfully with society. There is also little opportunity to develop an understanding of voices or building new relationships with themselves and their experiences. Ultimately a rejection of voices is experienced as having a higher cost and leading to more distress than having a space in which acceptance is supported.

"You can only take so much of something, and erm drink and drugs and hiding the voices robbed, robbed me of everything really. My family, jobs, everything. It robbed me." (Oscar)

"You can't function if your hearing voices if you're, just trying to drown them the entire time, trying to get rid of them because it's just become too aggressive to, just becomes too volatile." (Daniel)

The group offers a space where an acceptance of voices can be worked toward with support. Once a place of acceptance is reached, so is a sense of inner peace. Some members then view their voices and integral parts of their lives and identities –which they would not get rid of even given the opportunity to do so. In doing so, voices can become something members are proud of.

"I've been hearing voices for 42 years and they're just a part of me... And if they're gone... if I could take this magic pill and they'd disappear, I don't know what I'd do. I talk to my voices and my voices talk to me." (Simon)

I'm very open with my voices. My er, when I got to a veterans association or a remembrance parade. Whatever they say to me [name], you wear your voices like you wear your medals. I say I do cos I'm so proud of how far they've come." (Oscar)

Reflections: At interview, it was hard hearing the extent to which participants had gone to rid themselves of voices, and the radical change they have experienced as a result of acceptance. I was mindful of reflecting only the positives of accepting voices without acknowledging the sometimes-debilitating impact of voices and how difficult it may be for someone to accept their voices may never leave them.

#### b. Developing relationships with voices

With an acceptance of voices comes the opportunity to build meaningful connections with the voices. In which the wellbeing and perspectives of both voice hearer and voices are considered. Daniel has noticed that how he speaks to the voices can influence how they present. Daniel's voices often put him down or say horrible things to him, yet he had found the strength and ability to respond compassionately. Oscar now holds in mind how his voices may be feeling and reacts to how they are with compassion and curiosity. Members view developing relationships with their voices as a worthwhile investment in developing opportunities to make things right.

"You have to be kind and polite to the voices, manners actually matter and words, words count with voices or words count with my voices." (Daniel)

"You know, allow your voice, to say what's upsetting it and then maybe you can work to put that right." (Oscar)

Being empowered to communicate and build relationships with voices shifts how voices are viewed, seen as well intended and having a purpose as opposed to menacing. New meanings lead to new ways of managing and living harmoniously with voice hearing experiences. Voices are humanised and respected, and the needs of the voices are also held in mind. This notion of essentially stopping a struggle for power leads to a more harmonious relationship. This is not about accepting the distress associated with voices, but rather seek out the meaning behind their content and being supported to balance the power within the relationship between voice and voice hearer. Voices are viewed as equal and important parts of members' lives and are therefore treated as such.

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"Yeah, yeah, I've learned to ask. I've learned to ask them now and talk to them about it, because at the beginning they would create and never stop talking and erm, the the I've got one on each side and they'd talk across me and it was so distracting that I knew I couldn't go. But I used to think it was done deliberately to make life hard for me, but like I realise now that no, they're just thinking about my health." (Jane)

"Voices are people as well and they need to understand it" (Simon)

"Even if your voices are critical of you, it's just trying to make you come out of your shell a bit, to encourage you generally... You know, and I I took that and put it into my voice hearing and see them as more helpful." (Daniel)

Voices are seen as experiences that can be worked with and that the relationship with voices and voice hearer is fluid and changeable. A cohesive relationship can be developed, and voices can be experienced as a great resource as opposed to something to live with reluctantly.

"So they go through nursery to primary school, mine are in university now [laughs] you know what I mean. They're still learning and yeah I am proud of how far they've come. Erm, people say no it's me. But it's, it's us as a unit." (Oscar)

## 4. A secure base

The group is experienced as offering both choice and autonomy to those who attend. Members feel able to choose and decide how they self-describe and as to what they take from the groups. Other than the general ethos and manifesto of HVGs, members feel encouraged to choose what works for them. This theme will explore how other support such as mental health services may be experienced very differently and the impact of this. An equality of perspectives also perpetuates a message of all experiences and understandings being welcome and members are empowered to hold onto what

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makes sense for them. Members also offer the same privilege and respect to other members leading to a safe space where many ideas and views can be held equally and fairly – although this can result in navigating perspectives that may go against one's own values and beliefs. Lastly, the flexible structure and set up of HVGs are explored, and how this is experienced as largely positive in providing a secure base in which deeper connections and sense making can occur, but also how the configuration of the groups can shift how this flexibility is experienced.

## a. Empowered to have choice

Daniel shares experiences of being told what is 'right' and 'wrong' within mainstream services. Dominant narratives of what 'works' for those who hear voices can feel like they are being told to think or feel a different way, taking away from their beliefs and understandings. Oscar similarly shares how he was being told and given a diagnosis with no choice or consideration of his views. There is a sense of being done to and individual autonomy being neglected.

Don't ever start with 'no, but that's not right.' But some people always tell you that's not right. How you think... you shouldn't do that. And you should think a different way." (Daniel)

"You know and they kept saying I was schizophrenic, I was this I was that. And no one would listen to me and it was erm, things that I'd seen and been part of that caused them." (Oscar)

Again, spaces in which there is no freedom of choice or collaboration around decision making can lead to intense feelings of loss and in some cases, traumatisation by mainstream systems. For Daniel, being told he isn't 'trying' because the choices professionals made did not fit with what he needed has damaged his trust in mainstream services. Oscar speaks of a traumatic incident in which a lack of freedom to choose leads to interventions that professionals may have deemed appropriate, but he did not. The experience of diagnoses or mainstream services is not necessarily the primary issue, with it being more pertinent that those who hear voices feel they have autonomy and choice to choose and decide what makes sense and works for them. Individuals may feel so unheard and that there is a one size fits all approach to their experiences that they choose to withdraw from mainstream support. It can be difficult to come to a professional with a wealth of personal lived experience and sense making regarding your difficulties and experiences, and after a brief conversation, be given a label and/or medication can feel dismissive.

"Some people, like I say some people have said, well, you're not trying. I'm. I'm not trying. I'm not trying. I'm not trying by a lot of therapists throughout my time..." (Daniel)

"And then one day, they just come for me, and said right and took me in. And then I was given electric shock treatment. Erm, I'll always remember it. I'll always remember the faces of the people who took me in. I'll always remember the face of the psychiatrist who said I needed it. 18-year-old lad held down and shocked." (Oscar)

"Yeah, yeah they pushed the schizophrenia routes for many years. So I just sort of disappeared off the table and didn't go to doctors or anything again. Erm, but when I came out of the army I, I seen somebody and got diagnosed my PTSD. And I, since, I've I've been through the system and they've, all my diagnosis is PTSD." (Oscar)

Oscar reflects on more cohesive relationships he has experienced with mental health professionals, in which there is a sense of collaboration. He links this to experiences in the past in which he had very little choice, nor were his views and perspectives considered in decision making. He had to fight for his opinion to be heard and accepted. Daniel also speaks to the importance of feeling heard and that your needs are being held in mind and worked toward, being viewed as an individual.

"Finding something that works for you, and then your psychologist, psychiatrist, doctor, goes with that. You know and works with you on that." (Oscar) "I think the more people try to foster a bond with you as a person and understand what does and doesn't work with you can then... put in place a care package for you according to your needs because we are all individuals." (Daniel)

Groups offer a space in which members have a freedom to choose. Oscar speaks to how the group provides a library of coping mechanisms. There is an inferred choice as to which books or coping mechanisms Oscar chooses to use – they are not prescriptive. The group can offer a wide range of ways members may live with and relate to their experiences, but members are able to choose what they take or how they interpret and implement these suggestions.

## "Yeah yeah, it was like building a little library of coping mechanisms and it was so helpful. You know, and everybody found it really helpful." (Oscar)

Michael shares how hearing others' perspectives and interacting with their worlds is experienced as having an interaction with your own life and affecting it positively. Even when ideas are not agreed with, there is still a value perceived in learning about others' views. It may be that hearing views you disagree with help clarify more your own position. The idea of a 'kaleidoscope' speaks to the knock-on effect of hearing many different perspectives and ways of being, whilst also having autonomy to choose what aligns more closely with your own hopes and values. Elen speaks of hearing many different ways to speak about and understand her voices, able to pick and choose what most fits for her without fear of others telling her she is wrong. Members are able to pick and choose what makes sense to them and is most beneficial for their individual experiences.

"So yes I suppose we all help each other at that group cos everybody is thinking in their heads, it's like a kaleidoscope, that's what I tried to explain at one of the groups. It's like a kaleidoscope, you, your mind sets into different patterns and somebody else might have a different kaleidoscope and you might see each other eye to eye or a different point into that life and that kaleidoscope of life for that person." (Michael) "It's helped me kind of build an understanding of who they are and hearing someone say, you know something just like, oh, do you mean like this, and ill think, ah, I didn't think of it that way. So it's helped me understand my voices" (Elen)

## b. An equality of perspectives

Michael shares feeling he has somewhere to go to speak openly, no matter how 'insane' his perspectives or views were. Daniel similar shares feeling able to speak and to feel heard without fear of judgement. Jane reflects on how no one within the group need feel frightened to speak openly about whatever is on their mind. At meetings, all perspectives and views are experienced as being held equally allowing everyone to be transparent and open about how they make sense of the world and their experiences. There is a freedom to communicate openly about the ups and downs of life too. Whatever is brought or shared, it is responded to with respect and attentiveness. Having this space offers voice hearers a place to go where they can explore and broach anything that feels important to them and contributes towards the groups conversation and flow remaining flexible and guided very much by all attendees. Members are safe in the knowledge that what is discussed in the group remains within the group and this trust only grows over time as members grow to know one another. The group is not a space where the stereotypes and stigma experienced by members is replicated, linking closely with the themes around being connected by their voices as a common feature.

