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## **EXPLORING CONVERSATIONS ABOUT VOICE-HEARING**

Section A:

A Systematic Review and Thematic Synthesis of Literature Containing How Voice Hearers Experience Sharing Their Voice-Hearing Experiences with Others.

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Section B:

A Qualitative Study Exploring How Practitioners Working in Child and Adolescent Mental Health Services Facilitate Conversations with Service Users About Voicehearing.

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#### **Summary of Portfolio**

#### Section A

A systematic review of the literature pertaining to voice hearer's experiences of sharing their voice-hearing experiences with others is presented. Studies were quality assessed using the Critical Appraisal Skills Programme. Thematic synthesis developed four themes: 'telling others can mark a journey towards help'; 'a need for safety and understanding'; 'disclosure can lead to (feared) negative consequences'; and 'sharing to reduce shame: a way to move forward with voices'. Clinical implications, methodological limitations, and directions for future research are discussed.

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#### Section **B**

A qualitative study exploring how practitioners working in child and adolescent mental health services (CAMHS) speak to young people about their voices is presented. Reflexive thematic analysis was used to explore the experiences of twelve CAMHS practitioners, culminating in the

development of three themes and subsequent related subthemes. Results suggested that practitioners create space to explore voices with young people and attempt to ensure the safety of this space, yet they used a number of strategies to contain their anxieties. Clinical implications, methodological limitations, and directions for future research are discussed.

SECTION A: LITERATURE REVIEW	1
INTRODUCTION	2
Hearing Voices: Definition, Prevalence and Understandings	2
Sharing Experiences: Models of Disclosure	3
Sharing Experiences: Impact of Disclosure	4
Rationale for Review	6
Methods	6
Eligibility Criteria	6
Systematic Search Strategy	7
Study Selection	10
Data Extraction	10
Quality Appraisal	10
Data Synthesis Approach	11
RESULTS	
Overview of Studies	
Quality Assessment	17
Research Aims and Design	17
Recruitment and Participants	
Data Collection	
Data Analysis and Findings	20
Reflexivity and Ethics	21
Summary	22
Thematic Synthesis	22
Quality assurance	25
1. Telling Others Can Mark a Journey Towards Help	
2. A Need for Safety and Understanding	27
2.1 Empathy from Those with a Shared Experience Creates Safety.	
2.2 Sharing Without Shared Experience: Seeking to be Understood	
3. Disclosure can lead to (feared) negative consequences 3.1 Feeling ashamed: others will see "crazy" if they know	
3.2 Others Need to be Protected from the Burden of Voices	
4. Sharing to Reduce Shame: A Way to Move Forward with Voices	
Theme summary	
DISCUSSION	
Clinical Implications	
Future Research	
Limitations	
Conclusion	
References	
SECTION B: EMPIRICAL PAPER	53
ABSTRACT	53
INTRODUCTION	54
Background and Context	54
How Voice Hearers Experience Services	
How Practitioners Experience Working with Voice-Hearing	
Engaging In Challenging Conversations	
Rationale and Aim	
Метнор	

## **Table of Contents**

Design	60
Participants and Sampling	61
Procedure	62
Stakeholder Involvement	63
Interviews	63
Data Analysis	64
Reflexivity and Quality Assurance	65
Author Positionality	
Ethics	67
RESULTS	68
Theme 1. Creating a Safe Space	68
Building a Therapeutic Alliance	69
Tolerating and Containing Voice-Hearing Experiences	70
Checking in with the Young Person	71
Theme 2. Embarking On a Meaning-Making Journey Together	
Voices Are One "Piece of the Puzzle": Working with Other Experiences	73
Normalising Voice-Hearing Experiences	
Using Curiosity to Explore Voices	75
Making Links in the Pursuit of Understanding	
Theme 3. Practitioners Navigating Their Own Anxieties	77
Doubting Their Ability to Manage Voices	
The Pursuit of Containment for Practitioners	79
DISCUSSION	80
Methodological Limitations	84
Clinical Implications	85
Directions For Future Research	86
Conclusion	87
References	89
SECTION C: APPENDICES	96

## List of Tables and Figures

### Section A

Table 1. Eligibility criteria.	.7
Table 2. Boolean search terms used across PsycINFO, CINAHL and ASSIA	.8
Table 3. Table Containing Details of the Included Studies for Review	12
Table 4. Themes and subthemes created from dataset	.23
Table 5. Theme distribution	.24
FIgure 1. PRISMA diagram indicating process of systematic literature searching	9

## Section B

Table 1. Participant demographics	62
Table 2. Six stage process of thematic analysis as outlined by Braun and Clarke (2006)	64
Table 3. Summary of Themes	68

## List of Appendices

Appendix A- CASP Table	.96
Appendix B- Part A NVivo Coding Excerpts	99
Appendix C - Emails Sent to Practitioners	.100
Appendix D – Information Sheet	101
Appendix E- Consent Form	106
Appendix F- Interview Schedule	107
Appendix G – Excerpts from Research Diary	108
Appendix H- Code Drawings	110
Appendix I- Development of Thematic Maps	112
Appendix J- Part B Coding Excerpts	116
Appendix K – Ethical Approval from University	118
Appendix L - HRA Approval	119
Appendix M– Edits from HRA Approval	120
Appendix N– End of Study Report for Ethics Committee/Participants	121
Appendix O – Journal Guidelines	123
Appendix P – Coded transcript	134



#### **Section A: Literature Review**

#### Abstract

**Background:** Research suggests that voice hearing remains a stigmatised identity for many. Whilst sharing experiences with others can be helpful, many voice hearers find this difficult to share for several reasons. No review exists which combines findings from available studies, thus this systematic review aimed to synthesise and analyse available research to explore how voice hearers experience sharing their voice hearing with others.

**Method:** Three databases were searched and 23 qualitative studies, which included accounts from voice hearers' perspectives, were included for review. The Critical Appraisal Skills Programme was used to assess quality of studies.

**Results**: Utilising thematic synthesis, four themes were developed: *telling others can mark a journey towards help*; *a need for safety and understanding; disclosure can lead to (feared) negative consequences*; and *sharing to reduce shame: a way to move forward with voices*. Some themes had relevant subthemes.

**Conclusions:** Voice hearers experience barriers to disclosure, but it is largely identified as a positive experience when done. Implications suggest that professionals should be aware of stigma and handle this appropriately. They may wish to offer voice-hearers a space to talk about their voices with individuals who have shared experience. Limitations pertaining to lack of transferability are discussed.

Keywords: Voice-hearing, disclosure, sharing experiences

#### Introduction

#### Hearing Voices: Definition, Prevalence and Understandings

Hearing voices (HV) can be understood as a standalone experience or as part of a cluster of 'symptoms'. It refers to hearing things that others may not hear and sometimes is referred to as auditory hallucinations (Cooke, 2014). Findings from epidemiological research, single studies, and systematic reviews estimates the prevalence of HV to be relatively consistent across age groups, falling between 5-16% for children, adolescents, and adults (Sommer et al., 2010; Tien et al., 1991; Van Os et al., 2009). Beaven et al. (2011) identified the median percentage of voice hearing in adults to be 13.2% across 17 surveys. Whilst in a systematic review of children and young people's experiences, Kelleher et al. (2012) identified the median percentage of voice hearing to be 17% and 7.5% respectively. HV has therefore been posited to be a common experience which at least one in ten people may experience at some point in their lifetime (Mental Health Foundation, 2021).

Whether HV occurs along the continuum of normal human experience or whether it manifests in the context of a mental health disorder is disputed. Medicalised approaches that situate voice-hearing within the confines of a "serious mental illness" (Jones et al., 2003) are common in western societies, supported largely by the pharmaceutical industry (Pilgrim, 2007; Read et al., 2009). Such approaches have led to those who have voice-hearing experiences to be labelled as 'patients' or 'sufferers' (Cooke, 2014) reaffirming their position as someone who is unwell and in need of treatment.

Through the lens of the Diagnostic and Statistical Manual (5th ed.; DSM–5; American Psychiatric Association, 2013), HV is considered a symptom of a psychotic disorder. If paired with other 'positive' and 'negative' psychotic symptoms, HV can lead to a diagnosis of 'schizophrenia', where medication and therapy are a recommended as courses of action (National Institute for Health and Care Excellence [NICE], 2014). As well as 'schizophrenia', HV can also manifest as a defined symptom of other psychiatric disorders, such as in 'borderline personality disorder', 'post-traumatic stress disorder', 'bipolar disorder' and 'major depressive disorder' (Merrett et al., 2016; Toh et al., 2015; Waters et al., 2018). HV can also occur in neurological disorders, neurodegenerative conditions, and specific auditory disorders (Sommer et al., 2012).

Despite the dominance of the medical model, it is not the only explanation encapsulating how voice-hearing experiences are understood. Stip and Letourneau (2009) argue that voicehearing exists along a continuum of human experience. Only when influenced by an array of cognitive and cultural factors can voice-hearing "find a place in the DSM", yet most voice hearers do not receive a diagnosis or access help from services (Iudici et al., 2019). Of noteworthy opposition to the medical model is the Hearing Voices Movement. This movement seeks to surpass pathological descriptions and prioritises the meaning of voice-hearing experiences (Woods, 2015), which may be influenced by life experiences, relationships, culture, and living circumstances amongst other factors.

Unsurprisingly, culture plays a large part in attributions ascribed to hallucinatory experiences; research indicated that non-western societies tend to expand past the confines of medicalised understandings. Voices can be perceived as a normal part of life, as having spiritual underpinnings, and as positive guiding forces in life (Taitimu, 2008; Luhrmann et al., 2015), whereas in western societies, voices may be viewed as negative and only accepted in certain circumstances (Iudici et al., 2019).

#### **Sharing Experiences: Models of Disclosure**

Sharing ones' experience of mental health has been argued to be underpinned by complex processes requiring significant consideration. Two main models present disclosure mechanisms that can be mapped on to mental health: The disclosure decision making model (DDMM; Greene, 2009) and the disclosure process model (DPM; Chaudoir & Fisher, 2010). The DDMM outlines

that for disclosure of health information to occur, there is constant consideration of the risks and benefits (Greene, 2009). This includes assessing information, assessing the receiver, and considering disclosure efficacy. Firstly, information about the stigma, preparation, symptoms, and impact of disclosure on others is considered. Next, there can be the consideration of the potential reactions of the recipient and an assessment of relational quality between recipient and discloser. Finally, the sharer considers their ability to communicate their chosen information effectively

The DPM (Chaudoir & Fisher, 2010) argues that goals (which can be either avoidance or approach based) begin to determine the likelihood of disclosure of a concealable stigmatised identity. Upon sharing, individuals choose to share details about their identity and reactions can be (un)supportive, which may impact the relationship positively or negatively. This process is mediated by different factors: alleviation of inhibition, social support, and changes in social information. This is framed in the context of a feedback loop, where with each disclosure, individuals either become more open or more closed, linking to attempts to manage stigma. Both models look at sharing situated in self- and other-factors and the impact that this may have, ultimately highlighting the complexity of the decision to share sensitive and personal information with another.

#### **Sharing Experiences: Impact of Disclosure**

Many positive impacts have been argued to result from sharing mental health experiences. Research on sharing experiences of serious mental illness notes that disclosure can: lead to feeling less alone, act as a means to support recovery, and become a tool to fight stigma (Bril-Barniv et al, 2017). Young people at risk of psychosis can also use disclosure to seek help, particularly if speaking to the "right people" (Gronholm et al., 2017). Sharing with others who have similar experiences also can reduce isolation and create a sense of belonging, which can improve mental wellbeing (Law et al., 2021; Vickery, 2022); it can also allow for normalisation and support from social networks (Chen et al., 2013; Bril-Barniv et al., 2017) whilst helping others understand psychosis and improve their attitudes towards it (Hampson et al., 2020).

Despite possible positive outcomes, research has outlined barriers to sharing mental health experiences. Many fear the negative consequences of disclosure; fear of discrimination can become a barrier amongst social networks, such as friends and family, and within the workplace (Bril-Barniv et al., 2017; Peterson et al., 2011; Rüsch et al., 2014). This appears to be the case cross-culturally, where in Chinese culture fear relates to "losing face" and facing social alienation (Chen et al., 2013); and Black or Latina women in the United States fear being labelled "crazy" (Nadeem et al., 2007).

Negative perceived consequences also include the emotional cost of sharing and changes in the way individuals may be viewed. For example, individuals fear being seen as less capable and left subject to stigma, whilst some fear having their children removed (Brill-Barnive et al., 2017; Keller et al 2016; Law et al., 2021). Specific to those with a diagnostic label of 'schizophrenia', feared experiences include being "dropped as a friend" and receiving negative comments from others (Pandya et al., 2011). Similarly, those identifying as having 'psychosis' may not disclose due to fear of rejection, being treated differently, or the possible adverse impacts on others. Examples include: believing disclosure will lead to stigma by association (Burke et al., 2016), their voices harming others (Campodonico et al., 2022), and negative, judgemental reactions from others (Gronholm et al., 2017). Overall, general stigma around voice-hearing has been identified as a large barrier to sharing experiences (Vilhauer, 2017), and this appears to be both trans-diagnostically and cross-culturally, suggesting that disclosure is a challenging experience for many.

As suggested by both the DDMM and DPM (Greene, 2009; Chaudoir & Fisher, 2010), mental health disclosure is a complex process that requires much consideration. Sharing 5

experiences appears to primarily call for a trusting and close relationship to allow for safe disclosure (Gronholm et al., 2017; Campodonico et al., 2022).

#### **Rationale for Review**

Whilst the aforementioned research is discussed in broader mental health contexts, literature pertaining to the experiences of sharing solely voice-hearing experiences has not yet been synthesised. Considering the stigma attached to this, which can act as a barrier to disclosure for voice hearers (Vilhauer, 2017), it is crucial to explore sharing of experiences from voice hearers' perspectives, particularly considering the complexity ascribed to sharing information about stigmatized identities. Reviewing and synthesising first-hand experiences within the literature can help to identify barriers, facilitators and associated experiences of those who decide to share with others. The current paper aims to review and synthesise available literature that can answer the following question: "What are voice hearers' experiences of sharing their voicehearing experiences with others?".

#### Methods

#### **Eligibility Criteria**

In line with the aims presented by this review, papers were included if they provided information on individual's experiences of sharing their voice-hearing with others. Any papers with integrated findings from multiple perspectives were not included. Eligibility criteria are outlined in Table 1 below.

#### Table 1

#### Eligibility criteria

Inclusion criteria	Exclusion criteria
Studies using qualitative methodology Studies which include data relevant to voice hearer's experiences of sharing these experiences with others. Studies published in a peer-reviewed journal. Studies written in the English language.	Unpublished studies_i.e., dissertations Not empirical research i.e., book chapters Studies presenting data not solely from the perspective voice hearers Studies that didn't distinguish between voice hearers' and others' experiences. Systematic reviews Papers discussing disclosure in broader topics related to hearing voices, such as Psychosis

#### Systematic Search Strategy

A systematic search of the literature was conducted on 3<sup>rd</sup> October 2022. No date limits were applied, thus all studies relevant to the search terms since the inception of the databases were generated. Three databases were searched; PsycINFO, CINAHL, and Applied Social Science Index and Abstracts (ASSIA). These databases were chosen due to their reputability and relevance to the research question; CINAHL is a good source for primary qualitative studies (Wright et al., 2015), whilst PsycINFO and ASSIA provide access to relevant articles in psychology and the caring professions. Limits were placed to solely include studies published in the English language. Table 2 displays the search strategy applied.

#### Table 2

Boolean search terms used across PsycINFO, CINAHL and ASSIA.

Search terms	
distressing voice* or hallucina* or voice hear* of	or hear* voice
AND	
Qualitative or Grounded theory or Interpretive Thematic analysis or Content Analysis or Narrat Survey* or Interview*	
AND	
Experienc* or Perspective* or attitude* or enga Respon* or Phenomen* or percep* or View* or	

Search terms were decided on by scoping existing literature via Google Scholar and reading existing reviews. The "SPIDER" approach was used to outline the search areas (Cooke et al., 2012). This method identifies the sample (individuals who hear voices), phenomenon of interest (sharing voice-hearing experiences), design (type of qualitative research e.g., thematic analysis), evaluation (e.g. attitude/perception), and research type (qualitative). Broader synonyms for voice-hearing, such as 'psychosis' and 'schizophrenia' were not included due to the varying and integrated nature of their 'symptoms'.

The search was applied to the abstracts of relevant literature. Forward and backward searching of chosen papers was also conducted. Backward searching entails scanning the references of selected papers for relevant cited work (Webster & Watson, 2002), whereas forward searching endeavours to find work that has cited the paper since its publication (Levy & Ellis, 2006). Searches through this channel produced no new papers. For further details about the systematic search process, please see Figure 1.

#### Figure 1

#### PRISMA diagram indicating process of systematic literature searching



#### **Study Selection**

Studies were managed using the reference management software RefWorks. Duplicates were removed using RefWorks' duplication identification tool. During 'title screening' stages, further duplicates were identified and removed manually and papers that linked to voice hearing were kept for further assessment. Abstracts were screened against the inclusion criteria and papers with unclear eligibility were escalated to full-text screening. Upon full-text screening, papers that did not meet the inclusion criterion were excluded.

#### **Data Extraction**

Although some research focussed solely on disclosure, most papers presented data about sharing with others as part of a broader dataset. To ensure relevant data was synthesised, only qualitative data related to sharing voice-hearing with others was extracted. Excerpts were copied if relevant and stored in NVivo ready for synthesis.

#### **Quality Appraisal**

NICE (National Institute for Health and Care Excellence; NICE 2014) suggests that when reviewing a qualitative evidence base, the critical appraisal of studies should be based on the Critical Appraisal Skills Programme (CASP) framework. Whilst the CASP provides a helpful, structured, framework to critically evaluate studies, Long et al. (2020) note that in contrast to quantitative research, quality judgements for qualitative research are more subjective. Whilst subjectivity is necessary due to the experiential nature of qualitative research, there is a need for a reflexive approach when using the CASP framework. To privilege reflexivity in the current review, the author discussed uncertainties about appraisals with a colleague and bracketed preexisting biases to increase the validity of appraisals. See Appendix A for the CASP ratings for individual studies.

#### **Data Synthesis Approach**

Following on from critical appraisal, data was synthesised using thematic synthesis, in line with the three stages recommended by Thomas and Harden (2008). Please see 'thematic synthesis' section for specific details of this process.

#### Results

#### **Overview of Studies**

Following screening, 23 studies were deemed eligible for quality assessment. Of the included studies, only three endeavoured to explicitly explore the experiences of sharing voice-hearing experiences (Bogen-Johnston et al., 2017; Watkins et al., 2020; Coffey & Hewitt, 2008). The remainder of studies explored broader voice-hearing experiences: six explored experiences in group settings (Dos Santos & Beavan, 2015; Goodliffe et al., 2010; Newton et al., 2007; Nkouth et al., 2010; Oakland & Berry., 2014; Payne et al., 2017) and others explored topics of relationships, social 'worlds' and the impact of voices at work (Craig et al., 2017; Mawson et al., 2011; McCarthy et al., 2021; Sheaves et al., 2021). Papers also delved into the meaning-making and lived experience of voices (Hayward et al., 2015; Jackson et al., 2010; Kalhovde et al., 2014, Mayer et al., 2021; Milligan et al., 2014; Parry et al., 2021; Sinha & Ranganathan, 2020; Yttri et al., 2020) and how this can link to spirituality (Lewis et al., 2020) and the process of recovery (de Jager et al., 2016). For a detailed overview of the studies, please refer to Table 3.

#### Table 3

Table Containing Details of the Included Studies for Review

	Author and date	Study aim	Participants & demographics	Context	Design and analysis	Main findings
1	Bogen- Johnston et al. (2017)	To explore the barriers and enablers to disclosure of distressing voices to family, friends & health professionals	20 VHs <sup>1</sup> . Male (n=12), Female (n=8). Age range 19-35 years. Ethnicity NS <sup>2</sup> THV <sup>3</sup> <1 – 21 years.	Service users from early intervention in psychosis (EIP) service in UK.	Qualitative. Semi structured interviews. Thematic analysis	Disclosure could allow participants to access help, although some waited until crisis point. There was a fear of losing voices and feelings of shame. Voice hearers also worried about impact of disclosure on others and feared their responses.
2	Coffey & Hewitt (2008)	To establish views of voice hearers and nurses regarding helping response	20 VHs and 20 community mental health nurses VHs: Female (n=10) Male (n=10) Age 20-40 (n=9), Age >41 (n=11) Ethnicity NS THV 2-9 years (n=10), >10 years (n=10)	VHs recruited through community mental health nurse case load NHS Wales.	Semi structured interviews including forced choice and open questions Thematic content analysis	Voice hearers found talking about their voices with staff members largely helpful. Speaking to other voice hearers could mean they felt understood, or burdened by others' experiences.
3	Craig et al. (2017)	Explore lived experience of impact of voice hearing on working lives. Understand strategies used to manage.	5 VHs. All female. Age range 24- 61. Ethnicity NS THV not universally quantified	Recruited via voice hearing support website Seems based in UK.	Diary writing Thematic analysis	In the workplace, people feared stigma and judgement which led them not to disclose. Others such as family did not understand experiences, and disclosure could change how people at work looked at them. However, reasonable adjustments could also be made.
4	De Jager et al. (2016)	To address gap in the literature regarding recovery in voice hearing	11 VHs. Female (n=7), Male (n=4). Ethnicity: White (n=10), Asian (n=1) Age range 23-63 THV NS	Recruited from the Hearing Voices Network NSW and 5 from the Australian Schizophrenia Research Bank	Semi Structured interviews Narrative enquiry	Participants feared disclosing to others due to judgement and stigma as well as involuntary treatment. Participants were cautious who they chose to disclose to.
5	Dos Santos & Beavan (2015)	To explore member experiences of peer support groups	4 VHs. Male (n=2) Female (n=2). Age range 'early 30s to late 50s'. Ethnicity NS. THV between 16 months and >40 years.	All recruited from the hearing Voices Network NSW	Semi structured interviews Interpretive phenomenological analysis	In a group setting, it felt comfortable to share experiences. Sharing in the group could encourage people to share voice hearing outside of the group too.

