

**HOW DO MENTAL HEALTH SERVICE USERS EXPLAIN THE ORIGINS AND  
MAINTENANCE OF THEIR VOICE HEARING: A GROUNDED THEORY  
APPROACH**

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## **Thesis Abstract**

The current study sought to explore how, if at all, people construct an understanding of the origin and maintenance of their experience of hearing voices. An exploratory qualitative method, social constructionist grounded theory, was adopted throughout the research process. Theoretical sampling was utilised and eight participants who hear voices, or previously heard voices, and were distressed by this experience, were recruited through adult mental health teams. Each participant engaged in one digitally recorded interview.

A cyclical process of data collection and analysis was undertaken, utilising Charmaz's (2006) guidelines throughout. Three overarching descriptive categories were constructed regarding participants understanding of the development and maintenance of hearing voices which included; 'Search for meaning', 'View of self' and 'Explanations for voices'.

A sentence summary of the 'essence' of the developing grounded theory constructed is stated below:

*Participants attempted to construct an understanding of their voices through drawing on three main frameworks (inter, intra and para-personal), but the relative 'success' of this pursuit, and potential usefulness of an understanding, is effected by the sense of agency, stigma and hope(lessness) perceived by the individual.*

This study highlighted participants' attempts to search for meaning of their voices, but the utility of this was often linked to the hopelessness they experienced, and relatively few participants held an explicit theory of the development and maintenance of their voices.

This research offers a unique and distinct contribution to the current literature through illustrating how voice hearers actively searched for meaning in relation to their voice-hearing experience. This highlights the importance of helping people engage in meaning-making processes to help individuals understand the experience of hearing voices. Furthermore, the implications of imposing one theoretical framework, which may be incongruent to the voice-hearers own understanding, to the experience of hearing voices are discussed.

The study identified a number of clinical implications, such as the role of psychological formulation in generating a shared understanding of the voices. A number of methodological difficulties were encountered during the research process and are discussed. Future research is warranted to explore voice-hearers from a wider range of cultural, religious and spiritual backgrounds and to explore whether the experience of developing a shared framework to understand their voice hearing is valued.

## **Acknowledgements**

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### **Statement of contribution**

The main author was responsible for the following aspects of the research portfolio; project design, applying for ethical approval, writing the review of the literature, data collection, data transcription and analysis.

Dr Anna Tickle aided with the design of the study, recruitment of participants, provided research supervision and provided thoughtful comments on drafts of the write up.

Dr Mike Rennoldson, Dr Helen Johnson and Dr Paul Croucher provided assistance with recruitment of participants.

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## **Systematic Literature Review**

# Exploring the experience of hearing voices from a first person perspective: a meta-ethnographic synthesis<sup>1</sup>

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## Abstract

**Purpose** The purpose of this review was to identify, appraise and synthesise the current peer-reviewed qualitative literature which explores the phenomenon of hearing voices from a first person perspective.

**Methods** A comprehensive systematic search of the literature was conducted. Seven studies utilising various qualitative methodologies met the criteria to be included in the synthesis. An appraisal tool (Walsh & Downe, 2005) was used to assess their quality. A meta-ethnographic approach was used to synthesise the data extracted from them.

**Results** The interpretation of the findings suggested five key themes: identity of the voice(s), power of the voice(s), impact of hearing voices on relationships, relationship with the voice(s), and the distinction between thoughts and voices. The identity of the voices seemed inextricably linked to the perceived power the voice(s) wielded over the voice hearer. The quality of the studies included in the synthesis varied greatly.

**Conclusions** The findings of this synthesis highlight the importance of the voice hearer's individual frame of reference for understanding their experience.

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<sup>1</sup> Submitted manuscript that has been accepted for publication in *Psychology and Psychotherapy: Theory, Research and Practice*

Clinical implications include the need for mental health professionals to explore an individual's understanding of their experience of hearing voices and address the perceived power of the voice(s). Further research is indicated in this area with a focus of improving the quality of qualitative research studying this phenomenon.

## **Practitioner points**

- There are multiple frames of reference in which to understand an individual's experience of hearing voices.
- Mental health professionals should attend to the meaning and understanding voice hearers give to the experience.

## **Hearing Voices**

Traditionally in the West, hearing voices has been conceptualised within the biomedical model of mental illness (Blackman, 2000) and research has focused on the presumed deficits of the experience (Chadwick, 1997). The biomedical model judges the content of the voices as irrelevant (Read & Argyle, 1999) and the usual response has been to label them as symptomatic of mental illness and administer medication (Leudar, Thomas, McNally & Glinski, 1997). Consequently, there is a bias within research towards the form of hearing voices as opposed to the content and meaning of this experience, perhaps also due to the amenability of the former to systematic research (Boyle, 1992). This conceptualisation has been criticised as too narrow (Knudson & Coyle, 2002).

One alternative is the cognitive model, which asserts that hearing voices results from self-generated experiences being misattributed to sources external to the self (Bentall, Haddock, & Slade, 1994). Cognitive research has often utilised quantitative measures, which may not capture the richness of the phenomenon (Mawson, Berry, Murray, & Hayward, 2011) and risks fitting an individual's experience into a framework incongruent with their own understanding (Yardley, 2000). There is a danger of service users' experience being 'colonised' by research which draws on existing psychiatric language,



rather than allowing individuals to theorise using their own words (Harper, 2004). Furthermore cognitive models could be limited in their ability to account for a reflexive relationship between the individual and their experience of psychosis (Davies, Thomas & Leudar, 1999).

Recently, there has been a paradigm shift regarding how to understand and respond to individuals experiencing psychosis (Boyd & Gumley, 2007). The 'hearing voices movement' suggests that understanding the voice hearer's perspective and developing a frame of reference to enable them to attribute meaning to the voice(s) is essential to assisting them (Lakeman, 2001; Romme & Escher, 1989). The British Psychological Society (2000) asserts that mental health professionals should not insist service users accept any particular framework of understanding, but it is questionable whether clinical practice reflects this. One study highlighted that a fifth of participating mental health practitioners suggested attending to the content of hallucinations and delusions with clients would adversely affect their work, through difficulties distinguishing between reality and psychosis and the potential to suffer ridicule by other professionals (Aschebrock, Gavey, McCreanor, & Tippet, 2003). Coffey and Hewitt (2008) suggest that mental health nurses have been trained to 'reinforce reality' rather than attend to what voices say, but that this response appears discordant with what voice hearers perceive they need, including opportunities to discuss the content and meaning of voices.

A recent review suggested that the majority of research regarding 'auditory hallucinations' investigated their nature, potential causes and methods of eliminating voices or providing 'symptom relief', yet few researchers have explored the possible meaning of these experiences (Suri, 2011). There has

been an increase in scientific research examining individuals' personal accounts of psychosis (Geekie & Read, 2009) but there remains a dearth of research regarding voice hearers' interpretations of their experience (Knudson & Coyle, 2002).

Qualitative research gives the consumer a voice in relation to health care through the documentation of their experiences, priorities and preferences (Evans, 2002). However, qualitative studies conducted in isolation have been criticised as incapable of influencing either strategy or practice (Silverman, 1998). For qualitative research to be influential it must arguably be situated within a larger interpretive context (Sandelowski, Docherty, & Emden, 1997). Consequently, metasynthesis of qualitative studies has increased, making qualitative results more accessible to clinicians and policy makers and describing, building or explicating theories (Finfgeld, 2003), thereby aiding the formulation of evidence based interpretation of a phenomenon (Finfgeld-Connett, 2008). Metasynthesis refers to a family of methodological approaches designed to facilitate knowledge development based on a rigorous analysis of existing qualitative research (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004) beyond that which could be achieved in any individual qualitative study (Campbell et al., 2003).

One such approach to the synthesis of qualitative information is meta-ethnography (Noblit & Hare, 1988), which has its origins in the interpretivist paradigm (Campbell et al., 2003). This method entails the construction of an account of human experiential phenomena, which is always partial and positional; the intent is not to establish 'truth' but to engage difference in perspectives to enlarge and enrich human discourse (Thorne et al., 2004). It is

acknowledged that there are debates regarding different philosophical assumptions underpinning studies that are located in an interpretivist paradigm and how, or whether, to synthesise the findings of such studies (Atkins et al., 2008; Shaw, 2012). There are examples of meta-ethnographies which have included and synthesised papers rooted in different qualitative research traditions, such as phenomenology and ethnography (Campbell et al., 2003).

This review had two aims. First, to systematically locate and appraise research published within peer-reviewed journals that explored the phenomenon of hearing voices from the perspective of voice hearers. A systematic review was seen as advantageous because of its transparency and rigour, in contrast to the biases associated with other methods of identifying and assessing evidence (Dixon-Woods et al., 2007), such as narrative literature reviews. Peer review is not without its critics, but is seen to have benefits such as filtering out poorly conceived or executed research and improving the quality of published papers (Ware, 2008). This has an important protective role within evidence based policy and practice (Grayson, 2002).

The second aim of the present review was to synthesise the identified studies to explicate the phenomenon from the perspective of voice hearers. It is acknowledged that the methodology risks the exclusion of some studies, which could risk dominant views becoming accepted and more marginalised views excluded. However, narrative reviews also carry these risks and a pre-determined systematic methodology reduces author bias that could influence the direction or nature of future research. The methodology adds value by identifying similarities and discrepancies across existing studies and then synthesising these findings. This aims to increase the influence of qualitative

research which, when in the form of isolated studies, is often marginalised. Although qualitative research in this field has yielded a relatively small number of papers to date, explicating emerging understandings from those papers could develop understanding of the meanings given to this experience. This, in turn, could develop or even challenge current practice and also highlight directions for future research.

## **Method**

The review was conducted in three phases: systematic searching of the literature, critical appraisal of selected studies and meta-ethnographic synthesis as outlined by Noblit and Hare (1988).

### **Searching**

A comprehensive literature search was undertaken in June 2013 utilising six electronic databases: *PsychARTICLES (1894 – present)*; *PsychINFO (1806-2011)*; *MEDLINE (1950-2011)*; *Cumulative Index of Nursing and Allied Health Literature (CINAHL 1981-2011)*; *Applied Social Science Abstract Index (ASSAI 1987 - present)* and *Academic Search Complete (1887- present)*. A number of databases and search strategies were used to increase the effectiveness and comprehensiveness of the search (Evans, 2002), reflecting the acknowledgement that qualitative research spans varied disciplines (Barroso et al., 2003). The following search terms were used singularly and in combination:

**Terms:** Hearing voices, voice hearer, auditory hallucinat\*<sup>2</sup>, hallucinat\*, positive symptoms, psychosis, qualitative, discourse analysis, thematic analysis,

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<sup>2</sup> The suffix \* allows for truncation of the search terms in some databases to ensure a broad search of the literature

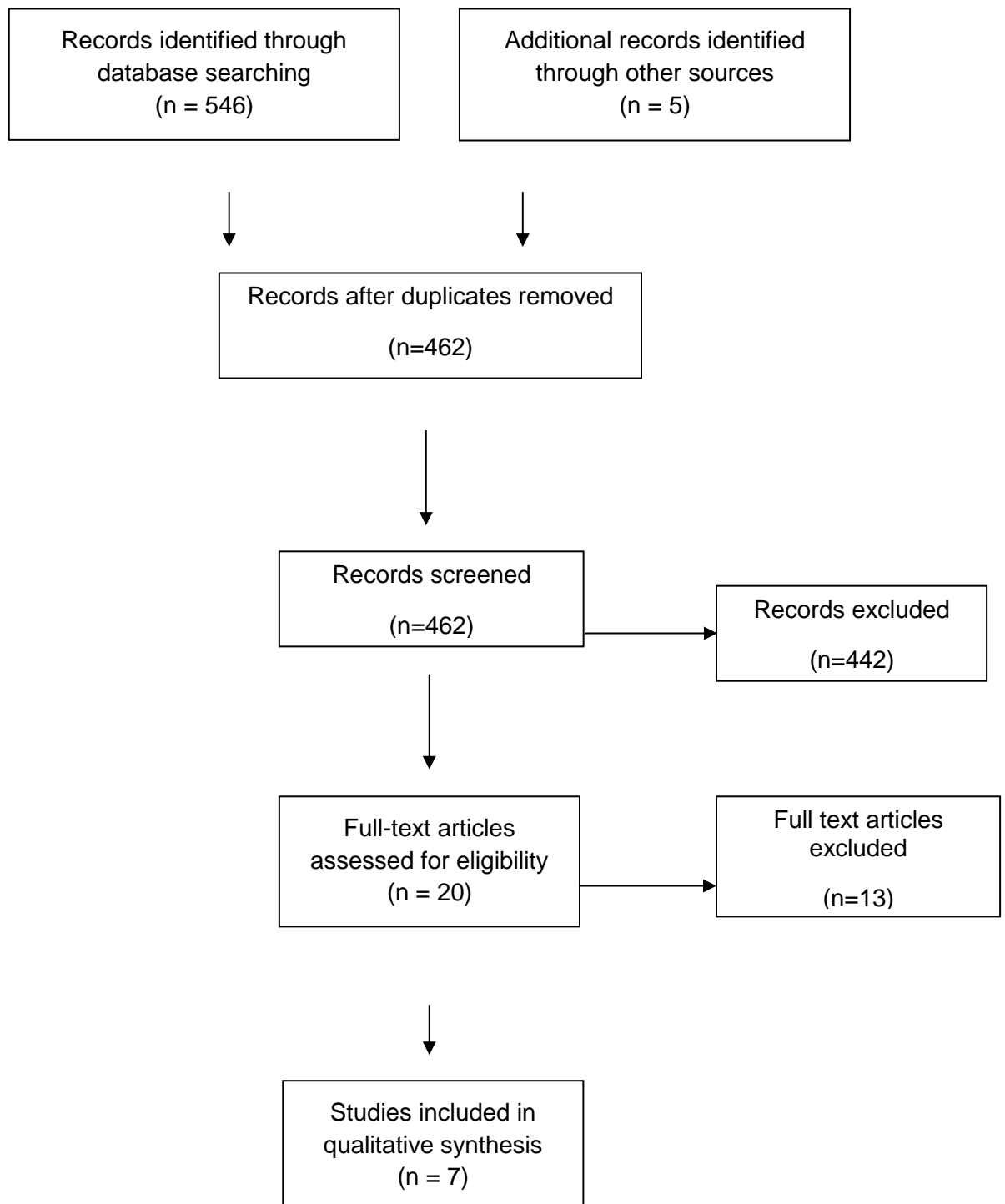
interpretative phenomenological analysis, phenomenological analysis, grounded theory, content analysis, ethnograph\*.