"Because hearing voices is one of the places where you can go, speak openly no matter how insane you are and talk about things, get it all off your chest and go away and think about it a bit and think oh you know I had a chance to speak about it, I had somewhere to go" (Michael)

"It's a safe space, to communicate the struggles that you have. Without erm, fear or prejudice. Because ... when you talk, you get listened to ... And there's not many places like that." (Daniel) "it's unique because like I say, everybody comes together and uh, nobody's frightened to talk about anything that's going on in their minds. If they have a problem with somebody else in the group or a problem with somebody else's voices, or, you know with themselves it it just like flows and gels."

#### (Jane)

Both Michael and Oscar speak to the importance of empowering all voices and an equality of ideas and perspectives within the group. All voices matter and each member is viewed as having a unique and important story to share. These stories may relate to voices, but also relate to other areas of life and experiences too. How these are expressed and talked about is almost irrelevant as long as a mutual respect is maintained for all perspectives brought. There is an equality of ideas and understandings and a responsibility of all members to ensure they allow everyone's voice to be heard and empower one another. Equality is promoted regardless of who you are or any other factor. The range of perspectives, opinions and understandings relating to voices within the group is viewed as an enriching factor, as opposed to a hinderance. There is no obligation to necessarily believe or adopt another person's perspective but equally all perspectives are treated with respect. Members may not fully understand another perspective, but remain openly curious, empathetic and compassionate towards others. Equally, if one idea of perspective does dominate within the group, this is experienced as uncomfortable by the group. Members want freedom to express themselves and for others to have the same courtesy. The group doesn't want to mimic what happens in wider society or within psychiatry – but rather offer an alternative way of being. This means that the same stigma, fear and shame that can be experienced in society when experiences are shamed or disbelieved does not occur within the group.

"Let other people speak let other people have a voice. All people have a right to speak not just me being overpowering." (Michael)

"A group, it wants to be, everybody's got to be equal no matter your race, religion, your beliefs. Everyone needs to be equal. Religion needs to be kept out of it. It's not about religion. Some people believe that, maybe your group on one of the sessions can touch on that, talk about that. Don't dismiss it, but we can talk about it and make them feel part of the group no matter what you think." (Oscar)

Equality of ideas and perspectives helps everyone to feel safe but can also be difficult to hear at times. Bringing together groups of people who may have otherwise not met, with different views and ways of navigating the world can on the one hand expand members ways of thinking, but this is sometimes experienced as difficult due to challenging their existing views. Elen shares how some members' views may feel infuriating, and this requires each member to respond and navigate these views respectfully. This can lead to disagreeing with other members, yet this does not directly impact the groups' dynamics. There may be views and ideas that a member finds more tolerable or acceptance than others, that are closer aligned with their world views and experiences. Whilst this can feel difficult, Michael shares how he sees value in there being no censorship and that members learn to open their minds up to other views and perspectives. Members are humanised by other members, and if they present with views others find challenging, a stance of agreeing to disagree tends to prevail. People can say what they feel they need to say without fear of being ostracised.

"With the whole range of people you get there, some of them have opinions that are just infuriating. Managing that that like not not building, you know, resentment towards that person or anything is sometimes difficult. Not that its, It's not like a really controversial, you know, place in people fall out no one really falls out or anything." (Elen)

"They're hard to accept sometimes. If you keep an open mind on feelings. That everyone's has feelings and knowledge and an open book inside them you'll try and listen to somebody else's point of view." (Michael)

"Even if you have a very intolerant perspective, you can still learn from it. If you don't agree, agree to disagree." (Michael) This acceptance of all perspectives differs from some members' experience of mainstream mental health services. Those who may hold religious understandings of their voices for example may not feel they fit the framework that exists within mental health services, primarily driven by the medical model and diagnoses as a means of determining suitability for services and interventions. Being offered alternative explanations for your experiences within a mental health framework is experienced as more dominating and that you are being told you are 'wrong'. This can leave voice hearers feeling they are not being heard or listened to and their perspectives neglected. Being offered a diagnosis is not necessarily the experienced issue, but rather the negotiation and collaboration experienced when exploring diagnoses as ways of making sense of someone's voices.

"What I didn't realise is that I had Schizophrenia myself when I was finally diagnosed and told. I think was diagnosed early but I wasn't told for a long time. A lot of people said I think you've got schizophrenia and mental patients and mentally ill people. I still say mentally ill instead of users and that cos that's, another way I used to describe myself or a person has become ill of some degree, my mind. According to other people's assumptions of me." (Michael)

"In hospital, you know you're a patient and therefore its implied. You know that you're there for an illness. Well, you have that for now, you have some kind of issue, so that is the primary focus. Whereas yeah, going to hearing voices groups I don't. (Elen) "It seems like sometimes it's one size fit all erm package." (Daniel)

Reflections: I initially found myself focussing only on the positive nature of an equality of perspectives and how this empowers members to feel heard and allow others to be heard too. I acknowledged a need to reflect how hearing different views is not always easy, even if it does create a safer environment for all members. I wondered how the groups would respond to someone who perhaps aligned themselves more closely with psychiatric or medicalised perspectives of voices. It also made me curious as to how the group naturally must have some boundaries and parameters that breach the ethos of the groups to prevent unacceptance language for example.

#### c. A flexible space

Jane experiences meetings as flexible spaces in which both conversation and engagement is free flowing and somewhat spontaneous. Conversations organically flow without strict agenda's leading to a sense of the group cohesively running itself. Even if loose structures are implemented such as setting agendas, the group are not too wedded to this process and can work flexibly to explore whatever is brought. Elen reflects on how she can choose how to engage with the meetings, able to take a less active role by listening and doing she needs to feel safe and engage if that is what they need. How people engage is open to change each meeting too, allowing members to bring their true selves on the day and engage however feels meaningful and feasible. Elen also captures how this openness can bring about uncertainty and unpredictability as to what is brought, similar to some of her anxieties prior to her first attendance of the groups.

"I mean it can change when, as soon as somebody starts talking about something and then it sparks something off in somebody else and they want to talk about that so. It it just runs itself basically." (Jane)

"And I guess there is an anxiety about that in more informal, unstructured situations like the Hearing Voices Group that not knowing if what someone might say or bring, but the same time there's like a freedom because, I suppose I can just be myself and if I want to come and sit." (Elen)

Daniel shares that his best advice would be to be a sponge, that benefits can be felt from the group simply by being present and absorbing what you see and hear. This infers that taking a more active role within the group can be of benefit, but even attendance in its most passive form can lead to meaningful change and positive experiences. Members can attend meetings as often or infrequently as they like, with no imposed rules around how often someone has to attend – the group remains open to all members at all times. This opportunity for continuity has allowed Daniel to develop deeper friendships than he perhaps would have otherwise. For Elen, she feels safe knowing that the group is available as required, and there is no obligation to attend each week nor consequence if she does not.

This free-flowing process not only allows people to take as long as they need to engage with other members and find their voice, but also to be able to prioritise other areas of life at different times. Even though the members may change, the space often remains constant, as does the ethos of the group.

#### If anyone comes the best advice that you can give them is be a sponge." (Daniel)

"But the continuity of going to the group every week, the continuity of friends, seeing the same people there week in week out, plus new people also come. Erm, the friendship of the group, the helpfulness of the group, the support of the group. It's, it's really turned me around." (Daniel)

"it's obviously good. You know, it's not, I have to sign up and say I will be coming or anything. Just turn up, erm, It's good if I think you know what I feel like going this week and I don't have to think I haven't been for however long. Yeah, it's, it's that sort of informal thing of just rocking up." (Elen)

The continuity and stability of the groups presence differs greatly from both Jane and Michael's experience of mainstream services. Both speak to the ever-changing availability of other sources of support whether that be mainstream services or day centres. An uncertainty as to what is available also links to everchanging criteria to access such provision too, making such resources feel more inaccessible and difficult to locate. Daniel and Simon reflect on their experience of psychological support through mainstream services and the limited resources available. Mainstream services offer a value space that may differ from HVGs. However, time-limited interventions and support can be obstacles for meaningful relationships or deeper conversations that the group facilitates to be had. Experiencing professionals as stretched for time can influence how much someone may disclose and how much capacity professionals have to attempt to understand experiences like voices.

"it's really stretched to breaking point in mental health crisis teams, and the mental health services as a whole. So there's, they've change so much of the, the manifest to get mental health treatment... but it's just about impossible to get a CPN or get into a programme, at [location]." (Jane)

"I used to attend day centres and that all one time but they've all stopped... All that seems left is the hearing voices and places like Andy's man club and stuff which I wouldn't want to go to." (Michael)

"I've seen psychiatrists, I've seen psychologists but. I thought it was helpful to a limited extent. It was only for twelve weeks and I didn't get that much out of it... I think it's because the amount of time. We only saw each other for an hour a week for 12 weeks so, 12 hours with a psychologist is not a very long time." (Simon)

"And she was the only psychologist at [location]. So she was stretched for time, she couldn't give her time, or enough time to patients. We touched on things, handling abuse, being more confident. Trying to be more assertive but. I wanted answers to the root cause of my problems, depression and voices." (Daniel)

#### **CHAPTER FOUR – Discussion**

I will now explore the findings of this study, pulling upon related literature and psychological theory. Firstly, each research question will be explored in turn and positioned within the current literature. I will outline the key findings. The strengths and limitations of this study will then be outlined. I will then consider the clinical implications of the findings and the implications for future research explored. Finally, I will offer a final reflexive passage followed by a concluding statement.