<sup>&</sup>lt;sup>1</sup> VHs = Voice hearers

Please note. Where other participants aside from voice hearers are in the studies, their demographics are not described. Furthermore, only findings related to the research question are summarised. Anything outside of the scope of the topic has not been included.

<sup>&</sup>lt;sup>2</sup> NS = Not specified

<sup>&</sup>lt;sup>3</sup> THV = Time hearing voices

6	Goodliffe et al. (2010)	To investigate experiences of people receiving cognitive therapy for voices	18 Vhs. Male (n=6) Female (n=12) Age range from 30 to 59 "majority White British", white European (n=1), Latin American (n=1). THV NS	Recruited from a closed person based cognitive therapy group in NHS in the UK.	Semi structured interviews in focus groups. Grounded Theory	Sharing experiences in group settings felt free of judgement. Rules around confidentiality were important; isolation could lead to avoidance of disclosure of voices.
7	Hayward et al. (2015)	to examine how/if people's relations with their voices changed over time.	12 VHs. Male (n=8), Female (n=4). Age range 20=69. THV 2-45 years. Ethnicity NS	Recruited from hearing voices network groups in England and Australia.	Semi structured interviews Thematic analysis	Voices seen as something that should be spoken about as soon as possible. Speaking to practitioners was both helpful for some, and unhelpful for others. Disclosure of voices in a respectful relationship was valued.
8	Jackson et al. (2010)	To explore how people develop positive relationships with voices & what factors impact. How relationships change over time.	12 VHs, Male (n=5) Female (n=7); Age 26-35 (n=4); Age 36-45 (n=3); Age 46-55 (n=3); age 56-65 (n=2) THV only quantified for some. Ethnicity White British (n=8), White irish (n=1), White Zimbabwean (n=1), French/British (n=1), Black Nigerian (n=1)	NHS services, community advertisement, Hearing voices Network. Seemingly in UK.	Semi structured interview Grounded Theory	Connecting with like-minded people was seen as important. Talking to others with similar voice hearing experiences gave participants hope.
9	Kalhovde et al (2014)	To explore how people with mental illness experience dealing with hearing voices and sounds in everyday life.	14 VHs Male (n=6) Female (n=8). Age range 19-57. THV 2-39 years. Ethnicity NS	community and outpatient services in Norway.	Semi structured interview Hermeneutical phenomenological approach	Individuals avoided disclosing to others and were careful about who they decided to share information with. They feared negative consequences. When sharing, some felt better and understood about this and they could access help.
10	Lewis et al (2020)	To explore and understand the experience of voice hearing from a spiritual perspective.	5 VHs Aged between 20-52 years. Male (n=3) Female (n=2). THV 3-47 years. All white British.	Recruited from community mental health teams and an EIP service seemingly in UK.	Semi structured interviews Interpretive phenomenological analysis	Disclosure could be helpful to seek support. Being understood by others was felt to be important. Voice hearing experiences could be difficult to express.
11	Mawson et al. (2011)	To qualitatively explore how voices are experienced in the context of interpersonal relationships.	10 VHs. Age between 26-51. THV 18 months -43 years. Ethnicity NS	Recruited from NHS services in England.	Semi Structured Interviews interpretative phenomenological analysis	Participants hid their voice hearing from non-close relationships to protect them and not be a burden. They viewed others as not understanding of their experiences so did not disclose. Some felt disclosure helped others to understand.
12	Mayer et al. (2022).	To explore how young people and their patents make sense of voice hearing in family contexts	7 VHs and 6 parents of VHs. VHs: Age 16 (n=1), 17 (n=3), 18 (n=2), 19 (n=1) White British (n=6), British Bangladeshi (n=1). THV NS	2 NHS trusts in northern England	Semi structured interviews Interpretive phenomenological analysis	Speaking to health professionals was a containing experience. Disclosure was carefully considered based shame, judgement, attitudes and wanting to protect others. Family members with no lived experience perceived to not understand.
13	McCarthy et al (2021)	To explore the experience of romantic and sexual relationships of VHs and how do	3 VHs. Male (n=1), Female (n=2). Age 28, 30 and 44. Ethnicity NS. THV not universally quantified	Hearing voices networks, researcher personal contacts, advertisements at	Semi structured interview, survey questions and electronic diary entries. Thematic analysis	How much people disclose in relationships was dependent on perceived understanding. Speaking to peers with similar experiences could be helpful.

		those experiences impact occupations.		university. US and Ireland		
14	Milligan et al <sub>.</sub> (2013)	To use IPA to examine voice hearers account of what it is like to live with voices over time.	6 VHs. Male (n=5), Female (n=1). Age range 17-30. Ethnicity NS. THV 9-252 months.	Local EIP services. Seemingly in UK.	Semi Structured Interviews interpretative phenomenological analysis	Crisis points helped voice hearers to share experiences with others. Some felt that open relationships where voices are spoken about were helpful; others worried about judgement. Speaking to others with similar experiences is useful.
15	Newton et al. (2007)	To explore the experience of a psychological group- therapy aimed at reducing distress, and increasing coping strategies, among a group of young people experiencing auditory hallucinations	8 VHs. Female (n-5), Male (n=3). THV between 5 months and 4 years. All aged either 17 or 18 at time of interview. Ethnicity NS.	Invited from group CBT sessions in London.	Semi Structured Interviews interpretative phenomenological analysis	Group therapy meant that people felt able to share their voice hearing experiences with others. Peers felt more able to empathise in comparison to family and friends. "unsafe" people could discriminate, adding to feelings of stigma.
16	Nkouth et al. (2010)	No clear aim stated. Appears to be presenting results from a group evaluation.	12 VHs. Ages 25-67. THV ranged from 3-30 years. Ethnicity and gender NS	Recruited from voice hearing group in Quebec.	Semi structured interview Qualitative content analysis	Group setting enabled VHs to discuss their experiences more openly. Sharing experiences helped VHs learn from each other and develop; relating to others experiences through disclosure reduced feelings of isolation. Environment was trusting and lacked independent when choosing to disclose
17	Oakland & Berry (2014)	to explore the experiences of individuals who attend Hearing Voices Network groups.	11 VHs. Age 32-60. Ethnicity, THV, and gender NS.	recruited from hearing voices groups. Location unclear but seems UK due to NHS setting.	Semi structured interview Thematic analysis	judgement when choosing to disclose. Groups gave participants an opportunity to talk and let off steam. Very different approach to health settings, where sharing voice-hearing experiences was often met by medicalised responses.
18	Parry et al. (2021)	To explore the form and function of voices in adolescence. To advance understanding from perspectives of young	74 self identified VHs. Age 13-18 years. 28% male, 61% female, 21% nonbinary ( <i>NB. total</i> = 117% so this is unclear). THV and ethnicity NS.	Participants recruited online with the help of health and peer-support organisations.	Manchester Voices Inventory for Children Qualitative survey Foucauldian-Informed Narrative Analysis	Perceived stigma, prejudice, and reactions from others could act as a barrier for young people in disclosing voice-hearing. Non disclosure also used to protect others from worrying about them. Fear of being disbelieved or misunderstood prevented disclosing for help. Some positive experiences from sharing with trusted others, particularly those with lived experience.
19	Payne et al. (2017)	people. To explore how attendees of Hearing Voices Network Groups experienced the group, changes in understanding of their voice hearing and its impact on their lives.	8 VHs. female (n=4), Male (n=4). Age range 26-60. Self-defined ethnicity: White British (n=2), White English (n=1), British (n=2), White British Jewish (n=1), European (n=1), Black British (n=1). THV NS	Recruited via hearing voices groups in the UK.	Semi Structured Interviews interpretative phenomenological analysis	In a voice hearing group, sharing experiences didn't feel shameful as was the case outside of these groups.

20	Sheaves et al. (2021)	To explore patients' experiences of being around people whilst hearing derogatory threatening voices.	15 VHs. Gender not specified. Age <20 (n=1), 21-30 (n=3), 31-40 (n=5), 41-50 (n=5), 51-60 (n=1). Ethnicity: White British (n=13), Chinese (n=1), Black British (n- 1).THV (Years): 1-5 (n=5), 11-15 (n=3), 16-20 (n=4), 21-25 (n=2), 26-30 (n=1)	Recruited via clinical teams in Oxford NHS trust	Semi structured interviews Thematic analysis	Participants found it difficult to be around (and to disclose to) others whilst hearing voices. They feared stigma/judgement and hurting others. Voices encouraged people to withdraw but reconnection and sharing could help with recovery.
21	Sinha & Ranganathan (2020)	To explore experiences of voice hearers in a context without hearing voices networks, how individuals deal with their voices, what happens when they engage with medical model?	27 VHs. Male (n=13), Female (n=14). Ethnicity and THV NS.	Inpatients or outpatients in a hospital in India.	Qualitative Maastricht Hearing Voices Questionnaire Thematic analysis	Talking about voices was a main control strategy utilised by participants. Trusting relationship felt by caregivers who voice hearers chose to disclose to.
22	Watkins et al. (2020)	To understand individuals experiences of talking about their voice hearing to people close to them.	5 VHs. Female (n=2) Male (n=3). Age range 24-51. THV 8-33 years. Ethnicity White British (n=5).	Recruited from NHS community mental health team	Semi Structured Interviews interpretative phenomenological analysis	Participants desired to talk about voices to help make sense of them. Voice hearers and others viewed voice hearing as unacceptable and experienced shame. Mixture of positive and negative reactions to disclosure
23	Yttri et al. (2020)	To explore age of onset and duration of hallucinations before disclosure and individuals reactions and understanding of this. To explore the reasons and circumstances for disclosure. The patients' reaction to and their comprehension of these phenomena.	20 VHs with a diagnosis of Schizophrenia. Female (n=12) Male (n=8). Age range 18-53. THV and ethnicity NS.	Recruited randomly from inpatient and outpatient clinics in Denmark.	Semi structured interviews. Method of analysis NS.	Disclosure tended to emerge out of desperation when participants needed help. Disclosure of voices tended to happen in a clinical setting, however some participants disclosed to friends and family members, although they were the minority.

Note: findings outlined in table three reflects the nuanced data extraction, with summaries reflecting relevant information from each research study and not

the named themes from broader topics presented by study authors.

#### **Quality Assessment**

Quality assessment of the included papers will be detailed under headings that correspond to relevant sections of the CASP tool.

#### **Research Aims and Design**

Qualitative methodology appeared to be appropriate for all research questions posed by included studies. A range of methodologies were utilised, including Interpretative Phenomenological Analysis (IPA) which allows for an in-depth exploration of individual experiences (Dos Santos & Beavan, 2010; Lewis et al., 2020, Mawson et al., 2011; Mayer et al., 2022; Milligan et al., 2013; Newton et al., 2007; Payne et al., 2017; Watkins et al., 2020). Thematic Analysis, used in Bogen-Johnston et al., (2017); Craig et al., (2017); Hayward et al., (2015); McCarthy et al., (2021); Oakland and Berry, (2014); Sheaves et al., (2021); and Sinha and Ranganathan., (2020), also allows for an exploration of individual experience, but perhaps in less depth than what is expected in IPA. Studies also used Qualitative Content Analysis (Coffey& Hewitt, 2008; Nkouth et al., 2010), Grounded Theory (Goodliffe et al., 2010; Jackson et al., 2010), Narrative Enquiry (De Jager et al., 2016), "Hermeneutical Phenomenological Approach" (Kalhovde et al., 2014) and Foucauldian Narrative Analysis (Parry et al., 2021). All papers either explicitly or implicitly outlined the aims or research question guiding their study except for Nkouth et al. (2010) who did not provide a direction for their research, making it difficult to understand their rationale; some papers also appeared to not justify their chosen methods (Hayward et al., 2015; Newton et al., 2007; Oakland & Berry, 2014), or did not explain the type of qualitative method adopted (Yttri et al., 2020). Sheaves et al. (2021), in particular, did not explain their rationale for adopting a thematic analysis approach on grounded theory data from a prior study.

#### **Recruitment and Participants**

Most papers explored experiences solely from the perspective of the voice hearers, apart from Coffey and Hewitt (2008) and Mayer et al. (2022) who included nurses' and parents' accounts respectively. Fourteen papers recruited only in the UK, whilst others recruited from India (Singha & Ranganathan 2020), the United States and Ireland (McCarthy et al., 2021); Norway (Kalhovde et al., 2010); Denmark (Yttri et al., 2010), Canada (Nkouth et al., 2010); England and Australia (Hayward et al., 2015) and Australia (De Jager et al., 2016; Dos Santos & Beavan, 2015). Parry et al. (2021) drew experiences from participants across eleven different countries.

Of the eight studies that included information about participant ethnicity, two papers included participants who were all White-British (Watkins et al., 2020; Lewis et al., 2020). Whilst the remainder included a wider range of ethnicities, the majority of participants were White or White-British (Sheaves et al., 2021; Payne et al., 2017; Mayer et al., 2022; Jackson et al., 2010; Goodliffe et al., 2010; De Jager et al., 2015). All but four papers specified the gender of their participants (Mawson et al., 2011; Nkouth et al., 2010; Oakland & Berry, 2014; Sheaves et al., 2021). Three papers specifically recruited "young people" (<19 years old) to explore their experiences (Mayer et al., 2022; Newton et al., 2015; Parry et al., 2021) and the remainder sampled adults over the age of 18. Whilst qualitative data does not aim for generalisable results in the sense that quantitative data does, the majority of findings reflect experiences from mostly White adults. This may skew experiences away from different cultural understandings of voices, such as those where voices are understood to be a positive entity or linked closely to spirituality (Luhrmann et al., 2015), which perhaps influences how voices may be shared with others. The bias towards adult participants also fails to account for different experiences that may occur from the perspectives of young people, who have been described as having a "broad understanding" of what HV means (Parry et al., 2021).

#### **Data Collection**

All studies provided sufficient detail about the data collection process. 15 papers included information about the questions used during data collection. Interview schedules were provided in appendices (Goodliffe et al., 2010; Mayer et al., 2022; Sheaves et al., 2021) and included in full-text tables (Craig et al., 2017; McCarthy et al., 2021). One paper explicitly referenced the Maastricht Hearing Voices Questionnaire (Sinha & Ranganathan, 2020), whilst those who opted for IPA methodology included the broader guiding questions from their interviews (Dos Santos & Beavan, 2015; Mawson et al., 2011; Newton et al., 2007; Watkins et al., 2020). Some presented the broad topics explored in interviews (Oakland & Berry, 2014; Hayward et al., 2015; Nkouth et al., 2010, Yttri et al., 2020) whilst Coffey and Hewitt (2008) provided some example questions from their schedule. The eight remaining papers provided no indication of questions used to collect their data. This lack of transparency makes it difficult to judge the credibility and coherence of the analysis and presented findings in these papers.

Patient and public involvement in research is something that can help to address power inequalities and to promote diversity and inclusion of perspectives (Ocloo et al., 2021). Of the selected papers, only seven included some form of lived experience or "stakeholder" involvement (Craig et al., 2017; Mawson et al., 2011; Mayer et al., 2022; Oakland & Berry, 2014; Payne et al., 2017; Sheaves et al., 2021; Parry et al., 2021), whilst the remaining 16 did not.

#### Data Analysis and Findings

All studies which used IPA and Thematic Analysis had appropriate participant numbers for their chosen research design (Clarke, 2010; Fugard et al., 2010) except for two. Craig et al. (2017) and McCarthy et al. (2021) recruited five and three participants respectively whilst using Thematic Analysis, which is arguably too small a sample for this methodology (Clarke & Braune, 2013); IPA may have been a more appropriate methodology, particularly as both studies explored lived experience in depth embodying the idiographic and subjective nature of IPA (Biggerstaff & Thompson, 2008). Those which use grounded theory were guided by theoretical saturation rather than an a-priori sample size, in line with literature recommendations (Vasileiou et al., 2018). One study failed to clearly state the method of analysis, leaving it difficult to understand how this linked to the research question (Yttri et al., 2020), this lack of clarity made it difficult to evaluate the appropriateness of the sample.

All findings were presented with sufficient supportive data relevant to the research question in cases where this was clearly defined (excl. Nkouth et al., 2010). Most papers discussed credibility of their findings, yet three papers failed to describe any methods used to assure such credibility (Goodliffe et al., 2010; Mayer et al., 2022; Nkouth et al., 2010). Most commonly, researchers discussed their codes and themes with other members of the research team, but in some cases, themes were checked by individuals with lived experience (Oakland & Berry, 2014; Parry et al., 2021; Sheaves et al., 2021), checked with the participants themselves (Jackson et al., 2010; Payne et al., 2017; McCarthy et al., 2021), or both (De Jager et al., 2016; Craig et al., 2017).

Multiple coders increase the diversity of perspectives but may cause challenges in reaching consensus. It is argued that this increases the rigour of analysis (Barbour, 2001)

regardless of whether it involves respondent validation or lived experience insight. However, there is a lack of consensus regarding the utility of multiple coders and respondent validation; validity in qualitative methods is a contentious topic, with qualitative research and validity described as an oxymoron due to the apparent mis-match between them as concepts (Onwuegbuzie & Leech, 2007). Braun & Clarke (2021), for example, argue that discussing codes is helpful due to the facilitation of reflection, but multiple coders to reach consensus is not required.

In terms of presented findings, all were discussed well in relation to relevant literature and implications appeared sensible and related to the research question. Regarding future directions, all but six studies recommended areas for exploration of further research (Bogen-Johnston et al., 2017; Coffey & Hewitt, 2008; Nkouth et al., 2010; Oakland & Berry 2014; Sinha & Ranganathan, 2020; Yttri et al., 2020).

#### **Reflexivity and Ethics**

Reflexivity is a fundamental aspect of qualitative research (Lazard & McAvoy, 2020) and consideration of reflexivity occurred in over half of the papers. Some researchers adopted methods such as using a reflexive journal or engaging in an interview or discussion to attempt to explore their biases (Craig et al., 2017; Hayward et al., 2015; Jackson et al., 2010; Lewis et al., 2020; Mawson et al., 2011; Milligan et al., 2013; Parry et al., 2021). Others, in lieu of a bracketing process, simply included a detailed reflection of their positioning and pre-existing biases within their research papers (i.e. Goodliffe et al., 2010). Other researchers mentioned reflexivity, but did not provide information about the processes underpinning this (De Jager et al., 2016; Dos Santos & Beavan, 2016; McCarthy et al., 2021; Watkins et al., 2020). The remaining nine papers failed to include any information about reflexivity, which reads as problematic during appraisal as reflexivity can increase credibility of findings due to an awareness of how one's bias may impact the analysis (Jootun et al., 2009).

Ethical approval was clearly discussed in all but four papers (Newton et al., 2007; Nkouth et al., 2010; McCarthy et al., 2021; Jackson et al., 2010); a large range of papers were lacking information on the more intricate ethical procedures, such as right to withdraw and participant wellbeing.

#### Summary

Of the 23 studies discussed, all were included in the final thematic synthesis, even if their quality appraisals were poor. For example, Nkouth et al. (2010) failed to clearly outline a research question, making it difficult to conduct further appraisals whilst Yttri et al. (2020) lacked clarity around how data were analysed. The decision to include all papers was rooted in the idea that whilst studies can be excluded (and it is sometimes appropriate to do so), the impact on final synthesis can be minimal (Carroll et al., 2012). This is, however, something that was noted during analysis to ensure no significant skewing of themes from poorer quality research.

#### **Thematic Synthesis**

To ensure a detailed synthesis, this was conducted in a multi-staged manner. Firstly, the relevant data was imported into coding software NVivo. Data was then coded line by line and codes were kept close to the initial data (e.g. "worried about parent's reaction"). In practice, this meant that new codes were given to each line or relevant codes were reapplied where appropriate; this resulted in 198 initial raw codes. Both semantic and latent codes were created to capture data relevant to the research question, and throughout the process, the researcher kept notes about potential thematic links as they emerged. Furthermore, a

research-trained colleague was given a random selection of three papers to check the validity of the codes. Codes were discussed and there was no disagreement about their relevance. Once the initial line-by-line coding was complete, codes were grouped together by relevance to create 16 initial descriptive themes (e.g. "fear of other's reactions) . Prior to the development of overarching interpretative themes, the papers were re-read and some new codes were applied whilst others were discarded. Finally, descriptive themes were refined and wider interpretative themes were created, capturing the data in a way that related to the review question (e.g. "Feeling ashamed: others will see "crazy" if they know").