The term 'schizophrenia' was not used in the final search strategy as, when employed, it produced heterogeneous results about psychosis without yielding further results pertinent to the synthesis. All searches included the limits of 'peer-reviewed' and the inclusion of participants aged 18 and above. No temporal constraints were placed on the search strategy. It is acknowledged that qualitative sources appear to be under-represented in databases (Walsh & Downe, 2006) or harder to identify (Shaw et al., 2004). In addition to the electronic database search, the journal 'Psychology and Psychotherapy: Theory, Research and Practice' was purposively hand searched as it featured regularly on the search results. The references of full text articles screened for inclusion in the synthesis were hand searched in an attempt to identify further studies.

### **Selection**

Figure 1 outlines the process of article selection in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Liberati et al., 2009).

Figure 1 Process of data selection and exclusion (Liberati et al., 2009)



Once duplicates were removed, the abstracts of the remaining articles were assessed to ascertain their eligibility for inclusion in the synthesis. This synthesis utilised Sandelowski and Barroso's (2003) typology of qualitative research tool, which places qualitative research on a continuum indicating the degree of transformation of the data, enabling the location and comparison of findings from different methodological orientations. Studies were included in the synthesis based on the following criteria:

- Investigated the experience of hearing voices from a first-person perspective of voice hearers.
- Employed a qualitative method for data analysis
- Peer reviewed article
- Participants who were 18 and above
- Written in the English language

Studies were excluded from the synthesis if they:

- Only included a second person perspective about the experience of hearing voices (e.g. family, mental health professionals).
- Included participants who heard voices due to organic reasons (e.g. dementia), due to recognition that such experiences are distinct from non-organic psychosis (e.g. Cutting, 1987) and that known organic causes may dominate the experience or explanation of hearing voices.
- Included participants who had a diagnosis of post-traumatic stress disorder. This related to findings regarding the differentiation of trauma re-experiencing symptoms from psychotic symptoms (Gaudiano &

Zimmerman, 2010). However, the search did not identify any papers that met this exclusion criterion.

- Included other experiences of psychosis e.g. delusions or visual hallucinations as such experiences may confound the way in which individuals experience or discuss voice hearing, which was the primary concern of the present study.
- Were identified as single case studies or identified as 'no finding' or topical survey when subjected to Sandelowksi and Barroso's (2003) typology of qualitative research tool.

Twenty full text articles were assessed further for their eligibility. There is debate regarding what constitutes qualitative research, including discussions about generic approaches versus specific methodologies, credibility and quality (e.g. Caelli, Ray, & Mill, 2008).

Based on the inclusion/exclusion criteria, 13 of the 20 full-text articles were excluded (Davies et al., 1999; Goldsmith, 2012; Heriot-Maitland, Knight & Peters, 2012; Jarosinski, 2008; Jones & Coffey, 2012; Karlsson, 2008; Legg & Gilbert, 2006; Reiff, Castille, Muenzenmaier & Link, 2012; Shepherd et al. 2012; Strand & Tidefors, 2012; Suri, 2011; Taylor & Murray, 2012; Thomas, Bracken & Leudar, 2004;). Four were case studies; five (including one case study) included participants' experiences of both visions and hearing voices; one focused on childhood relationships; one was an internet survey comparing associations between child abuse and the content of psychotic symptoms; one was a discursive analysis of published accounts; one was a secondary analysis which could be argued not to offer a first person perspective about this experience; and one was classed as a topical survey. Consequently, seven



qualitative studies were included in the meta-ethnography, consistent with the suggestion that this method should be applied to a small group of closely related studies (Noblit & Hare, 1988).

### **Quality appraisal**

Judgement of quality using robust quality markers is essential if qualitative research is to credibly inform evidence based practice (Walsh & Downe, 2005). There is debate about evaluating qualitative research given there are no unequivocal quality criteria (Fingeld-Connett, 2008). This review utilised Walsh and Downe's (2006) appraisal checklist, which offers criteria grounded in the subjectivist epistemological position, synthesised from a variety of sources.

All included studies demonstrated their focus, linked their research to existing knowledge and outlined the selection criteria for participants, the contexts in which data collection took place and the approach to analysis. All interwove analysis with existing theories and discussed how their explanatory propositions or emergent theory might fit with other contexts. The interpretations offered by all of the papers seemed plausible to the reviewers. The quality of included studies was variable in relation to all other quality markers used for the appraisal.

Some studies failed to state their epistemological position (Fenekou & Georgaca, 2010; Jackson, Hayward & Cooke et al., 2011; Jones et al., 2003), which assists identification of relevant concepts and constructs as well as how the data is interpreted (Paterson & Canam, 2001). Other studies lacked extensive participant quotes to illustrate how they derived interpretations

(Fenekou & Georgaca, 2010) with two not incorporating any participant quotes (Beavan, 2011; Jones et al., 2003). Furthermore, not all studies demonstrated a process of reflexivity (Fenekou & Georgaca, 2010; Jones et al., 2003; Karlsson, 2008) despite the assumption from the interpretivist paradigm that any research entails part of the researcher (Noblit & Hare, 1988). It is evident that the quality of research investigating the first person perspective of hearing voices warrants improvement.

### **Data abstraction**

The seven phases of the meta-ethnographic approach (Noblit & Hare, 1988) were followed. The papers were read, re-read and the data were systematically extracted, including research findings, interpretative commentary, discussions and conclusions of each study. Data were compiled into first, second and third order constructs (Malpass et al., 2009) as advised in an adapted version of meta-ethnography for health research (Britten et al., 2002). First order constructs are participants' accounts and interpretations of experience; second order constructs are the authors' interpretations of participants' experiences, expressed in terms of themes and concepts; and third order constructs are the views and interpretations of the synthesist, expressed in terms of themes and concepts. A hand-drawn matrix was used to compare constructs, with lines and arrows drawn to indicate relationships between constructs in different studies (Campbell et al., 2003).

There are three possible forms of meta-ethnographic synthesis which can be achieved (Noblit & Hare, 1988), each employed sequentially within the current review:

(1) *Reciprocal translation*: accounts deemed similar across the papers were identified and either accounted for using existing concepts from one study or incorporated under new metaphors which could readily account for the interpretation of findings across the papers.

(2) *Refutational synthesis*: accounts that conflicted and contested one were identified and synthesised under a theme that allowed for the disparity between findings.

(3) *A line of argument synthesis*: similarities and differences across the papers were synthesised and contextualised to bring about new meaning.

## **Results**

This synthesis incorporated the findings from seven papers, with 139 participants in total, ranging from 19 – 84 years of age. Fifty-two percent of participants were female, 48% male. Three studies stated participants' ethnicity (Beavan, 2011; Chin, Hayward & Drinnan, 2009; Jackson et al., 2011;) and two studies commented upon the religion of participants (Jackson et al., 2011; Jones, Guy, & Ormrod, 2003). To collect data, one study utilised a focus group (Karlsson, 2008) and another used Q-sort methodology alongside a semi-structured interview (Jones et al., 2003). Q-Methodology sits between quantitative and qualitative approaches, but is said to have the strengths of both approaches (Akhtar-Danesh, Baumann & Cordingley, 2008) and is interested in the subjectivity of a situation (Brown, 1996). This study was included because the focus was specifically on the exploration of voice hearers' understanding of their experiences. The remaining five studies collected data through interviews. Methods of analysis varied amongst the studies. Within the broader remit of

investigating voice hearers’ understanding of their experiences, the studies had different research questions and aims. These, together with the characteristics of included studies, are outlined in Table 1.

Table 1 Characteristics of studies included for review

Study No:	Authors, year of publication and country	N	Context of recruitment	Data analysis method	Research Aims
1	Mawson, Berry, Murray and Hayward 2011 UK	10	NHS mental health services	Interpretative phenomenological analysis (IPA)	How are participants' voices experienced within the context of other interpersonal relationships?  In what ways, if any, are voices and social relationships understood to compliment, extend or oppose one another?  What are the similar or different styles of relating evident across these interactions?
2	Feneukou and Georgaca 2010 Greece	15	Inpatient and outpatients of a psychiatric hospital	Abbreviated version of grounded theory	To investigate the complexity of hearing voices, the interpretations voice hearers give to their experiences and the strategies they use to cope with them.
3	Beavan 2011 New Zealand	50	National multi-media appeal for people who hear voices that other people do not	Thematic analysis	To present a model of the essential characteristics of the hearing voices experience and to provide an alternative, stigma-neutral framework upon which voice hearers and those working with them can hang the experience
4	Chin, Hayward and Drinnan 2009 UK	10	NHS community mental health teams	IPA	How do participants understand their voice hearing experience in relation to themselves?  Are issues of power and intimacy of relevance within processes of constructing meaning?  If a relational framework is meaningful for them, how do voice hearers understand the development of the 'relationship' with their voice(s)?

<b>5</b>	Jones, Guy and Ormord 2003 UK	20	Hearing Voices Network, NHS mental health services, public notice boards and churches	Q-methodology	Why do voice hearers believe they hear voices and how do they make sense of their experiences?
<b>6</b>	Karlsson 2008 Sweden	22	Advertisements in scientific journals, newspapers and personal contacts	Phenomenological analysis	What is the phenomenon of (inner) voices and how does a person know that s/he hears voices?  Described how participants account for and understand their voice-hearing experiences.
<b>7</b>	Jackson, Hayward and Cooke 2011 UK	12	Hearing voices groups, local NHS services and community advertisements	Grounded Theory	How do people develop positive relationships with their voice(s)?  What factors, both internal and external, affect those relationships?  How do these relationships change over time?

## Interpretation of findings

Through the meta-ethnography, key themes were identified cluster around five main third order constructs: (1) Identity of the voice(s), (2) Power of the voice(s), (3) Impact of hearing voices on relationships, (4) Relationship with the voice(s) and (5) The distinction between thoughts and voices. Within the key themes, there appeared to be additional sub-themes. These were identified and included within the cross-comparison (Table 2).

### Identity of the voice(s)

Reciprocal translation established 'identity of the voice(s)' as a recurrent theme. In all but one of the studies (Fenekou & Georgaca, 2010), participants referred to the identity of the voices they heard. Participants tended to assign a 'characterised identity'<sup>3</sup> that personified the voice(s), for example assignment of a name to the voice(s) (Beavan, 2011). This is highlighted from one participant's description of two voices she hears. <sup>4</sup>*"Sometimes it's [Bridgets voice] kind sometimes it shouts, but more kind. Mr Jones' voice is not very kind"* (Mawson et al., 2011 p.262). Chin et al. (2009) noted that some participants refused to assign the voices a name, but the personification of the voices was demonstrated in other ways, such as assigning gender. Frequently this was identified through the use of person pronoun when describing the voice(s), indicating a subjective character of the experience (Karlsson, 2008).

Identities of voices ranged from reflecting people previously or currently present in the voice hearers' social worlds (Chin et al., 2009; Jackson et al., 2011;

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<sup>3</sup> Inverted commas indicate direct quotes from the authors of the studies

<sup>4</sup> Speech marks and italics indicate direct quotes of participants in original studies

Table 2 Cross comparison of study reports (grouped findings)

Theme	Mawson et al (2011)	Fenekou and Gennaro Beavan (2011)	Chin et al (2009)	Jones et al (2003)	Karlsson (2008)	Jackson et al (2011)
Identity of the voice(s)	*		*	*	*	*
Power in relation to the voice(s)	*	*	*	*	*	*
- Struggle for control	*		*			
- Strategies of the voice(s)	*	*	*		*	
- Strategies of voice hearer	*	*	*			*



---

## Impact of hearing voices and relationships

\* \* \* \* \*

### - Relationship with the self

\* \*

### - Relationships with others in the social world

\* \* \* \*

### - Voice(s) fulfilling the friendship world

\* \* \* \*

## Relationship with the voice(s)

\* \* \* \*

## Distinction between thoughts and voices

\* \* \*

Mawson et al., 2011), to spiritual forces (Jackson et al., 2011; Jones et al., 2003; Karlsson, 2008) and strangers (Beavan, 2011). Jackson et al. (2011) conceptualised a second-order construction of 'personification of voices' as a continuum from 'lower beings' to 'ordinary beings' to 'divine beings' (p.490), but found that the identity of a voice could move along the continuum across time.

Chin et al. (2009) described a theme of 'intimate knowing' of the voices' personalities, with participants describing voices as possessing sensory, cognitive, affective and behavioural capabilities, demonstrated in a participant quote: *"Every thought I'm thinking, they're hearing and they're saying 'well that thought is wrong you should change it like this' "*(p.8). Such qualities attributed to the voices were alluded to in all other studies and appeared to be inextricably linked with the voice hearer's perception of the power of the voice.

### **Power in relation to the voice(s)**

Five studies discussed a recurring theme of power attributed to the voice(s) by the voice hearer (Chin et al., 2009; Fenekou & Georgaca, 2010; Jones et al., 2003; Karlsson, 2008; Mawson et al., 2011). Although Jackson et al. (2011) alluded to power through both of the core processes they captured under the second order constructs of 'diminishing fear' and 'establishing control'. 'Power' was not defined by any of the studies, but was discussed in terms of characteristics of the voice(s). It was seen as relational, in that participants' perceptions of their own power was relative to the amount of power attributed to the voices. This appeared to lie along a continuum: some people positioned themselves as completely powerless and passive to the influence of the voices whilst at the other end of the spectrum some felt they had the ability to take control and exert power over the voices (Jackson et

al., 2011; Jones et al., 2003). This often appeared to be linked to the participants' explanations of their experience. For example, participants who perceived that they heard voices as a result of a neurochemical imbalance or spiritual possession reported feeling powerless in relation to their voices (Jones et al., 2003). The voices were described as having an 'invasive quality', which seemed to highlight the inescapable power of the voices for many of the participants (Chin et al., 2009). However, this was not evident in the study specifically investigating positive relationships with voices (Jackson et al., 2011).