The research questions for this project were as follows:

What are the experiences of those attending a community Hearing Voices Group and the sense made of these experiences?

- Why do participants attend Hearing Voices Groups?
- What do participants find beneficial about Hearing Voices Groups?
- What do participants find less helpful about Hearing Voices Groups?
- How might participants relationship with voices change from attending Hearing Voices Groups?

#### Study findings in relation to research questions

6 attendees of two community HVGs offered varied accounts of their attendance of groups. How they made sense of these experiences appears driven by their own unique contexts and histories. Their accounts of these experiences and interpretations are not static, but rather subject to change as they continue to attend groups and experience other types of support. I will explore each research question in turn.

## Why do participants attend Hearing Voices Groups?

Participants often attend HVGs upon recommendation of trusted mental health professionals already involved in their care. Those who trust involved professionals share stories of being supported to first

meetings and developing meaningful coping strategies to manage initial apprehensions and barriers. Voices can impact an individuals' abilities to trust others (Woods et al., 2015), therefore these trusting and pre-existing relationships are important. As professionals were not interviewed, it is difficult to understand the motivators and experiences of professionals. However, their role in supporting initial attendance was consistently reported. The culture and ethos of services and professionals therefore may mediate how likely voice hearers are to be recommended or supported to these groups. consistent with findings from Hornstein et al. (2020) and McCluskey et al. (2022).

Many members' decision to attend the group held some relation to their past experiences as voice hearers, often involving feeling stigmatised and isolated, consistent with previous literature (Zhang et al., 2017). For some, initial attendance is driven by a hope for change. For members like Simon, the group may be perceived as offering new opportunities, in which more favourable change may be possible that moves away from a constant battle with his experiences. Others, like Oscar, hold a curiosity that spurred on his attendance of the group, disbelieving that others hear voices too. He had internalised a narrative that voices are to be kept secret, and that sharing of voices would lead others to judge you negatively. For Oscar. feeling let down by mental health services also motivated him to seek out spaces where he had freedom to express himself and feel heard, a commonly reported benefit of HVGs (Shaefer et al., 2021). This project found that attendance facilitates a greater sense of hope for voice hearers, consistent with findings from Oakland and Berry (2015), that may keep participants attending. This hope can come from a sense of belonging, and realisation that you are not the only one who hears voices. This experience also aligns with both instillation of hope through hearing others' stories and the universality of meeting other voice hearers, two therapeutic factors of groups as outlined by Yalom and Lescze (2005) and observed in peer-support groups more broadly.

Feedback from participants suggests that HVG provide a unique and important alternative to mainstream services, consistent with Longden et al. (2018). HVGs are experienced as flexible and open spaces in which each member has choice and autonomy as to how they contribute, how often they attend and what they take from the group. Members recounted many contrasting experiences of

feeling unheard by the mental health system and that their voice gets lost amongst rigid frameworks and limited flexibility in how voice hearing is understood and made sense of, aligning with findings from Harrison et al. (2022).

Members decide whether to attend groups or not each week based on a variety of factors. For some, a difficult week of voice hearing encourages attendance, seeing it as a sanctuary to share their distress. Others have learned that they need time alone when things are too difficult. For others, their attendance is mediated through juggling other commitments and/or navigating changes in physical health for example. Two participants reflected on resistance from their voices, who did not want them to attend groups. Whilst it could make attendance more difficult at times, the voices views did not appear to prevent attendance. The resistance of voices to attend was briefly captured in this project, but more notably so an influence on attendance in research from Hendry (2011), where negative responses from voices as a result of group attendance limited members' capacity to attend.

Most importantly, there is a flexibility as to whether members attend or not each week, and their reasons for attending can be multifaceted. The groups' secure and flexible structure facilitates this, as members do not fear being discharged or unable to attend in the future should they not attend one week – or for more prolonged periods of time. Attendance is not necessarily motivated by fears of losing the support. What keeps participants attending is captured in what they find beneficial, such as the autonomy and freedom experienced within the group, with aspects of the group less helpful indicating reasons why members may choose not to attend. These will be discussed in the next section.

#### What do participants find beneficial about Hearing Voices Groups?

Those who hear voices are commonly isolated from others and withdraw as a result of their experiences (Zhuo et al., 2019). Contrastingly, participants in this project experience HVGs as spaces where relationships with themselves, others and society can change and grow. Whilst connection is

formed on the level of being members of a group, relationships grow beyond this, with organic friendships and a sense of community developing from attendance. This nurtures a group cohesiveness – a known important factor for group effectiveness (Yalom and Leszcz, 2005). Connecting as voice hearers, an often stigmatised and isolated group, leads to a strong sense of group identity which is empowering and normalising for members. Whilst connecting with others brings about relational risks, such as disagreements as noted by Hendry (2011), these connections are viewed as largely positive and allow for a development of socialising techniques (Yalom and Leszcz, 2005). This is consistent with the findings of both Payne et al. (2017) and Schaefer et al. (2021) who found HVGs support voice hearers making new and meaningful connections with others. The ups and downs of relationships could be viewed as natural and help those who have felt isolated for some time assimilate back into healthy relational patterns in a safe space. As a result, social connectedness in HVGs can lead to increased self-esteem and confidence in interacting with others, consistent with previous research (Abram et al., 2000; Rufato et al., 2023).

Both Dos Santos and Beaven (2015) and Tomlins and Cawley (2016) found HVGs nurture a strong group identity. This project found that members share experiencing a strong sense of group identity, which can facilitate genuine social connection. This allows members to feel they have a place within society once more, moving away from being a "freak" or feeling ostracised from mainstream society. Evrard et al. (2024) considers this an alternative socialisation in which voice hearers begin to occupy a more rewarding place within western society, such as that of mystics and shamans within other cultures. Participants spoke of not feeling accepted by society and viewed only as a voice hearer. The group creates a space of acceptance, where people can openly speak of voice hearing, but also their identities beyond this experience.

Developing a greater awareness of one's own identity is thought to be a crucial part of the recovery process (Shea, 2010) and there are known barriers to this such as societal stigma (de Wet al., 2015). Findings from this project suggest that HVGs may overcome these barriers though members having a greater sense of self and self-esteem within the group. Connecting on this level appears to alleviate the

impact of stigma as there is a camaraderie – attendees can relate to one another on a deeper level. All members being voice hearers offers something significant and unique, as found by Schaefer et al. (2021) and their connection reduces stigma and promotes safety. Research highlights the importance of integrating the identity of voice hearer alongside the other multiple identities voice hearers hold, in addition to how they identify with others, such as members of a group (Hogg et al., 2023).

Members feel able to explore their identities beyond being voice hearers, and that parts of them that had been lost could come to the forefront again. Members speak to increased confidence in socialising again and being encouraged and welcomed to speak about other aspects of their lives such as family, hobbies and employment – all considered important and valuable aspects of one's life. This is consistent with findings from Oakland and Berry (2015) who found HVG attendees to feel more valued as human beings as a result of being viewed outside of a single lens of being a voice hearer. This also facilitates a greater sense of togetherness as connections occur on a level deeper than as voice hearers, in addition to dismantling stigma and stereotypes as to what a voice hearer may 'be' or 'look like' as reported by Rufato et al. (2023)

Participants spoke of the value of seeing others succeed who they wouldn't normally as a means of inspiring hope and learning new ways of coping. However, there was also value in members feeling equipped to help other members too, a bi-directional system of support. This affirms both Borkman's theory of experiential knowledge (1976) and the works of Festinger (1954) in which sharing a common experience allows for relating on a much deeper level. Both upward comparison – seeing others succeed, and downward comparison, able to see others struggling and offer support, offer members a sense of hope and purpose. These effects have also been noted between those who report identifying with having shared experiences in a one-to-one setting (White et al., 2020). This facilitation of hope and hearing other experiences is consistent with existing HVG literature (Longden et al., 2018; Oakland and Berry, 2015; Schaefer et al., 2021) and appears to lead to new and explorative ways of coping and living with voices (Dos Santos and Beavan, 2015).

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Participants share how an acceptance of all beliefs and perspectives creates a safer space. This may reduce the likelihood of epistemic injustice (Harris et al., 2022). Epistemic injustice refers to neglecting another's beliefs, expertise or abilities due to belonging to a marginalised group. Participants in this project experienced mainstream services as expert-led, uncollaborative and often dismissive of their own expertise and perceptions. A lack of choice within mainstream services can be experienced as traumatising and drives people away from wanting to access services. This goes beyond a lack of choice and begins to question the act of cohesion or secrecy in which voice hearers are done to against their will and without their consent, such as receiving ECT as Oscar describes. Research has found that voice-hearing continues to be associated with negative stereotypes and attitudes in society (Huggett et al., 2018), which has significant impact on both emotional wellbeing and recovery (Burke et al., 2016). This is affirmed through the findings of this project. It should be noted that some research finds that service users may be more inclined to seek voice cessation than professionals (Longden et al., 2024). Whilst this may relate to self-stigma and the internalisation of dominant narratives around hearing voices being a negative experience to be suppressed, it suggests that choice may include voice hearers being entitled to want voices to stop, but for other narratives to be held equally too.