The final thematic analysis of the papers resulted in the generation of four themes, some of which contained subthemes (Table 4). Relevant quotes from papers have been selected to illustrate the findings, and distribution of themes is shown in Table 5. Please refer to Appendix B for NVivo coding excerpts.

#### Table 4

Theme	Contration of the second
Theme	Subthemes
1. Telling others can mark a journey towards	
help	
2. A need for safety and understanding	2.1 Empathy from those with a shared
	experience creates safety
	2.2 Sharing without shared experience:
	seeking to be understood
	seeking to be understood
2 Disalogura can load to (fourad) nagativa	3.1 Feeling ashamed: others will see
3. Disclosure can lead to (feared) negative	e
consequences	"crazy" if they know
	3.2 Others need to be protected from the
	burden of voices
4. Sharing to reduce shame: A way to move	-
forward with voices	

Themes and subthemes created from dataset

# Table 5Theme distribution

mark a journey2.1 Empathy from those with2.2 Sharing without shared3.1 Feeling ashamed:3.2 Others need to be protectedshared waytowards helpa sharedexperience:others will seefrom the burdenmov forw		1. Telling others can	2. A need for safety and understanding		3. Disclosure ca (feared) negati	4. Sharing to reduce	
et al. (2017) Coffey & $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Hevitit (2008) Craig et al. (2017) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ De Jager et al. (2016) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Beavan (2015) $\checkmark$ $\checkmark$ $\checkmark$ Goodliffe et al. (2010) Hayward et al. (2016) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2015) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2016) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2017) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2018) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2019) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2019) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2011) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Mawson et al. (2022). Milligan et al. (2021) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2012) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2013) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2014) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Newton et al. (2015) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2017) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2018) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2019) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2019) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2011) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2011) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2012) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2013) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2014) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2015) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2017) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2018) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2019) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2019) $\land$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2014) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2014) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2014) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ (2015) $\checkmark$		mark a journey towards	2.1 Empathy from those with a shared experience	without shared experience: seeking to be	3.1 Feeling ashamed: others will see "crazy" if they	3.2 Others need to be protected from the burden	shame: A way to move forward with voices
Hevrit (2008) Craig et al. (2017) De Jager et al. (2016) Do Santos & Beavan (2015) Goodliffe et al. (2010) Hayward et al. (2015) Jackson et al. (2015) Jackson et al. (2016) Jackson et al. (2017) Jackson et al. (2017) Mawson et al. (2017) Mawson et al. (2017) Mawson et al. (2017) Milligan et al. (2017) Nevton et al. (2017) Nevton et al. (2017) Nevton et al. (2017) Nevton et al. (2017) (2018) (2017)		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
2017) $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ De Jager et al. $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Dos Santos & $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Goodliffe et $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Hayward et al. $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ $\checkmark$ Jackson et al. $\checkmark$			$\checkmark$	$\checkmark$			$\checkmark$
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Sheaves et al. (2021) Sinha & Ranganathan (2020)	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	25
Watkins et al. (2020)	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
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*Note:* The theme distribution table demonstrates the variability of theme frequency across papers. Papers which contained more disclosure-related data appear to have a higher theme frequency compared to those which disclosure was only a small part of their findings.

#### Quality assurance

During thematic synthesis the same methods of quality assurance were employed to those used during initial quality appraisal. Researcher reflexivity was facilitated through the use of research supervision and discussions with peer researchers. Additionally, a brief bracketing interview was completed with a research peer to explore expectations from the analysis. These methods were utilised to help the researcher recognise how their subjectivity and context may influence the development of themes, as suggested by Olmos-Vega et al. (2023).

#### 1. Telling Others Can Mark a Journey Towards Help

Needing help led voice hearers to disclose their experiences in five papers (Bogen-Johnston et al., 2017; Milligan et al., 2013; Craig et al., 2017; Lewis et al., 2020; Yttri et al.,2020), whilst not perceiving they needed help acted as a reason to keep voice-hearing experiences to themselves (Bogen-Johnston et al., 2017; Lewis et al., 2020). For some, it seemed that they had little choice with the voices pushing them to crisis point, which although was a distressing experience, meant that they could access help:

"It was like an explosion in my head and then the voices just took over completely...I was in the cell for two and a half hours just listening to these voices going over and over in my head. Sam then described how it was "then I told my dad that I thought I needed help and then I went to the doctors." (Milligan et al., 2013)

"As voices continued, a vital point in the journey was reached: hearers felt that they had no other alternative but to disclose their experiences, enabling them to seek professional help and support from others" (Bogen-Johnston et al., 2017)

This decision to disclose was seen to be an important part of the help-seeking process:

"Participants described a process that determined whether they sought external help. For some, disclosing their experiences was an important part of this process." (Lewis et al., 2020)

In some cases, disclosure and help were closely linked. Those seeking help did disclose, whereas those not seeking help seemed to withhold. For one, he "*hadn't felt as though he needed additional help as he had already sought the help of god'*" (Lewis et al., 2020),

demonstrating the possible relationship between existing personal resources and disclosing to seek help.

#### 2. A Need for Safety and Understanding

The need for safety and understanding was referenced across all 23 papers. This was in the context of sharing with other voice-hearers and people without lived experience.

2.1 Empathy from Those with a Shared Experience Creates Safety. The impact of sharing with other voice-hearers and receiving empathy was discussed in 15 papers. Experiences were explored in relation to voice-hearing groups (Dos Santos & Beavan, 2015; De Jager et al., 2016; Goodliffe et al., 2010; McCarthy et al., 2021; Newton et al., 2007; Oakland & Berry, 2014; Payne et al., 2017; Sheaves et al., 2021;) and general discussions with those with shared experiences (Coffey & Hewitt, 2008; Jackson et al., 2010; Milligan et al., 2013; Watkins et al., 2020). Groups were seen to be safe spaces where other voice hearers could understand and accept voice-hearing experiences, which perhaps could not be done elsewhere. One paper notes: "peers with similar difficulties were more able to understand and empathize with their difficulties, and therefore more able to provide them with meaningful support" (Newton et al., 2007)

For some, the sharing in this context enabled them to feel better prepared to share their experiences more widely:

"informants feeling more able to speak about their voices experiences with others outside of the group: I am more comfortable to talk with them (parents) and my grandparents and my auntie and uncle, and that's from the group" (Dos Santos & Beavan, 2015) One participant inferred the value of disclosing to others with lived experiences, implying that those without simply could not understand:

"Alice, spoke about how she felt she "couldn't talk to [her] friends" because they had not encountered the same experiences as her." (Lewis et al., 2020)

Important to note, however, is that one participant highlighted his disdain for sharing with other voice-hearers, providing a contradictory account to other participant experiences in the same paper:

"'the last bloody thing I'd want to do is talk about...somebody else's...illness...I have enough of my own'. Eric was concerned that talking to other voice hearers would add to the burden of his symptoms" (Coffey & Hewitt, 2008)

Despite this, seemingly common narratives encapsulated the safety of sharing amongst others with lived experience. Group settings were seen to be a place where voice-hearers could openly disclose without judgement and be understood. Whilst outside of groups, opportunistic sharing with others with lived-experience appeared to provide equivalent value to voice-related groups.

**2.2 Sharing Without Shared Experience: Seeking to be Understood.** Participants discussed their experiences of disclosing to those without lived experience, some of which were positive, and some less helpful. 18 papers (all except: Goodliffe et al., 2010; Jackson et al., 2010; Milligan et al., 2013; Nkouth et al., 2010; Payne et al., 2017) made reference to experiences sharing with friends and family, colleagues and professionals.

Many people either feared or had experienced a lack of understanding from people who did not hear voices themselves. This left a prevailing sense of loneliness around the experience of voice-hearing and a wish to be understood, as one participant notes when speaking to her mum that "*She understand, but she didn't*" (Newton et al., 2007). This absence of relational understanding also spanned to interactions with professionals. For some, this was due to a lack of trust, either from professionals sharing the voice-hearer's experiences without permission (Kalhovde et al., 2014), discussing their experiences in "*narrow contexts*" (Hayward et al. 2015), not taking conversations seriously (Craig et al., 2017), or receiving particularly medicalised responses in abrupt conversations (Oakland and Berry, 2014).

Whilst studies mentioned the impact of a lack of safety and understanding, others described contrary accounts of compassionate relationships where they felt able to share their experiences with those without lived experience. For one participant, sharing helped his family to *"develop a deeper understanding of his experiences and needs in the context of voice hearing"* (Mawson et al., 2011). Professionals could be seen to provide a space for voice-hearers to talk openly, perhaps with an assumption that they will understand:

"when this is actually happening it can be very frightening and if you can talk to someone who's got some kind of understanding about it, it would help" (Coffey & Hewitt, 2008)

It was particularly important that these experiences were shared "*in the context of a therapeutic relationship with the nurse*" (Coffey & Hewitt, 2008), or with "*Care providers whom they trusted*" (Kalhovde et al., 2014). What appears to be common is the need for safety and acceptance in disclosure relationships, and the value of feeling understood:

"All participants talked about being understood as being important to them" (Lewis et al., 2020)
Despite there being a range of experiences of disclosing to those without lived experience, the recipient of the disclosure may be less important, instead, having a relationship built on respect and trust appears to be the necessary condition for disclosure to feel safe.

"talk to somebody, who, anybody that they've got some kind of respect for, so you know that could be like a GP or it could be a support worker, or if they've got a really good friend" (Hayward et al., 2015)

## 3. Disclosure can lead to (feared) negative consequences

14 papers outlined fears about the negative impact of sharing voice-hearing experiences. Whilst for some this conversation was based around feelings of shame and judgement, others related this to the feared negative burden on others.

**3.1 Feeling ashamed: others will see "crazy" if they know.** Explicit ideas of shame were touched upon in the following papers: Bogen-Johnston et al. (2017); Kalhovde et al. (2014); Mayer et al. (2022); Payne et al. (2017); Watkins et al. (2020). Voice-hearers explained that HV was something shame-laden for them, and this could lead to a reluctance to share experiences with others. One participant reported "*I didn't feel I could really tell people. I felt quite ashamed*" (Payne et al., 2017) and similar shameful feelings led others to not share their experiences: "*I didn't tell my family for months, and months, and months. I kept it to myself*." (Bogen-Johnston et al. 2017). Others chose not to speak about their voices to keep the associated "*traumatic or shameful experiences (e.g. sexual and physical abuse)*" (Kalhovde et al., 2014) concealed.

As well as being a pre-emptive barrier to disclosure and a fear for many, for some, others' reactions to their disclosure reinforced shameful feelings. People "*responded with* 

*panic and distress, which led to the participant feeling upset and ashamed*" (Watkins et al. 2020). Upon disclosing to their family, one account described believing "*her family felt that her experiences brought shame to the family as a whole*" (Watkins et al. 2020). Shame seemed to encapsulate voice hearers' perceptions of having something fundamentally wrong with them, perhaps representing a form of internalised stigma, reinforced by strong societal narratives and media portrayals of voice hearers as mad and unsafe (Watkins et al., 2003).

Across many papers, participants were largely fearful of being judged. For some, this manifested in a fear of being seen as crazy. People want to avoid sharing their experiences for fear of being "considered 'crazy and unfit to work" (Craig et al., 2017), seen as "Barking [mad]" (Bogen-Johnston et al., 2017), "Insane" (Parry et al., 2021), and causing "others to doubt their sanity" (Kalhovde et al., 2014), feeling "Looked upon [...] differently" (Yttri et al., 2020). This was even evident in the interview for some participants, where they checked whether they were being perceived as "unusual" or "bizarre" (Lewis et al., 2020). Furthermore, participants had worries about the possible removal of children (Kalhovde et al., 2014) or being remanded involuntarily into treatment (Watkins et al., 2020; De Jager et al., 2016). For one participant, a powerful image of their imagined judgements were depicted:

" "I don't think they'd ... look at it too nicely ... [PAUSE] ... they'd, they'd think I was a monster or something like that" (Watkins et al., 2020)

In one example, disclosure was used to mitigate the risk of judgement so that others could understand when they responded to voices (Sheaves et al., 2021). In cases where avoiding sharing wasn't possible, remaining "*cautious when discussing their voice hearing experiences*" was utilised as a strategy to manage the negative perceptions that others may hold (Watkins et al., 2020). It appears that even when others are invited into the world of the

voice-hearer, there remains a self-protective barrier in place to manage the consequences of disclosure.

**3.2 Others Need to be Protected from the Burden of Voices.** Six papers discussed the possible impact of disclosure on others. There was a focus on protection, particularly feelings that other people needed to be shielded from their voice-hearing experiences. Shared information was viewed as burdensome, leading some to opt for dealing with experiences by themselves:

"Did you tell anybody about it? No! Why not? I wanted to help myself. I wanted to get rid of it myself instead of putting the burden on other people. (P12)" (Bogen-Johnston et al., 2017)

"This seemed related to participants' belief that they were a 'burden' (Pat) on other people and fuelled a need for independence from social others" (Mawson et al., 2011)

"a relational barrier to disclosing voice hearing was that young people were concerned about protecting others" (Parry et al., 2021)

Individuals used non-disclosure as a way to manage others' emotions. They hid their voices because for others, they "*don't want them to get upset*" (Mawson et al., 2011) and "*don't want her to get hurt by it [...] there's no good that can come from it by telling her*" (Sheaves et al., 2021). It was felt that in addition to freeing others from 'burden', keeping their experiences a secret could also keep others safe from the voices themselves:

"her family would come to harm if she told them: 'if I told someone else they would also know, and then the [voices] would try and kill them as well'". (Sheaves et al., 2021)

#### 4. Sharing to Reduce Shame: A Way to Move Forward with Voices

In over half of the papers, positive outcomes associated with sharing voice-hearing experiences were noted. Conflicting with previous subthemes which posited shame as a barrier to disclosure, disclosure was also described as somewhat of an antidote to shame. Individuals felt pleasantly surprised that their experiences were accepted by others, and *"calmer responses appeared to reduce some of the shame and fear"* (Watkins et al., 2020). Practically, sharing experiences had a positive impact on the reducing distress that voices were able to cause and increasing voice hearer's coping skills. Ultimately, sharing was described as *"helpful to the process of understanding their experiences"* (Bogen-Johnston et al., 2017), and this sentiment is reaffirmed by the below quote:

"yeah I think it's important that you talk to them because it it's a good way of getting things out into the open and analysing them and sort of making assumptions as to what's causing this to happen" (Coffey & Hewitt, 2008).

Opening up was one of the "*control strategies*" (Singha & Ranganathan, 2021) used by some who experienced talking to professionals as particularly therapeutic. Others found that they could also begin to accept reassurance from listeners, which helped them to live with their voices (Coffey & Hewitt, 2008). Notable differences in the power that voices held over participants also stemmed from disclosure as illustrated below:

"One participant described how, when he met a care provider who listened to what he had to say, he could cry and the knot inside him was loosened, he was able to sleep and the voices lost their power" (Kalhovde et al., 2014)

"'the more I could open up, the more I let my mates know, the more everything has settled down' (V5)" (Sheaves et al., 2021).

#### Theme summary

Seemingly, sharing voice-hearing experiences requires much consideration. Individuals not only felt weighed down by the shame and judgement they felt, but also felt a duty to protect others from any distress associated with their disclosure. Despite the perceived negative consequences, voice hearers could experience a positive change upon disclosing. This was in the context of a reduction in shame and a better relationship with their voices, ultimately redistributing the power back to the individual.

# Discussion

This report intended to systematically review experiences of those who share their voice- hearing experiences with others by thematically synthesising relevant data reported in qualitative studies on this topic. The review sought to answer the question "What are voice hearers' experiences of sharing their voice-hearing experiences with others?". Thematic synthesis produced four overarching themes and findings are discussed in the context of relevant literature and clinical implications. Limitations and recommendations for future research are also outlined.

The findings from the theme "**Telling others can mark a journey towards help**" outlined that sharing voice-hearing experiences can facilitate help-seeking processes. This is something that has been a suggested function of sharing other mental health related information. In research exploring concealment of serious mental illness, Bril-Barniv et al. (2017) found that disclosure could lead to support from others, which could address unmet psychological needs. Similarly, research has indicated that young people at risk of psychosis, when speaking to "the right people" can open up and seek help, although this may only happen when approaching breaking point (Gronholm et al., 2017), as also reflected by some studies in the current review. The theme **"a need for safety and understanding"** was explored in relation to two subthemes: **"empathy from those with a shared experience creates safety"** and **"sharing without shared experience: seeking to be understood"**. Disclosing to others with a shared experience, where individuals can be accepted and not judged, was framed as invaluable. Similar sentiments are echoed in perinatal and men's mental health settings, where a sense of shared understanding is truly valued (Law et al., 2021; Vickery, 2022). Gronholm et al. (2017) also cite this, stating that the ability to relate to someone depends largely on similar characteristic or shared similar experiences.

Interestingly, the idea of support groups as a helpful place to disclose is something that is not entirely agreed upon. Other findings from the psychosis literature have argued that groups of this type can be "disappointing" or "insufficient" (Compodonico, 2017). Whilst this could be indicative of a difference between those disclosing in support settings for psychosis in comparison to HV groups, it may also be something unique to the experience of younger clients as this is the reflective demographic in Compodonico's research. Largely, sharing with others with similar experiences appears to be valuable and can be a supportive mechanism for wellbeing.

In terms of sharing with non-voice hearers, the sentiment that close relationships are imperative is also reflected in the psychosis literature. Trust in interpersonal relationships appears to mitigate risks of negative disclosure consequences, such as gossip, when sharing with those who do not have similar experiences, (Gronholm et al., 2017). When discussing with professionals, again the characteristics of kindness and patience without judgement are noted to be key (Campodonico et al., 2022). This reaffirms the importance of relational safety when managing complex disclosure situations.

The third theme, **"disclosure can lead to (feared) negative consequences"**, is split into two subthemes: **"Feeling ashamed: others will see "crazy" if they know"** and **"others need to be protected from the burden of voices"**. Sharing experiences of HV created shameful feelings, bringing shame upon the family for some. Research in China on sharing mental illness reflects similar themes; individuals feel ashamed due to stigma, and family members view them as shameful (Chen et al., 2013). This is also a concern in the UK and Australia, as individuals with psychosis tend to avoid disclosing for fears of negative judgements (including labelling and stigma), shame, and rejection (Burke et al. 2016; Gronholm et al., 2017; Hampson et al., 2020). Research specific to 'psychosis' has shown that individuals fear disclosing their experiences to others due to feeling burdensome, fearing potential harm, and wanting to avoid being treated differently (Burke et al., 2017; Campodonico et al., 2022; Gronholm et al., 2017). These concerns also present as barriers to disclosure for voice-hearers in the current review.

The final theme, "**sharing to reduce shame: a way to move forward with voices**" encapsulated voice hearers' understanding that sharing experiences can help to reduce shame whilst also helping them to cope. This appeared paradoxical, because on the one hand sharing felt shameful, whilst on the other it was a tool to fight this. Bril-Barniv et al. (2017) found that telling others about mental illness led to a sense of freedom and was a means to support recovery and to fight stigma. Disclosure may also help others to understand and can help to build better communication and attitudes (Hampson, 2020), demonstrating that sharing in itself can be a helpful approach to nurturing wellbeing.

When considering existing models of disclosure, the findings from this review appear to map onto processes within the DDMM (Greene, 2009) and less so to the DPM (Chaudoir & Fisher, 2010). In Greene's model, it is proposed that sharers are assessing information, the receiver, and their disclosure efficacy. Findings of this review indicate that individuals do indeed assess the weight of stigma and the impact of disclosure on others whilst monitoring the strength and safety of the disclosure relationship. Little attention however was found to relate to the sharer's ability to communicate information effectively. In terms of the DPM, the current findings did not seem to describe processes that fit into the avoidance or approach goals, nor did they explicitly highlight a feedback loop. However, papers did discuss the role of stigma and again reference the importance of others' reactions, which were either supportive or unsupportive.

### **Clinical Implications**

Firstly, it is important to note that the experiences highlighted within this review may not be unique to those who hear voices, and instead may provide some insight into the shared experiences of disclosing mental health difficulties across different typically stigmatised diagnoses. Regardless, healthcare professionals may wish to consider the barriers in place for voice-hearers in disclosing their experiences and seeking help, particularly as diagnoses related to voice-hearing remain increasingly stigmatised in comparison to other mental health disorders (Hazell et al., 2022). Professionals may be able to alleviate some fears by actively exploring them i.e. naming the feared consequence, such as being sectioned, and opening up discussion around this safely. They may wish to use the DDMM (Greene, 2009) as a framework to understand that voice hearers may be wary of stigma and the impact of their disclosure on others, as well as holding concerns about practitioners' reactions and their relationship. Working with these possible barriers may help the process of disclosure, as has been shown to be the case for other diagnoses (i.e. as shown in Greene et al., 2013).