Four studies discussed participants' perceptions that the voice(s) employed strategies to maintain a position of power (Chin et al., 2009; Fenekou & Georgaca, 2010; Karlsson, 2008; Mawson et al., 2011). Common perceived properties of the voice(s) included their ability to issue commands and punishments. This seemed to be influenced by the perception of voice(s)' awareness of the voice hearer's perceived weaknesses., e.g. *"They'll magnify whatever it is I'm concerned about, or they'll comment on something I'm concerned about which isn't very helpful and quite often makes me more stressed than I was"* (Chin et al., 2009 p.9). The form of communication used by the voice(s), such as critical, demeaning and abusive language, was also seen as a strategy by which they exerted power. Through the synthesis it appeared that the perceived power of the voice(s) was inextricably linked to the identity of the voices, as discussed above. One study commented that voices could be perceived as more powerful when attributed to 'authoritarians in the dominant culture' e.g. God (Chin et al., 2009).

Two studies referred to the 'battle for control' between the voice(s) and the voice hearer (Chin et al., 2009; Mawson et al., 2011). Some participants discussed how they utilised strategies in an attempt to redistribute the power balance (Chin

et al., 2009; Fenekou & Georgaca, 2010; Jackson et al., 2011; Mawson et al., 2011). Common strategies included the implementation of boundaries and 'guidelines' with the voices, the use of distraction and self-assertion techniques. One participant highlights this is, "*at work... when I serve... I am a waiter... I am completely distracted... I hear them but I pretend I don't hear them...because I am working... I am listening to other people*" (Fenekou & Georgaca, 2010 p.138). In contrast 'actively engaging' with the voices empowered the voice hearer e.g: '*Somehow in listening to the voices and dialoguing with them and figuring out who they are, the power balance shifts*' (Jackson et al., 2011, p.490). This reiterates the relational nature of power and suggests it can be bi-directional.

### **Impact of hearing voices on relationships**

Both reciprocal and refutational translation identified the impact on the voice hearers' social world and relationships as a third order construct evident in six of the studies (Chin et al., 2009; Fenekou & Georgaca, 2010; Jackson et al., 2011; Jones et al., 2003; Karlsson, 2008; Mawson et al., 2011). Three third order subthemes were constructed to reflect clear distinctions at a second order level: relationship with self, relationships with others and the voice(s) fulfilling the friendship role.

Two studies discussed the impact of hearing voices on the voice hearers' relationship with themselves (Jackson et al., 2011; Mawson et al., 2011). Voice hearers often viewed themselves unfavourably as a result of the voices, perhaps through a process of downward social comparison, e.g. blaming the voices for failures to reach life goals such as marriage or employment (Mawson et al., 2011). On the other hand, encouraging content of voices can contribute to the hearer

developing a 'stronger sense of self and independence' (Jackson et al., 2011). An example of content aiding this process included the voice encouraging the hearer to be more assertive in a difficult situation (Jackson et al., 2011). Hearing voices was reported to impact on the participants' social world in four studies (Fenekou & Georgaca., 2010; Jackson et al., 2011; Karlsson, 2008; Mawson et al., 2011). Social interactions were seen to help participants preserve a sense of 'normality'; however it could be effortful to maintain relationships (Mawson et al., 2011) because more frequently, voices prevented hearers from living an 'ordinary life in reality' (Karlsson, 2008, p.369). This was perceived as one consequence of the power exerted by the voice(s) during social interactions, e.g. "*We were sitting there...3...4 people, having a cup of coffee and the voice told me to get up and leave the table... 'you have nothing do with these 3...4 people... and I don't want to ever see you with them again' "*" (Fenekou & Georgaca, 2010 p.137). Other reasons given for the distance between the voice hearer and others in their social world included: not wanting to burden others with their experience of hearing voices; responses of others to voice hearers' experience; and the voice(s) suggesting other people are untrustworthy e.g. "*I thought they were going to poison me, 'cause that's what the voices said they were going to do*" (Mawson et al., 2011 p.12).

The sense of distance between participants and their social world seemed to be, at times, alleviated through the voice(s) occupying the role of significant other or friend. Jackson et al. (2011) found this to be true only of voices conceptualised by participants as 'divine beings', such as God, angels or spirit guides, with whom participants reported close and trusting relationships. Five studies (Chin et al. 2009; Fenekou & Georgaca, 2010; Jones et al., 2003;

Karlsson, 2008; Mawson et al., 2011) did not make such a distinction between types of voices, but identified that voice(s), at times, were a source of comfort and companionship for the voice hearer, e.g. *“I haven’t got many friends...so the only thing I can stay very close to are the voices and I do stay very close to them”* (Chin et al., 2009 p.9). Loneliness in the social world seemed to be reduced by contact with the voice(s), even if on some occasions they were perceived to be the source of isolation from others.

For some individuals who identified as having a positive relationship with voices it seemed more possible to actively increased their social networks to include those who shared similar belief systems, e.g. through spiritual or church groups or the Hearing Voices Network (Jackson et al., 2011). Such connections were seen to develop a sense of belonging and, in turn, contribute to ‘developing a personally meaningful narrative’ and coherent understanding of the voice(s).

### **Relationships with the voice(s)**

Four studies identified a theme of the relationship the voice hearer has with the voice(s) (Beavan, 2011; Chin et al., 2009; Jackson et al., 2011; Jones et al., 2003). One study reported a continuum of responses to the notion of a close relationship with the voice(s), from active rejection of a union with the voice(s), e.g. *“I don’t want to make friends with them because I don’t want to invite them into my life.”* (Chin et al., 2009, p.11). At the other end of the continuum, participants accepted the constant link and relationship with the voice(s), e.g., *“as soon as I started hearing them it, it just seemed to naturally be there as a relationship so it wasn’t as if any ground was set or anything”* (Chin et al., 2009 p.10). This was supported by Jackson et al.’s (2011) finding that all participants had integrated the

voice(s) into their lives and valued their contribution. For some, the relationship with the voice(s) evolved over time (Beavan, 2011; Chin et al., 2009; Jackson et al., 2011).

### **The distinction between thoughts and voices**

Refutational synthesis identified the distinction between thoughts and voices as a recurrent theme in three studies, despite no studies explicitly investigating this (Beavan, 2011; Fenekou & Georgaca, 2010; Karlsson, 2008). Two studies (Beavan, 2011; Karlsson, 2008) reported that participants perceived thoughts and voices to be separate entities with different origins. Voices were generally experienced by participants as coming from outside the self but manifested inside the body whereas thoughts were perceived as 'belonging' to the self, e.g.

*"Thoughts I have inside me. I know that the thought is mine; yes, I absolutely feel it, when I am thinking that thought. But the voice I feel, that is absolutely not mine, and that is a voice inside me. I know for sure that it is someone else's voice. It is not integrated in myself..."* (Karlsson, 2008 p.368).

In direct contrast, one study reported that some participants experienced thoughts and voices as one and sought to explain the relation of their voices to reality and to their thoughts, e.g. *"I respond to my thought 'go away' leave me alone"* (Fenekou & Georgaca, 2010, p.140). Interestingly, this study recruited solely from a psychiatric hospital and many participants had been in contact with psychiatric services for many years. They reported that the majority of participants understood their experience of hearing voices in terms of biological causation e.g. *"I believe they come from inside my brain... some brain dysfunction"* (Fenekou &

Georgaca, 2010, p139). The original authors acknowledged that participants will have been influenced by the dominant biomedical discourses which they had been subjected to. The two other studies contributing to this third order construct included participants who had not utilised mental health services as well as those who had. It is not possible to know whether there was any relationship between accessing services and viewing thoughts and voices as separate entities, but possible that those without a purely biomedical discourse might be more inclined to hold this view. It is also possible that the services accessed by participants in the studies in New Zealand (Beaven, 2011) and Sweden (Karlsson, 2008) were not only dominated by biomedical discourses but open to other explanations of voices, in contrast the psychiatric context of the Fenekou and Georgaca (2010) study.

### **Line of argument synthesis**

A 'line of argument synthesis' requires the construction of an interpretation (Noblit & Hare, 1988) that serves to uncover what is hidden in individual studies. By synthesising the seven original papers, the present review highlighted the seemingly inextricable link between the personification and identity assigned to the voice(s) by the voice hearer and the power balance in the relationship, due to the complex sensory capabilities attributed to the voice by the voice hearer. A question raised but unanswered by the reviewed studies is whether the content of the voices invariably influenced the identity they were assigned by the hearer or their perceived power.

Control in the relationship between voice hearers and voice(s) seemed to be perceived as being on a continuum and affected by the power distribution,



which can change over time. The studies fall short of exploring in detail what might bring about such change. The experience of hearing voices can have a significant impact on the voice hearers' social world and interpersonal relationships, the nature of which is complex. It is interpreted that hearing voices may not only affect existing social relationships but also contribute to maintaining social isolation for those individuals who perceive voices as a source of comfort and companionship, thereby alleviating the need to seek social contact with other people. However, a clear exception to this for some individuals is the importance of seeking and connecting with 'like-minded' people in order to develop a sense of belonging and a personally meaningful narrative about the experience of hearing voices.

## **Discussion**

This meta-ethnography aimed to appraise existing qualitative research into the phenomenon of hearing voices from a first person perspective and synthesise its findings. The review has highlighted a number of potential implications for both future research and clinical practice.

A critique of the meta-ethnographic approach is its failure to specify how studies in the synthesis should be sampled and appraised (Dixon-Woods et al., 2006), which may reflect a tension within qualitative research in general (Fingeld-Connett, 2008). The quality of the included studies varied greatly. Future research in this area would benefit from attending to quality issues, including justifying the use of a qualitative methodology, specifying epistemological position and reporting the researchers' role within the production of the research.

The present findings might usefully contribute to the knowledge of professionals working with voice hearers, informed by voice hearers perspectives.

This may encourage a shift away from practices that discourage discussion about the content and meaning of voices towards approaches more congruent with voice hearers' reported needs (Coffey & Hewitt, 2008).

The findings support cognitive research's premise that an individual's appraisal of the voice(s) is a key factor in the level of distress experienced (Birchwood et al., 2004). The findings highlight the potential diversity of voice hearers' perceptions of experiences broadly categorised as 'hearing voices'. For clinical practice, this emphasises the importance of formulation-based approaches that take close account of the individual's beliefs about the identity, characteristics and power of the voice(s) they hear, including whether they distinguish between voices and thoughts. Without assessing and formulating such issues it would be impossible to design an appropriately targeted intervention, as 'voice hearing' is clearly not a homogenous experience.

It seems reasonable that strategies aimed at supporting people to question and even challenge the power of voices should be a key focus. It is acknowledged that such interventions are already used within cognitive-behavioural therapy for psychosis and inform the approach taken within the Hearing Voices Movement (e.g. Romme et al., 2009). The results of the present strengthen the rationale for such approaches by connecting it with the peer-reviewed research into the first-person perspectives of voice-hearers.

The finding that some voice hearers have existing and sometimes effective strategies to increase their sense of control suggests the importance of clinicians asking about such strategies. This could emphasise an individual's strengths in

managing distressing experiences and both draw and build upon their own resources in order to generalise effective strategies to a range of situations.

The present review indicates the potential benefits of broadening the focus of interventions beyond the target of voices as a 'symptom'. The finding that voices are perceived to magnify the 'weaknesses' of the individual hearing them suggests the potential value of interventions aiming to promote the individual's sense of self-worth. This insight has also been recognised in narrative therapy work (Verco & Russell, 2009). Interventions to reduce stress and concerns might support the individual by leading to a greater sense of control over the relationship with the voices.

The finding that voices can take the role of 'friend' 'companion' or 'protector' supports literature which suggests that for some people the voice(s) may serve an adaptive role (Benjamin, 1989). Although not explicated in the studies, a key implication of the review is the possibility that the perceived companionship provided by voices might maintain social isolation, as their presence diminishes the need to seek social interaction. In this sense, the voices might not only impact on existing relationships but preclude the development of new ones. This might be usefully explored by future research and could be a helpful focus of assessment, formulation and intervention. For individuals who are socially isolated, the findings suggest that it might be helpful to seek social interaction with people who share similar belief systems. Specifically, learning from others who have gained power in relation to voices could be invaluable for individuals who feel powerless. Research into the potential clinical benefits of connections with 'like-minded' others outside mental health service could determine whether promoting such connections has a place within evidence-based clinical practice.

Participants' diverse causal explanations further highlights the various frames of reference voice hearers have for their experience (Romme & Escher, 1989) and may reflect uncertainty in medical and scientific communities about this phenomenon (Knudson & Coyle, 2002). However, contact with mental health services, diagnosis and respective treatment will influence an individual's understanding of the experience (Drinnan & Lavender, 2006). Although Fenekou and Georgaca (2010) implied the significance of contact with psychiatric services in developing biological explanations, other studies did not investigate this and further research would be required to draw any conclusions. It is acknowledged that studies in this synthesis failed to investigate how useful voice hearers found these frames of reference, although it is of interest that individuals who specifically identified as having positive relationships with the voice(s) drew on spiritual and trauma-based, rather than medical, understandings (Jackson et al, 2011).

There was discrepancy between studies regarding the status of thoughts, voices and inner dialogue. Previous research indicated that roughly the same number of individuals assigned voices as coming from 'inside the head' as 'outside the head' (Honig et al., 1998). Another study stated voices can be identified as 'others' but could also be construed as dialogical engagement with the 'I' (Leudar et al., 1997). Such discrepancies appear to be linked to the identity assigned to voice(s) and the perceived cause of the experience, again emphasising the importance of an individual's frame of reference. Although this synthesis provided some insight into the experience of hearing voices from a first person perspective, it appears the published peer-reviewed research in this area remains limited.

The current synthesis has limitations. There is an inherent difficulty when synthesising studies in trying to distinguish between first and second order

constructs, as data extracts selected by original authors may not represent the totality of participants' experiences (Atkins et al., 2008). Furthermore, it was difficult to decipher to what extent authors' interpretations were influenced by their background in the absence of information about their theoretical stance. Although limiting the synthesis to peer-reviewed articles aimed to improve quality of included research, this may have restricted the findings through not including grey literature. This potentially excludes marginalised views, but this choice was made due to the value placed on peer-reviewed research in informing practice and policy (Grayson, 2002). The review highlights implications relating to both the quality and focus of the identified studies that are pertinent to all future research, peer-reviewed or otherwise. However, future studies may wish to include grey literature.

To conclude, this synthesis reiterates the importance of practitioners attending to voice hearers' views, including an exploration of the content and meaning of hearing voices. Such approaches are likely to increase the potential for more accurate assessments and formulations. This in turn should lead to more person-centred, appropriate and effective interventions, although research would of course be needed to demonstrate whether this was the case. Further research exploring this phenomenon is indicated, with an emphasis on improving the quality of research produced.