Diagnoses or conceptualisations of mental health difficulties being given to voice hearers prescriptively without collaboration can lead to a 'looping effect' in which a voice hearer's perception of themselves, how they are perceived by others and how much flexibility or potential there is for change is impacted (Hacking, 2007). Michael spoke to how his diagnosis of 'chronic' schizophrenia inferred to him a long-lasting illness unlikely to change, affecting his sense autonomy over change. Both Daniel's and Oscars diagnosis led to viewing themselves are 'riskier' and more dangerous. Oscar describes having to fight for his diagnosis to align with his understanding of his experiences. It is known that some psychiatric diagnoses are more stigmatising than others due to externalised stigma and societal views being internalised, limiting hope (Zhang et al., 2017). A flexibility and choice as to how voices are understood for each individual offers alternative frames of reference that move away from highly stigmatised concepts and acknowledge important facets of individuals lives and cultures such as religion, contributing to the social constructions of mental illness (Bradley, 2023) on the basis of empowered narratives of experiencers that are normalising. Some voice hearers may want to receive information and advice from 'experts' as Michael shares but also want a say in what is done with this information, as reported by Elen. HVGs are experienced as safe spaces in which voice hearers can choose their own discourse around their experiences and feel like they have autonomy and volition within the group.

It is clear that autonomy and choice are important for voice hearers. Being supported and worked with collaboratively to choose how they conceptualise and develop narratives about their experiences and how they are supported is key. Community psychology principles (BPS, 2023) actively strive towards such ways of working, including active efforts for those with lived experience to advocate for what they want and need, and how they want their experiences to be talked about and understood. Furthermore, this field challenges the dominance of individualised models of psychological adjustment and intervention, instead striving to meet people where they are at and within their own contexts. These principles show close alignment with the findings of this project and the principles outlined by the HVN. Therefore, this project's findings support the expansion and usefulness of Community Psychology. Community psychology also works to support communities to advocate for their own narratives and understandings (Banks et al., 2017), drawing parallels with voice hearers wanting to challenge dominant societal beliefs about voice hearing in favour of their own. Furthermore, these community HVGs are embedded within their communities, utilising community spaces and do not require a referral or other commonly seen practices within mainstream mental health services. An awareness of how members of HVGs have felt traumatised by a lack of voice within mental health services can guide and refine how trauma informed practice is understood and where it may need to focus to reduce experiences of re-traumatisation within services. Its key principles of "safety, trust, choice, collaboration, empowerment and cultural consideration" (Office for Health Improvement & Disparities, 2022) appear to move towards toward more alignment with how community HVGs are positively experienced.

### What do participants find less helpful about Hearing Voices Groups?

Whilst participants find groups beneficial, perhaps indicated by their ongoing attendance, many factors that are viewed positively can also have polarising effects dependent on context and individual preference. Firstly, before ever attending a group, members experience uncertainty and apprehension as to what to expect, with information about HVGs feeling difficult to access for new members. Potential new members rely heavily on mental health professionals and word of mouth. People cannot attend groups if they do not know about them, nor can they fully prepare or know what to expect without being provided clear information. The main way members hear about the groups appears to be through healthcare professionals, who often may be uncertain as to the value of HVGs, or do not have a full understanding of what groups entail, as found by McCluskey et al. (2022) and Renaud et al. (2024).

Participants shared experiencing stigma and discrimination as a result of hearing voices, known to increase the likelihood of withdrawal from society (Vilhauer et al., 2017). Their voices may also make them distrustful of others (Woods et al., 2015), and experience a lesser self-esteem, self-worth and confidence. When new members attend groups for the first time, they carry with them these past experiences and expectations of themselves and of others. The open and warm nature of groups can therefore be experienced as unhelpful and somewhat threatening and overwhelming. Members past experiences appear to mediate how they experience the first meeting(s), with some members finding it difficult hearing others speak so openly about voices, with other members finding the informal and open nature of the group unnerving and uncomfortable.

Whilst largely positive, strongly relating to and connecting with others can lead to a sense of a responsibility for the wellbeing of others, or that members begin to feel less validated or cared for in comparison to others, a potential limitation of peer support previously noted by Helgeson and Gottieb (2000). If someone does not return to groups, members may experience worry and uncertainty, or even a sense of loss of relationships. Hearing others' stories may also lead to re-traumatisation or a sense of guilt if they perceive others to have it 'worse' than they do. Relationally, difficulties may also

arise when different perspectives or ideas go against your own. The groups acceptance of all perspectives equally is viewed as beneficial and a key aspect of the group. However, for Elen, hearing others almost promoting substance use when she had struggled with this can feel conflicting. Members have to find ways of holding multiple perspectives and allow others to make their own sense of things whilst tentatively offering alternatives which is not always easy. Whilst problematic views may be expressed, members appear to manage this as a collective through open communication and recognising their views as their own. This can nurture interpersonal learning through navigating different views and feedback from other members (Yalom and Lesczc, 2005), but may feel too difficult for some members, affecting their experience of attendance (Hendry, 2011).

Whilst groups advertised on the HVN website are assumed to structure themselves through the HVN principles and ethos, groups may slightly differ. This can lead to inconsistencies in experiences that in some ways, may be unavoidable, such as the group being a product of its members. In turn, this may affect how aligned members feel to one another, and how many of the 'ingredients' of therapeutic groups spaces are present (Yalom and Lesczc, 2005). Other factors, such as how closely aligned the facilitator or members are with HVN principles can significantly impact members desire to continue attending. Oscar spoke of experiencing groups in which religious perspectives felt more privileged within the group, at the cost of other ideas and views. There were also issues with confidentiality, leading to Oscar seeking out a different group. For Elen, she reflected on structural issues within the group she attended in which there were often more 'professionals' than voice hearers, which she felt affected the entire experience of the group. Whilst group differences cannot be fully isolated, these two shared experiences appear to demonstrate a deviation from how the HVN set out their principles and how HVGs are intended to be facilitated and structured.

# How might participants' relationship with voices change from attending Hearing Voices Groups?

All but one of the participants in this project spoke specifically about a changing relationship between themselves and their voices. It is well established that those who hear voices learn to keep them a secret, becoming increasingly isolated and withdrawn due to shame and fear (Volpato et al., 2022). This project captures the often-extreme steps voice hearers will take in attempt to rid themselves of voices, including self-harm and withdrawing from others, perpetuated by both the distress of the voices and internalised fears and stigma driven by societal narratives. Mental Health Services often view a reduction or absence of voices or other experiences as an indication of 'recovery' (Eisenstadt et al., 2012), perhaps inadvertently perpetuating narratives around not accepting or seeking to understand voices, indicated through the offered interventions. For some members, an acceptance of voices means an acceptance of not being trusted or able to work in certain types of employment. Self-acceptance is a key benefit of peer-support groups more broadly (Davis et al., 2014; Klarare et al., 2022). HVGs encourage and facilitate an acceptance of voices – something not to be hidden but rather embraced and celebrated. As Oscar describes, members may wear their voices like badges, proud of their existence. Finding yourself amongst others who accept their voices allows new members to lean toward acceptance too – something more difficult to do within wider society.

Acceptance not only helps members turn toward and better understand their voices but reduces internalised stigma and factors that may promote withdrawal and isolation, such as fear of responding to voices in public or others finding out about their experiences. The group's shared identity of 'voice hearers' appears to facilitate a safety in sharing without fear of upsetting or shocking others, something observed in peer-support in other contexts (Hardy et al., 2019). A sense of shame is almost lifted as members accept their experiences for what they are and newer more positive narratives about their voices existence are given space to develop. This holds some parallel to movements such as Mad in the UK (https://www.madintheuk.com) who seek to reclaim narratives around mental health including reclamation of different phrases and narratives.

HVGs encourage a process in which members turn toward their voices to develop relationships and understanding. This is often experienced as a significant shift in how voices are approached in comparison to other narratives outside of the group and demonstrates how stigma and dominant medical narratives can be internalised. Relational frameworks of voice hearing have demonstrated that active engagement with an individuals' experiences to understand their meaning and purpose can promote positive and more harmonious relationships (Jackson et al., 2011), often a feature noted in those who hear fewer distressing voices (Moseley et al., 2022). A culture of acceptance and empowerment within the group appears to lead to experiences being appraised more positively – viewed as offering important and helpful messages that aim to protect the individual. As members view their voices as more benevolent or less powerful, more positive and adaptive means of living with the voices may emerge (Tsang et al., 2021), such as negotiating boundaries and learning about triggers or things the voices dislike as reported by participants. Developing relationships with voices and feeling empowered to challenge and establish boundaries in a respectful manner can provide the voice hearer with an increased sense of power, and therefore voices may be experienced as more flexible and less powerful, perceiving the voices as less dominant, consistent with previous findings by Deamer and Hayward (2018). An increased understanding of voices leading to a shift relationally with voices and having more control is consistent with previous studies of HVGs (Payne et al., 2017; Rácz et al., 2017; Ruddle et al., 2014).