Furthermore, NICE recommends family intervention and peer support for 'psychosis' and/or 'schizophrenia' (NICE, 2014); to take this further, the current review indicates that

offering family spaces for those who hear voices, regardless of diagnosis, may be useful to help manage ideas of stigma, judgement, and perceived pressure within family systems around the voice hearer. This aligns with the valued principles of Open Dialogue, whereby dialogical approaches are understood to be healing within a network through the creation of shared emotional experiences of new shared language (Seikkula & Trimble, 2005). Finally, there is benefit of voice-hearers discussing their experiences with those with lived experience. Services may wish to ensure that this is an available option either through signposting to HV Network groups or the provision of peer support even if a diagnostic label of 'schizophrenia' or 'psychosis' isn't indicated.

## **Future Research**

Future research would benefit from qualitatively exploring the experiences of sharing voice-hearing experiences from a more ethnically diverse perspective. This is particularly important as research suggests that there is a difference in the way that these experiences are understood, thus disclosure process may reflect this difference (Luhrmann et al., 2015). Furthermore, young people's disclosure experiences could also be qualitatively researched. Research may also wish to focus on the disclosure recipient's experiences of conversing with the voice-hearer; this may be family, friends, or professionals. In particular, the process of engaging in these conversations may be of interest. Any findings from those studies can be compared to the findings from this review to note common themes between those involved in the conversation.

# Limitations

For a relatively large meta-synthesis with broad inclusion criteria, involving 23 papers, the lack of diversity of the papers may have impacted the findings. Firstly, nearly all papers involved participants who are predominantly White, which may skew the findings

towards a White lens, which undoubtedly has been reinforced by the analysis being completed by a White-British researcher. This is also the case for age brackets, as nearly all papers drew solely on adult experiences, thus further limiting transferability of the findings. A final limitation to note is that very few research papers focussed solely on the experiences of sharing voice-hearing. For some papers, this was only present in part of the qualitative findings; the synthesis of data in this review may therefore be disproportionately representative of those papers with richer related findings and is something that should be noted when engaging with the presented results. Despite this, protocols to increase levels of rigour in this review were applied such as the use of CASP appraisals and peer-reviews of codes and themes.

## Conclusion

By systematically searching and thematically synthesising existing qualitative research from the voice- hearing literature, this review sought to provide an updated insight into the experiences of sharing one's voice-hearing experience with others. Four main themes were derived, some with associated subthemes, which highlighted the existing fears associated with disclosure, as well as some of the positive qualities. Methodologically, studies were largely robust; critiques arose largely in studies that failed to examine the relationship between researcher and participant in sufficient depth. Due to the lack of diversity in age and ethnicity among these papers, the findings may not be applicable crossculturally. Future research directions and clinical implications arose from the findings and were outlined for future use.

#### References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596
- Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog?. *BMJ*, *322*(7294), 1115-1117. <u>https://doi.org/10.1136/bmj.322.7294.1115</u>
- Beavan, V., Read, J., & Cartwright, C. (2011). The prevalence of voice-hearers in the general population: a literature review. *Journal of Mental Health*, 20(3), 281-292. https://doi.org/10.3109/09638237.2011.562262
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214-224. https://doi.org/10.1080/14780880802314304

Braun, V., & Clarke, V. (2021). Thematic analysis: A practical guide. Sage Publications.

- Bril-Barniv, S., Moran, G. S., Naaman, A., Roe, D., & Karnieli-Miller, O. (2017). A qualitative study examining experiences and dilemmas in concealment and disclosure of people living with serious mental illness. *Qualitative Health Research*, 27(4), 573-583.
  <a href="https://doi.org/10.1177/1049732316673581">https://doi.org/10.1177/1049732316673581</a>
- Burke, E., Wood, L., Zabel, E., Clark, A., & Morrison, A. P. (2016). Experiences of stigma in psychosis: A qualitative analysis of service users' perspectives. *Psychosis*, 8(2), 130-142. <u>https://doi.org/10.1080/17522439.2015.1115541</u>
- Bogen-Johnston, L., de Visser, R., Strauss, C., Berry, K., & Hayward, M. (2019). "That little doorway where I could suddenly start shouting out": Barriers and enablers to the disclosure

of distressing voices. Journal of Health Psychology, 24(10), 1307-1317.

https://doi.org/10.1177/1359105317745965

- Campodonico, C., Varese, F., & Berry, K. (2022). Trauma and psychosis: a qualitative study exploring the perspectives of people with psychosis on the influence of traumatic experiences on psychotic symptoms and quality of life. *BMC Psychiatry*, 22(1), 1-12. <u>https://doi.org/10.1186/s12888-022-03808-3</u>
- Carroll, C., Booth, A., & Lloyd-Jones, M. (2012). Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews. *Qualitative Health Research*, 22(10), 1425-1434. https://doi.org/10.1177/1049732312452937
- Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity. *Psychological bulletin*, *136*(2), 236. <u>https://doi.org/10.1037/a0018193</u>
- Chen, F. P., Lai, G. Y. C., & Yang, L. (2013). Mental illness disclosure in Chinese immigrant communities. *Journal of Counseling Psychology*, 60(3), 379. https://doi.org/10.1037/a0032620
- Clarke, V. (2010). Review of the book "Interpretative Phenomenological Analysis: Theory, Method and Research". *Psychology Learning & Teaching*, *9*, 57-56.
- Clarke, V., & Braun, V. (2013). *Successful qualitative research: A practical guide for beginners.* Sage publications.

- Coffey, M., & Hewitt, J. (2008). 'You don't talk about the voices': Voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing*, *17*(12), 1591-1600. <u>https://doi.org/10.1111/j.1365-2702.2007.02185.x</u>
- Cooke, A. (ed) (2014) Understanding Psychosis and Schizophrenia. Leicester: British Psychological Society. Available at: <u>http://www.bps.org.uk/networks-andcommunities/member-</u> microsite/division-clinical-psychology/understanding-psychosis-andschizophrenia
- Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, 22(10), 1435-1443. <u>https://doi.org/10.1177/1049732312452938</u>
- Craig, L., Cameron, J., & Longden, E. (2017). Work-related experiences of people who hear voices: An occupational perspective. *British Journal of Occupational Therapy*, 80(12), 707-716. <u>https://doi.org/10.1177/0308022617714749</u>
- De Jager, A., Rhodes, P., Beavan, V., Holmes, D., McCabe, K., Thomas, N., McCarthy-Jones, S., Lampshire, D. & Hayward, M. (2016). Investigating the lived experience of recovery in people who hear voices. *Qualitative Health Research*, 26(10), 1409-1423. <u>https://doi.org/10.1177/1049732315581602</u>
- Dos Santos, B., & Beavan, V. (2015). Qualitatively exploring hearing voices network support groups. *The Journal of Mental Health Training, Education and Practice*. <u>https://doi.org/10.1108/JMHTEP-07-2014-0017</u>
- Fugard, A. J., & Potts, H. W. (2015). Supporting thinking on sample sizes for thematic analyses: a quantitative tool. *International Journal of Social Research Methodology*, 18(6), 669-684. <u>https://doi.org/10.1080/13645579.2015.1005453</u>

- Goodliffe, L., Hayward, M., Brown, D., Turton, W., & Dannahy, L. (2010). Group person-based cognitive therapy for distressing voices: views from the hearers. *Psychotherapy Research*, 20(4), 447-461. <u>https://doi.org/10.1080/10503301003671305</u>
- Greene, K. (2009). An integrated model of health disclosure decision-making. In T. Afifi & W. Afifi (Eds.), Uncertainty and information regulation in interpersonal contexts: Theories and applications (pp. 226–253). New York: NY: Routledge.
- Greene, K., Carpenter, A., Catona, D., & Magsamen-Conrad, K. (2013). The brief disclosure intervention (BDI): Facilitating African Americans' disclosure of HIV. *Journal of Communication*, 63(1), 138-158. <u>https://doi.org/10.1111/jcom.12010</u>
- Gronholm, P. C., Thornicroft, G., Laurens, K. R., & Evans-Lacko, S. (2017). Conditional disclosure on pathways to care: Coping preferences of young people at risk of psychosis. *Qualitative Health Research*, 27(12), 1842-1855. <u>https://doi.org/10.1177/1049732316680337</u>
- Hampson, M. E., Watt, B. D., & Hicks, R. E. (2020). Impacts of stigma and discrimination in the workplace on people living with psychosis. *BMC Psychiatry*, 20(1), 1-11. https://doi.org/10.1186/s12888-020-02614-z
- Hassett, A., Green, C., & Zundel, T. (2018). Parental involvement: A grounded theory of the role of parents in adolescent help seeking for mental health problems. SAGE Open, 8(4), 1–15. <u>https://doi.org/10.1177/2158244018807786</u>
- Hayward, M., Awenat, Y., McCarthy Jones, S., Paulik, G., & Berry, K. (2015). Beyond beliefs: A qualitative study of people's opinions about their changing relations with their voices. *Psychosis*, 7(2), 97-107. <u>https://doi.org/10.1080/17522439.2014.926388</u>

- Hazell, C. M., Berry, C., Bogen-Johnston, L., & Banerjee, M. (2022). Creating a hierarchy of mental health stigma: testing the effect of psychiatric diagnosis on stigma. *BJPsych Open*, 8(5), e174. <u>https://doi.org/10.1192/bjo.2022.578</u>
- Iudici, A., Quarato, M., & Neri, J. (2019). The phenomenon of "Hearing voices": Not just psychotic Hallucinations—A psychological literature review and a reflection on clinical and social health. *Community Mental Health Journal*, 55(5), 811-818. <u>https://doi.org/10.1007/s10597-018-0359-0</u>
- Jackson, L. J., Hayward, M., & Cooke, A. (2011). Developing positive relationships with voices: A preliminary grounded theory. *International Journal of Social Psychiatry*, 57(5), 487-495. <u>https://doi.org/10.1177/0020764010368624</u>
- Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, *23*(23), 42-47.
- Jones, S., Guy, A., & Ormrod, J. A. (2003). AQ-methodological study of hearing voices: A preliminary exploration of voice hearers' understanding of their experiences. *Psychology and Psychotherapy: Theory, Research and Practice*, 76(2), 189-209. <u>https://doi.org/10.1348/147608303765951212</u>
- Kalhovde, A. M., Elstad, I., & Talseth, A. G. (2014). "Sometimes I walk and walk, hoping to get some peace." Dealing with hearing voices and sounds nobody else hears. *International Journal of Qualitative Studies on Health and Well-Being*, 9(1). http://dx.doi.org/10.3402/qhw.v9.23069
- Kelleher, I., Connor, D., Clarke, M. C., Devlin, N., Harley, M., & Cannon, M. (2012). Prevalence of psychotic symptoms in childhood and adolescence: a systematic review and meta-analysis of

population-based studies. *Psychological Medicine*, *42*(9), 1857-1863. https://doi.org/10.1017/S0033291711002960

- Keller, A. O., Valdez, C. R., Schwei, R. J., & Jacobs, E. A. (2016). Disclosure of depression in primary care: a qualitative study of women's perceptions. *Women's Health Issues*, 26(5), 529-536. <u>https://doi.org/10.1016/j.whi.2016.07.002</u>
- Law, S., Ormel, I., Babinski, S., Plett, D., Dionne, E., Schwartz, H., & Rozmovits, L. (2021). Dread and solace: Talking about perinatal mental health. *International Journal of Mental Health Nursing*, 30, 1376-1385. <u>https://doi.org/10.1111/inm.12884</u>
- Lazard, L., & McAvoy, J. (2020). Doing reflexivity in psychological research: What's the point? What's the practice?. *Qualitative Research in Psychology*, 17(2), 159-177. <u>https://doi.org/10.1080/14780887.2017.1400144</u>
- Levy, Y., & Ellis, T. J. (2006). A systems approach to conduct an effective literature review in support of information systems research. *Informing Science*, *9*.
- Lewis, S. H., Sanderson, C., Gupta, A., & Klein, C. (2020). "Maybe it's kind of normal to hear voices": The role of spirituality in making sense of voice hearing. *Journal of Spirituality in Mental Health*, 22(1), 49-64. <u>https://doi.org/10.1080/19349637.2018.1520183</u>
- Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis.
   *Research Methods in Medicine & Health Sciences*, 1(1), 31-42.
   <a href="https://doi.org/10.1177/2632084320947559">https://doi.org/10.1177/2632084320947559</a>

- Luhrmann, T. M., Padmavati, R., Tharoor, H., & Osei, A. (2015). Hearing voices in different cultures: A social kindling hypothesis. *Topics in Cognitive Science*, 7(4), 646-663. <u>https://doi.org/10.1111/tops.12158</u>
- Mawson, A., Berry, K., Murray, C., & Hayward, M. (2011). Voice hearing within the context of hearers' social worlds: An interpretative phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, 84(3), 256-272.

# https://doi.org/10.1348/147608310X524883

- Mayer, C., Dodgson, G., Woods, A., & Alderson-Day, B. (2022). "Figuring out how to be normal": Exploring how young people and parents make sense of voice-hearing in the family context. *Psychology and Psychotherapy: Theory, Research and Practice*, 95(2), 600-614.
   <a href="https://doi.org/10.1111/papt.12381">https://doi.org/10.1111/papt.12381</a>
- McCarthy, K., Gottheil, K., Villavicencio, E., & Jeong, H. (2021). Exploring voice hearers' occupational experience of romantic and sexual relationships. *The Open Journal of Occupational Therapy*, 9(1). <u>https://doi.org/10.15453/2168-6408.1713</u>
- Mental Health Foundation (2021). *Hearing voices*. Retrieved October 30, 2022, from <a href="https://www.mentalhealth.org.uk/explore-mental-health/a-z-topics/hearing-voices">https://www.mentalhealth.org.uk/explore-mental-health/a-z-topics/hearing-voices</a>
- Merrett, Z., Rossell, S. L., & Castle, D. J. (2016). Comparing the experience of voices in borderline personality disorder with the experience of voices in a psychotic disorder: a systematic review. *Australian & New Zealand Journal of Psychiatry*, 50(7), 640-648. https://doi.org/10.1177/0004867416632595
- Milligan, D., McCarthy-Jones, S., Winthrop, A., & Dudley, R. (2013). Time changes everything? A qualitative investigation of the experience of auditory verbal hallucinations over time.

Psychosis, 5(2), 107-118. https://doi.org/10.1080/17522439.2012.667438

Nadeem, E., Lange, J. M., Edge, D., Fongwa, M., Belin, T., & Miranda, J. (2007). Does stigma keep poor young immigrant and US-born Black and Latina women from seeking mental health care?. *Psychiatric Services*, 58(12), 1547-1554. <u>https://doi.org/10.1176/ps.2007.58.12.1547</u>

National Institute for Health and Care Excellence. (2014). *Psychosis and schizophrenia in adults: prevention and management*. Clinical guideline [CG178]. https://www.nice.org.uk/guidance/cg178

- Newton, E., Larkin, M., Melhuish, R., & Wykes, T. (2007). More than just a place to talk: Young people's experiences of group psychological therapy as an early intervention for auditory hallucinations. *Psychology and Psychotherapy: Theory, Research and Practice*, 80(1), 127-149. <u>https://doi.org/10.1348/147608306X110148</u>
- Oakland, L., & Berry, K. (2015). "Lifting the veil": a qualitative analysis of experiences in Hearing Voices Network groups. *Psychosis*, 7(2), 119-129. <u>https://doi.org/10.1080/17522439.2014.937451</u>
- Ocloo, J., Garfield, S., Franklin, B. D., & Dawson, S. (2021). Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews. *Health Research Policy and Systems*, 19(1), 1-21. <u>https://doi.org/10.1186/s12961-020-00644-3</u>
- Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 45(3), 241-251. https://doi.org/10.1080/0142159X.2022.2057287

- Onwuegbuzie, A. J., & Leech, N. L. (2007). Validity and qualitative research: An oxymoron?. *Quality & Quantity*, *41*, 233-249. <u>https://doi.org/10.1007/s11135-006-9000-3</u>
- Pandya, A., Bresee, C., Duckworth, K., Gay, K., & Fitzpatrick, M. (2011). Perceived impact of the disclosure of a schizophrenia diagnosis. *Community Mental Health Journal*, 47(6), 613-621. https://doi.org/10.1007/s10597-010-9341-1
- Parry, S., Loren, E., & Varese, F. (2021). Young people's narratives of hearing voices: Systemic influences and conceptual challenges. *Clinical Psychology & Psychotherapy*, 28(3), 715-726. <u>https://doi.org/10.1002/cpp.2532</u>
- Payne, T., Allen, J., & Lavender, T. (2017). Hearing Voices Network groups: experiences of eight voice hearers and the connection to group processes and recovery. *Psychosis*, 9(3), 205-215. <u>https://doi.org/10.1080/17522439.2017.1300183</u>
- Peterson, D., Currey, N., & Collings, S. (2011). "You don't look like one of them": disclosure of mental illness in the workplace as an ongoing dilemma. *Psychiatric Rehabilitation Journal*, 35(2), 145. <u>https://doi.org/10.2975/35.2.2011.145.147</u>
- Pilgrim, D. (2007). The survival of psychiatric diagnosis. *Social Science & Medicine*, 65(3), 536-547. <u>https://doi.org/10.1016/j.socscimed.2007.03.054</u>

Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis:

Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiology and Psychiatric Sciences*, *18*(4), 299-310. <u>https://doi.org/10.1017/S1121189X00000257</u>

- Rüsch, N., Brohan, E., Gabbidon, J., Thornicroft, G., & Clement, S. (2014). Stigma and disclosing one's mental illness to family and friends. *Social Psychiatry and Psychiatric Epidemiology*, 49(7), 1157-1160. <u>https://doi.org/10.1007/s00127-014-0871-7</u>
- Seikkula, J., & Trimble, D. (2005). Healing elements of therapeutic conversation: Dialogue as an embodiment of love. *Family Process*, 44(4), 461-475. https://doi.org/10.1111/j.1545-5300.2005.00072.x
- Sheaves, B., Johns, L., Černis, E., Griffith, L., & Freeman, D. (2020). The challenges and opportunities of social connection when hearing derogatory and threatening voices: A thematic analysis with patients experiencing psychosis. *Psychology and Psychotherapy*, 94(2), 341-356. <u>https://doi.org/10.1111/papt.12303</u>
- Sinha, N., & Ranganathan, S. (2020). Living with voices: a thematic analysis of individuals' experiences of voice-hearing in India. *Psychosis*, 12(2), 115-127. <u>https://doi.org/10.1080/17522439.2020.1720271</u>
- Sommer, I. E., Daalman, K., Rietkerk, T., Diederen, K. M., Bakker, S., Wijkstra, J., & Boks, M. P. (2010). Healthy individuals with auditory verbal hallucinations; who are they? Psychiatric assessments of a selected sample of 103 subjects. *Schizophrenia Bulletin*, *36*(3), 633-641. <u>https://doi.org/10.1093/schbul/sbn130</u>
- Sommer, I. E., Koops, S., & Blom, J. D. (2012). Comparison of auditory hallucinations across different disorders and syndromes. *Neuropsychiatry*, *2*(1), 57.
- Stip, E., & Letourneau, G. (2009). Psychotic symptoms as a continuum between normality and pathology. *The Canadian Journal of Psychiatry*, 54(3), 140-151. <u>https://doi.org/10.1177/070674370905400302</u>

- Taitimu, M. (2008). Ngā whakawhitinga: standing at the crossroads: Māori ways of understanding extra-ordinary experiences and schizophrenia [Doctoral dissertation, ResearchSpace Auckland].
- Tien, A. Y. (1991). Distribution of hallucinations in the population. *Social Psychiatry And Psychiatric Epidemiology*, *26*(6), 287-292.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology, 8(1), 1-10. <u>https://doi.org/10.1186/1471-2288-8-45</u>
- Toh, W. L., Thomas, N., & Rossell, S. L. (2015). Auditory verbal hallucinations in bipolar disorder(BD) and major depressive disorder (MDD): A systematic review. *Journal Of Affective*

Disorders, 184, 18-28. https://doi.org/10.1016/j.jad.2015.05.040

Van Os, J., Linscott, R. J., Myin-Germeys, I., Delespaul, P., & Krabbendam, L. J. P. M. (2009). A systematic review and meta-analysis of the psychosis continuum: evidence for a psychosis proneness–persistence–impairment model of psychotic disorder. *Psychological* 

Medicine, 39(2), 179-195. https://doi.org/10.1017/S0033291708003814

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*, 18, 1-18. https://doi.org/10.1186/s12874-018-0594-7

Vickery, A. (2022). 'It's made me feel less isolated because there are other people who are

- experiencing the same or very similar to you': Men's experiences of using mental health support groups. *Health & Social Care in the Community*. <u>https://doi.org/10.1111/hsc.13788</u>
- Vilhauer, R. P. (2017). Stigma and need for care in individuals who hear voices. *International Journal of Social Psychiatry*, 63(1), 5-13. <u>https://doi.org/10.1177/0020764016675888</u>
- Waters, F., Blom, J. D., Jardri, R., Hugdahl, K., & Sommer, I. E. C. (2018). Auditory hallucinations, not necessarily a hallmark of psychotic disorder. *Psychological Medicine*, 48(4), 529-536. <u>https://doi.org/10.1017/S0033291717002203</u>
- Watkins, J., Romme, M., & Escher, S. (2003). Hearing voices: A common human experience. Nordic Journal of Psychiatry, 57(2), 157-159. <u>https://doi.org/10.1080/08039480310000996</u>
- Watkins, S., Gupta, A., & Sanderson, C. (2020). The experience of talking about hearing voices with family, friends, and others. *Psychosis*, 12(1), 1-10. <u>https://doi.org/10.1080/17522439.2019.1690561</u>
- Webster, J., & Watson, R. T. (2002). Analyzing the past to prepare for the future: writing a literature review. *Management Information Systems Quarterly*, 26(2). xiii-xxiii.
- Woods, A. (2015). Voices, identity, and meaning-making. *The Lancet*, *386*(10011), 2386-2387. https://doi.org/10.1016/S0140-6736(15)0120
- Wright, K., Golder, S., & Lewis-Light, K. (2015). What value is the CINAHL database when searching for systematic reviews of qualitative studies?. *Systematic Reviews*, 4(1), 1-8. <u>https://doi.org/10.1186/s13643-015-0069-4</u>

**Section B: Empirical Paper** 

A Qualitative Study Exploring How Practitioners Working in Child and Adolescent Mental Health Services Facilitate Conversations With Service Users About Voice-Hearing.