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## **Journal Paper**



**“Opening the curtains”: How do mental health service users make sense of the origin and maintenance of their experience of hearing voices?<sup>5</sup>**

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**Abstract**

**Objectives:** The current study sought to explore (1) how, if at all, people construct their understanding of the origin and maintenance of their experience of hearing voices and (2) whether individuals find frameworks of understanding voices useful.

**Design:** An exploratory qualitative method, social constructionist grounded theory, was adopted throughout the research process.

**Methods:** Eight participants who hear voices, or previously heard voices, and were distressed by this experience, were recruited. Each participant engaged in one semi-structured interview.

**Results:** Three overarching descriptive categories were constructed regarding participants' understanding of the development and maintenance of hearing voices; 'Search for meaning', 'View of self' and 'Framework for understanding voices'. Not all participants had an explicit theory of their experience of hearing voices, but all actively searched for meaning. The 'essence' of the developing grounded theory constructed that individuals actively searched for meaning of their

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voices through different frameworks, but the relative 'success' of this pursuit, and potential usefulness of an understanding, is influenced by the sense of agency, stigma and hope(lessness) perceived by the person.

**Conclusions:** This research illustrates how voice hearers actively searched for meaning in relation to their voices and the challenges they encountered during this process. One implication from this study emphasises the role of psychological formulation in generating a shared understanding of the voices. Future research is warranted to explore voice-hearers from a wider range of cultural, religious and spiritual backgrounds and whether the experience of developing a shared framework to understand their voice hearing is valued

## **Practitioner Points**

- Voice-hearers actively seek to make sense of their experience of hearing voices. Professionals should assist this meaning-making process, without imposing one theoretical framework which may be incongruent to the person's understanding.
- This study illustrates the importance of sense-making-in-process through enquiring about the experience of hearing voices

## **Introduction**

The experience of hearing voices has been defined as, "hearing voices speaking when there is no-one there" (British Psychological Society, 2000, p.8). From a biomedical perspective, the content of voices is viewed as largely irrelevant symptoms of mental illness (Read & Argyle, 1999). However, it has been claimed this approach and associated use of medication for treatment has failed to successfully manage psychotic phenomena (Zuk & Zuk, 1998). There is an increasing movement questioning the utility of functional psychiatric diagnoses, arguing for a paradigm shift that contextualises human distress (Division of Clinical Psychology, 2013).

Psychosis is increasingly being viewed as lying on a continuum with normal experiences (van Os, Hanssen, Bijl, & Ravelli, 2000). This perspective is supported by various epidemiology studies, one of which indicates that 10-15% of the general population have experienced a hallucination at some point in their life (Tien, 1991). The hearing voices movement, pioneered by Romme and Escher (1993, 2000), asserts that hearing voices is a common phenomenon which reflects

an individual's relationship to the environment and their life history. Within the literature, an increase in the exploration of non-psychiatric voice hearers has been observed in an attempt to improve the available coping strategies for those who are distressed by the experience (e.g. Taylor & Murray, 2012; Andrew, Gray, & Snowden, 2008). This alternative approach to viewing psychosis argues that since there is no complete understanding of the complex causes of mental health difficulties, clinicians should respect each individual's construction of their own experiences (British Psychological Society, 2000).

There is a lack of agreement within the literature regarding what constitutes a theory (Dey, 2007) due to differing epistemological positions on how knowledge is produced and therefore judged. Positivist approaches emphasise the role of prediction, explanation and generalizability in comparison to an interpretivist focus upon understanding, patterns and presenting arguments about the world (Charmaz, 2006). For the purpose of this paper, theories refer to a set of ideas that are developed and tested to explain phenomena. In comparison, the term framework refers to flexible, looser conceptual notions that have perhaps not been empirically tested but may be the foundation blocks for building theory. There are different psychological theories regarding the origin and maintenance of hearing voices such as; an individual's interpretation upon subsequent distress (e.g. Chadwick, 2006), intra-psychic conflict (e.g. Jackson, 2001), childhood trauma (e.g. Read, Agar, Argyle, & Aderhold, 2003) and abnormal inner speech (e.g. Fernyhough, 2004). Many of the theories appear to overlap in certain areas such as such as the role of abuse, extreme threat or events which produce overwhelming emotions (BPS, 2000). There are also accounts that draw upon looser conceptual frameworks, such as spiritual understandings (e.g. Clarke,

2010) in the attempt to search for meaning to make sense of anomalous experiences (Chadwick, 2006).

There is a growing recognition upon the importance of exploring lived experiences (Harper, 2004). However, it appears there is a dearth of literature which explores the experiences of hearing voices from the perspective of the individual (Beavan, 2011). Furthermore, of the limited studies which have explored a first person perspective of hearing voices it is suggested the quality of this research warrants further improvement (Holt & Tickle, n.d). Due to this, there are few well-established theories about the experience of hearing voices that are grounded in data from the perspective of the voice hearer.

Current guidance suggests that mental health professionals should act as collaborators, developing a shared framework of understanding the voices as opposed to adopting an expert position (BPS, 2000). This is supported within the literature, which advises that for professionals to help voice hearers alleviate distress, an understanding of this experience and the meaning the person attributes to their voices is vital (Lakeman, 2001). The meanings and stories that are constructed about an individual's experience of mental health are thought to be a significant mediator in the process of recovery (Care Services Improvement Partnership, Royal College of Psychiatrists, and Social Care Institute for Excellence, 2007).

Despite this, it is questionable whether this is reflected within clinical practice. Research suggests a common perception held by mental health practitioners was their work would be adversely affected should they attend to the content of psychotic phenomenon (Aschebrock, Gavey, McCreanor, & Tippet, 2003) despite

the contrary wishes of mental health service users (Coffey & Hewitt, 2008). When working with people who hear voices, it could be argued that it may be of greater utility to focus upon the 'fit' between an individual's belief constructions and the way they wish to live their life (Harper, 2004). One clinical implication of this may be the development of different frameworks to understand the experience of hearing voices, as opposed to imposing an existing theoretical model which is incongruent with the person's unique understanding (Yardley, 2000). Furthermore, it is important to consider the role of clinicians and their openness to a range of frameworks when working with voice hearers. Potentially, the role of psychological formulation could be argued to be of benefit in deriving a shared understanding of this experience, to help inform interventions with the aim of decreasing the distress experienced by the voice hearer (Sivec & Montesano, 2012).

Therefore, the current study aimed to:

- Explore how mental health service users', who had been distressed by their experience of hearing voices, made sense of the origin and maintenance of their voices.
- To explore how, if at all, individuals develop a framework of understanding their voices and whether this was useful to the voice hearer

## **Method**

### **Grounded theory methodology**

Grounded theory is a methodology designed to facilitate the process of theory generation when there is a need to challenge existing theories or in an area that has relied on other forms of study or inquiry (Charmaz, 2006). This is evident in

the current literature about people who hear voices. In line with the researcher's epistemological stance, a social constructionist version of grounded theory was utilised during the research process (Charmaz, 2006).

### **Participants**

Eight participants in total were recruited for the study, consistent with previous published examples of grounded theory studies (e.g. Braehler & Schwannauer, 2012; Hirschfeld, Smith, Trower, & Griffin, 2005). Five men and three women, all of White British ethnicity, who self-identified as voice-hearer were recruited (please refer demographic information in table 3). All participants received a service from NHS in relation to their mental health difficulties although, the intensity of support received varied amongst participants from accessing services daily to once every three months. Two participants identified themselves as being currently involved with a local Hearing Voices Group (HVG), with one participant previously attending a HVG which had since disbanded and one participant attending one session of a 'schizophrenia self-help group'. One participant was currently residing in a locked recovery rehabilitation unit, under section 3 of the Mental Health Act.

Table 3 : Participant demographic information

Participant	Age	Age started to hear voices	Services received from NHS	Frequency of contact with NHS	Length of time received services from NHS	Current/ previous Involvement in peer support groups
<b>'John'</b>	63	33	Care co-ordinator, Psychiatrist, Community Psychiatric Nurse (CPN) and Support worker	Fortnightly	21 years	Yes – previously attended a 'schizophrenia self-help group' but felt the voices prevented him from participating
<b>'Ian'</b>	41	28	Psychiatrist, CPN and Support worker	Twice weekly	10 years	No
<b>'Helen'</b>	51	3	Psychiatrist	Every 6 weeks	10 years	No
<b>'Pete'</b>	37	22	CPN, Psychiatrist, Care co-ordinator, Day Services and Crisis Team	Fortnightly	10 years	No
<b>'Shirley'</b>	48	18	Psychiatrist, Clinical Psychologist and CPN	Fortnightly	22 years	Yes – Currently attends independent mental health day support service Previously attended a Hearing Voices Group (group has since disbanded)
<b>'Dave'</b>	50	43	Psychiatrists, CPN and Care co-ordinator	Monthly	7 years	Yes, Hearing Voices Group and Depression and Anxiety support group
<b>'Katie'</b>	25	22	Psychiatrist	Once every 3 months	4 years	Yes, Hearing Voices Group and Bipolar support group
<b>'Steve'</b>	46	27	Clinical Psychologist, Associate nurse, Psychiatrist and support workers	Daily	20 years	No



## **Ethical considerations**

Ethical approval was obtained from a Research Ethics Committee and from the Research and Development departments within two mental health trusts from which the participants were recruited. All data obtained has been anonymised and identifiable information has been changed to protect confidentiality of the participants.

## **Researcher perspective**

The main author conducted this research as part of her Clinical Psychology Doctorate qualification. She is a White, British female in her mid-20's, with no personal experience of psychosis. She adopts a critical psychology position and the stance of utilising psychological formulation to make sense of specific experiences as opposed to relying on psychiatric diagnosis within her clinical work. Her personal construction of the experience of hearing voices is that this is a common phenomenon which individuals may seek support for if they find it distressing, however, does not feel it necessarily needs to be framed as a mental illness. The main author adopts a position that there may be multiple perspectives to understand the experience of hearing voices, but is sceptical of any approach that assumes there is a sole explanatory theory applicable to all individuals who hear voices.

Cutcliffe (2000) asserts that the researcher needs to openly discuss previous experiences, knowledge and values in relation to how it has affected theory development. Utilising guidance from Henwood and Pidgeon (2003) the author explored the various theoretical sensitivities involved during the analysis, including the researcher's positioning, documenting transparently how this effected theory

development through the use of memo-writing. The main author accessed regular supervision and kept a reflective journal throughout the research process.

### **Procedure**

Theoretical sampling was employed during recruitment of participants in an attempt to seek pertinent data to develop an emerging theory (Charmaz, 2006). Therefore, recruitment of participants who hear, or had previously heard voices, which were distressing to them were asked to participate in the research. Individuals were recruited through local NHS Adult Mental Health Teams and Hearing Voices Groups. The researcher received feedback from a Service User and Carer Advisory Panel, some of whom were voice hearers, in relation to developing the initial interview schedule. Semi-structured interviews were conducted with individuals in a private room, were digitally recorded and lasted between 35-80 minutes. Intensive interviewing techniques were utilised to stimulate each participant's in-depth interpretation of their experiences (Charmaz, 2006).

### **Analysis**

A cyclical process of data collection and analysis was utilised which enabled the author to refine and adapt the interview schedule in response to previous participant's responses. Charmaz (2006) recommends two stages of coding before abstracting the data to a theoretical level; initial and focused coding. Initial codes were short, spontaneous, specific and active, sticking closely to the data and to the language used by participants (Charmaz, 2006). The constant comparative method was utilised to generate more focused coding. Theorising in grounded theory refers to an iterative process of progressively moving between more

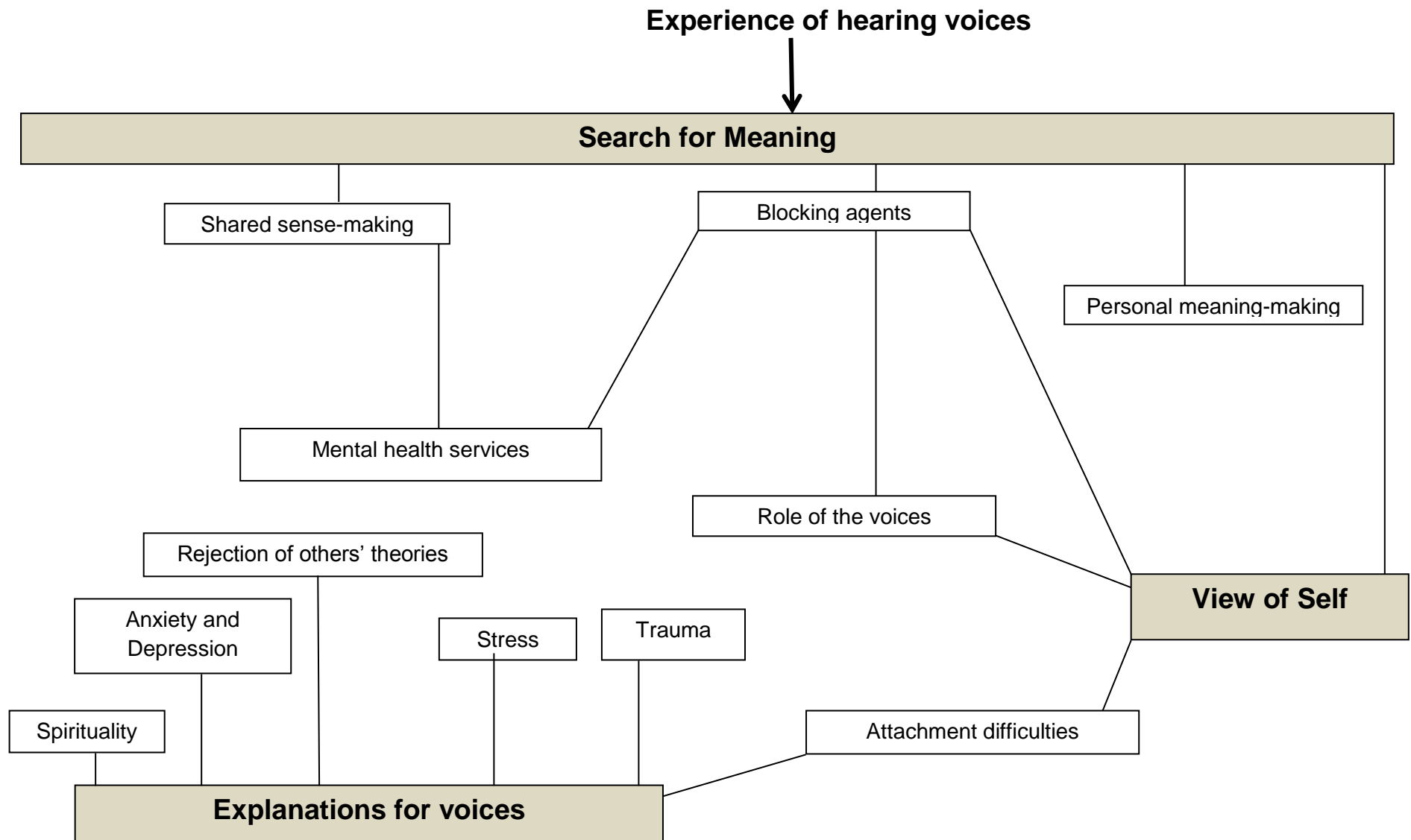
focused coding of the data and developing more abstract concepts, specifying the relations between them (Bryant & Charmaz, 2010). Memo-writing was used throughout the research process to document the abstraction of data to a theoretical level. A literature search was conducted to sensitise the author to the gaps within the literature and to aid contextualisation.