Studies have captured how cultural influences can affect how voices are appraised, and therefore affect how voices are experienced (Jones et al., 2021). It may be that HVGs facilitate or replicate how different cultures understand and respond to voices, for example by supporting acceptance and appraising voices positively leading to less voice-related distress (Luhrmann et al. 2015). It is widely accepted that relationships with voices are subject to variation and change (Toh et al., 2020) and attending HVGs which promote and support acceptance of voices and building meaningful relationships leads to a greater ability to live with voices, improved self-confidence in navigating these relationships, and a greater awareness and reappraisal of the voices. For example, seeing their

distress or nastiness as trying to look out for the voice hearer as reported in this project. Emerging theories of voice hearing from Allison (2024) propose a tripartite relationship which highlight the importance of the relationship(s) between voice, voice hearer and mental health professionals (or others). This framework may offer insight into the importance of accepting and interacting with voices as a voice hearer, but also the role of social connection with other voice hearers, and other voice hearers also connecting with others' voices as is facilitated within HVGs. This also highlights the importance of how professionals relate to voices, and the impact of professionals feeling their expertise are insufficient to support those struggling with voices and therefore moving away from exploring such experiences (Allison, 2024). Allison proposes that the interpersonal dynamics between voices, voice hearers and professionals needs to be improved through more collaboration and sense making, something that appears more thought of within HVGs. Opportunity to speak about and make sense of experiences leads to improved relationships with voices and leads to voices being appraised more positively, consistent with previous findings (Rácz et al., 2017; Ruddle et al., 2014), thus enhancing these relationships.

For many attendees, this shift in how voices are related to leads to a more fulfilled life living alongside voices and viewing their voices as part of them. Many members spent years finding ways to rid themselves of voices but now share how they would not want to lose the voices even given the opportunity as they have become an integral part of their identity.

# Key findings:

- HVGs show consistent benefits and limitations as presented in other peer-support contexts and demonstrate a strong alignment with Yalom's therapeutic factors model of groups (Yalom and Lesczc, 2005).
- HVGs may fulfil needs unmet by mainstream services and therefore is a valuable alternative or addition to existing support for voice hearers, supporting the notion of a plurality of approaches to voice hearing.
- Meaningful connections with others and reintegration into society can be supported through attending HVGs and having opportunity to relate to others in a safe environment.
- Relational factors with self, others and voices can be explored and changed through attendance and appear to play a key role in levels of distress and ability to live with voices and has implications for how professionals work with voices and their confidence to do so.
- Groups promote a turning toward, accepting and understanding voice hearing experiences.
   This appears to lead to more possibilities for living with voices.
- HVGs can provide a safe space in which any and all understandings of voice hearing can be expressed and explored, in turn reducing stigma and promoting autonomy and choice as to how voice hearers work with and live with their voices.
- Professionals play an important role in the advertisement of HVGs and disseminating information and supporting individuals to attending groups in the first instance. However this depends on the culture and ethos of services aligning and believing in HVGs.
- Whilst long term members largely value the groups, barriers do exist in the form of adjusting to often radically different ways of relating that go against past experiences and narratives and navigating individual values and perspectives within a group of diverse perspectives.
- Findings support the need for a cultural shift in how services work with individuals, pointing towards more trauma-informed and relational ways of working with and conceptualising mental health difficulties.

Whilst HVGs do not offer a 'preventative' intervention that can tackle the onset of distressing experiences in relation to trauma, adverse events, biological influences or other proposed theories of voice hearing, they appear to be able to offer a unique space in which many of the known mediating factors of how voices are experienced and the impact they have on one's life can be altered for the better, whether that be moving toward a reintegration of society, connecting with others, feeling heard for the first time or making sense of your experiences. The findings of this study offer potential implications both within research and clinically.

#### **Study strengths**

From the very beginning, this project was developed with the ideas and perspectives of those who work closely with voice hearers, who hear voices, and who facilitate HVGs, building upon the limitations of Hendry (2011). It offers an up-to-date synthesis of HVG literature post-covid and integrates more contemporary research within both the introduction and discussion. It offers both findings that provide further evidence for past projects exploring the experience of HVGs and their potential mechanisms of change, in addition to offering novel findings surrounding not only how relationships with voices change, but also the changes in how members relate to themselves and society more broadly.

The interview schedule was developed through reviewing up-to-date literature by Allison (2024) who captures the importance of the relationship(s) between voice, voice hearer and mental health professionals (or others). This project fulfils a gap in the literature that considers the multitude of relationships that exist for voice hearers and how the experiences of mainstream services may affect and interact with this. Furthermore, this project focussed specifically on community HVGs to allow results to reflect the experiences of those who attended groups that closely aligned with HVN principles as opposed to sitting under NHS or private services where referral criteria for example may represent a deviation from the principles of HVGs.

## Collaboration with those with lived experience

Including the voices of those with lived experiences led to meaningful changes surrounding the design and implementation of this project as detailed in the methodology. Having the perspectives of those who have both facilitated groups and been part of similar research helped this project become more accessible and ensure the language reflected that used and understood by those who hear voices. Developing relationships with group facilitators, and their support in recruitment intended to facilitate more members to participate in this project through receiving information from an unbiased and trusted individual. As captured within the methodology, feedback from consultancy with those with lived experience and opportunities to co-produce resources including the interview schedule led to meaningful changes and limited the potential for my own views and perspectives to bias the questions. The findings of this study therefore have relevance and are of interest to those within research, clinical spaces, and those who hear voices themselves as they helped shape the direction of the project.

The project also overcomes limitations outlined by Hendry (2011) who reflected on the risks of being too integrated into HVGs through attendance in the process of recruitment. I attended one HVG in person to disseminate information about the project, but actively chose not to repeatedly attend groups after this. This was to reduce likelihood of participants censoring what was brought to interview as a result of an existing relationship.

# Making space for the experiences of those with lived experience

This project focusses specifically on understanding the experiences and views of those with experiences of voice hearing, bridging a gap between research and clinical practice. The findings of this project provide direct input from those who have often experienced various aspects of services and interventions, but at times have felt unheard.

## Validity and transparency

As detailed within the methodology, several creditability checks were established early on in this project and were carried out throughout. These included but were not limited to:

- Ongoing reflexivity of the researcher to capture my own assumptions.
- Providing transparency in my interpretations through providing quotes to ensure a grounding in the data.

Furthermore, effort was made to build rapport with participants and minimise any risks or potential negative implications of this project, as seen in the ethical considerations section. This study has strived to capture the language used by voice hearers and to acknowledge when such terminology has not been used to best reflect the available and relevant literature.

## Homogeneity of groups

This project sought to explore the experience of members who attend HVGs. There are over 180 HVGs in the United Kingdom (Branitsky et al., 2020), each with their own individual members, who meet in a variety of spaces. Establishing homogeneity for the purpose of research relies on the assumption that each HVG operates strictly within the HVN ethos and principles and therefore, each participant would have similar experiences with respects to how the group is structured and the fundamental principles held, regardless which group they attend. Whilst this was confirmed as far as feasible through both groups being advertised on the Hearing Voices Network website and establishing their commitment to the principles of the network. Limitations of homogeneity will be discussed later. Some differences between recruited groups were known, such as one group has been established for many more years than the other and has kept a consistent main facilitator over this time. Whilst the group participants attended were made anonymous at the point of writing results, there was no notable differences or unique themes amongst the two groups that required consideration.

# Highlighting the importance of relational processes

This project provides results that build upon existing literature, specifically in capturing the importance of both relationships and relational processes within HVGs. Parallel processes were noted between the acceptance of voices, a greater felt acceptance of self, and a greater felt sense of acceptance by others. This led to changes in how members related to their voices, self and others, allowing for new boundaries to be set and a greater sense of control and confidence in interacting with their experiences and other people. This supports research by Allison (2024) who considers the importance of relations between professional, voice hearer, and voice. These findings also support the continual research and evaluations of therapeutic interventions such as Avatar Therapy (Ward et al., 2022) and Relating Therapy (Hayward et al., 2017). These interventions focus more explicitly on the relationships between voice and voice hearer. I will go on to discuss how these findings may influence if and how HVGs principles may be integrated within mainstream services and the implications for future research.

#### **Study limitations**

## Sample bias

Given the aims of this project, only those who attended HVGs were eligible to participate. Convenience sampling was used, allowing for to potential sampling bias. Participants were more likely to sit towards having more favourable perspectives and experiences of groups. Whilst facilitators disseminating information about the project can be viewed as a strength, it may also have influenced how safe those with more critical views or opinions felt to share. Information potentially identifying which group participants attended were removed to encourage transparency at interview. Whilst shared experienced included more critical views of HVGs, hearing the voices of those who no longer attend groups would likely offer a more balanced perspective of how these spaces are experienced, or better highlight barriers to attendance.

## *Homogeneity of the individual experience*

This project intentionally sought to explore the individual experience of attending HVGs and how each member made sense of these experiences. Members brings with them varied perspectives and experiences, influencing how they made sense of their attendance. Whilst these differences formed an important part of this project, it should be acknowledged that this limits homogeneity between participants on the level of past experiences. Whilst all participants in this project had taken antipsychotic medication and used mainstream mental health services, their experience of each of these interventions varied greatly. However, homogeneity is established through the consistent structure and ethos of both HVGs. HVGs are a product of their members and what each member brings can guide the conversation. Factors such as how many attendees there are, the views of each member and the balance of professionals within the group can all influence and affect how members experience the group.