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SALOMONS INSTITUTE CANTERBURY CHRIST CHURCH UNIVERSITY

# **Section B: Empirical Paper**

#### Abstract

**Introduction:** Voice-hearing is a common experience that can result in adverse personal consequences. Literature suggests that voice-hearers value discussing their voices with practitioners, particularly if contained within a therapeutic relationship. Although practitioners do engage in conversation about voices, research indicates that practitioners find speaking about voices and entering risk-laden conversations challenging.

**Methods:** Semi-structured interviews were used to explore twelve practitioners' experiences of working with voice-hearers. Participant accounts were analysed, and themes were developed using reflexive thematic analysis.

**Results:** The resulting themes outlined that practitioners value creating a safe space with young people prior to embarking on a meaning-making journey with them and their voices. Throughout these conversations, practitioners also had to navigate their own anxieties, using different resources and techniques to do so.

**Conclusion:** Practitioners in this study do endeavour to explore voice-hearing with young people and employ numerous processes to do so. However, there are barriers to this, and relevant clinical implications are outlined. Limitations and future suggestions are also discussed.

Keywords: Voice-hearing, qualitative, CAMHS practitioners.

#### Introduction

# **Background and Context**

Voice-hearing is not uncommon in children and young-people (CYP). A recent systematic review and meta-analysis has suggested that the lifetime prevalence of voicehearing is 12.7% for children and 12.4% for adolescents (Maijer et al., 2018). Many contributing factors have been proposed, including chronic stress of living in an environment lacking resources (Hastings et al., 2019); abuse and neglect (Sheffield et al., Whitfield et al., 2005); and in response to significant emotional events or trauma (Romme & Escher, 1989). Voice-hearing may also be secondary to sleep and mood disorders (Fortuyn et al., 2009; Edelsohn, 2006), as well as part of normal childhood development (Maijer et al., 2018).

When CYP hear voices, although these experiences can be transient, adverse outcomes can result from the associated distress; these include loneliness, self-harm and suicidal behaviour (Kapur et al., 2014; Kelleher et al., 2012; Maijer et al., 2019). Individuals who hear voices can experience stigma and shame about their experiences, which can impact wellbeing and functioning and prevent disclosure of voices (Phalen et al., 2019; Vilhauer, 2017). Furthermore, CYP with psychotic experiences, of which voice-hearing is one aspect of, are at an increased risk of developing later affective, behavioural, anxiety and substance abuse disorders, as well as a four-fold increase in risk of a psychotic disorder (Healy et al., 2019). Thus, whilst there is little consensus about the reasons CYP hear voices, the personal impact of these experiences can be detrimental to wellbeing. It is therefore crucial that voicehearing in CYP is identified at an early stage so that appropriate support can be offered to mitigate adverse effects. Whilst there is an array of meanings that can be ascribed to voice-hearing, child and adolescent mental health services (CAMHS) in the United Kingdom approach voices through the lens of a deficit model, where voices are viewed as a symptom of psychosis or severe mental illness that requires intervention (Kapur et al., 2014). There are currently no guidelines for the management of voice-hearing, instead this is substituted by guidelines for "psychosis and schizophrenia" (National Institute for Health and Care Excellence; NICE, 2013). For the care of CYP presenting with difficulties understood to be in this category, the treatment guidance differs dependent on whether symptoms are understood as part of 'psychosis' and 'schizophrenia' or are labelled as transient experiences. Regardless of treatment given, NICE suggests that frequent referrals to different teams should be avoided to ensure the continuity of therapeutic relationships. Value is placed on offering care within the confines of a "trusting, supportive, empathic and non-judgemental relationship" that respects different cultural understandings of experiences (NICE, 2013, p.7).

### **How Voice Hearers Experience Services**

Although guidelines exist to promote the use of best practice by clinicians, it is also important to consider the experiences of service users. Stakeholder involvement is crucial to improve the quality of care provision and, therefore, gaining qualitative service user feedback can be invaluable (Small et al., 2017). Literature outlining how voice hearers without a diagnosis of a psychotic disorder experience services is sparse, however empirical studies involving individuals with psychosis highlight some common themes. Research emphasises the importance of a strong therapeutic relationship; in a study exploring the experiences of mothers with post-partum psychosis, participants spoke positively about times when they had consistency in their care. It was felt that building a trusting new relationship was something that took time, demonstrating the containing nature of some continuity in care (Roxburgh et al., 2022). This sentiment of consistency was also valued in those accessing support for psychotic disorders in the NHS; Laugharne et al. (2011) highlighted that service users found it challenging to navigate transitions of practitioners, and they valued relationships that embodied trust, kindness, and self-disclosure. Additional studies have outlined that discussion of voices was indeed felt to be helpful, yet only if it was contained in a therapeutic relationship (Coffey & Higgon, 2004; Coffey & Hewitt, 2008). Whilst these findings stem from research situated in adult mental health contexts, these reported experiences appear to also be relevant to CYP. Kapur et al. (2014) interviewed CYP who hear voices about their experiences of mental health services, and themes reflected that CYP desired spaces to share and express their feelings without judgement, particularly as this appears to embody a holistic approach to care. Thus, whilst NICE guidance provides a thorough roadmap towards best practice in managing 'psychosis' and 'schizophrenia', the quality of the relationship between service user and practitioner may be the key factor underpinning good care for those with voice-hearing experiences.

## How Practitioners Experience Working with Voice-Hearing

Whilst literature outlines one picture of care provision for voice-hearing from a service user perspective, research suggests that service user and staff experiences are not necessarily always congruent (Papastavrou et al., 2011). Accessing mental health services is a process that typically requires a two-way relational component, and guidance emphasises the co-creation of a relationship in services for those who hear voices (NICE, 2013). To understand more about how voice-hearing is managed in services, it is crucial to understand the experiences of staff members.

Bandura's (1977) theory of self-efficacy outlines that mastery of experiences, vicarious experiences, social persuasion and emotional states all contribute towards the development of self-efficacy, which is an important factor that can determine an individual's performance. Self-efficacy theory has been linked to workplace performance in several studies and, in mental health settings, relates to how professionals manage their anxieties in sessions with clients (Cherian & Jacob, 2013; Hadi, 2023; Larson & Daniels, 1998). For practitioners working with voice hearers, however, self-efficacy appears to be an area of concern. In a recent meta-synthesis of five qualitative studies, it was revealed that practitioners find interactions with voice-hearing individuals somewhat challenging (McCluskey et al., 2022). Engaging service users was understood to be difficult and practitioners felt anxious about how their colleagues would perceive their interactions with service users. Furthermore, all included papers referenced feelings of uncertainty and selfdoubt about practitioner's abilities to work with service users who hear voices, for example nurses in Coffey and Hewitt's (2008) research described feeling anxious about engaging with voices due to a perceived lack of skillset. Participants also alluded to an absence of appropriate training, although some feelings of inadequacy remained apparent even following the provision of voice-specific training in one study (Bogen-Johnston et al., 2020). Taken together, it is plausible that feelings of low self-efficacy may impact practitioners' abilities to actively engage in voice-hearing conversations.

Amongst the difficulties identified by practitioners working with voice hearers, four studies within the review by McCluskey et al. (2022) also referenced the importance of the therapeutic relationship (Bogen-Johnson et al., 2020; McClusky & DeVries, 2019; McMullan et al., 2018; White et al., 2019) These findings appear consistent with those discussed from a service user perspective (i.e. as reported by Coffey & Higgon, 2004; Coffey & Hewitt, 2008;

Laugharne et al., 2011; Roxburgh et al., 2022). Taken together, this supports the argument for the importance of the therapeutic relationship, however it is important to note that the studies included in this review synthesised findings solely from a nursing perspective. CAMHS teams in the United Kingdom usually adopt a multi-disciplinary approach to supporting CYP involving other professionals aside from nurses in their approach (NHS, 2019). Findings may therefore not be reflective of how CAMHS clinicians from wider disciplines approach voice-hearing.

### **Engaging In Challenging Conversations**

There is currently no literature that outlines the experiences of practitioners discussing voices with CYP. However, as voice-hearing has been described as a difficult topic to discuss when working with adults (McCluskey et al., 2022), it may be relevant to understand how practitioners engage in broader difficult conversations with CYP in mental health settings. Speaking to CYP about mental health has been described as a "tricky business", particularly as in initial assessments practitioners are often strangers searching to elicit personal and sensitive details about a CYP's inner world (Kivimba & O'Reilly, 2018). Role theory suggests that individuals act in line with the role they are given, aligning their behaviours with the expectations ascribed to that role (Biddle, 2013). The confines of a role can provide some certainty in uncertain situations by outlining directions for behaviour (Hogg, 2000). According to the 1989 Children's Act (Lindsay, 1990), ensuring the safeguarding of CYP is a paramount responsibility of a professional working with them. Research indicates that staff practitioners use certain methods to fulfil their role by exploring risk and keeping young people safe. In a study using conversation analysis, O'Reilly et al. (2016) found that to navigate risk-laden conversations, practitioners approach the topic incrementally, by building up to the question, or they externalise and normalise the question by naming it as standard

procedure. Interestingly, whilst some processes are commonly adopted, it appears that less than half of CYP are directly asked about risk and only 50% of counsellors feel prepared to assess for suicide and risk in adolescents (Gallo, 2018; O'Reilly et al., 2016). Taken together, there appears to be conflict when working with CYP, whereby roles are embodied, yet individuals carry anxiety and doubt about their ability to fulfil their duties effectively, which links to sentiments raised by practitioners working with voice-hearing adults (McCluskey et al., 2022).

### **Rationale and Aim**

Although research has explored the experiences of practitioners who work with voice hearers in mental health services, all existing studies have been situated in adult mental health from largely a nursing perspective. Little is known about how voice-hearing is approached and spoken about in CAMHS with CYP. When considering the array of adverse outcomes that can result from voice-hearing, it is imperative that how practitioners engage in conversation with CYP about their voices is understood.

By completing this research and understanding these experiences, this may improve service user's experiences of the NHS by helping to inform how practitioners can engage in these conversations in a way that is safe and effective, achieving the basic quality of care; thus aligning with the NHS values 'improving lives' and 'commitment to quality of care'. To address the gap in the literature, this qualitative study aimed to explore the following research question: How do practitioners in CAMHS facilitate conversations with service users about voice-hearing?

#### Method

# Design

This study adopted a qualitative study design involving a reflexive thematic analysis (RTA) of individual semi-structured interviews with twelve CAMHS professionals. Qualitative approaches to research are predominantly concerned with exploring, describing, and interpreting individuals' social and personal experiences (Smith, 2015). 'Big Q' methods (Kidder & Fine, 1987), such as thematic analysis, are situated away from dominant positivistic scientific frameworks and towards a space that values researcher subjectivity and engagement with the data. The use of thematic analysis lends itself to a flexible approach that can be used to explore patterns in data about lived experience, views, perspectives, behaviours, or practices (Clarke & Braun, 2017). This aligns with the research aim, allowing for an exploration of participants' practices in the workplace through the lens of their experiences rather than creating a robust grounded theory, which typically requires continual sampling that can require longer time frames to achieve data saturation (Starks & Brown Trinidad, 2007). RTA was adopted due to the use of an organic and recursive coding process and the value that is placed on subjectivity, reflection, and in-depth engagement with the data (Braun & Clarke, 2019).

The epistemological positioning for this study embodied a social constructionist approach, whereby meaning and knowledge are understood to be co-created with another through language (Walker, 2015). A critical realist ontological approach was assumed, which views the production of knowledge to be subjective, despite the existence of 'truths' in an individual's world (Willig, 2013). These positions align with RTA methodology, recognising the subjectivity of knowledge creation yet also valuing the expertise of participants' understanding of their worlds.

# **Participants and Sampling**

Twelve participants were recruited from two NHS trusts for the purpose of this research. Inclusion criteria included practitioners working in CAMHS who had at least one experience working with a CYP who reported voice-hearing. This aligned with the aims of the research which was to explore processes from the perspective of CAMHS practitioners. Four additional participants expressed their desire to attend an interview but withdrew participation due to time commitments. Participants were offered £10 remuneration for their time. Table 1 includes participant information:

# Table 1

# Participant Demographics

Pseudonym	Gender	Age range	Ethnicity	Occupation	Time working in CAMHS
Dayna	Female	41-50	White European and Black Caribbean	Art Psychotherapist	15 years
Sarah	Female	21-30	White British	Primary mental health worker	1.5 years
Mabel	Female	31-40	White British	Senior mental health practitioner	6 years
Lucy	Female	31-40	White British	Cognitive behavioural therapist	3 years
Lillian	Female	41-50	White British	Senior clinical psychologist	6 years
Charlie	Male	41-50	White British	Neurodivergent nurse and psychotherapist	4 years
Pippa	Female	21-30	White British	Clinical psychologist	1.5 years
Alex	Male	31-40	White British	Highly specialist clinical psychologist	8 years
Josephine	Female	51-60	White Irish	Social worker	17 years
Belinda	Female	Not disclosed	Black British	Systemic psychotherapist	15 years
Ada	Female	61-70	White British	Principal child and adolescent psychotherapist	23 years
Emily	Female	31-40	White British	Clinical psychologist	10 years

# Procedure

Participants were identified through a database of referrers to a specialist service for the psychological treatment of distressing voices in one NHS trust (Trust A) and emails were sent to these practitioners (Appendix C). The research was discussed in research meetings in Trust A to identify suitable participants. The research was initially planned to be situated solely in this trust, however due to issues with recruitment, this was extended to a second trust, Trust B. In Trust B, potential participants were approached in meetings, via email, and through word of mouth in discussion with clinicians that led supervision groups for voice-hearing. However, the researcher attempted to ensure diversity in core occupation amongst participants by encouraging the sharing of research with wider NHS professions. All participants were provided with an information sheet and consent form (appendices D and E) at least 24 hours prior to their interview. They were informed that they could discuss any queries with the researcher prior to the interview to ensure that they could provide full informed consent. Interviews were audio recorded on a password-protected audio-recorder.

## **Stakeholder Involvement**

Participant-facing materials were reviewed and co-developed with stakeholders; two CAMHS clinicians external to the research team were consulted, and documents were updated in line with their feedback. Following the development of initial interview questions by the researcher and research team, these were revised and developed in collaboration with stakeholders. Feedback outlined the need to revise questions away from a delineation of exploring "positive" and "negative" experiences, as stakeholders reflected that often practitioners' experiences may not be black and white and instead sit in grey areas. Furthermore, the interview schedule was adapted to invite participants to reflect on one instance of working with a CYP in more detail, honing in on the phenomenological as well as procedural elements of this.

# Interviews

The final semi-structured interview schedule consisted of some initial demographic questions, plus seven exploratory questions with recommended prompts for each one

(Appendix F). Questions aimed to explore processes of exploring voices alongside participants' own experiences and related feelings. Interviews were conducted online via Zoom and lasted between 42 and 67 minutes. Following interviews, the researcher wrote a short passage summary to encourage reflection; a research diary was also kept (Appendix G)

# **Data Analysis**

Data was analysed using RTA outlined by Braun and Clarke (2019). This entailed

following the flexible six-step guidance outlined by Braun and Clarke (2006); see Table 2 for

the process in detail.

# Table 2

Six stage process of thematic analysis as outlined by Braun and Clarke (2006)

Stage		Description of outlined process		
1.	Familiarisation with the data	Transcription of data alongside an initial reading and re-reading of transcripts. Noting down of initial emerging ideas.		
2.	Generation of initial codes	Systematically coding relevant features of th data across an entire data set. Collating data relevant codes.		
3.	Searching for themes	Bringing codes together to form potential themes and collating data for these themes.		
4.	Reviewing themes	Checking whether themes work in partnership with coded data and across the whole data set. Thematic maps of the analysis can be developed at this stage.		
5.	Defining and naming themes	Themes and the overall story they tell are refined. Clear names and definitions for each theme are developed.		
6.	Writing the report	Analysis can continue to this final point. Upon extraction of examples for reports, there can be a final analysis of such extracts. These are ther situated in the research question, related back to the literature, and written in a scholarly report.		

To ensure a depth of engagement with the data, the researcher transcribed all twelve transcripts and drew out initial thoughts and ideas for each interview (Appendix H). An inductive approach was applied to data analysis to allow for themes to be grounded in data instead of shaped by pre-existing theories (Thomas, 2006). Although not always argued as necessary, particularly when adopting big Q methodologies such as RTA (Braun & Clarke, 2022), codes were reviewed by the research team and by one senior researcher not related to this research to encourage reflexivity and credibility and coherence of the analysis. Data were analysed using data management software NVivo. See appendices I and J for the development of thematic maps and NVivo codes created during analysis. These maps are reflective of the movement from narrower interrelated themes to ones that captured broader overarching themes. As shown, some themes with less supporting data were discarded due to the absence of richness i.e. 'involving the wider system in voice-hearing conversations' or 'having a duty of candour'. These themes, among others, were also discarded due to their lesser relation to the research question. Supervision and reflexive journaling were deemed helpful in highlighting this. Overarching themes were refined to ensure they related more to the specific research question as well as capturing multi-level nuances in the data.

#### **Reflexivity and Quality Assurance**

Researcher reflexivity is an integral part of conducting qualitative research. It is a process that encourages the use of self-awareness to limit the inevitable impact of researchers' own experiences on data (McGhee et al., 2017). Although creating a piece of qualitative research completely free from biases and assumptions does not align with the principles of big Q methodologies (Kidder & Fine, 1987), researchers can examine the ways in which one's attributions have been shaped and developed as a method of bracketing assumptions (O'Connor, 2011). Two bracketing interviews were completed with a peer
researcher: one prior to commencing interviews and another alongside data analysis. Please see section on author positionality for insight partially emerging from this.

In addition to bracketing interviews, to increase quality, codes were checked and discussed within the research team and research supervision was used to encourage reflection regarding theme development. Supervisors shared their ideas and made suggestions for refining emerging concepts. It is important to note that one supervisor had a special interest in voice-hearing, thus the influence of their input on the data was considered. Braun and Clarke (2021) suggest that one important step in creating quality findings is allowing time for immersion in the data; the researcher allotted ample time and space for analysis, allowing a circular development and refinement of themes.

Finally, the researcher kept hand-written reflective notes throughout the course of the research. Whilst these methods are specific examples of reflexivity that arguably contribute to increased rigour in qualitative research (Johnson et al., 2020), a reflexive approach has been adopted through all stages of this research, as recommended by Braun and Clarke (2021).

# **Author Positionality**

Prior to presenting my findings, I would like to acknowledge my position as someone who is not a qualified member of CAMHS. I also do not hear voices myself. I have, however, worked as a healthcare assistant in an inpatient setting with CYP who hear voices where risk was managed as a team. In my training, I have been encouraged to view voicehearing as a transdiagnostic experience that can be spoken about openly to surpass the restrictions of societal stigma. I believe that CYP can find it hard to speak about experiences and that clinicians have a role to name the unnameable at times. I also notice a bias in wishing to advocate for conversations about voices without the need for specialist support. This is largely based on my inpatient experience and so I am curious whether this is a sentiment shared in the community with the participants in this project.

#### Ethics

This research received ethical approval from the researcher's university (Appendix K). Approval was also granted by the Health Research Authority (Appendix L) and the two NHS trusts that participants were recruited from. Minor amendments made during the research also received relevant approvals (Appendix M).

The British Psychological Society (BPS) outlines a code of ethical conduct that psychological practice abides by, including research (BPS; 2021). It highlights the importance of practicing with respect, competence, responsibility and integrity; the researcher used these principles throughout. To ensure confidentiality, participants were provided with pseudonyms and their ages were replaced by age ranges when presenting their demographics. Whilst confidentiality was assured, participants were also informed that any issues pertaining to risk or malpractice would require a break in confidentiality to ensure the safety of either themselves or service users. Participants were also informed they were under no obligation to complete interviews and could withdraw at any time; they also had the right to refuse to answer any questions. Whilst no participants experienced distress during interviews, protocols were put in place to signpost them to further support should this occur.

#### Results

The RTA of the data in this research generated three overarching themes and nine subthemes (see Table 3) that directly related to the research question. They represented the process undertaken by practitioners discussing voices with CYP as well as how the practitioners experienced these conversations. The themes are outlined and discussed with reference to relevant quotes in the dataset.