## **Results**

### **Descriptive categories**

From the analysis three overarching descriptive categories were constructed; 'The search for meaning', 'View of self' and 'Explanations for voices'. Whilst being distinct, it is acknowledged there are relationships between the overarching categories and subthemes, as illustrated in figure 2.

Figure 2: Figure of descriptive categories constructed from the data



## **The search for meaning**

The 'search for meaning' represents the beginning of the journey for participants in their attempt to understand their experience of hearing voices. Three subcategories were constructed to synthesise participant's account about how, and what influenced, this search; 'Personal meaning making', 'Shared sense-making' and 'Mental health services'. Although the subcategory 'Blocking factors' was significant for the individual's perceived ability to engage in different meaning-making processes, this seemed to be inextricably linked and influenced by the 'View of Self'.

Personal meaning-making refers to the voice hearers' active attempt to make sense of their voices individually through private enquiry. Six participants described their struggles and attempts to make sense of their experiences. During the struggle to understand the experience, it seemed that some participants asked questions either to themselves, or to their voices. For example, Ian stated that his voice claimed it "was a clairvoyant", although he did not accept this understanding.

The 'success' of the struggle to make sense led some participants to develop a theory for understanding their voices which they endorsed. For example, some participants attempted to identify who/what the voice represented to them, such as Shirley who drew upon an interpersonal relational framework attributing meaning to her voice as representing her abusive mother.

*"Yeah it [the voice] was her [my mother] you know. So I was always wondered why it's male and not female." (Shirley)*

Shared sense-making reflected the process that individuals engaged in when faced with a frustrating inability to make sense of their voices through individual, private enquiry. For example, Katie and Dave discussed how they sought information about hearing voices through the use of the internet to aid their search for meaning. Other participants seemed to rely on mental health services to help them construct an understanding of their voices. A seemingly important link in the ability to utilise shared sense-making processes to search for, and construct, an understanding of their voices was the availability of support to do this. However, this did not necessarily equate to an acceptance of the shared sense-making process as highlighted by Dave;

*“There are common threads and you think oh yeah I do that I do that that you can pick up on. And there can be totally different backgrounds...And I get so far and I think I’m doing well. I think woah hang on...and all of a sudden they say I lived in Tanzania or that er their wife left them or that er their aunty was a you know something or and I’d think bugger well that’s torn that theory.” (Dave)*

All participants discussed the role of mental health services specifically in their search for meaning. Services were constructed mainly as a ‘blocking’ factor in the process of meaning-making (although other blocking processes will be discussed under ‘View of self’). Some participants spoke of their attempts to gain information about voices from services as being met with increased medication. Five participants reported that they did not discuss the experience of hearing voices with mental health services.

*“No one’s really sat with me like this. And actually spoke to me about it [the voices] ever.” (Steve)*

One inference could be made is that a lack of available information or open discussion about hearing voices restricted participants from feeling as though they were able to actively search for meaning through shared sense-making processes. Therefore, it could be interpreted that when participants sought support from mental health services to aid their meaning-making process that, at times the search for meaning was impeded, as the experience of hearing voices was not asked about. This was illustrated by Shirley:

*“I feel all they [mental health services] were doing were pulling the curtains around it [the voices]... [but] psychiatrists and anyone who have anything to do with mental illness shouldn’t pull curtains over it [the voices]. Because it will still come out in the end. There’s no use masking somebody’s illness. You need to be able to underlying it because it will just get worse and fester.” (Shirley)*

The action of undertaking the interview, and enquiring about this experience, enabled the researcher to observe sense-making in process. For example, Ian stated he was unsure why his voices began, but during the course of the interview began to make links to his life experiences.

*(Ian) “Once I went back to college... And yeah then it [experience of the voices stopping] lasted about eight months actually and I broke into voices again. ...I was busy at work yeah work again yeah.*

*(Interviewer) "it sounds like that the time when you've heard voices, if I'm right, it sounds like it's been at times of stress?"*

*(Ian) Actually yeah... [I was] under pressure quite a lot really yeah."*

This highlights the important role mental health services can have in supporting the search for meaning through asking questions about the experience of hearing voices and assisting service users to develop understandings of their voices that they endorse.

### **View of Self**

View of self refers to beliefs that individuals held about themselves that impacted their ability to make sense of the origin and maintenance of the voices they hear.

This was constructed around two subcategories; 'Blocking agents' and 'Role of the voice(s)'.

The term blocking agents refer to factors which either impeded or restricted the participants' search for meaning through individual or shared processes. The utility of an explanation of hearing voices was not seen by all participants as being valuable and was constructed as one potential blocking factor that impeded the search for meaning. This seemed to be inextricably linked to the hope (or lack thereof) of some individuals and their perceived inability to alter their experience of voices.

*"Why it [the voices] won't leave me alone I don't know. I broke down and they don't know, the doctors and my CPN. Or anyone else I talk to about... Nothing they can do... There's nowt I can do about it." (Pete)*



The fear of judgement from others and from the self was interpreted as another blocking process in the search for meaning, due to the fear of confirming the view of self as 'mad'. Helen explained how she had only recently disclosed her experience of hearing voices, after 47 years of hearing voices, due to the fear of being placed in an 'asylum'.

The role of the voices and their perceived capabilities significantly impacted upon their view of the self. Some participants seemed to be fearful of engaging in a search for meaning in case it confirmed the belief of the self as 'bad'. This was discussed in relation to the identity and content of the voice, and the fear of accepting the voice as being generated by the self.

*"they [the voices] say such horrible things... they are things I wouldn't say but how can I how can hear them in my voices and it not be me. That's the problem... I can't never ever strive to be the person I really want to be. I hate the person that says them things." (Helen)*

The content of the voice seemed to confirm a negative view of the self and for some participants provided an explanation of their voices which they endorsed. For example, Katie spoke of how the voice used her fears against her and drew upon an intrapersonal framework of the self not being 'good enough' to understand the development and maintenance of her voice hearing;

*"I think a lot of my fears are that I'm not good enough... You know for other people I think and I think that [the voice] went along with sort of that but that's sort of engrained in me all the time really" (Katie)*

Furthermore, as well as seemingly being conferred by the voices, Shirley highlighted how daily experiences reinforced a negative view of the self and is replicated in her interactions with others:

*“But I do believe that we can go around with a you know a certain word written on our foreheads and people just pick upon that and they know...[for me it is] Bullied. You know bully me. I’m weak bully me...That’s why I try to not let people know [about the voices].” (Shirley)*

When the voices were perceived as being powerful and having physical capabilities, it seemed to have the effect of restricting the voice hearer’s search for meaning due to the threat of being harmed or fear of harming others.

*“I was frightened of the things they [the voices] were saying they were rather frightening... I decided that I thought the voices were evil. I didn’t want anyone to get involved with them” (John)*

### **Explanations for voices**

Five participants stated they were unable to make sense of the origins and maintenance of their voices and reported not to hold a solitary theory. However, participants seemed to draw upon different frameworks when discussing their voices, although they did not make their own connections between different explanations with their own experiences and at times actively rejected theories imposed on them by others. Six subcategories were constructed to integrate participants’ explanations for understanding the origin and maintenance of voice hearing which were; ‘Stress’, ‘Trauma’, ‘Attachment difficulties’, ‘Anxiety and depression’, ‘Spirituality’ and ‘Rejection of others’ theories’

All participants discussed the impact of stress upon their understanding of hearing voices. This involved discussions about stress being both a precipitant, and for some participants the main maintenance factor for hearing voices. The nature of the stressful experiences varied between participants but included transitions within the person's life, the 'battle' with the voices and specific life events e.g.

*"all of my life I've had such a lot of difficult situations to cope with... I've never been free of something being stressful.... So it's like I never ever am free of not just normal stress but added stress on top" (Helen)*

Four participants discussed the role of trauma in the development and maintenance of their experience of hearing voices including sexual abuse, domestic violence, bullying and physical assault. Trauma was perceived as being distinct from the subcategory of stress due to the underlying threat of danger to the individual. Furthermore, a distinction was made between physical abuse (sustained abuse by someone known to the individual) and physical assault (an isolated incident perpetrated by strangers). Steve discussed his belief that the onset of his voices was triggered following a physical assault.

*"I was about 27 and I got mugged and I had my jaw broke and I had my cheekbone broke and the trauma of the actual er beating. There was three of them [people attacking him]... at first I didn't understand what was happening [when the voices started]... I was like hearing voices in my head" (Steve)*

The subcategory 'attachment relationships' was constructed as distinct from 'trauma' as individuals described how this had impacted on their view of the self, as it was inferred from the data that some participants developed their view of the

self based upon their relationships with others. All three female participants discussed the difficulties in their relationship with their early attachment figures as framing their experiences of voices. Helen attributed the origin of her voices as arising from being separated from her mother when she went to nursery, and the fear that she would not return.

*“I first went to nursery...I was terrified... I remember mum leaving me and I just I felt absolutely as though she'd [left me] you know ...it [voice said] er mainly things like you know she doesn't care about you anyway you know and er you're not good enough you know she doesn't love you... that's why she's left you there.” (Helen)*

The experience of anxiety and depression was seen as co-morbid and intertwined with the experience of hearing voices, as well being cited as a maintaining role of the voices, which distinguishes this from the subcategory of stress. Although it is acknowledged the two are closely linked. Two participants directly attributed the role of depression and anxiety as the origin of their experiences of hearing voices.

The framework of spirituality or of mystical experiences was discussed in four participants' accounts in relation to the voices' content. However, this understanding did not seem to be endorsed by voice hearers. The questioning of the possibility of the role of the paranormal in voices seemed to be raised when participants struggled to make sense of their experiences as other 'physical' ways of knowing could not provide an adequate theory accepted by the voice hearer.

*“there's no way on earth that another person can be doing it [the voices] so it's either a I don't know a spirit or something like that or someone back from the dead... I don't know I can't explain it.” (Pete)*

Despite discussing different explanations for understanding the voices, many participants actively rejected other people's theories that were imposed upon them.

*"they [mental health professionals] all seem to think a part of your mind becomes detached and er does it does it to you... I don't believe it." (John)*

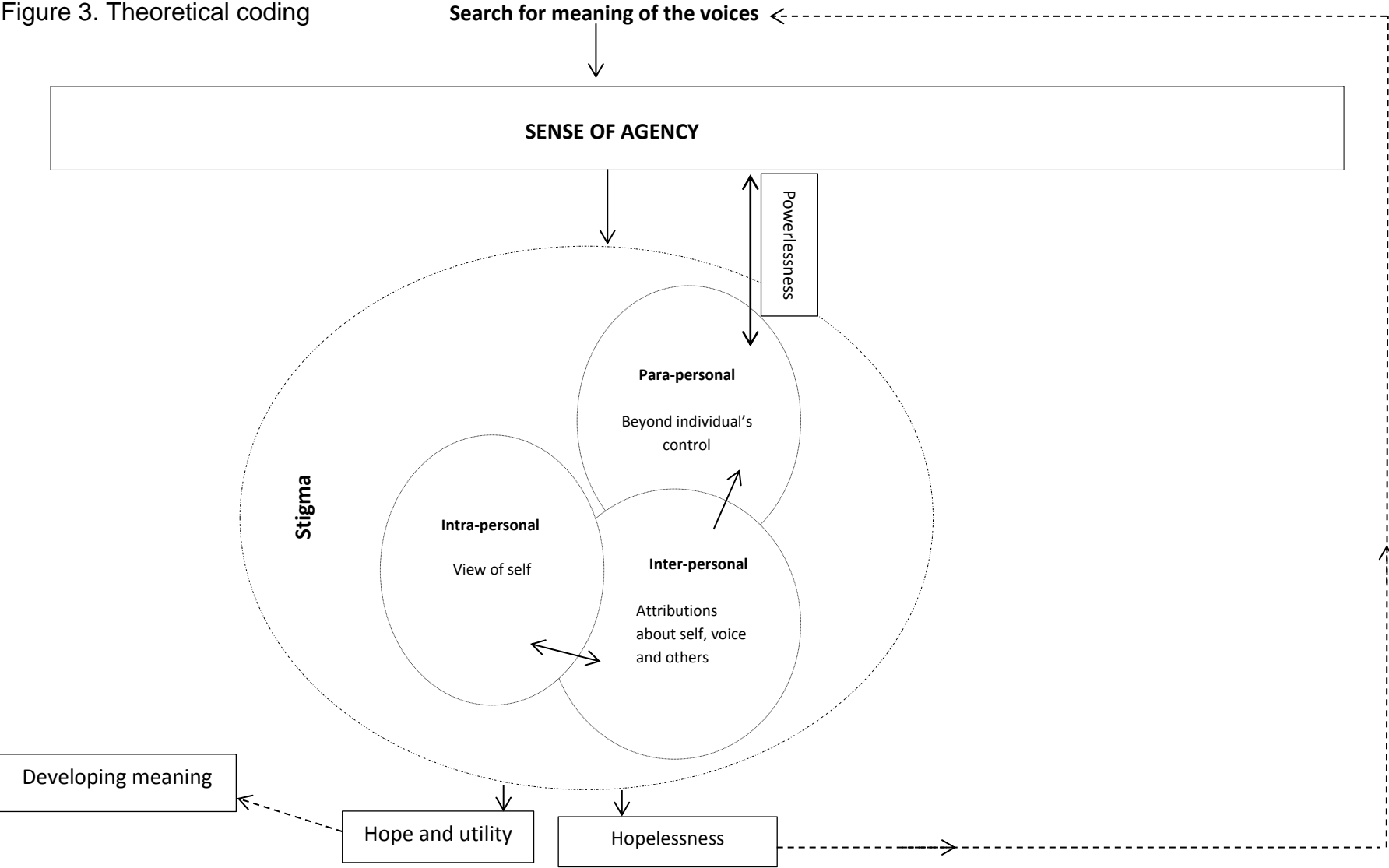
Despite their attempts, some participants were still continuing in their struggle to make sense of the voices, holding no current understanding of the voices. This is highlighted by Pete who describes how he has *"tried to come up with reasons over the years about what it could be"* with little success.