All participants identified as White British. Whilst there is limited information regarding individual characteristics and HVGs it seems reasonable to propose that a more diverse sample population may have yielded differing experiences of HVGs in addition to different perspectives on voice hearing itself. There is a known issue within research more broadly in which there is a lack of representation of those from the Global Majority. Also, cultural understandings of voices are known to have some influence on how distressing voices may be in addition to how they are understood. A more diverse sample may bring about different benefits or difficulties in HVGs. The diversity of participants may have been limited by one inclusion criteria being a need to speak fluent English. This criterion was based on IPA recommendations to enhance my ability to interpret what was brought to interview, but also results in the voices of other individuals who may attend groups and feel less confident in English as a primary language being unheard. There is an abundance of literature that reflects the inequalities and barriers of People of the Global Majority (PoGM) experience in trying to access mainstream mental health services (Ajayi Sotubo, 2021; Harwood et al., 2023).

Purposive sampling may have proven a feasible alternative method of recruitment, with a focus on recruiting those who attend groups infrequently, or to identify POGM to participate in this project for example. Whilst this may overcome limitations around sampling bias, it still leaves the potential for such biases by limiting who is eligible for participation and would rely on my own judgement of which demographics or criteria to privilege at the point of recruitment. Recruiting from a wider pool of HVGs would also increase the likelihood of a more diverse sample but may still yield similar results.

# No expert by experience within the research team

Whilst efforts were made to collaborate and consult with a variety of individuals with lived experience of voice hearing, no member of the core research team identified as having direct lived experience. In recruiting a voice hearer, this project would have no doubt had further insights and reflections that would enhance the research throughout. As the literature indicates, there is an importance and great value of experiential knowledge and expertise that was not present within the research team. The involvement of those with lived experience from the beginning of this project through until the end, including being involved in the analysis process would have provided useful insights and reflections that may have guided the project in different directions or led to potentially different outcomes.

## Study design

This study sought to explore the experience of those attending community HVGs with criteria requiring members to have attended at least twice in the past 6 months. This ensured participants had recent experiences upon which to explore. However, some participants had attended HVGs for many years, with one participant having attended several different groups. Therefore, the study design at times relied on retrospective accounts of attendance. For those who had heard voices for many years, and had experienced lots of different support and services, their recollection of how they have experienced the groups presented as difficult to recall, specifically when thinking about how they first heard of or attended the groups.

Whilst credibility checks were in place, and a reflexive log was kept, it is accepted within IPA that the researchers' subjective views, perceptions and experiences may influence all aspects of the study. My multiple roles as a member of the public, a clinical psychologist and a researcher have influenced how I understand the experiences of those who attend HVGs and subsequently how I perceive how this project may fit within the wider literature.

## **Clinical implications**

## Research

The findings of this project suggest that the needs and experience of those who hear voices are diverse, posing an ongoing challenge for both HVGs and mainstream mental health services. Findings support a need for a plurality of approaches for working with voices and voice hearers that are adaptable and flexible, meeting the diverse ways in which voices are experienced, with a distinct focus on relational processes and factors. There is also an importance of offering opportunity to explore and change relationships with voices through meaningful dialogue. This provides support for the ongoing research into newer dialogical and relational approaches to working with voices, such as Avatar therapy (Ward et al., 2022) and the Talking with Voices approach (Longden et al., 2021) in a bid to offer more ways of working with voices and voice hearers. The findings of this project also support the use of outcome measures or measures of efficacy that go beyond symptom reduction only and include measures that capture for example the relationship with professionals (such as the Session Rating Scale – Duncan et al., 2003) or measures of hope. The lack of diversity within the sample of participants, particularly PoGM, demonstrates an ongoing limitation of research more broadly and its ability to offer equitable opportunity and accessibility for the voices of some to go unheard and be illreflected within the literature. Additionally, research scarcely captures the perspectives of those who have chosen to opt out of mainstream support and may be distrusting of research and clinical practices more generally. Whilst methodologically challenging, this project highlights a need to continue to

pursue the perspectives of those who may offer a more critical perspective on a variety of research areas including HVGs.

## Mental Health Services

Mental health services provide an important role in supporting those who hear distressing voices, amongst other issues. Findings from this project demonstrate both experiences of trusting and meaningful relationships being developed, but also negative experiences of services. These broadly capture how services may perpetuate stigma, isolation, withdrawal, distress and re(traumatisation) whether indirectly or directly, leaving some to feel unheard and untrusting of services (Grossman et al., 2021). HVGs are often valued for offering opportunity for more perspectives, autonomy and freedom to express experiences, contrasting how mainstream services may be experienced. Experiences of services holding rigid frameworks of what voices are and are not can perpetuate feeling isolated and othered, and lead to further withdrawal. Conceptualisations of voice hearing such as through a diagnostic lens are at times useful and welcomed by voice hearers, but these diagnoses or understandings need to be flexible and collaboratively developed. Consideration must be given as to what understandings or conceptualisations are more widely accepted in western society and privileged over others, such as understanding voices as a symptom of a mental disorder as opposed to a religious experience. Space should be made within mainstream services and public health more generally to demonstrate an openness and awareness of multiple narratives and perspectives of voice hearing and other mental health experiences.

The findings also have implications as to how important the perspectives of mental health professionals are. Professionals are known to generally have an awareness of groups, but often are unsure as to what to expect from the groups (Renaud et al. 2024), meaning voice hearers may not have equitable opportunity to access this support. Renaud et al. (2024) report that professionals may not acknowledge the HVGs are a viable addition or alternative even though it may not match their expectations or frameworks in which they work. Consideration should be given as to how

experiences, in addition to their confidence to work flexibly and consider alternative ways of working such as supporting individuals to HVGs. Furthermore, the power and influence of mental health professionals and how their personal views and perspectives as 'experts' are often privileged above those of the voice hearer must be held in mind both clinically and within research.

These findings highlight possible directions in which mental health services may choose to move. For example, the recovery model of psychosis (Leonhardt et al. 2020) moves towards working with the experiences of voice hearers within their own contexts as opposed to predefining ones experiences through whichever dominant lens exists. Similarly, there is increasing focus within the NHS to ensure a Trauma Informed approach operates within services and practice more broadly of which shows some parallels with what participants find helpful about HVGs, such as promoting safety and choice within mental health services, across all interactions and actively considering the influence and importance of cultural contexts (Office for Health Improvement & Disparities, 2022). Such approaches hold parallels with Open Dialogue of which adopts a social networks perspective, leaning into the importance of social connections, and seeks to provide flexibility in how experiences are understood and supported, and involving service users in all decision making (Lakeman, 2014)

Thought must be given, as Schaefer et al. (2021) propose, as to how HVGs can co-exist with mainstream services, or how the principles of the HVN can be adopted or influence existing practice within mainstream services to address these issues. Their usefulness in this capacity should not be diminished and mental health services can potentially learn from both the negative experiences of voice hearers in mainstream support and the positive experiences of HVGs. This project also supports the use of peer-support and peer-support workers, providing evidence for the ongoing development of peer-support roles and a shift towards more recovery focussed approaches within services broadly.

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## Hearing Voices Groups

Whilst groups are generally appraised positively by those who attend, there are areas for potential improvement. The findings of this project suggest that HVGs are poorly advertised and there is a reliance on word of mouth or knowledge from professionals. The HVN may wish to think about how they advertise their spaces, including more collaboration with mainstream services to get the word out and offer clearer information as to what the groups are and are not. Developing relationships or channels of communication with mainstream services and/or other organisations and community spaces may increase attendance and increase awareness of the HVN principles and approach towards those who hear voices. HVGs are felt most beneficial when multiple perspectives can be heard and held simultaneously, even if these opposing perspectives can feel difficult and jarring. However, there is potential for some groups to hold less tightly onto the principles of the HVN. It may be that how HVGs are regulated and deemed in alignment with the principles of the network should be reviewed to prevent members potentially being retraumatised or experiencing groups negatively as was found by Hendry (2011).

## **Implications for future research**

As aforementioned, future research should focus on seeking the experiences and perspectives of those who do not attend HVGs, and also those commonly underrepresented within the literature, such as PoGM. This also highlights a need for a greater understanding of the barriers of attending HVGs. This may help to address potential biases in experiences as a result of methodological issues around recruitment. The works of Hendry (2011) and this project have captured the varied responses and resistances of voices toward attending the group. Future research should begin to explore the responses and perspectives of voices more specifically, whether this be regarding HVGs or other forms of support.

One of the HVGs in which participants were recruited from in this project had a facilitator who also had lived experience of mental health services. There is no immediately available data exploring the experience of facilitating HVGs. Research exploring the experience of peer-support workers and/or facilitators of HVGs would also offer an interesting and valuable perspective as to what is experienced within groups and build upon the findings of this study. For example, how to facilitators experience facilitating multiple perspectives with opposing views in meetings.

There should be ongoing evaluation of professional attitudes towards HVGs and the implementation of education or training into widening perspectives around voice hearing and supporting voice hearers, building upon the works of Renaud et al. (2024). Professionals play a key role in sharing information about HVGs and supporting voice hearers to meetings should they want to attend. This project focussed on the experience of those attending community HVGs.

There are emerging studies exploring the feasibility and usefulness of HVGs within other contexts, such as inpatient settings (McManus et al., 2023), and for those with an identified learning disability (Roche-Morris et al., 2019). Expanding research into different clinical and non-clinical contexts only serves to contribute further to the existing evidence base for the use of HVGs and may lead to appropriate adaptations that further improve accessibility and applicability to groups. This includes the facilitation of HVGs online, something that became more commonplace during the Covid-19 pandemic. Branisky et al. (2024) offer one such example highlighting differences in group cohesion and how connections are made when groups are facilitated virtually. This project recruited from face-to-face attendance which brought with it its own barriers.