#### Table 3

# Summary of Themes

Theme	Subtheme
1. Creating a safe space	Building a therapeutic alliance Tolerating and containing voice-hearing experiences Checking in with the young person
2. Embarking on a meaning-making journey together	Voices are one "piece of the puzzle": working with other experiences Normalising voice-hearing experiences
	Using curiosity to explore voices
	Making links in the pursuit of understanding
3. Practitioners' own anxieties	Doubting ability to manage voices
	The pursuit of containment for practitioners

# Theme 1. Creating a Safe Space

Practitioners expressed the value of working with CYP to build a safe space to facilitate exploration of voices. Building a therapeutic alliance, tolerating and containing

voice-hearing experiences, and checking in with CYP represented steps along the journey towards a safe space.

# **Building a Therapeutic Alliance**

It was felt that fostering a positive alliance within the practitioner and CYP's relationship was an essential process that needed to occur before conversations about voices could take place. Such relationships required trust and respect, which set the benchmark for exploration going forward:

"I'd say good therapeutic practice means creating trust through contracting and- and setting appropriate boundaries. So it's- so building a relationship with someone doesn't mean they're gonna like me. Yeah, but what I want to do is for them to trust me and to know what I'm all about" (Charlie)

"...begin the relationships and really pay attention to what it feels like to be with another person in a room and- and and there's sort of trust and safety. Because once that's established and we'd call that therapeutic alliance, then anything can be said" (Ada)

When reflecting on their previous work with CYP, practitioners noted that their relationship with CYP allowed them to explore the voices, and that this may not have been the case had the relationship held less safety:

"... I had to try and like build her relationship to help I guess- or like build her trust and then reduce her anxiety enough to have a helpful conversation about the voices, and what that might mean, and how to sort of help yourself. And in the end actually- we actually really did link it to her experience of bullying" (Pippa)

"...without that kind of careful building up on the relationship and to get at some of that stuff, I think I don't think we would have ever really understood the voices." (Josephine)

# **Tolerating and Containing Voice-Hearing Experiences**

Participants described their role as containers when discussing voices with CYP. This was communicated explicitly in some cases by outlining to CYP that nothing they disclose will feel intolerable, and thus they had permission to bring difficult experiences into the room:

"This is a place where you cannot believe things I've heard. So if you want to share with me things that you haven't been able to talk to other people about that's what I'm really open to" (Ada)

"You want to say I'm- I can hear this stuff, I'm open to this discussion. If- you know, maybe they've never been asked that question" (Lillian)

This containment was also communicated implicitly through the actions of practitioners who, upon disclosure, did not panic or run away; this perhaps demonstrates to CYP that voice-hearing is not as terrifying nor taboo as they initially thought. It also indicated that voices had a space to be spoken about: "I'm not freaking out. I'm not panicking, which it's conveying something to the young person, like, OK, this is an experience that we can talk about" (Alex)

"The fact that you don't kind of fall down dead or go rushing out, calling an ambulance. I think they kind of feel like, OK, this is someone I can talk to about this" (Josephine)

By demonstrating to CYP that they weren't terrified of their voices, practitioners elevated the safety in the relationship and conveyed that voice-hearing experiences were a manageable problem. This appeared to send a message to CYP that they were no longer managing their voices alone, lessening the isolation that can be felt with voice-hearing experiences.

"...for them to know that the person they're telling can hold that in mind and not be scared by it and not sort of leave them alone with it." (Belinda)

# Checking in with the Young Person

Participants portrayed a picture whereby CYP's autonomy over their decision to share their voices was respected. It was recognised that there were no rigid expectations of the disclosure or exploration of voices, and instead the power was held by CYP. In some cases, consent to explore voices was explicitly sought by asking permission:

"I'd ask them if it's all right to explore a bit more and then I'd kind of say, oh, I guess I linked it to stress" (Emily) "I'd always check in with her as to whether she wanted to talk about those things" (Lucy)

Whilst some CYP granted permission to explore their voices further, the right to disengage from voice-hearing conversations was seen as essential. As Sarah mentions, the conversations should "*Not (be) forced on to someone*":

"she said I don't want to talk about it, like, I'm crazy and- and- she really couldn't even think about the voices or anything like that at all and so we didn't- we didn't, you know, I didn't press her" (Pippa)

Though some CYP outwardly stated their wish to steer away from discussing their voices, some practitioners alluded to tuning in to the emotional temperature of the room. In this sense, they used their intuition to assess whether it was an appropriate time to speak about voices, basing this on signals from CYP:

"I always check in on the body language as well and if I think it's going too fast, so I think they're getting a bit anxious or I think it's a bit much, I'll check in and say, you know it feels- this feels a bit much, what do you think?" (Belinda)

"they were getting louder and telling her to not talk to me about it, which was causing her to feel understandably really quite agitated, um so I just said to her shall we take a breather and talk about something else, she said yeah (Sarah)"

#### Theme 2. Embarking On a Meaning-Making Journey Together

Making sense of the voices was a journey that participants embarked on in collaboration with CYP. This involved participants firstly understanding that voices were just one piece of the puzzle. They could then normalise CYP's voice-hearing experiences, use curiosity to explore the voices, as well as making links together to explore the meaning of the voices.

# Voices Are One "Piece of the Puzzle": Working with Other Experiences

Voices were largely understood as being part of a bigger picture, or one "*piece of the puzzle*" (*Alex*). They were not seen as existing in isolation from other complex experiences brought to mental health service and practitioners perceived that working with the voices was not necessarily the main priority when supporting CYP

"all the time that's ongoing, this almost seems a bit- because by working on the voices we're working on the symptom, but actually that's not the bit that needs addressing" (Lillian)

Sentiments appeared to reflect an understanding that working with voices sometimes entails a holistic approach, working beyond the voices and giving other concerns space for exploration. In some cases, practitioners felt that by diving past the voices and exploring the complexity hidden within the CYP's inner worlds, they noticed a knock-on effect on the voices:

"I brought them every week for a long time, but actually now we haven't discussed their voices very much at all, and since other things we're talking about and I did check in last week and the voices, the voices are still there, but I think because she has spoken about the trauma that had led to voices, I think they're not quite as traumatic for the young person" (Josephine)

"you may not need to like specifically work on the voices if that makes sense. Especially if they're understanding it is like something about the way they're feeling at the moment. Then if you work on that then, naturally, the voices might sort of reduce or have less of an impact" (Pippa)

#### Normalising Voice-Hearing Experiences

Participants had an understanding that the CYP they worked with likely understood their voices in a way that was clouded in stigma and reaffirmed by harmful societal narratives. CYP could feel *"worried they've got schizophrenia, or they're mad, or they're gonna be locked up"* (Lillian} and practitioners recognised that hearing voices would leave some with the idea *"that they're crazy" (Belinda)*. It was therefore seen as the practitioners' responsibility to dispel the myths of madness and situate CYP's voice-hearing experiences away from the narrative of abnormality:

"in sort of psychoeducation and just discussions in sessions about how actually voicehearing can be quite a normal human experience [...] giving them some statistics or facts around that or um just sharing anecdotally. Sort of, referring to confidentially other young people I've worked with who have similar experiences. It can be really helpful and again sort of in reducing the distress around how serious or severe these experiences might be for them." (Lucy) "we can all have quite murderous thoughts and we can, you know, this is what we do as human beings. And the difference is are we going to act on them? Because otherwise there'd be a lot of dead people around and- and- and they kind of get that kind of get that" (Ada)

Whilst normalisation was seen as helpful, and was something mentioned by all participants, for some, there was reference to the balancing act. This reflected navigating the fine balance between normalisation and minimization of CYP's voice-hearing. On the one hand, practitioners wanted to convey that voices are not necessarily a sign of madness, yet on the other they wished to validate the distress that CYP were experiencing:

"I really believe in value that it is a normal part of human experience and I say that as an adult who's not hearing voices. For young people, I've learned that you really can't go in with that like, you know, like or leading with normalising all the time because it can just invalidate people's distress. So I've learned that you really need toyou know, I'm not going to say to a young person "yes, OK. You've got schizophrenia"" (Alex)

# Using Curiosity to Explore Voices

Curious questioning was described as a tool to unearth valuable information about CYP's experiences. It helped practitioners to understand how the voice was experienced by CYP, embodying a phenomenological approach to questioning. The openness portrayed by curious questions appeared to set the precedent for new information to emerge: "you're asking questions about you know how many? who are they? What are their names? what their ages? what are their genders?" (Charlie)

"how many voices are there, is it a boy or a girl? Is it a male or female? I get into that. And I also ask things like you know is the voice a big voice is it a small voice. what do you feel when you hear the voice? You know what time of the day does the voice visit" (Belinda)

Curiosity was also used to explore the level of risk posed to CYP by their voices, particularly when voices appeared harmful. In this sense, questions appeared more specific and reflected a need for clear answers so that risk could be assessed:

"do they tell you to hurt yourself? Do they tell you to kill yourself? Do they tell you to hurt other people? Do they come at night? Do they come at school? When you're on the bus?" (Mabel)

# Making Links in the Pursuit of Understanding

Practitioners referenced making links explicitly with CYP between their voices and other possibly related experiences. Together, they tentatively explored what the voices may be trying to communicate, often linking them to a previous trauma from their life:

"it's about making those connections between what that person was experiencing and the context in which they were existing you know, their, yeah, their sort of process. So so part of the work with her was about saying you know, discovering the connection between voice-hearing" (Charlie) "I'd say maybe half of those clients, we did link the voice-hearing to a trauma experience um from when they were much younger, so the voices did seem to represent things that people they knew had said to them previously." (Lucy)

This process, referenced by most practitioners, gave space for the meaning of the voices to emerge, enabling for them to be worked on in the room together in a manner that invited CYP into this wider lens of understanding. It represented a journey towards co-creation of meaning, valuing both the expertise of the practitioner and of CYP.

# Theme 3. Practitioners Navigating Their Own Anxieties

Whilst practitioners seemed aware of the anxieties that CYP could bring into the room, they also reported noticing their own anxieties. They appeared to feel not good enough sometimes and could end up doubting their ability to manage voices. For some, they began to pursue ways to contain these anxieties so that they were able to support CYP to the best of their abilities.

# **Doubting Their Ability to Manage Voices**

Participants either explicitly stated or implicitly alluded to doubting their ability to manage voices. This seemed to particularly relate to a fear of missing something important in the conversation.

"there are times where I just feel a bit out of my depth" (Alex)

"I think personally that bought up a bit of anxiety as to whether I was missing something." (Mabel)

"I was really worried when we're missing something, was there more than mental health meaning to these voices, did I need to- Did I need to do something more?" (Josephine)

Participants seemed to also draw a distinction between voice-hearing in the context of psychosis versus trauma. They appeared to doubt their ability more when working with psychosis presentations and felt it was crucial that the young people accessed appropriate support:

"I think that can be difficult because it's really it can be really hard to follow what the other person's- the young person's thinking. And- and I guess it's you- it's really hard to actually understand like what exactly is going on in their mind in terms of voice-hearing and- and kind of I guess you may not be able to predict how the sessions gonna go" (Pippa)

"I'm not trained to assessing psychosis, so I was just worried really that that that I would miss something for them. But perhaps you know, if it was bad then they could access treatment much earlier?" (Josephine)

"I think there's that quality of of lack of reality or reflection that would then- I would then talk to the early intervention psychosis team" (Ada)

# The Pursuit of Containment for Practitioners

Participants referenced an array of methods that helped to contain their own anxieties and increase their confidence in speaking to CYP about voices. It was recognised that this was something that felt difficult for participants earlier in their careers, and that an increase in confidence typically came with an increase in experience.

"The main thing that's been difficult is being aware of my lack of maybe in depth training on it, and I know that training and experience makes me feel more confident" (Sarah)

"imposter syndrome, whether I was good enough for that kind of questioning etcetera. But then the more experience I've got and the more I see these kids it just becomes more part of the process" (Mabel)

Taking a structured approach felt more containing for practitioners, where there was a framework that could be lent on. Whether this be a pre-made therapeutic protocol or utilising psychoeducation:

"when you're working short term with people, having structure- having more structure in sessions can feel more containing" (Charlie)

"the easier side of it. um it's definitely the psychoeducation. um I think that's it, its that's quite an easy ish piece of work that can have a real impact" (Lucy) References were also made to the utility of voice-specific training as a way of learning more about the experiences. This perhaps demonstrated a desire for certainty where participants felt better equipped to navigate voices the more that they knew:

"The voice collective do really kind of helpful structured training" (Emily)

Finally, some participants sought expertise from others who were more experienced in working with voices. This was either through attending specialist supervision groups or seeking consultation from other teams:

"So EIS joined me for an assessment and said no actually it's a trauma presentation that needs to be treated first and then once that's treated then that should reduce the voice-hearing So it really helped because I probably wouldn't- you know I think I was going "aaaah risky" [laughs] so that was really helpful to have that extra expertise" (Mabel)

"if there are things I'm not sure about, I can check in with other people, I can bring it to the team meeting or supervision and get other people's voices on it" (Belinda)

#### Discussion

This study aimed to qualitatively investigate how practitioners in CAMHS facilitate conversations with service users about hearing voices. Several themes were developed from the data, which are discussed below in the context of relevant theoretical and empirical literature. The first theme outlined that CAMHS practitioners valued "creating a safe space" for the CYP they worked with. This theme was underpinned by three subthemes, one of which was "building a therapeutic alliance" grounded in trust and respect, linking to findings from both practitioner and service-user perspectives within the wider voice-hearing literature. In a systematic review on nurses' experiences of working with voice-hearing, McCluskey et al. (2022) stated that a strong therapeutic relationship is a building block to good care, allowing voice hearers to engage with practitioners more frequently about their voices. Furthermore, adult service users with psychosis have outlined the value of a trusting, supportive relationship (Laugharne et al., 2011; Roxburgh et al., 2022), and similar sentiments have been shown in research from the perspective of CYP who hear voices (Kapur et al., 2014). It appears that a good therapeutic alliance is widely sought after, thus the current findings support the emphasis placed on the relationship between CYP and practitioner in NICE (2013) guidance for the management of 'psychosis' and 'schizophrenia'.

In addition to the therapeutic alliance, results also indicated that practitioners tried "tolerating and containing voice-hearing experiences" whilst also "checking in with the young person" during these conversations. Interestingly, this did not align with previous research that explored interactions between practitioners and adult voice hearers (McCluskey et al., 2022). This discrepancy could be due to the differences between participant occupation in the cited literature and within this study. The current study recruited CAMHS clinicians that undertake therapeutic interventions with CYP, yet there appears to be a larger focus on management from a medicalised perspective for psychiatric nurses in the adult research (McCluskey & DeVries, 2020). Role theory stipulates that individuals act within the confines of what is expected of their role (Biddle, 2013), thus CAMHS clinicians may be more likely

to check in and contain voice-hearing if their role entails a less medicalised therapeutic approach.

The second theme in this study outlined that practitioners began "embarking on a meaning-making journey together" with CYP. They understood that "voices are one "piece of the puzzle" and attempted to navigate whether they should explore other important difficulties or remain solely focussed on the voices. They also valued "normalising voicehearing experiences" to remove some of the associated shame and stigma that can act as a barrier to disclosure (Phalen et al., 2019; Vilhauer, 2017). In a study exploring experiences of early intervention practitioners working with adults who hear voices, participants stated that non-judgemental conversations about voice-hearing worked to normalise their experiences, which could render them less frightening (Bogen-Johnson et al., 2020). Furthermore, normalising has been reported as a strategy used by staff, alongside an incremental approach to questioning, to explore self-harm and suicide with young people (O'Reilly et al., 2016). Interestingly, there was no mention of an incremental approach to exploring voices within the current research, however this may be due to the difference in methodology to O'Reilly et al (2016); they utilised conversation analysis which allows a detailed exploration of conversational methods, however the current research relied on practitioners' accounts of historical conversations. Despite this, when considering and situating the results amongst wider literature, normalising appears to be a strategy used across both adult and CYP disciplines; it could therefore be a helpful recommendation for working with voices regardless of the client age group.

Two further subthemes were also included in the theme "embarking on a meaningmaking journey together": "using curiosity to explore voices" and "making links in the pursuit of understanding". Whilst there is no specific guidance on the use of curiosity when working with CYP who hear voices, NICE guidance (2013) outlines that in addition to normalising, CYP should be supported to make links between their "thoughts, feelings, or actions and their current or past symptoms, and/or functioning". This is, however, suggested as a method to be used when delivering manual-based cognitive behavioural therapy (CBT). Many participants in the current study did not work in a CBT-informed way, thus it appears that supporting CYP to make links in the pursuit of understanding is something that can be done flexibly outside of a manualised approach. NICE recommendations may therefore be portraying link-making as a skill that falls within the remit of CBT-trained staff and not all CAMHS practitioners.

The final theme, "Practitioners navigating their own anxieties" contained two subthemes: "doubting their ability to manage voices" and "the pursuit of containment for practitioners". They embodied practitioners' shared feelings about finding voice-hearing conversations anxiety-provoking due to doubts about their skillset. To manage these anxieties, practitioners sometimes lent on structure in sessions or sought consultation from experts; they also recognised the value of voice-specific training to develop their skillset. This aligns with concepts outlined by Bandura's (1977) theory of self-efficacy, where individuals can build self-efficacy through vicarious experiences amongst other methods. It may be by that seeking consultation and supervision from other members of staff whom they perceive as successful in working with voices, practitioners are attempting to build their selfefficacy in their given roles.

Wider research also supports the finding that practitioners experience self-doubt about their abilities (McClusky et al., 2022), particularly in terms of working therapeutically with

voices (White et al., 2019). Whilst practitioners tend to yearn for training to develop their skillset (i.e. McCluskey & DeVries, 2020), some feelings of inadequacy and self-doubt can persist following voices-specific training (Bogen-Johnson et al., 2020), thus demonstrating that training may be an idealised quick fix for inevitable anxieties that accompany the uncertainty of working with voices. Interestingly, within the current study, it appeared that following disclosure, the same practitioners continued their work with CYP despite anxieties. This supports the desires and wishes of service users to have some consistency in the clinicians providing their care (Laugharne et al., 2011; Roxburgh et al., 2022) and aligns with NICE (2013) recommendations for changes in practitioners and teams to be kept to a minimum.

#### **Methodological Limitations**

Despite the helpful insights provided by this research, there are methodological limitations to be addressed. Firstly, it is important to review participant sampling; whilst convenience sampling is a common approach in participant-based research (Patton, 2002), partially recruiting via a specialist voices service, including senior practitioners with interests in voice-hearing may have had an impact on the types of participants attending interviews. There was also no involvement of psychiatry or nursing, meaning that the views of those working from a more medicalised perspective have not been included. Most participants in this research understood voice-hearing through a transdiagnostic lens; it is therefore difficult to know if the processes outlined above would be relevant to disciplines with a more medicalised understanding of voice-hearing. Participants were also mostly female and from a White-British background which may mean that the developed themes represent the process of speaking about voices through a white, female lens, particularly as the researcher analysing the data is also a White-British female. Whilst drawing on practitioners' past experiences allowed for the emergence of fruitful data, choosing a method reliant on memory may have meant that the process was not captured in a way that may have been done more objectively through different live methods, such as conversation analysis. Additionally, it is important to note that although the researcher implemented strategies to ensure high levels of rigour and reflexivity in this study, such as using drawings to support coding, engaging in bracketing interviews, writing reflective notes, and comparing codes with other researchers, themes inevitably have been influenced by the researcher's biases. Whilst this is a key part of qualitative methodology, it is crucial to note that the processes outlined in the above results are not objective outlines, and instead represent a co-creation of meaning between researcher and participants.

#### **Clinical Implications**

Despite methodological limitations, the results of this research provide a valuable contribution to our understanding about how conversations about voices occur with CYP. With a large focus placed on the value of a therapeutic alliance, practitioners should ensure time for this relationship building prior to implementing interventions for voice-hearing.

In agreement with suggestions made by Rammou et al (2023), as practitioners appear to value the anticipated increase in confidence that voice-specific training could give, it could be helpful to ensure that practitioners are offered more knowledge in this area as well as access to materials and resources to support voice-related conversations with CYP. Yet, whilst they may yearn for certainty through the provision of training, and this could indeed be helpful, any voices-specific training can be offered to practitioners alongside training on how to sit with and manage uncertainty and anxieties, whilst also building skills in facilitating openness and curiosity, valuing the phenomenology of the CYP's experience, as suggested by Coughlan et al. (2022).

Consultation and supervision spaces that are available for staff wishing to seek further support around working with CYP may help to prevent unnecessary referrals to other teams. Through containing practitioners' anxieties and upskilling them through supervision, this can allow them to continue exploring a CYP's disclosure about voice-hearing; perhaps further encouraging the development of their self-efficacy (Bandura, 1977). At a service level, this may entail selecting one member of a team to engage in further specialist training and creating a supervisory consultant role for them within their team. To ensure cost-efficacy, group supervision spaces may prove fruitful; they could also provide space for practitioners to develop from sharing ideas amongst their colleagues (Taylor, 2013).