### **Theoretical coding**

The social constructionist grounded theory approach emphasises the importance of exploring variation within the studied phenomenon and the social processes enacted (Charmaz, 2011). It aims to move beyond what is being said to extrapolate an understanding of why these processes are occurring. Through abstracting the data in this manner, the resultant grounded theory is situated within a cultural frame highlighting the wider significance of these socially situated experiences (Henwood & Pidgeon, 2003).

Three theoretical categories were constructed to understand whether and how participants generate an understanding of their experience of hearing voices; 'Meaning making processes', 'Sense of agency' and 'Stigma', as illustrated diagrammatically in figure 3.

Figure 3. Theoretical coding



## **Meaning making processes**

Participants seemed to draw upon three main frameworks to explore the development and maintenance of their experience of hearing voices. These were; 'inter-personal', 'intra-personal' and 'para-personal', which are defined in table 4. The ability to engage with meaning-making processes is theorised to be affected by the person's sense of agency, as well as the stigma experienced by the individual.

Table 4: Definitions of meaning-making processes

Term	Definition
<b>'intra-personal'</b>	<p>Definition of 'intra' offered by Oxford Dictionary:</p> <p>"Existing or occurring within the individual self or mind"</p> <p>The term intra-personal refers to meaning-making processes that draw upon the individual's view of the self.</p>
<b>'inter-personal'</b>	<p>Definition of 'inter' offered by Oxford Dictionary;</p> <p>A prefix meaning between or among</p> <p>Therefore, the term inter-personal refers meaning-making processes that draws upon relationships or communication between people</p>
<b>'para-personal'</b>	<p>Definition of 'para' offered by Oxford Dictionary:</p> <p>A prefix meaning either;</p> <ol style="list-style-type: none"> <li>1. beside; adjacent to</li> <li>2. beyond or distinct from, but analogous to.</li> </ol> <p>Origin of the word 'para' being derived from Greek language meaning 'beside'; in combinations often meaning 'amiss, irregular' and denoting alteration or modification</p> <p>The term 'para-personal' refers to meaning-making processes that draw upon the perception of something being beyond the individual's control but attributed as 'part of them', for example biological causation or spiritual frameworks of understanding</p>

Drawing upon inter-personal frameworks to aid meaning making processes helps to explain how some people conceptualise the origin and maintenance of hearing voices. A seemingly pivotal factor in this process is the attributions people made about others, the self and the voices. It has been suggested that the attributions frequently made about the experience of the voices is replicated in people's social relationships, positing themselves a lower social rank than others and the voices



(Gilbert et al., 2001; Birchwood et al., 2000). Therefore, this may affect the person's perception about the actions which are permitted by their social rank in relation to developing meaning about the voices.

This developing theory suggests interpersonal trauma and stress (Zubin & Spring, 1977) play a significant role in both the origin and maintenance of the experience of hearing voices, as well as appraisals made by the individual about others and the resulting impact upon the view of the self. Therefore, inter-personal processes are closely linked to intra-personal frameworks within the meaning making process. Previous research suggests the view of the self is connected to inter-personal relationships (Mawson, Berry, Murray, & Hayward, 2011) as it relates to other people's expectations and fear of being judged negatively if these are not met. The theory of attachment could potentially help build an understanding of the inter-personal processes within the experience of hearing voices, as well as the replication of these attachment in subsequent relationships, and the development of beliefs about the self (Berry, Barrowclough, & Wearden, 2007). Intra-personal processes can help us understand why some individuals may or may not seek understanding of their voices. One potential reason could be through fear of re-confirmation about negative beliefs of the self

Para-personal frameworks relates to situations where the person perceives neither they, nor anybody else, can help to solve the problem resulting in the individual experiencing 'universal helplessness' (Abramson, Seligman, & Teasdale, 1978). Para-personal and inter-personal processes may at times be linked due to some individuals' experience of relationships that seem beyond their control and the helplessness they may experience as a result of this. Furthermore,

this impacts upon the perceived utility of searching for meaning of the voices when the voices are attributed as being beyond the control of the individual.

### **Sense of agency**

The sense of agency refers to the perceived ability of the individual to seek out, and draw upon, different meaning making processes. There seems to be a limited number of frameworks available for voice hearers to construct an understanding of the voices they hear. Influencing an individual's sense of agency are the dominant discourses of pathology, mental illness and Western cultural assumptions of autonomy (Blackman, 2000). Although not necessarily endorsed by the voice-hearer, the reproduction of these dominant discourses, through institutions such as mental health services places the individual in a 'double-bind' (Burr & Butt, 2000) between personal responsibility and a perceived incompetence to act. This effectively 'dis-ables' the individual: they are unable to increase their sense of agency in relation to understanding their experience of hearing voices, contributing to a sense of hopelessness.

Through drawing on para-personal processes, the individual is 'relinquishing' control of the understanding of the experience of hearing voices, whether this is to the field of mental health professionals or spiritual frameworks. Previous research suggests that attributing meaning to the voices as originating from spiritual possession or neurochemical imbalances increased the perception of powerlessness of the person in relation their voices (Jones et al., 2003).

Therefore, processes that draw upon para-personal frameworks is argued to influence the experience of hope, as establishing meaning of the voices and the

individual's perception of control may diminish the experience of fear (Jackson, Hayward & Cooke, 2010).

## **Stigma**

The enactment of meaning making processes occur within the context of stigma, which impacts the individual's frame of reference for understanding their voices, as well as the available support to access this information from. The experience of social stigma has been found to impact the individual's relationship with their voices (Mawson et al., 2011) and could therefore be argued to influence the available frameworks for people to make sense of their experience of hearing voices. Factors hypothesised to impact on this process include; gendered assumptions (Schon, 2009), discourses surrounding mental illness and help-seeking behaviour (Corrigan, 2004) and the dominant professional frameworks to understand the experience of hearing voices (Harper, 2004). Negative interactions with mental health services and the effect of stigma have been suggested to contributed to numerous losses, most significantly the loss of hope (McCarthy-Jones, Marriott, Knowles, Rause & Thompson, 2013).

## **Discussion**

The primary aim of this study was to explore how, if at all, people construct an understanding of the origin and maintenance of their experience of hearing voices and whether individuals find these frameworks useful. The author found it useful to think about the 'essence' of the generated theory through a one sentence summary): *Participants attempted to construct an understanding of their voices through drawing on three main frameworks (inter, intra and para-personal), but the relative 'success' of this pursuit, and potential usefulness of an understanding,*

*is effected by the sense of agency, stigma and hope(lessness) perceived by the individual.* This study highlighted participants' attempts to search for meaning, but the utility of this was often linked to the hopelessness they experienced. The failure to adopt a meaningful framework to understand the experience of hearing voices has been argued to prevent the voice hearer progressing to the organisation phase of their relationship with their voices, decreasing levels of anxiety (Romme & Escher, 1989).

Although some participants did not have an explicit theory regarding the development and maintenance of the voices, the *attempt* to attribute meaning to their experience of voices was evident. Previous research with people who held alternative frameworks in relation to hearing voices, self-identified Clairaudients, indicated this experience was initially perceived as distressing but this changed through the process of understanding and attributing personal meaning to the voices (Taylor & Murray, 2012). The authors suggested that an engagement with the experience of hearing voices aided this meaning-making process which developed into an explanatory framework which was meaningful to the individual. It seemed that some participants had not been supported in the opportunity to develop an understanding of their voices. This is consistent with fears voiced within the literature regarding the colonisation of service users understandings by dominant professional conceptualisations (Harper, 2004) and the expectation that contact with mental health services influenced some participants' interpretation of their experience (Drinnan & Lavender, 2006).

The search for meaning is argued to represent an attempt by the individual to learn how to cope with their voices (Jones & Coffey, 2012). Within this study, all participants actively searched for meaning and this might represent a helpful

starting point for clinicians. The clinical implication of this illustrates the important role mental health services have in asking questions about the experience of hearing voices. During the research process, the author observed 'sense-making-in-action' through enquiring about the voices, which is supported by claims that through being interesting and asking about the voices can have a 'therapeutic side-effect' (Longden, Corstens, Escher, & Romme, 2012). There is a body of research which has aimed to explore the effectiveness of different coping strategies for people who are distressed by the experience of hearing voices. However, it has been claimed that exploring the use of different coping strategies in isolation from the meaning attributed to the voices has relatively little meaning (Knudson & Coyle, 2002).

Previous research indicates that some voice hearers are dissatisfied with the care they receive from mental health services due to the limited range of frameworks through which to view the voices, with a clear emphasis on a biomedical model (Coffey & Hewitt, 2008). Furthermore, it is argued that meaning attributed to the voices which are privileged and reproduced in daily interactions are those which reflect the interests of the dominant, powerful groups, such as mental health professionals (Jones & Coffey, 2012). Whilst the focus of this research was not aimed at exploring service users' satisfaction with mental health services, it illustrated that some participants actively rejected, misunderstood or experienced an increased sense of hopelessness when an implicit biological framework to the voices was used by professionals. However, this places clinicians in a challenging position of managing a balance between their professional knowledge and resisting imposing their interpretation through this lens (Goldsmith, 2012), being open to frameworks which they may have little knowledge of. Therefore, the

challenge to mental health services is how to provide a containing experience whilst being open to multi-explanations for voice hearing. This may represent a clinical need for staff training to improve their confidence in discussing alternative frameworks.

The results also highlighted that individuals may not hold necessarily hold a solitary framework to understand their experience of hearing voices, as highlighted by the numerous factors which impacted a person's meaning-making process. Therefore, it could be argued that through imposing one framework of understanding, at times, led to a confused understanding for participants who drew on multiple frameworks without necessarily endorsing one theory of hearing voices. A further clinical implication of this is the need to shift from one model of viewing voices and one mode of treatment, to offering the possibility of adopting a variety of practices to help people in distress by the experience of hearing voices that is congruent with their understanding (Harper, 2004). Furthermore, it has been suggested that individuals with an explanatory framework of their voices often utilised coping strategies for managing distress in accordance with their understanding of their voices (Romme & Escher, 2000). One clinical implication of this highlights the utility of psychological formulation to aid the development of a shared, meaningful framework to understand the experiences of hearing voices.

There were some limitations of the current study which must be acknowledged.

Firstly, the sample size was relatively narrow and small; it did not represent individuals from a wide range of cultural, religious and ethnic backgrounds.

Previous research has suggested the potential utility of researching the experience of people who do not seek help from mental health services (e.g. Andrew et al., 2008). Although the author attempted to incorporate this to broaden

the range of experiences studied, through approaching various HVGs, there were some recruitment problems encountered when trying to do this. Another limitation of this study is that it does not include participant feedback about the results of the research, although a letter was sent to each participant outlining the findings.

The research was evaluated utilising criteria outlined by Charmaz (2006) based on whether the constructed grounded theory could substantiate claims of credibility, originality, resonance and usefulness. The current research could be argued to have gone some way into developing an interpretative theory, providing a significant and original contribution to knowledge. However, due to the limitations of the study, the claims made by the research are modest but are supported and generated from the data.

To conclude, this study offers a unique and distinct contribution to the current literature through illustrating how voice hearers actively searched for meaning in relation to their voices. This highlights the importance of helping people engage in meaning-making processes to help individuals understanding the experience of hearing voices. One implication from this study emphasises the role of psychological formulation in generating a shared understanding of the voices. Future research is warranted to explore voice-hearers from a wider range of cultural, religious and spiritual backgrounds and whether the experience of developing a shared framework to understand their voice hearing is valued.

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## **Extended Paper**

## **1. Introduction**

### **1.1 Psychosis**

The term psychosis is often conceptualised in Western culture as being symptomatic of serious mental illness (Jones, Guy, & Ormrod, 2003). The umbrella term 'psychotic experiences' is used to describe unusual perceptions and beliefs that an individual may hold (British Psychological Society (BPS), 2000). These experiences are often associated with levels of distress which are assumed to impact on everyday functioning. Various frameworks are utilised in an attempt to understand these experiences. One study found that following a first episode of psychosis, a large proportion of participants reported severe low mood, which carries a high risk of suicide (Birchwood, Iqbal, Chadwick, & Trower, 2000a). The reported high risk of suicide attempts by people with psychosis has been well documented in the literature (e.g. Falloon & Talbot, 1981). This highlights the clinical importance of trying to understand this experience in an attempt to manage the severe distress experienced by some people who hear voices. To achieve this, an understanding of different explanatory frameworks which are utilised for people who hear voices will be discussed.

### **1.2 Explanatory models of hearing voices**

#### **1.2.1 Medical model.**

The aim of any medical explanatory framework is to identify, describe and explain patterns and grouping related phenomenon through an underlying physical cause (Boyle, 2002a). Therefore, the biological model views hearing voices as a symptom or manifestation of a disturbed brain process located within the individual (Birchwood & Jackson, 2001). Typically, the treatment implications of this approach is the prescription of medication to manage distress associated with the voices (Leudar, Thomas, McNally, & Glinski, 1997) and the content of the experience is deemed mainly irrelevant (Read & Argyle, 1999). The language used to describe these phenomena includes terms such as delusions, auditory hallucinations, thought disorder and positive symptoms. An individual who presents with a cluster of such symptoms for a given time period is likely to be assigned to a diagnostic category such as schizophrenia. In line with this



biological emphasis on schizophrenia, medication is seen as the treatment of choice (Boyle, 2002b). This is highlighted in current guidance for the management of these symptoms through the administration of various anti-psychotic medications (National Institute of Clinical Excellence (NICE), 2011). Therefore, the origin and maintenance of voice hearing is viewed as a response to an untreated biological dysfunction.