There is also value in seeking out the applicability of HVG principles and features for other experiences, such as paranoia or visions. A recent study by Nguyen et al. (2021) notes similar findings to this project regarding a peer-support group within EIP services more generally. This group does not necessarily focus on voice hearing specifically but the broader ranges of experiences and beliefs that exist within EIP services. Peer-support groups do exist through the National Paranoia Network (https://nationalparanoianetwork.org/self-help-groups/), however there is little research into this area.

Future research synthesising both qualitative and quantitative methodologies, with their research questions being guided by the findings of this project would help to identify aspects of HVGs that work well and understand areas that do not. This would offer further insights as to how policy makers may choose to learn from or assimilate HVGs and their founding principles into mainstream services, how services could collaborate with these groups more or whether a distinct separation between community HVGs and mainstream mental health services is most appropriate.

# **Closing reflections**

I set out to explore the experience of attending community Hearing Voices Groups, driven not only by the existing gap within the literature but also a history of working with those who hear voices and observing the varied and complex journeys these individuals often embark upon. I assumed that much of this project to focus on the experience of voice hearing, both good and bad and that members would largely be those who had abandoned mainstream mental health services – based on my experience of working with and alongside those who hear voices.

Whilst my assumptions were in part correct, what unfolded was a vast array of experiences of voice hearing, HVGs and other support. Members of the groups truly embody the ethos of the HVG, including a respect and – for some – acceptance of more medicalised understanding of voices. Groups are experienced as a place for everyone. I was struck by the perceived benefits and values of HVGs and how many of these factors did not relate to voice hearing per se. Connecting with others and having opportunities to grow and develop as a person outside of the identity of voice hearer were both areas that I had not fully considered nor appreciated going into this project. I still strongly believe that more power and consultancy is required with those with lived experiences in any areas of mental or physical health, and that their views should be translated into meaningful action and change within existing systems. I feel incredibly humbled from my experience of completing this project and it serves as a reminder to myself that my own values and perspectives are important, but ultimately each individual experience of hearing voices and what they want and need will vastly differ from person to person and that making space to consider all identities of a voice hearer, including their experiences, relationships, hobbies, hopes etc., is important.

## **Concluding statement**

Community HVGs offer a space that may otherwise be inaccessible in mainstream mental health services within the United Kingdom. They can be experienced as quite radical initially, given the very different stance and ethos they maintain in comparison to more dominant and commonly experienced reaction to voice hearing within society more broadly. These groups can be experienced as positive spaces in which members develop more positive relationships with themselves, others and their voices and promote opportunities to make sense of and acknowledge each individual context each member brings without fear of judgement or repercussion. In this context, members can essentially buy into the HVG principles and endorse them both within and outside of the group. HVGs have potential to be both collaborative with and offer an alternative to the standard services/support for those who hear voices both distressing and not. Its integration and adaptation into other areas relies not only on a widening of perspectives within mainstream services but also a shift in culture and perspectives within mental health professionals, linked/integrated with ongoing exploratory and evaluative research. This may facilitate a move away from the identity of a passive 'patient' toward a more autonomous and valued member of society.

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## Appendices

#### Appendix A – Ethical approval



Medicine and Health Univ Ethics Review MREC 22-076 - Study Approval Confirmation To: Ashley Watson, Cc: Tracey Smith, Alastair Cardno

23 June 2023 at 11:54

Details

Dear Ashley

MREC 22-076 – An Interpretative Phenomenological study exploring the experience of attending a community Hearing Voices Group

NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.

We are pleased to inform you that your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the documentation received at date of this email.

Please retain this email as evidence of approval in your study file.

Please notify the committee if you intend to make any amendments to the research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see <a href="https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/">https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/</a> or contact the Research Ethics & Governance Administrator for further information <a href="mailto:fmtuniethics@leeds.ac.uk">fmtuniethics@leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/</a> or contact the Research Ethics & Governance Administrator for further information <a href="mailto:fmtuniethics@leeds.ac.uk">fmtuniethics@leeds.ac.uk</a> if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes Sou Chung *On behalf of Dr Naomi Quinton, CHAIR, SoMREC* 

## Appendix B – Recruitment poster

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## A study exploring the experience of attending a Hearing Voices Group



From Stephen Frasers film, 'What it feels like'.

Have you attended a Hearing Voices Group at least twice in the past 6 months?

Are you interested in taking part in an interview, exploring your experiences of attending a Hearing Voices Group?

My name is Ash, and I am a trainee clinical psychologist. I am really interested in better understanding how people experience Hearing Voices Groups and would like to hear your perspectives. I don't have direct experience of voice hearing, and think it is important that we make space to hear from those who do.

If this sounds like something you are interested in, you can ask your Hearing Voices Group facilitator for an information sheet or email me directly at <u>umawa@leeds.ac.uk</u> to chat about the project further.

Thankyou!

#### Appendix C– Information sheet

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#### Participant Information Sheet

#### Research project title

An Interpretative Phenomenological study exploring the experience of attending a community Hearing Voices Group

Lead Researcher Ashley Watson (Psychologist in Clinical Training)

Contact information Umawa@leeds.ac.uk

#### Supervisor information

Dr Tracey Smith (T.E.Smith@leeds.ac.uk) Clinical Psychology, Level 10, Worsley Building, University of Leeds, Clarendon Way, LS2 9NL

Dr Alastair Cardno, (a.g.cardno@leeds.ac.uk).

Clinical Psychology, Level 10, Worsley Building, University of Leeds, Clarendon Way, LS2 9NL

#### Introduction

This is to invite you to take part in a research project that seeks to explore the experience of people attending Hearing Voices Groups. It is important for you to understand why the research is being done and what it involves. Please take time to read the following information carefully and discuss it with others if helpful. Please ask if there is anything that feels unclear, or if you would like more information, before deciding if you want to take part in this project.

This project is being carried out by myself, a Psychologist in Clinical Training who is independent of your Hearing Voices Group. This project has received ethical approval by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (DClinREC ref number XXXX). This study is funded through Leeds University as part of a Doctorate in Clinical Psychology programme.

#### What is the purpose of the project?

How we think about and understand voice hearing has changed a lot in recent years, and more importance is given to learning from those who hear voices.

Research has found that peer support groups, like Hearing Voices Groups, can be a helpful alternative, or addition to support offered in mainstream mental health services (like medicine, or talking therapies). These groups are becoming more popular around the world too. However, we want to better understand how people experience these groups to help develop our understanding of what is helpful and unhelpful about attending, and how relationships with voices and others might change as a result.

This research project aims to explore the experience of people attending Hearing Voices Groups, adding to existing research in this area. It is hoped that gaining more perspectives of these groups can help develop our understanding of why people may attend. It also helps us to think about how to shape future services or support for people who hear voices to best

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meet their needs and hopes. Lastly, it might help us to better understand the changes that Hearing Voices Groups might or might not bring about for voice hearers.

#### Why have I been chosen?

You have been chosen to participate in this project as you are attending a Hearing Voices Group. You do not need to have, or identify with any specific diagnosis, nor make sense of their experiences as voice hearing specifically. There is no requirement for you to be actively hearing voices, be receiving any additional support, or taking medication – although you may be asked about these things during the interview.

To be eligible to take part, there are a few things required:

- You are over the age of 18.
- You consider yourself fluent in spoken English, as the interview will be in spoken English.
- · You have direct experience of hearing voices or other related experiences.
- You have attended a hearing voices group at least twice in the past 6 months, so that you have recent experiences in mind.

#### Do I have to take part?

It is your choice as to whether you choose to take part in this study or not – participation is completely voluntary.

If you do wish to take part, you will be given this information sheet to keep, and asked to email the lead researcher (Ash) to arrange a time to meet, ask any further questions and complete a consent form. Even once you have provided consent, you can still withdraw at any time up until two weeks after the interview has been completed. You do not have to give a reason for withdrawal, and withdrawing will not affect any payment or rewards.

#### What do I have to do? What will happen to me if I take part?

If you wish to partake in the study, you will be asked to attend an interview, either by video (online) or in person (at the same venue where you attend the Hearing Voices Group). Travel costs can be reimbursed, and you can choose which option is best for you.

The interview will involve me asking you some questions about your experience of attending hearing voices groups. The interview should last up to around 90 minutes. Our conversation will be recorded with a digital audio device. After the interview, the recordings will be transcribed (typed up) so key themes can be identified across each interview, and across all interviews. A report will eventually be written, which can be made available to you if you wish.

You can bring someone with you to the interview if this feels more comfortable, but the focus will remain on your personal experiences of attending a Hearing Voices Group.

#### What are the possible disadvantages and risks of taking part?

It is not expected that partaking in the study will cause any distress or discomfort. Sometimes, speaking about past and even present experiences might feel difficult for some

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people, and some of the questions asked relate to your experiences. There are several things in place to reduce the likelihood of experiencing distress, and in supporting you if this does happen:

- Please feel free to bring someone with you for support.
- At interview, we can take a short break if helpful.
- After the interview, time can be spent checking in on how you are feeling.
- You do not have to answer any question(s) that you do not wish to.
- · You can end the interview at any time.

If at interview, there are concerns regarding you feeling able to keep yourself or others safe, this will be shared with the Hearing Voices Group facilitator as a matter of keeping everyone safe. This is important as your wellbeing is of the utmost importance.

#### What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will help to develop our understanding of Hearing Voices Groups. Some people also find it beneficial to speak with others about their experiences. You will be paid £15 in vouchers for your time and participation in the study.