Finally, services may wish to outline that exploring voices with CYP is an explicit expectation of the role of a CAMHS clinician. This explicit identification of role, paired with the development of supportive spaces to fine-tune skills, may increase the likelihood that voice-hearing conversations are continued with CYP (Biddle, 2013). All implications point to the need of a service-level approach; in particular, action is needed to create a workplace culture where practitioners can feel confident in their skillset, thus inviting CYP into a nonjudgemental and safe space where their voice-hearing experiences can be held and explored.

#### **Directions For Future Research**

Whilst this research provides valuable information about the experiences of staff working with CYP, it may be of interest for future studies to explore the perspectives of CYP, particularly as service user and staff perspectives do not always align (Papastavrou et al., 2011). This could help to identify whether the processes that practitioners adopt are what service users find most helpful. Findings from this research could be triangulated with the current findings to develop an initial theoretical framework to guide such conversations, informing guidance for staff working with voices. It may also be beneficial to explore how friends and family discuss voices with CYP because interactions with CAMHS are potentially minimal in comparison to CYP's interactions with others in their system. Findings could then inform how CAMHS services offer help to family and friends that support CYP with their voices, particularly as family intervention approaches are one recommendation set out by NICE guidance (NICE, 2013).

# Conclusion

The current study explored how CAMHS practitioners facilitate conversations with service users about voice-hearing. It appeared that practitioners valued the importance of creating a safe space for these conversations to happen, underpinned by a strong therapeutic alliance where they could demonstrate that they could contain voice-hearing experiences. They ensured CYP were empowered by checking in with them and seeking consent to pursue these conversations. Once this safety had been established, practitioners could then build a shared understanding of the meaning of voices. This entailed using curiosity to find out more about the CYP's experience, whilst normalising voice-hearing when it was spoken about. Furthermore, practitioners understood that voices may only be one piece of the puzzle and helped to enable CYP to link their voices to previous experiences, helping them to build a narrative to aid their understanding. Throughout their work with CYP, practitioners often were aware of their own anxieties which created doubt in their minds as to whether they could support the CYP; this further led to them seeking support from others.

Despite the outlined limitations, this research has provided valuable insight into how practitioners explore voice-hearing with CYP. It highlights that anxieties exist across

multiple disciplines, and that the therapeutic alliance is something valued by all. Although it is challenging to provide robust clinical recommendations due to the subjectivity embedded within the research and the lack of voice from a CYP perspective, the findings do align with previous qualitative studies. Findings also appear to map onto NICE guidance for supporting CYP. Some achievable future recommendations for research have also been suggested.

#### References

- Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191. https://doi.org/10.1037/0033-295X.84.2.191
- Biddle, B. J. (2013). Role theory: Expectations, identities, and behaviors. Academic press.
- Bogen-Johnston, L., deVisser, R., Strauss, C., & Hayward, M. (2020). A qualitative study exploring how practitioners within early intervention in psychosis services engage with service users' experiences of voice hearing?. *Journal of Psychiatric and Mental Health Nursing*, 27(5), 607-615. https://doi.org/10.1111/jpm.12612
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. https://doi.org/10.1191/1478088706QP063OA
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806
- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis?. *Qualitative Research in Psychology*, *18*(3), 328-352. https://doi.org/10.1080/14780887.2020.1769238
- Braun, V., & Clarke, V. (Eds.) (2022). Thematic analysis: a practical guide. Sage, London, UK.
- British Psychological Society (2021). Code of Ethics and Conduct. Leicester: Author. https://explore.bps.org.uk/content/report-guideline/bpsrep.2021.inf94
- Cherian, J., & Jacob, J. (2013). Impact of self efficacy on motivation and performance of employees. *International Journal of Business and Management*, 8(14), 80. https://doi.org/10.5539/ijbm.v8n14p80
- Clarke, V., & Braun, V. (2013). *Successful qualitative research: A practical guide for beginners*.. SAGE publications.

- Coffey, M., & Hewitt, J. (2008). 'You don't talk about the voices': Voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing*, *17*(12), 1591-1600.
- Coffey, M., Higgon, J., & Kinnear, J. (2004). 'Therapy as well as the tablets': an exploratory study of service users' views of community mental health nurses'(CMHNs) responses to hearing voices. *Journal of Psychiatric and Mental Health Nursing*, *11*(4), 435-444.
- Coughlan, H., Humphries, N., Clarke, M. C., Healy, C., & Cannon, M. (2022). Psychotic-like experiences? Trajectories and typologies of hallucinations and delusions from early adolescence to early adulthood in a population-based sample of Irish youth. *Irish Journal of Psychological Medicine*, *39*(2), 207-222. <u>https://doi.org/10.1017/ipm.2021.31</u>
- Clarke, V., & Braun, V. (2017) Thematic analysis, The Journal of Positive Psychology, 12:3, 297-298, DOI: <u>10.1080/17439760.2016.1262613</u>
- Department of Health & Department for Education. (2017). *Transforming Children and Young People's Mental Health Provision: a Green Paper*. APS Group.
- Edelsohn, G. A. (2006). Hallucinations in children and adolescents: considerations in the emergency setting. *American Journal of Psychiatry*, 163(5), 781-785. https://doi.org/10.1176/ajp.2006.163.5.781
- Evans, B., Rahman, S., & Jones, E. (2008). Managing theunmanageable': interwar child psychiatry at the Maudsley Hospital, London. *History of Psychiatry*, *19*(4), 454-475.
- Fortuyn, H. A. D., Lappenschaar, G., Nienhuis, F. J., Furer, J. W., Hodiamont, P. P., Rijnders, C. A., Lammers., G. J., Renier, W. O., Buitelaar, J. K., Overeem, S. (2009). Psychotic symptoms in narcolepsy: phenomenology and a comparison with schizophrenia. *General Hospital Psychiatry 31*, 146–154. <u>https://doi.org/10.1016/j.genhosppsych.2008.12.002</u>
- Gallo, L. L. (2018). The relationship between high school counselors' self-efficacy and conducting suicide risk assessments. *Journal of Child and Adolescent Counseling*, *4*(3), 209-225.

- Hadi, P. (2023). The influence of self-efficacy on employee performance mediated by work motivation and work engagement. *International Journal of Research in Business and Social Science (2147-4478)*, 12(2), 653-661.
- Hastings, P. D., Serbin, L. A., Bukowski, W., Helm, J. L., Stack, D. M., Dickson, D. J., & Schwartzman, A. E. (2019). Predicting psychosis spectrum diagnoses in adulthood from social behaviors and neighborhood contexts in childhood. *Development and Psychopathology*, 1–15. <u>https://doi.org/10.1017/S095457941900021X</u>
- Healy, C., Brannigan, R., Dooley, N., Coughlan, H., Clarke, M., Kelleher, I., & Cannon, M. (2019).
   Childhood and adolescent psychotic experiences and risk of mental disorder: a systematic review and meta-analysis. *Psychological Medicine*, 49(10), 1589-1599.
   <a href="https://doi.org/10.1017/s0033291719000485">https://doi.org/10.1017/s0033291719000485</a>
- Hogg, M. A. (2000). Social identity and social comparison. In J. Suls & L. Wheeler
  (Eds.), *Handbook of social comparison: Theory and Research* (pp. 401–421). Kluwer
  Academic Publishers. <u>https://doi.org/10.1007/978-1-4615-4237-7\_19</u>
- Johnson, J. L., Adkins, D., & Chauvin, S. (2020). A review of the quality indicators of rigor in qualitative research. *American Journal of Pharmaceutical Education*, 84(1).
- Kapur, P., Hayes, D., Waddingham, R., Hillman, S., Deighton, J., & Midgley, N. (2014). The experience of engaging with mental health services among young people who hear voices and their families: a mixed methods exploratory study. *BMC Health Services Research*, 14(1), 1-9.

https://doi.org/10.1186/s12913-014-0527-z

Kelleher, I., Lynch, F., Harley, M., Molloy, C., Roddy, S., Fitzpatrick, C., & Cannon, M. (2012).
Psychotic symptoms in adolescence index risk for suicidal behavior: findings from 2
population-based case-control clinical interview studies. *Archives of General Psychiatry*, 69(12), 1277-1283.

- Kiyimba, N., & O'Reilly, M. (2018). Reflecting on what 'you said'as a way of reintroducing difficult topics in child mental health assessments. *Child and Adolescent Mental Health*, 23(3), 148-154.
- Larson, L. M., & Daniels, J. A. (1998). Review of the counseling self-efficacy literature. *The Counseling Psychologist*, 26(2), 179-218.
- Lindsay, M. J. (1990). The Children Act 1989: A consideration of implications for children's rights. *Maladjustment & Therapeutic Education*, 8(3), 167–173.
- Maijer, K., Begemann, M. J., Palmen, S. J., Leucht, S. J. M. C., & Sommer, I. E. (2018). Auditory hallucinations across the lifespan: a systematic review and meta-analysis. *Psychological Medicine*, 48(6), 879-888. https://doi.org/10.33612/diss.94597038
- Maijer, K., Hayward, M., Fernyhough, C., Calkins, M., Debbané, M., Jardri, R., Kelleher, I.,
  Raballo, A., Rammou, A., Scott, J. G., Shinn, A. K., Steenhuis, L. A., Wolf, D. H. & Bartels-Velthuis, A. (2019). Hallucinations in Children and Adolescents: An Updated Review and
  Practical Recommendations for Clinicians. *Schizophrenia Bulletin*, 45.
  <u>https://doi.org/10.1093/schbul/sby119</u>
- McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60(3), 334-342.

National Institute for Health and Care Excellence. (2013). *Psychosis and schizophrenia in children and young people: recognition and management* [Clinical Guideline CG155]. https://www.nice.org.uk/guidance/cg155/chapter/Recommendations

NHS (2019). Children and young people's mental health services (CYPMHS). https://www.nhs.uk/nhs-services/mental-health-services/mental-health-services-for-young-people/children-young-people-mental-health-services-cypmhs/

- O'Connor, S. J. (2011). Context is everything: the role of auto-ethnography, reflexivity and selfcritique in establishing the credibility of qualitative research findings. *European Journal of Cancer Care*, 20(4), 421-423.
- O'Reilly, M., Kiyimba, N., & Karim, K. (2016). "This is a question we have to ask everyone": asking young people about self-harm and suicide. *Journal of Psychiatric and Mental Health Nursing*, *23*(8), 479-488.
- Papastavrou, E., Efstathiou, G., & Charalambous, A. (2011). Nurses' and patients' perceptions of caring behaviours: quantitative systematic review of comparative studies. *Journal of Advanced Nursing*, 67(6), 1191-1205.
- Patton, M., Q. (2002). *Qualitative research & evaluation of methods* (3<sup>rd</sup> ed.) Thousand Oaks., CA: Sage.
- Phalen, P., Warman, D., Martin, J. M., Lucksted, A., Drapalski, A., Jones, N., & Lysaker, P. (2019).
  Public understanding of different kinds of voice-hearing experiences: Causal beliefs,
  perceptions of mental illness, and stigma. *Psychiatric Rehabilitation Journal*, 42(4), 331.
- Rammou, A., Berry, C., Fowler, D., & Hayward, M. (2023). "Attitudes to voices": a survey exploring the factors influencing clinicians' intention to assess distressing voices and attitudes towards working with young people who hear voices. *Frontiers in Psychology*, 14, 1167869. <u>https://doi.org/10.3389/fpsyg.2023.1167869</u>
- Romme, M. A., & Escher, A. D. (1989). Hearing voices. *Schizophrenia Bulletin*, *15*(2), 209-216. <u>https://doi.org/10.1093/schbul/15.2.209</u>
- Roxburgh, E., Morant, N., Dolman, C., Johnson, S., & Taylor, B. L. (2022). Experiences of mental health care among women treated for postpartum psychosis in England: a qualitative study. *Community Mental Health Journal*, 1-10.

- Sheffield, J. M., Williams, L. E., Blackford, J. U., & Heckers, S. (2013). Childhood sexual abuse increases risk of auditory hallucinations in psychotic disorders. *Comprehensive Psychiatry*, 54(7), 1098-1104. https://doi.org/10.1016/j.comppsych.2013.05.013
- Small, N., Brooks, H., Grundy, A., Pedley, R., Gibbons, C., Lovell, K., & Bee, P. (2017).
  Understanding experiences of and preferences for service user and carer involvement in physical health care discussions within mental health care planning. *BMC Psychiatry*, *17*(1), 1-12.
- Smith, J. A. (2015). Introduction. In J. A. Smith (Eds.), *Qualitative psychology: A practical guide to research methods. Qualitative psychology*, (pp. 1-3). SAGE Publications.
- Starks, H., & Brown Trinidad, S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, *17*(10), 1372-1380.
- Taylor, C. (2013). Receiving group clinical supervision: a phenomenological study. *British Journal of Nursing*, 22(15), 861-866. <u>https://doi.org/10.12968/bjon.2013.22.15.861</u>
- Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American journal of evaluation*, 27(2), 237-246. Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, 27(2), 237-246.
- Vilhauer, R. P. (2017). Stigma and need for care in individuals who hear voices. *International Journal of Social Psychiatry*, 63(1), 5-13.
- Wardle, C. J. (1991). Twentieth-century influences on the development in Britain of services for child and adolescent psychiatry. *The British Journal of Psychiatry*, *159*(1), 53-68.

Whitfield, C. L., Dube, S. R., Felitti, V. J., & Anda, R. F. (2005). Adverse childhood experiences and hallucinations. *Child Abuse & Neglect*, 29(7), 797-810.

# https://doi.org/10.1016/j.chiabu.2005.01.004

# Section C: Appendices

Appendix A.CASP Table											
Author & Date	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	
Bogen- Johnston et al. (2017)	Yes	Yes	Yes	Yes	Yes	Partially	Partially	Yes	Yes	Yes	
Coffey & Hewitt (2008)	Yes	Yes	Yes	Yes	Yes	No	Partially	Yes	Yes	Yes	
Craig et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
De Jager et al. (2016)	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	
Dos Santos & Beavan (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Partially	No	Yes	Yes	
Goodliffe et	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Partially	Yes	

# al. (2010)

Hayward et al. (2015)	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jackson et al. (2010)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Kalhovde et al (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Lewis et al (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mawson et al. (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mayer et al (2022)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Partially	Partially	Yes
McCarthy et al. (2021)	Yes	Yes	Yes	Yes	Yes	Can't tell	No	Yes	Yes	Yes
Milligan et al. (2013)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Newton et al. (2007)	Yes	Yes	Can't tell	Yes	Yes	Partially	No	Yes	Yes	Yes
Nkouth et al. (2010)	No	Can't tell	Can't tell	Can't tell	Can't tell	No	No	Cant tell	Yes	Partially

Oakland & Berry (2014)	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Partially
Parry et al. (2021)	Can't tell	Partially	Can't tell	Can't tell	Can't tell	Partially	Yes	Yes	Can't tell	Yes
Payne et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Partially	Yes	Yes	Yes
Sheaves et al. (2021)	Yes	Yes	Can't tell	No	Yes	Partially	Yes	Partially	Yes	Partially
Sinha & Ranganath an (2020)	Yes	Yes	Yes	Can't tell	Yes	No	Yes	Yes	Yes	Yes
Watkins et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Yttri et al. (2020)	Yes	Yes	Can't tell	Partially	Yes	No	Yes	No	Yes	Partially

# **Appendix B: Part A NVivo Coding Excerpts**

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*Please note: These excerpts represent the themes pre-refinement. Upon writing this report, the file had corrupted rendering the new themes inaccessible* 

	10	54		POSITIVE CONSEQUENCES OF	11	21	:
	12 5	54 11		• OTHERS	2	2	:
BURDEN ON OTHERS burden of disclosure on ot	2	3		Disclosure can help others	1	1	:
<ul> <li>Disclosure will place press</li> </ul>	1	1		positive reception to disclo	1	1	:
non disclosure to protect o	2	3		▼ SELF	9	18	:
non disclosure to protect r	1	1		disclosure helpful to under	1	1	
want-ing to protect others.	2	3		disclosure led to reasonabl	1	1	
JUDGEMENT AND SHAME	11	34		disclosure of the positive a	1	1	
concerns about way they a	1	1		disclosure took away voice	1	1	ł
disclosing to avoid judgem	1	1		<ul> <li>Discussing voices can lead</li> </ul>	1	1	
disclosure to avoid being s	1	1		gaining hope and inc under	1	1	
exploring safety prior to dis	1	1		<ul> <li>openness in realtionships h</li> </ul>	1	1	:
Fear of being labelled as cr	1 2	2		positive response to disclo	1	3	:
fear of being labelled crazy fear of family response	2	2		Services helped to make s	1	1	,
fear of how family would re	1	1		<ul> <li>talking about voices helps t</li> </ul>	1	1	,
fear of others' reactions an	1	1		<ul> <li>Talking about voices reduc</li> </ul>	1	1	,
non disclosure due to fear	1	1		<ul> <li>talking can lead to support</li> </ul>	1	1	,
people take the mickey	1	1		Talking more leads to being	1	2	:
► O SHAME	5	14		talking to others about voic	1	1	,
superficial disclosure to m	1	1		<ul> <li>talking to others gives hope</li> </ul>	1	1	,
UNWANTED PERSONAL CON Disclosing to health profes	6	9 1	1	Speaking about voices challe	1	1	:
disclosure could lead to an		1	1				
Disclosure could lead to un		1	1				
disclosure to colleages can		1	1				
fear of being rejected and		1	1				
treated differently followin		1	1				
Voices as companion - fear		1	1				
A JOURNEY TOWARDS HELP		5	17				
crisis led to seeking help		1	1				
desperation leads to disclosure		1	1				
Disclosing to close family and		1	1				
🔵 disclosing to get help in depe		1	1				
disclosing to health providoe		1	1				
disclosing voices to seek help		1	2				
🔵 disclosure to get help against		1	1				
🔵 disclosure to get professional		1	1				
disclosure to get rid of voices		1	1				
disclosure to get treatment		1	1				
disclosure to services helpful		1	1				
🔵 disclosure versus suicide		1	2				
Distressing voices require dis		1	1				
seeking help from god so did		1	1				
unproblematic voices not disc		1	1				

# **Appendix C - Emails Sent to Practitioners**

# Dear XXX

My name is XXX and I am a Trainee Clinical Psychologist and I am looking to recruit volunteers to a research project in [Trust].

# The project:

This is a qualitative study which will be exploring experiences of clinicians discussing hearing voices with young people.

# It will involve:

Attending 1 interview or focus group with a researcher to discuss your experiences having conversations with young people who hear voices about their voices. You may also be contacted and asked to attend a second interview or focus group. Your interviews will be transcribed and data will be analysed to help us to learn more about these conversations.

# The potential benefits of taking part:

By taking part in this study you can help us to better understand staff experiences of discussing voices with young people.

# **Reward:**

You will be offered a £10 Amazon voucher for your participation.

# If you would like to find out more information about how to take part or express your interest:

Please email XXX

Best wishes, XXX



# **Appendix D – Information Sheet**

Please note that emails have been removed from this version to protect confidentiality

Ethics approval number:

V:\075\Ethics\2019-20

Version number: 2 Participant Identification number for this study:

Salomons Institute for Applied Psychology One Meadow Road, Tunbridge Wells, Kent TN1 2YG www.canterbury.ac.uk/appliedpsychology

#### Information about the research

#### Title: A Qualitative Exploration of How Staff in Child and Adolescent Mental Health Services Facilitate Conversations with Service Users about Hearing Voices

Hello. My name is Kerrina Ryan and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study, but firstly, thank you for taking the time to read this and for your interest in this study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you. Any reference to 'we' refers to myself and Canterbury Christ Church University. This research is being supervised by Tamara Leeuwerik and Mark Hayward, and they are both qualified clinical psychologists by background. Mark Hayward currently works in **X** Trust and Tamara Leeuwerik works at **X**. Their email addresses are X and X

Please feel free to talk to others about this study should you wish to. If you have any questions about the study, you can contact me in the first instance by emailing me at  $\underline{X}$ , alternatively you can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me, Kerrina Ryan, and I will get back to you as soon as possible and address any queries you might have.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

#### Part 1

#### What is the purpose of the study?

Hearing voices can be a distressing experience for young people, yet research indicates that disclosure of these experiences to services can be difficult. The purpose of this research project is to explore what it is like for staff members working with young people who hear voices, specifically looking at the process of how these conversations occur and how decisions are made about what to do next. By understanding this process, we can hopefully gain a good insight into what facilitates and inhibits these conversations.

#### Why have I been invited?

You have been invited to take part in this research as you are currently a mental health professional working within a child and adolescent mental health setting who has worked with a service user that hears voices, therefore your experience will be valuable to this research and your participation is greatly appreciated.

#### Do I have to take part?
It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form and you are free to withdraw from this study without giving a reason. You may ask for your interview data to be destroyed up to one week after your interview has taken place, after which it will not be possible to exclude your data from analysis. This is because the timeframe for this project is quite short.

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

If you decide to take part, you will be invited to attend an interview, either online or in person. Interviews should take no longer than one hour and you will be asked a series of questions about your experiences of discussing voices with service users; you will be encouraged to discuss the topic in depth but you do not need to answer any questions that do not feel comfortable to do so. I will make every effort to create a safe and comfortable space within the interviews to discuss your professional experiences. You will be free to not answer questions, take a break or to stop the interview at any time. You will also be asked some sociodemographic questions so that we can understand who is taking part in the study. The interviews will be recorded and transcribed to be used for later analysis, and I will require your consent for this to happen. The audio recordings will be deleted as soon as the interview has been typed up by myself. These interviews will either occur one to one, or may be in a focus group setting.