The origins of the medical approach to understand the experience of hearing voices is often dated back to Emil Kraepelin (1887). Kraepelin, often hailed the 'father of modern psychiatry', explored the potential similar trajectories of mental illness and physical disease processes, which would locate the biological origin of madness (Bentall, 2003). He later coined the phrase 'dementia praecox' to describe a group of symptoms he had observed in young adolescent men which would lay the foundations for the modern concept of schizophrenia. A wealth of literature has attempted to investigate the possibility of a genetic origin to 'madness,' ranging from genetic heritability to neurodevelopmental theories of schizophrenia (Birchwood & Jackson, 2001). It is argued that within modern mental health services Kraepelin's model remains largely unchallenged (Bentall, 2003).

This biomedical approach to understanding the origins and maintenance of voice hearing has been frequently critiqued within the literature due to the lack of evidence of an assumed primary biological causal mechanism to categorise the experience of hearing voices as a disease process (Johnstone, 2007). Furthermore, it has been suggested that the experience of being told that the voices are a symptom of an underlying brain disease ignores the reality of the voice hearer's experience which may be invalidating and of little value to the individual (Cockshutt, 2004).

In mental health care, the application of the medical model to the experience of hearing voices suggests that the concept of recovery is viewed as symptom elimination and represents an unlikely prospect for sufferers (Pitt, Kilbride, Nothard, Welford, & Morrison, 2007). However, it has been claimed the biomedical framework and associated use of medication for treatment has failed to successfully manage psychotic phenomena, leading to questions about the utility

of this approach (Zuk & Zuk, 1998). The recovery movement challenges the view that 'schizophrenia' is an inevitable, deteriorating condition in which recovery can only equate to an elimination of voices (Silverstein & Bellack, 2008). This has led to literature increasingly becoming focused upon the meaning of the experience of hearing voices. This represents a shift in the conceptualisation of what 'recovery' in mental health means and research began to investigate not only the meaning attributed to the voices, but also the relationship the voice hearer has with their voices (e.g. Benjamin, 1989).

### **1.2.2 Psychodynamic model.**

Another approach often utilised as an explanatory framework for the experience of hearing voices draws upon psychodynamic theory. The psychoanalytic tradition represents a multiplicity of approaches and ideas, tied together with the common thread of a focus on emotional pain and the structure of the psyche to cope with this (Leiper, 2006). In relation to hearing voices, psychoanalytic approaches aim to "make sense of the incomprehensible and apparently meaningless thinking and behaviour commonly associated with psychotic states of mind" (Jackson, 2001 p.4). From this perspective, the meaning of the psychosis can be understood through the activation of defence mechanisms to manage intra-psychic conflict (Hingley, 1997). Therefore, experiences of psychosis are viewed as meaningful and as manifestations of intolerable unconscious anxieties. The origin of all mental anguish is thought to be traceable to the person's current or childhood relationships (De Masi, 2009), this principle could be applied when trying to understand the experience of hearing voices.

Kleinian perspectives emphasise the importance of early developmental experiences of the child and the development of primitive defence structures of their internal mental world (Jackson, 2001). The infant is conceptualised as being capable of experiencing anxieties and able to use defences to protect the self against intra-psychic conflict (Klein, 2011). One cited example given for early anxiety in the infant is the 'death instinct', the fear of one's own annihilation (Klein, 1946). The thoughts, wishes and feelings which arise as a result of the unconscious anxiety are intolerable to the infant (Watkins, 2008). It is proposed, in

an attempt to manage this extreme anxiety, these feelings are projected onto others, which develops into a fear of persecution from others (Hingley, 1997).

Psychosis is viewed as a regression by the individual to primitive defences which were developed during early childhood. Early defences of the infant are argued to meet the inner needs of the child through the distortion of external reality including; denial of external reality, distortion and delusional projection (Hingley, 1997). One primitive defence, which is thought to be central to psychosis from this viewpoint, is postulated to be projection. The mechanism of this defence is described as “externalisation of an intra-psychic conflict into external reality” (De Masi, 2009 p.5). However, a critique of the psychodynamic literature is that the premise of this theory is based on speculation and subjective concepts. One consequence of this is the inherent difficulty in measuring something which cannot be observed (de Pauw, 1994) to be able to prove the existence of these theoretical constructs. Therefore, it is argued there is a lack of empirical evidence to support claims made by this approach.

Another psychodynamic explanation of hearing voices concerns the perceived regulatory actions of the superego. This draws upon Freud’s topographical model of the unconscious, when primitive unconscious drives are perceived as unacceptable to the self, “voices can be seen as stemming from a stern super-ego expressing criticism towards the drives of the id” (van Laarhoven, 1993, p. 156). The unacceptable drive is not repressed within psychosis, it is proposed that it is the perception of external reality which is repressed to manage this conflict (De Masi, 2009). This draws on the assumption that the role of voices is similar to the role of the super-ego. Research suggests that individuals perceive their voice to regulate their behaviour through prohibition, evaluation and direction (Leuder & Thomas, 2000) which could be argued to resemble a similar role of the proposed super-ego. However, this predicates on the assumption of the existence of the unconscious, and the topographical model posited by Freud, which has not been empirically demonstrated.

The clinical implication of psychodynamic theories upon the voice hearer emphasises the importance of understanding both the underlying meaning and function of the voices. Both the origin and maintenance of voice hearing is posited

within unresolved intra-psychic conflict. Through establishing the meaning of the voices, as well as uncovering what the defence mechanism is protecting, the individual can realise the unconscious conflict and it can be integrated into the self as opposed to being silenced (Ritsher, Lucksted, Otilingam, & Grajales, 2004). Therefore, the aim of therapy from a psychoanalytic tradition would be to decrease the need for defences through acceptance of the vulnerable aspects of the self.

### **1.2.3 Cognitive models.**

The understanding of the experience of psychosis by mental health professionals is claimed to have undergone a shift (Boyd & Gumley, 2007). Cognitive models of psychosis typically reject the illness based model of schizophrenia and promote a symptom-based approach to hearing voices (Chadwick, 2006). A symptom-based approach argues that given the poor validity associated with the concept of schizophrenia as syndrome-based illness, it is more parsimonious to study individual symptoms of psychosis in an attempt to understand them (Bentall, Jackson & Pilgrim, 1988). Similarly to psychodynamic models, cognitive approaches suggest that the experience of voices as meaningful phenomena and not abstract, irrelevant symptoms. The premise of any cognitive approach posits that distress “is not an inevitable consequence and occurs only when these events have a particular meaning” (Chadwick, Birchwood, & Trower, 1996, p.6). This would suggest that voice hearing occurs in the general population, yet may not cause distress to everyone, which is supported by epidemiological research on non-psychiatric voice hearers (e.g. Tien, 1991). It has been argued that perceiving the experience of psychosis as lying on a continuum with normality represents a more useful conceptualisation than categorical frameworks (van Os et al., 1999). The presence of voice hearing in non-help seeking community samples emphasises that this experience may not always be distressing to the extent of seeking support (Birchwood et al., 2004).

It is claimed that cognitive theories are often built on the premises and assumptions outlined in psychodynamic theory, leading to significant overlaps between the two theories when trying to understand the experience of hearing voices. For example, one cognitive approach, which seemingly draws upon the

mechanism of projection, suggests that voices potentially represent an attempt to protect the self through attributing internal mental events to sources external to the self (Bentall, Haddock, & Slade, 1994). This transformation is thought to provide the person with some relief as it is argued to represent a less painful experience than the intolerable internal conflict (Watkins, 2008). One study, which seems to support this hypothesis, concluded that negative voices appeared to represent externalisation of negative childhood experiences of being criticised, rejected and shamed, thereby acting as a defence against depression (Gilbert et al., 2001).

The proposed maintenance mechanism of psychosis is the role of appraisal of events, which causes distress and feeds into the experience of psychosis (Drinnan & Lavender, 2006). Frequently this focus has emphasised the individual's relationship with the voice, as opposed to content or topography, to aid understanding about the generation of distress (Birchwood, Meaden, Trower, Gilbert, & Plaistow, 2000b). One cognitive approach suggests the role of four types of beliefs in the maintenance and emotional response to voices; voice purpose, voice identity, omnipotence and beliefs regarding the consequences of disobedience to the voice (Chadwick, 2006). Therefore, the aim of therapy is to discover the psychological processes that elicit the experience of psychosis and associated behaviours (Morrison, Renton, Dunn, Williams, & Bentall, 2004). Change is aimed at the behavioural level of the coping strategies the individual utilises as opposed to attempts to change the symptom, i.e. the voices, and upon the reappraisal of the voice-hearing experience.

The cognitive model emphasises the impact of the individual's beliefs and interpretation upon subsequent levels of distress. Clinical guidelines currently recommend the use of CBT, for a minimum of 16 sessions, for individuals with a diagnosis of schizophrenia (NICE, 2011). The clinical implication of utilising this framework is that the individual's own explanation for their voice-hearing experience can be accepted and worked with collaboratively (McCarthy-Jones, 2012). Given the importance placed on the person's belief system upon subsequent levels of distress, cognitive research has often focused upon the development of beliefs about the voices and the individual's life history. The relationship between voice hearer and their voices is argued to be characterised

by subordination to an omnipotent powerful other (Birchwood et al., 2000b). Furthermore, it is suggested that an individual's relationship with their voices may mirror their relationships within the social world (Mawson, Berry, Murray, & Hayward, 2011).

The focus placed on internal mental events by a cognitive approach is argued to make it inherently difficult to account for the reflexive relationship between the voice hearer and their voices (Davies, Thomas, & Leudar, 1999). It could be argued that the voices are internal mental events and therefore the relationship is also an internal mental state. Furthermore, the evidence base for the effectiveness of CBT in alleviating distress for people who hear voices is often based upon case studies and it is claimed evidence from randomised controlled trials of CBT for psychosis as being relatively weak (McCarthy-Jones, 2012).

#### **1.2.4 Inner speech models.**

Another explanatory framework used to understand the experience of hearing voices is the perspective that voices represent an unusual form of inner speech (Leudar et al., 1997). Theories of inner speech predicate on the assumption that the self is dialogical and is the product of an individual's engagement with the social world (Lysaker & Lysaker, 2001). Therefore, a primary assumption of this model is that inner speech retains the dialogic qualities from the social world it is derived from (Jones & Fernyhough, 2007). This is supported by research which indicates inner speech and voice-talk share many similarities (Leuder & Thomas, 2000). A dialogical approach to hearing voices emphasises the person's explanatory framework, making it possible to explore the relationship between the voice hearer and their voices (Davies et al., 1999).

Similarly, to other psychological approaches, this model posits that inner speech in itself represents an aspect of healthy functioning (Pérez-Álvarez, García-Montes, Perona-Garcelán, & Vallina-Fernández, 2008). The experience of psychosis is viewed as a 'breakdown' in the dialogue within and between the self and others (Lysaker & Lysaker, 2001). The attribution of inner speech is conceptualised as alien to the self and not recognised as a form of inner dialogue (McCarthy-Jones & Fernyhough, 2011). It is the interpretation of this experience as external to the self which is thought to result in distress (Fernyhough, 2004).

This approach shares many similarities with cognitive approaches to understanding hearing voices. Inner speech, similarly to cognitions, cannot be observed and therefore assumptions regarding its properties relies heavily on extrapolating features of the presumed precursor to inner speech, egocentric speech (Jones, 2009).

### **1.2.5 Trauma-based explanations.**

It is suggested that the experience of trauma or abuse during childhood can affect how people interpret information in later life (BPS, 2000). The association between early childhood trauma, specifically interpersonal abuse, and psychosis has been investigated extensively within the literature. Generally, there appears to be an increased likelihood of individuals who have suffered interpersonal trauma in childhood developing psychosis in adulthood (e.g. Kilcommons, Morrison, Knight, & Lobban, 2008). One study suggested that hearing voices may represent an individual's coping mechanism in response to trauma (Honig et al., 1998). The association between traumatic childhood experiences and the development of psychosis has been argued to emphasise the role of appraisal and interpretation of events in psychosis (Morrison, Frame, & Larkin, 2003).

Quantitative studies exploring the role of trauma in relation to hearing voices suggest that voice content was related to the experience of childhood abuse, with a clinical note review claiming that 54% of all voice content was clearly linked to previous trauma (Read & Argyle, 1999). Furthermore, an association between high levels of trauma in both non-psychiatric and psychiatric voice hearing populations has been established (Andrew, Gray, & Snowden, 2008). One study claimed that 70% of participants began hearing voices after a traumatic experience (Romme & Escher, 1989).

A potential explanation of the role of trauma in hearing voices, which draws on psychodynamic theory, is that of dissociation. Dissociation is argued to represent a protective function through the unconscious 'splitting' of the mind (van Laarhoven, 1993). Some authors argue that during a trauma, an individual may dissociate as a defence mechanism and as a result certain aspects of the trauma do not form part of the episode when it occurs, which is presumed to operate at a subconscious level (van der Hart, 1993). The experience of trauma, and the

intense emotional reaction accompanying it, does not become a fully integrated memory, leaving an 'emotionally charged state' which is re-triggered through associations with the initial trauma (van der Hart, 1993).

The mechanism of dissociation is argued to represent the attempt of the individual to regulate affect in relation to the trauma, which may be expressed as psychotic symptoms (Read, Agar, Argyle, & Aderhold, 2003). Attempts have also been made to frame psychotic experiences positively using trauma as a mediator, such as the development of paranoia as previously bring a helpful survival strategy which may have outlived its usefulness (Read, Os, Morrison, & Ross, 2005). However, it is unclear whether this can be extrapolated to the experience of hearing voices.

Romme and Escher (1989) began to question the role of trauma in hearing voices. The content and subsequent meaning attributed to the voices was argued to be associated with an individual's life history (Romme & Escher, 2000). The voice hearer's experience is thought to transition through three phases; startling phase, phase of organisation and stabilisation phase (Romme & Escher, 1989). It is suggested that as the voice hearer develops a relationship with their voice, the relationship between the voices and the person develops a consistent coping mechanism to manage this experience (Romme & Escher, 1993). It is inferred that a failure to do this means the individual remains in the startling phase, one which is perceived as frightening to the individual (Romme, Honig, Noorthoorn, & Escher, 1992).