#### What will happen to my personal information?

All contact information collected (e.g. name, email address, telephone number) during the research process will be kept strictly confidential and will be stored separately and securely from the research data and the results. Your name will not be linked to the data once transcription starts four weeks after the interview. All identifiable information will be stored securely on university approved online servers. Relevant sections of the data collected during the study may be looked at by individuals from the University of Leeds or from regulatory authorities to check the quality of the research. Data will be stored for up to three years.



#### What will happen to the results of the research project?

Audio recordings will be made using a digital audio device, and then transcribed. Several steps are taken to ensure personal information is confidential:

At the point of transcription, you will be given a pseudonym (false name).

- There will be no information kept that indicates which Hearing Voices Group you attend, to allow you to speak more freely about your experiences.
- Any reference to specific locations, services or individuals will be anonymised or removed.
- All electronic data will be stored on a password protected computer, on a secure, university approved server.

Some background information may be used to develop a 'pen portrait', to offer context around your experiences of attending a Hearing Voices Group. This is intended to capture more accurately your experiences and story. Information such as religious beliefs, experience of services, and how long you have attended Hearing Voices Groups for may be included. Additionally, the final research report will use direct quotations from interviews. In addition to the above steps, several further will be taken to maintain confidentiality when developing pen portraits.

- Information such as specific age will not be used. Instead, you will fall within an age bracket (e.g. 30-39).
- No specific names, dates or locations will be in the final report, with pseudonyms used.

You are most welcome to receive a copy of the finalised write-up of the project should you wish. This will be facilitated through your Hearing Voices Group facilitator.

You can click here to see the full <u>University Research Participant Privacy Notice</u> or visit https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf

# What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

You will be asked questions relating to your experience of attending hearing voices groups. The research project is keen to hear your honest, open views and experiences of attending the group. It is important to note that the researcher is not associated with your Hearing Voices Group, and details of which group you attend will not be kept after the interview.

#### Will I be recorded, and how will the recorded media be used?

The audio recording of your interview during this research will be used only for analysis. No other use will be made of the recordings without your permission, and no one outside of the project will be allowed access to the original recordings. Recordings will be transcribed and then analysed for key themes that help to capture the experiences of attending hearing voices groups. This means that your group facilitators will *not* have access to the recordings or written transcripts, to ensure you feel able to speak freely about your experiences.

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#### How do I participate?

If you wish to participate in the project, or have any further questions, you can speak to your group facilitator who can pass on your details. Alternatively, you can email the lead researcher on <u>umawa@leeds.ac.uk</u>.

In the email, please let me know which Hearing Voices Group you attend, and how many times you have attended in the last 6 months.

You then have opportunity to read the consent form, ask any further questions, and provide consent should you wish to proceed with the project. A mutually convenient time, date and means of conducting the interview can be arranged.

# Thank you for taking the time to read the information. You will be given a copy of this sheet to keep for your future reference, but please do not hesitate to ask any further questions.

Project title	Document type	Version #	Date
Exploring the experience of attending a	Information sheet	2	20/06/
Hearing Voices Group.			2023

#### Appendix D - Interview schedule

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#### Exploring the experience of attending a Hearing Voices Group Interview Schedule

#### Introduction

- When did you first attend a Hearing Voices Group?
- When did you first start hearing voices?
- What past support or interventions have you had? (Such as hospital, therapy, medication).
- Have you ever been given a diagnosis? (That you may not identify with).

#### Interview schedule

- 1. Tell me about the first time you attended a Hearing Voices Group?
  - a. What did you think/ feel before?
  - b. What were your thoughts/feelings after?
- 2. Have you found anything helpful about going to the group?
  - a. Clarify experiences
- 3. Have you found anything less helpful about the groups?
  - a. Clarify experiences
- 4. How do you decide whether to go to meetings?
  - a. Clarify nature of factors (i.e. practical, social, emotional)
- How would you explain the group to another person?
   a. Would you encourage others to join and why?
- 6. Are there things you might change about the group?
- How has attending the group changed your relationship with yourself/others?
   a. What has changed?
  - b. Why do you think this is?
- 8. How has attending the group changed your relationship with voices?
  - a. What has changed?
  - b. Why do you think this is?
- 9. How would you compare your experience of Hearing Voices Groups compared to other support or things you might have experienced in the past?
- 10. Is there anything else about your experiences of attending the group you would like to share?

#### Post-interview information

Collection of demographic information (age bracket, ethnicity, religion, gender).

Project title	Document type	Version #	Date
Exploring the experience of attending a	Interview Schedule	1	28-
Hearing Voices Group.			11-22

#### **Appendix E** – Signposting information

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#### Exploring the experience of attending a Hearing Voices Group Signposting sheet (Bradford).

Thank you for taking part in this research project. Please find some resources below that you may find helpful if you would like further support – either now or in the future.

#### Samaritans

116 123

Bradford First Response (24hr mental health support) 0800 9521181

Useful links

https://www.bradford.gov.uk/health/improve-your-health/mental-health/

It is also encouraged that you speak with your GP or any trusted health professional, or any other person you feel able to speak with should you find this helpful.

Project title	Document type	Version #	Date
Exploring the experience of attending a	Signposting worksheet	1	28-
Hearing Voices Group.			11-22

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#### Exploring the experience of attending a Hearing Voices Group Signposting sheet (Wakefield).

Thank you for taking part in this research project. Please find some resources below that you may find helpful if you would like further support – either now or in the future.

Samaritans

116 123

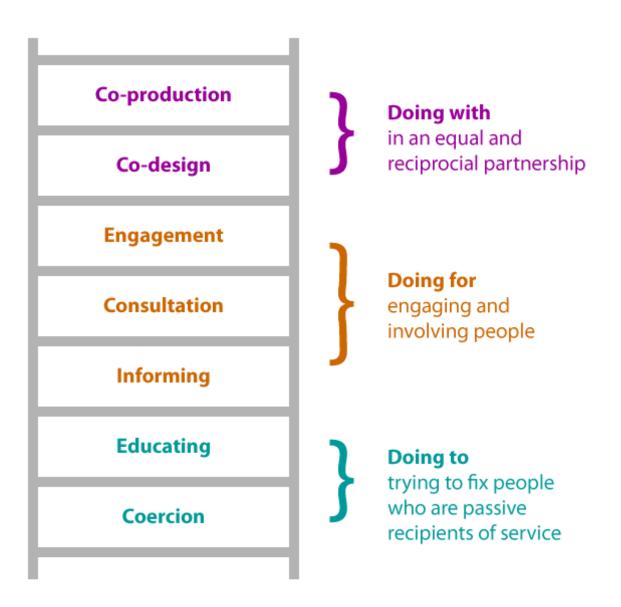
Wakefield Single Point of Access (24hr mental health support) 0800 9521181

**Useful links** 

https://www.wakefield.gov.uk/health-care-and-advice/public-health/mental-health-wellbeing/mental-health-support?

It is also encouraged that you speak with your GP or any trusted health professional, or any other person you feel able to speak with should you find this helpful.

Project title	Document type	Version #	Date
Exploring the experience of attending a	Signposting worksheet	1	28-
Hearing Voices Group.			11-22



## Appendix G – Sample transcript analysis

A mixture of emotions around initial attendance. The 'realisation' or penny drop moment of not being the only one.		<b>P:</b> Yes, trepidation, scared, loneliness, isolation. And then that realisation that, it's not just me I'm not the only one, and it's a wonderful feeling when it just clicks.	Initial attendance is daunting but not being the only one
	501 502	I: Mm yeah. No that's that's perfect. And I think I know the answer, but would you encourage others to join the groups?	is an invaluable revelation
	503	answer, but would you encourage others to join the groups:	
Medication as	504	P: Oh yes, most definitely, most definitely. It's singularly the	
'functional' and useful but only one	505	best thing you could do. Medication is functional where the	
piece of the puzzle.	506	groups are, the group share a purpose. Medication only does so	
Groups are the 'best' thing for	507	much, it just dampens the voices down.	Groups offer something unique,
Simon – a shared purpose – is this	508		a shared identity.
not the case for meds?	509	I: Ok yeah.	
meus:	510		
The group as	511	P: And makes life a little bit more comfortable, bearable, most	
compared to medication. Meds	512	of the time. But the group can offer support in so many	
make life bearable; groups give you	513	different ways that medication can't do. And you build up that	Groups provide
connection.	514	ever so important friendship with other people. So you don't	social connectedness
	515	feel isolated and alone.	and identity.
	516		

## Appendix H – Consent form

School of Medicine

## UNIVERSITY OF LEEDS

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Title of research Project: An Interpretative Phenomenological study exploring the experience of attending a community Hearing Voices Group Lead researcher: Ashley Watson Contact details: umawa@leeds.ac.uk	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated [Insert date of which consent form is signed] explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any point up <b>until 14 days</b> after the completion of the interview, and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
I understand that members of the research team may have access to my responses. I understand that my name and other identifiable information will not be linked with the research materials, and I will not be identified in the report or reports that result from the research.	
I am aware that some information may be retained to build a pen portrait of my experiences. However, steps will be taken to protect identity (e.g. not reporting any names, place names, using age ranges).	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities to check the quality of the research. Data will be stored for up to three years.	
I understand that signed consent forms and original audio recordings will be retained securely in line with Leeds University protocol, for up to two years.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date	

Project title	Document type	Version #	Date
Exploring the experience of attending a	Consent form	1	03-
Hearing Voices Group.			01- 2023

Version 1

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