#### **Expenses and payments**

Should you choose to participate in this study, you will be offered £10 Amazon voucher to show our appreciation for your time and participation. Please let the researcher know if this is something you would be happy to accept.

#### What will I be asked to do?

During your interview, you will be invited to talk openly about your experiences working with young people who hear voices. You will be asked questions relevant to this and encouraged to explore your answers in depth. Please be reassured that this is a non-judgemental space and that the aim of the research is to develop a deeper understanding of these experiences. There are no wrong answers and this space is open to for you to bring a range of these experiences.

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

You may find the experience of being interviewed and discussing complex professional decisions uncomfortable. I will make every effort to create a warm, safe and comfortable space within the interviews to discuss your professional experiences. You are welcome to take a break, ask to move on to a new topic or stop the interview at any time – your wellbeing is the priority. You may discuss any concerns you have at any time with the researcher and have the right to withdraw your data up to one following your interview. Should you wish to access further support, you can reach the Samaritans by phoning 116 123. Alternatively you may wish to access X Employee Assistance Programme. This is a free and confidential 24 hour helpline which can be reached by phoning X

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

The study may not benefit you directly, but the information you provide will very helpfully contribute to our understanding of how conversations about hearing voices occur with young people. This may inform the development of future training programmes to meet the needs of staff, enabling better care for clients.

#### What if there is a problem?

Any issues that may arise (or complaints) about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

#### Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others.

The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decisions.

#### Part 2

#### What will happen if I don't want to carry on with the study?

If you decide to withdraw within the one week timeframe post-interview, your data will be extracted and destroyed. Unfortunately, it may not be possible for your data to be extracted and destroyed if you decide to withdraw more than one week after your interview.

#### What if there is a problem?

Should you experience a problem at any stage in this research study, you are entitled to discuss this with the researcher, or you may submit a complaint to the funding university as detailed below.

#### **Concerns and Complaints**

If you have a concern about any aspect of this study, you can ask to speak to me and I will do my best to address your concerns. You can contact me by emailing  $\underline{X}$ , alternatively you may leave a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me, Kerrina, and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology  $\underline{X}$ 

Alternatively, you can contact the Patient Advice and Liaison Service within XXX on the following contact details: Email:  $\underline{X}$  Tel: X

#### How will we use information about you?

We will need to use information from you for this research project.

This information will include your

- name
- contact details
- information you provide in the interviews

People will use this information to do the research or to check your records to make sure that the research is being done properly. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

#### What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

#### You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to kr374@canterbury.ac.uk or
- by ringing us on 01227 927070.

#### Will information from or about me from taking part in the study be kept confidential?

The information that you choose to share in the interviews will be kept strictly confidential (subject to legal limitations). Data collected from yourself will be pseudo-anonymised when it is confidentially stored, any names and places will be replaced with pseudonyms so that your identity remains hidden. Only the principle researcher on this project will have access to any non-anonymised data. The only time when I would be obliged to pass on information from you to a third party would be if, as a result

of something you told me, I were to become concerned about your safety or the safety of someone else. I would endeavour to discuss this with you in the first instance and you will be kept informed about the process. If there is risk or you disclose harm to yourself or others, we will have to act on this in line with our legal responsibilities. Your data will be retained for a period of 10 years, in line with guidance by the Medical Research Council. After this period, your data will be disposed of securely.

As the supervisors for this project may know some of the clinicians in the CAMH services from which participants will be recruited, it may be possible for them to identify participants. Every effort to anonymise data will be taken before discussing it in supervision to try to minimise the risk to participants. Supervisors will also not hear the audio recordings of interviews and will only have access to parts of pseudo-anonymised transcripts. Your demographic data will be separated from your transcripts too to protect your identity; preserving your anonymity is our priority.

Information you provide in the interview will be kept confidential and will only be discussed with my research supervisors. However, I may have to break confidentiality if a safeguarding or practice concern is raised in the interview. We understand that this is unlikely and I would endeavour to discuss this with you where practicable so that you are involved in every step of the process. I would then discuss my concern with my research supervisors.

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

The results of this study will be used in the researcher's major research project in partial fulfilment of the Doctorate of Clinical Psychology at Salomons Institute of Applied Psychology. The results may be published within an academic journal. Following its completion, you may request an electronic copy of the project by emailing the researcher. All results will be pseudo-anonymised so that it will not be possible for readers to identify you in any published documents. Quotes from your interview may be published in both the thesis and peer-reviewed papers under an alias.

#### Who is sponsoring and funding the research?

All research at Canterbury Christ Church University is looked at by a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Salomons Research Ethics Committee.

#### Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

## You can keep this copy of this information sheet and a signed copy of the electronic consent form; a copy will be kept on the researcher's secure drive for the researcher's reference.

#### Further information and contact details

Thank you for taking time to read this information sheet.

If you would like to speak to me and find out more about the study or have questions about it answered, you can email me in the first instance. My email is <u>kr374@canterbury.ac.uk</u>. Alternatively, you may leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Kerrina, and leave a contact number so that I can get back to you.

If you would like to access the university's privacy notice, this can be found at the following online location: <u>https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx</u>

#### **Appendix E- Consent Form**

#### Salomons Institute for Applied Psychology One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: Version number: 1 Participant Identification number for this study:

#### **CONSENT FORM**

#### Title of Project: A Qualitative Exploration of How Staff in Child and Adolescent Mental Health Services Facilitate Conversations with Service Users about Hearing Voices.

Name of Researcher: Kerrina Ryan

Please initial box

1. I confirm that I have read and understand the information sheet dated...... (version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw up to one week following my interview without giving any reason.

3. I understand that relevant data collected during the study may be looked at by the supervisors on this research project, Tamara Leeuwerik and Mark Hayward. I give permission for these individuals to have access to my data.

4. I agree for the interview to be audio recorded.

5. I agree that verbatim quotes from my interview and other data may be used in published reports of the study findings. Pseudonyms will be used to hide your identity.

6. I agree for the data I provide to be stored (after it has been assigned a pseudonym for anonymity purposes) for up to 10 years after the research project.

7. [Optional] I agree for my pseudo-anonymised data to be used in further relevant research studies supervised by the same lead supervisor.

8. I would like to receive a copy of my results. If yes, please provide email address here:

9. I agree to take part in the above study.

Name of Participant	D	ate

Signature		
Signature		

Name of Person taking consent Date

Signature \_\_\_\_\_

#### **Appendix F- Interview Schedule**

#### Thank you for agreeing to do this study.

- Will be asking you some questions about your experiences of talking to young people about hearing voices.
- You don't have to answer anything that doesn't feel comfortable and your data will be kept anonymous
- Please ensure you do not disclose any identifiable information about this service user such as their name.

What is your age?

What is your gender?

What is your ethnicity?

What is your current job title?

How long have you worked in CAMHS?

How long have you worked in this role for?

- What is your understanding of why children and young people hear voices?
   a. Where does this understanding come from?
- 2) Does having conversations about hearing voices with young people matter? Why?
- 3) Can you tell me about your experience of working with young people who hear voices?
  - a. Do you routinely ask about voice hearing experiences?
  - b. How, if you do, do you ask them about their voices?
    - i. Could you tell me about the process of this, step by step?
    - ii. Do you use any tools? If so, can you tell me about these?
    - iii. Are you aware of any tools that you can use?
- 4) How have you experienced having conversations about their voices?
  - a. What feelings arise when you are involved in these conversations?
  - b. What, if anything, have you found difficult about having these conversations?
  - c. Do you experience having any barriers to these conversations and why?
  - d. What, if anything, have you found easy about having these conversations? What has helped?
  - e. How have you perceived the young people's reactions to these conversations?
- 5) Could you describe an instance that stands out to you (or a recent example) where you had a conversation about hearing voices with a service user? <u>*Please ensure you do not disclose any identifiable information about this service user such as their name.*</u>
  - a. What happened?
  - b. What was the nature of the conversation?
  - c. How did you feel during this conversation?
  - d. How do you make sense of this conversation now?
  - e. What happened next?
- 6) Thinking about the young people, what do you think the impact is of having conversations about voices is on them?
- 7) Thinking about your previous and current experiences, what have you learned about having conversations about voices with young people?

#### Appendix G – Excerpts From Research Diary

#### May 2022

- Things seem to be moving pretty quickly since I have got ethical approval. I think this is a good thing! I had quite a few emails of interest from [trust] which has left me feeling optimistic. I've booked in my first participant for next week and am looking forward to finding out more about their experiences. I think doing my bracketing interview has been quite helpful in thinking about my positioning towards this topic and hopefully it will help me to interview with my biases less at the forefront.

#### July 2022

#### First step in theoretical sampling

Recruited my first 3 participants and decided to meet with my supervisor to have a think about where the research is going next. I like that grounded theory seems to be quite flexible. We have decided to not change the interview schedule and to now recruit practitioners with a little bit more experience working with voices (i.e. 'experts') to explore more about the concept of anxiety related to inexperience.

#### October 2022

#### Train broke down

- I had a participant booked in for today and my train broke down on the way to university! I couldn't believe it. She said she is now not able to take part in the research which is a real shame as I was looking forward to speaking with her and I am mindful that my research is running behind schedule. I am feeling a bit worried about my lack of participants and the timeframe.

#### November 2022

- Just finished an interview with a participant today and feel like I learned a lot about the philosophy of voices. Our conversation left me questioning consciousness and how voices might fit into this and I felt quite privileged to have had such a long and in depth conversation, particularly as this participant is an NHS employee and time is stretched!

#### January 2023

- The Christmas break didn't give rise to any new participants which has left me feeling more concerned about meeting the deadline for this project. I met with my supervisors to discuss this and we have decided that it would be sensible to change methodology to reflexive thematic analysis. I feel a bit more at ease because some research studies have ~8 participants and so I could find 2 more and still manage to produce an analysis. I suppose I am feeling a little disappointed that recruitment hasn't allowed for a grounded theory approach as I really think it would be great to build a model out of the findings. I just need to apply for an amendment in my ethics and find out how to get approval to recruit in [trust b] - so I'm hoping this won't take too long.

#### February 2023

- I am finding transcribing quite tiring but I am also enjoying the fact that I am immersing myself in the interviews. I read somewhere that initial thoughts and reflections don't always need to be formal written notes and can have a bit of a creative flair. I've taken to doing mind maps and doodles alongside transcribing to begin mapping out some initial thoughts and ideas. I realised that some of the themes

and ideas that I expected to come up have actually not been as prominent as I thought. I think this shows the value of being reflexive along the way to ensure I am not coding in a way that leads the research towards my beliefs!

- I finally got approval from [trust B] yesterday! I have been anxiously waiting for this for a while and was getting very nervous about recruitment. I have 6 interviews done and after mentioning it to a few different teams in my placement yesterday I've had 4 people express interest which is fantastic. I definitely didn't expect this much of an uptake this quickly but its looking good in terms of diversity of professions.

#### March 2023

- I finished my last interview today. I had to stop myself from getting carried away with the questions I was asking as the participant had so much interesting stuff to say and I was genuinely curious. Its left me feeling on a high because the conversation was so stimulating but also its my last interview! Looking forward to getting my teeth into the analysis now.
- Now all of my transcripts are written up, I am deep into the analysis. I debated whether to do it old school and cut pieces of paper up, particularly because I enjoyed writing handwritten notes when transcribing and after interviews. I decided to go with NVivo in the end because I think I can get feedback and share my ideas a a little easier. I am really trying to hold on to the idea that themes are not topic summaries and I am resisting the temptation to categorise them in this way. Reading Braun & Clarke's book has been helpful to really guide me through the process. As much as this analysis is taking up my brain space (and popping up in my dreams!), I am enjoying it.

#### April 2023

- I applied for an extension to ensure that I had enough time to realty immerse myself in the data. I think taking time off placement has really helped. I am finding it helpful to have a balance between complete immersion and taking lots of breaks to allow some space. It does feel a little tricky to know when to leave the analysis but I like the way it is heading. Meetings and discussions with Mark and Tamara have been really useful in developing these themes into a sensible narrative.

#### **Appendix H- Code Drawings**





#### **Appendix I- Development Of Thematic Maps**







discussing voices can be anxiety provoking for practitioners

Training and experience increases confidence in speaking about voices

113



### Appendix J- Part B Coding Excerpts.

Name		Files	References
CREATING A SAFE SPACE		12	68
UILDING A THERAPEUTIC ALLIANCE		10	24
<ul> <li>— Build a safe relationship first</li> </ul>		9	13
co creating meaning rather than jumping to strategies - importance of pace		1	1
Do not rush into fixing - formulate first		1	1
hearing the YP before offering strategies - containing		1	1
importance of a safe environment to discuss voices		1	1
Holding a safe and non judgemental space		2	2
Holding hope for the voice hearer		4	5
joining alongside - slow pace and checking in		1	2
Practitioner easing YP to talking about voices		1	1
Practitioners provide safety in the room		1	1
CHECKING IN WITH THE YOUNG PERSON		8	27
<ul> <li>measuring the temperature in the room</li> </ul>		5	5
using body language to seek permission to explore further		1	1
respecting window of tolerance in conversation		4	5
Respecting YP's decision whether to speak about it		3	5
seeking permission from YP for referral following disclosure		2	3
seeking permission to explore voices with YP		6	9
V O TOLERATING AND CONTAINING VOICE-HEARING EXPERIENCES		7	17
containing the young person by offering them a space to explore voices		3	4
V 🔵 letting the YP know you can hold their experience		7	13
Being there and tolerating the YP's experience		1	1
Being there for the YP even when you don't want to be		1	1
Providing an honest space for young people		1	1
EMBARKING ON A MEANING-MAKING JOURNEY TOGETHER		12	2 156
MAKING LINKS IN THE PURSUIT OF UNDERSTANDING		1	1 36
Coming alongside the YP to facilitate exploration		Ę	5 6
drawing out voices		2	2 3
empathising with VHing			1
<ul> <li>Helping to make links between voices and previous experiences</li> </ul>		-	7 14
<ul> <li>creating links to give the voice meaning</li> </ul>		2	
Creating links to reduce VH's distress			 1 '
<ul> <li>Helping the YP to understand rather than VH strategies</li> </ul>			1
<ul> <li>Providing space for YP to understand the voice</li> </ul>		2	-
providing YP a place to explore voices and drop stigma		2	
		-	1 1
remaining open to diff understanding of voices to create meaning			
Talking about voices to construct meaning Try to find meaning of the voice		3	
Valuing the YP's understanding - helping co construct meaning		2	
O NORMALISING VOICE HEARING IN YOUNG PEOPLE		12	
Balancing normalising and validating vs minimising			2 7
Direct questions can reduce stigma in YP around voices	4		1 '
helpful to use resources to contain YP			2 2
Normalise before asking about vioces - many people have unusual experiences			2 2
Normalising taboo experiences - providing safe space			1 '
Normalising the young person's experience			1 4
Normalising VHing- other YP hear it too			2 2
Normalising voice hearing through statistics to reduce distress		3	3 4
Other YP might hear them, do you			1 '
providing space to normalise and challenge societal narratives about VH		10	20
reassuring and validating their experience			1 '

✓	æ	10	40
asking age appropriate questions		3	5
Shortcut to Node 1s to ascertain distress		1	1
asking questions to assess frequency and severity of voice		1	1
asking questions to co construct meaning with the YP		1	1
asking questions to distinguish VH from psychosis		1	1
Asking questions to explore impact of voices		1	1
asking questions to explore longevity of the voice		1	1
asking VH questions to explore YP understanding		1	1
curious questions to guide exploration		2	4
O do you ever hear anything that other people don't hear		1	1
Exploring phenomenological aspects of voice hearing		2	2
Holding curious thougts about voices from the outset		1	1
phenomenological exploration of voices		1	1
questions to determine whether experiences are thoughts		1	1
Use of phenomenological questions to explore voice hearing		7	9
<ul> <li>Using child appropriate questins</li> </ul>		1	1
using curiosity stemming from demedicalised approaches		1	1
Using curiosity to explore YP experience		2	3
using direct questions with yes no answers to access inner world		1	1
Using open curious questions to explore voices		2	2
using questions to unpick experience and explore helpful strategies		1	1
VOICES ARE ONE PIECE OF THE PUZZLE		9	33
exploring internal world rather than voices		1	1
exploring underlying issue can reduce voices		1	1
Exploring underneath the iceberg		4	7
HV is one piece of the puzzle		5	5
Navigating whether to stay on top or below the iceberg		1	1
Not asking about voices as not concerned		1	1
prioritising what to work with - voices vs other issues		1	1
Voices explored as only one part of the puzzle		2	2
working with voices is working at the tip of the iceberg		3	4
You need to work underneath the iceberg		3	3
PRACTITIONERS OWN ANXIETIES		12	96
OUBTING OWN ABILITY TO CONTAIN VOICES		9	33
anxiety related to getting VH conversations wrong		3	4
doubting ability to work with voices		2	3
fear of missing something		3	3
feeling like an imposter		1	1
I'm not good enough as a practitioner to handle these voices		1	1
out of their depth with voice hearing conversations		2	2
> operation of the second s		5	19
O PRACTITIONERS OWN ANXIETIES		12	96
O DOUBTING OWN ABILITY TO CONTAIN VOICES		9	33
anxiety related to getting VH conversations wrong		3	4 '
O doubting ability to work with voices		2	3 :
<ul> <li>fear of missing something</li> </ul>		3	3 :
feeling like an imposter		1	1 :
I'm not good enough as a practitioner to handle these voices		1	1 :
out of their depth with voice hearing conversations		2	2 :
Operation of the second sec		5	19 :
THE PURSUIT OF CONTAINMENT FOR PRACTITIONERS		11	63
<ul> <li>O referrals for further help</li> <li>O seeking expertise is containing</li> </ul>		5 9	11 '
<ul> <li>O seeking expertise is containing</li> <li>O training &amp; experience helpful to talk about voices</li> </ul>		9 10	24 : 28 :
		10	20 .

# **Appendix K – Ethical Approval from University** *This has been removed from the electronic copy.*

**Appendix L - HRA Approval** *This has been removed from the electronic copy.* 

# **Appendix M – Edits From HRA Approval** *This has been removed from the electronic copy.*

#### Appendix N– End of Study Report for Ethics Committee/Participants

*Please note:* This letter will be distributed following completion of viva voce. This is to avoid any confusion with the findings if any results are required to be edited.

Date

Dear Salomon's Ethics Committee/Participants

# **<u>RE:</u>** Research project investigating how practitioners working in child and adolescent mental health services facilitate conversations with service users about voice-hearing.

I am writing to inform you that the abovenamed research project has now finished, and I am writing with a summary of findings. I wanted to extend a big thank you to the participants that kindly gave their time to share their experiences with me.

**Introduction:** Voice-hearing is a common experience that can result in adverse personal consequences. Literature suggests that voice-hearers value discussing their voices with practitioners, particularly if contained within a therapeutic relationship. Although practitioners do engage in conversation about voices, research indicates that practitioners find speaking about voices and entering risk-laden conversations challenging.

**Methods:** Semi-structured interviews were used to explore twelve practitioners' experiences of working with voice-hearers, looking in to how these conversations occur. Participant accounts were analysed, and themes were developed using reflexive thematic analysis.

**Results:** The resulting themes outlined the ways that practitioners engage in conversations. Firstly, value was placed on creating a safe space with young people. To do this, building a therapeutic alliance was key, and practitioners spoke of demonstrating they could contain young people's experiences. Furthermore, checking in with the young person during conversations was deemed important.

Once safety was established, practitioners outlined that they could build meaning with the young person. This entailed normalising their experiences, using curiosity to explore voices, and making links to help build an understanding of the voice. Voices were also understood to be only one piece of the puzzle so practitioners sometimes worked with other experiences instead of directly with the voices.

Finally, throughout these conversations, practitioners also had to navigate their own anxieties, which sometimes manifested in doubting their abilities. Several supportive methods could be used for containment, such as seeking supervision or joint-working with EIP practitioners. Additionally, using structure and resources could also provide some containment amongst anxieties.

**Conclusion:** Practitioners in this study do endeavour to explore voice-hearing with young people and employ numerous processes to do so. However, anxieties can sometimes make this feel challenging and practitioners may require support.

**Clinical implications:** Practitioners may wish to ensure time for relationship building prior to implementing interventions for voice-hearing. Furthermore, voices-specific training could be offered alongside training in skills of managing uncertainty and facilitating openness and curiosity. Consultation and supervision spaces in services should be made available for staff working with voice-hearers.

**Research implications.** Future studies may wish to explore the perspectives of young people to cross-reference findings and develop an initial theoretical framework to guide such conversations, informing guidance for staff working with voices. It may also be beneficial to explore how friends and family discuss

voices with young people. Findings could then inform how CAMHS services offer help to family and friends that support CYP with their voices, particularly as family intervention approaches are indicated by guidelines.

If you have any further questions, please do not hesitate to get in touch via email.

Thanks and best wishes, Kerrina

### Appendix O – Journal guidelines

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### Appendix P: Coded transcript

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