One clinical implication for professionals working with people with psychosis could potentially be exploring how the experience of trauma impacts upon the experience of hearing voices. This may include exploring an individual's beliefs regarding possible similarities between the trauma experience and the voices. It is assumed that the origin and maintenance of voice hearing is through the interpretation of the event and possible re-experiencing of the initial trauma. One of the recommendations arising from this body of literature is the integration of trauma models within the response to people who hear voices (Read et al., 2003).

However, this predicates on the assumption that childhood trauma is causal in generating the experience of hearing voices. Despite the high correlations



between trauma and psychosis observed in these studies, this must not be confused with causation. A limitation of these studies is that they fail to adequately explain the remaining individuals who have psychosis who do not report having experienced interpersonal trauma. Alternatively, it fails to capture the number of individuals who have experienced trauma but have not experienced psychosis. The body of literature which claims a causal link between trauma and psychosis suffers from inherent methodological difficulties including the lack of healthy control groups and the use of crude measures of childhood trauma (Fisher et al., 2009). The existing literature may not take into account the difficulties of disclosing abuse by the person who may feel unable to report the trauma, perhaps particularly when they are acutely psychotic. It has also been suggested that people who experienced trauma in their childhood were also more likely to have experienced other factors which may contribute to the development of psychosis such as poor relationships to their parents and social deprivation (Bendall, Jackson, Hulbert, & McGorry, 2008). Furthermore, the focus upon correlations and attempts of prediction neglects the perception of individuals who had experienced interpersonal trauma and whether they thought this was associated with their experience of psychosis.

#### **1.2.6 Hearing Voices Network.**

The hearing voices movement, pioneered by Romme and Escher (1993, 2000), challenges the perception that voice hearing is indicative of organic pathology. Instead they assert that hearing voices represents “an interactional phenomenon reflecting the nature of the individual’s relationship to their environment and vice versa” (Romme & Escher, 1993, p. 16). They claim that hearing voices is not the problem but rather the inability to cope with them which causes distress. The guiding principle of the Hearing Voices Network (HVN) is each individual should be supported and respected for their individual framework of understanding voices (Blackman, 2000). They welcome all explanatory models to understand the experience of hearing voices (McCarthy-Jones, 2012) refusing to privilege one single framework (Bracken & Thomas, 2001). One aim of the HVN is to help others understand the experience of hearing voices as being valid (Meddings et al., 2004).

The consequences of hearing voices, rather than the experience per se, are often targeted as an intervention in cognitive models of psychosis (Lakeman, 2001). Furthermore, this approach stated that voice hearing was a common phenomenon which occurs both psychiatric and non-psychiatric populations (Romme & Escher, 1989). This is similar to other psychological models frameworks of understanding voices. One implication of this approach is to question the utility of the medical model towards hearing voices and the view that voices are somehow an 'unreal' event by denouncing voices as irrelevant pathological phenomena (Heery, 1993).

The work pioneered by Romme and Escher has led to the development of the HVN and commended the importance of peer support groups. The HVN philosophy engenders "a distinct and very different organisation to that of the Mental Health Services in terms of culture, ethos, philosophy and values" (Hearing Voice Group Charter, 2012). It could be inferred that this is not necessarily the case uniformly in mental health services, given the multi-disciplinary nature of teams which inherently include a range of psychiatric and psychological perspectives. The development of such groups is said to be based on the belief that those who have endured similar experiences and have overcome adversity can offer useful support, encouragement and mentorship to their peers (Davidson, Chinman, Sells, & Rowe, 2006).

One implication of the HVN is the importance placed on the individual's unique meaning-making process of the experience of hearing voices as opposed to imposing frameworks of understanding on service users. This suggests that clinical services may benefit from adopting the ethos espoused by the HVN. Although it is acknowledged that there is limited research into the effectiveness of self-help groups for voice hearers (Hendry, 2011). A recent review of HVGs' recommended that future research should focus upon predictors of outcomes and mechanisms of change to refine HVGs' (Ruddle, Mason & Wykes, 2011). There is a lack of literature exploring whether individuals have an explanation of their voices prior to entering a HVG, or whether the group is helpful in developing this. Furthermore, the HVN has been critiqued for prioritising trauma-based explanations above others despite claiming all explanatory models as equal (McCarthy-Jones, 2012). This highlights a gap within the literature about what

information people draw on when developing their understanding of hearing voices, or whether this is useful for the individual.

The aim of therapy when utilising this framework is to help individuals cope with the voices as opposed to the eradication of this experience (Romme & Escher, 2000). Again, this approach is similar to other psychological theories of hearing voices such as the cognitive approach. Therefore, this approach suggests that it would be useful clinically to explore with an individual their relationship with their voices and their meaning to help the transition to the organisational and stabilisation of hearing voices.

### **1.2.7 Stress-vulnerability model.**

The stress-vulnerability model to viewing psychosis stipulates that everyone has a susceptibility to this experience which predicates on their inborn and acquired vulnerability (Zubin & Spring, 1977). This model arose from a position of pragmatism, incorporating information from prevailing models during that time based on people with a diagnosis of schizophrenia. Zubin and Spring (1977) regarded the ever-present threat of a person's vulnerability as being the main feature of schizophrenia. This model of psychosis emphasised the role of interacting individual factors in the origin of this experience (Nuechterlein & Dawson, 1984). Therefore, this approach would assume that during times of stress, an individual would be more likely to experience psychotic phenomena.

Within the literature, periods of stress and transitions are frequently cited in relation to the experience of hearing voices. This is evident in other psychological models of hearing voices such as the role of trauma in this experience. For example, one study reported that experiences of peer rejection and bullying, which could be identified as a periods of stress, were found to increase the likelihood of an individual's vulnerability to psychosis (Campbell & Morrison, 2007). Another example which illustrates this within the literature is the experience of voices following a bereavement (Rees, 1971). However, there does not appear to be extensive recent research into the stress-vulnerability model of psychosis. Despite this, the application of psychosocial interventions for people who hear voices is dominant within mental health services, for example, the use of Thorn training courses for professionals. Although this approach provides an

understanding of the origin of hearing voices, it could be argued that it fails to adequately explain why this experience is maintained or whether this framework is useful for voice hearers.

### **1.2.8 Spiritual and religious frameworks.**

One salient theme within the literature on psychosis is the use of religious and spiritual frameworks by individuals in assisting meaning making of their voice hearing experience (Drinnan & Lavender, 2006). Throughout history, it has been inferred that the experience of hearing voices has been attributed to a supernatural origin and on some occasions has led to the founding of some religious movements (Watkins, 2008). Some notable individuals who are thought to have experienced voices that are frequently cited in the literature include Joan of Arc, Socrates and Mahatma Ghandi to name a few (Leuder & Thomas, 2000).

It is argued that perceptions of psychosis and spirituality share some similarities in that both concepts are often undervalued, neglected within mental health services and lie outside the realm of logical discourse (Clarke, 2010). A recent qualitative study illustrated the importance of wider social contexts, such as spirituality, when exploring the relationship a voice hearer has with their voice (Chin, Hayward, & Drinnan, 2009). It has been suggested that individuals who had a more positive experience of hearing voices often drew upon spiritual frameworks (Jackson, Hayward, & Cooke, 2011).

There has been an increase in the number of studies which aim to explore non-psychiatric voice hearers, including mediums and clairaudients, with the aim of developing coping mechanisms for psychiatric voice hearers for the distress they experience. For example, one qualitative study explored the meaning-making process of clairaudients in relation to hearing voices which claimed that central to all participants was an explanatory framework that seemed to enable the ability to accept the experiences of voices (Taylor & Murray, 2012). Another study which explored voice hearers' understanding of their experience recommended that future research should investigate further the range of constructions that people have about voice hearing (Jones et al., 2003). The findings from this study (which included mental health service users, non-users and spiritualists) found that individuals had a complex 'constellation' of different beliefs about their voice

hearing. Interestingly, mental health service users were more likely to perceive their experience of voice hearing as more frightening and negative than non-users. The authors suggested that potentially non users of mental health services were able to frame their experience positively because of their belief constructions about their voices which included spiritual and religious frameworks of understanding. It is suggested that both psychiatric and non-psychiatric voices hearers experience negative voices, but non-psychiatric voice hearers are still able to function well (Romme & Escher, 2000).

Further research also suggests that due to the complexities of the phenomena of hearing voices and voice hearing relationships that the area warrants future research to explore this phenomenon more thoroughly (Mawson et al., 2011). This illustrates the importance for clinicians to be aware of alternative frameworks for understanding hearing voices which the service user may have and to avoid the temptation to impose one theoretical framework upon their experience (Taylor & Murray, 2012).

### **1.2.9 Culture.**

The experience of hearing voices is argued to be shaped through the cultural lenses with which it is viewed from, affecting the expectations and how this phenomenon is responded to within the society. It is argued that social networks, events and reactions cannot be isolated from one another and the political, social and cultural realities in which we exist should be central to an understanding of hearing voices (Bracken & Thomas, 2001). Environmental and cultural influences are argued to shape the meaning and form of hearing voices, regardless of the explanatory framework utilised either by professionals or the voice hearer (Ritsher et al., 2004). In some societies, hearing voices is viewed as a valued and sought after experience (Lakeman, 2001). Cross cultural research indicates the experience of hearing voices is not isolated to Western cultures, nor is it necessarily presumed to represent pathology (Al-Issa, 1990). Directly contrasting this, western cultural assumptions regarding the self as 'controller', asserts the belief that behaviour controlled by something else other than the self as pathological and abnormal (Landrine, 1992).

Explanatory frameworks of hearing voices which do not incorporate an individual's cultural, spiritual and religious sphere of reference have been argued to be reductionist and incomplete (Ritsher et al., 2004). However, it could be argued that research fails to investigate how these frames of reference impact on an individual's beliefs on the origin of voices or the continuance of this experience. The clinical implication of this suggests that a comprehensive account of the development and maintenance of voice hearing should incorporate how cultural influences shape the individual's experience of psychosis.

### **1.3 Responses of mental health professionals**

Current guidance suggests that mental health professionals should act as collaborators of developing a shared framework of understanding the voices as opposed to adopting an expert position (BPS, 2000). This is supported within the literature, which advises that for professionals to help voice hearers alleviate distress, an understanding of this experience and the meaning the person attributes to their voices is vital (Lakeman, 2001). Whilst there are various explanatory models of hearing voices, these frameworks need not be considered as mutually exclusive (Ritsher et al., 2004). The meanings and stories that are constructed about an individual's experience of mental health is thought to be a significant mediator in the process of recovery (Care Services Improvement Partnership, Royal College of Psychiatrists, and Social Care Institute for Excellence, 2007). Furthermore, one of the founding principles of the service user involvement movement, is the importance of valuing the person's direct experience of mental health difficulties (Division of Clinical Psychology, 2010). This suggests that searching for an individual understanding of a person's mental health experience aligns with recovery and service user involvement movements.

However, it is questionable whether this approach is reflected within clinical practice. A piece of research suggested a common perception, by mental health practitioners, was if they were to discuss the content of psychotic phenomenon their work would be adversely affected (Aschebrock et al., 2003). The medical model could be argued to remain one of the prevailing approaches to understanding voices (Hewitt & Coffey, 2005). This potentially could help to explain the reticence in discussing the experience of voices, as from the

biomedical perspectives hearing voices is considered a largely irrelevant symptom of underlying biological dysfunction. It has been argued that professionals have been trained and encouraged to 'reinforce reality' in response to people who hear voices despite the contrary wish of mental health service users (Coffey & Hewitt, 2008). The biomedical model explanation of hearing voices often places control of the phenomenon beyond the voice hearer's grasp and may not be helpful in assisting the person to manage this experience (Romme & Escher, 1989).

### **1.3.1 Psychological Formulation.**

Within the field of clinical psychology, the role of psychologists in disseminating and applying recovery principles within multi-disciplinary teams has been championed (DCP, 2010). One way of achieving this may be through the use of formulation. Psychological formulation aims to collaboratively develop a joint understanding of a person's difficulties (Sivec & Montesano, 2012). The value of a formulation is argued to lie in the ability to inform interventions from a coherent and justifiable account of a person's presenting problems (Kuyken, Fothergill, Musa, & Chadwick, 2005). It is suggested that psychological therapy for individuals who experience distress, which is attributable to their psychosis, should start with a detailed theory regarding the origin of these experiences (Morrison et al., 2004).

Psychological formulations can draw on a range of theories, such as cognitive, psychodynamic and systemic, and can be targeted at different levels ranging from a situation to case level specific (Stephens, unknown). The use of case formulation for the experience of psychosis has shown to be useful to therapists and their perception of building the therapist-client alliance, although participants experiences of this were more varied (Chadwick, Williams, & Mackenzie, 2003). There seemingly is limited research into the experience of psychological formulation for the voice hearer, and whether developing an understanding of their voices is beneficial and useful to them.

## **1.4 The search for meaning**

Philosophical thinking has often debated man's search for meaning in situations which are perceived as hopeless and meaningless. One example of this is writing

on the experience of Jewish people during the Holocaust (e.g. Frankl, 2011). Rather than passive recipients of information, it is argued that “we do not just attach and attribute meanings to things, but rather find them; we do not invent them, we detect them” (Frankl, 1985, p.31). This suggests that an individual actively strives to make sense of or understand the world as they uniquely experience it (Darlaston-Jones, 2007). The search for meaning has been claimed to represent an achievement of inner harmony through meeting the demands of the situation and an understanding of the self (Längle, 2007). Furthermore, through searching for meaning in our experiences it ‘unlocks’ potential for action (Pattakos, 2010). Many psychological approaches, such as the cognitive model of hearing voices, suggests the experience of psychosis are expressions of the search for meaning in response to ambiguous, unusual or painful life experiences (Chadwick, 2006). Research has indicated that developing meaning for psychotic experiences has the potential effect of altering the individual’s experience of the self and their social relationships in a positive manner (Dilks, Tasker, & Wren, 2008).

#### **1.4.1 Clinical implications of searching for meaning.**

One clinical implication of this, if it is extrapolated to the experience of hearing voices, is querying whether individuals seek to make sense of this experience, and if so, what frameworks they utilise to seek meaning. Research has illustrated how developing a personally meaningful framework may help the voice hearer foster a positive relationship with their voices (Jackson et al., 2011). However, this would assume that people are able, and want to, understand their experience. A common source of distress associated with the experience of hearing voices is claimed to be the lack of an ‘obvious source’ to the voices (Martin, 2000). It appears there is limited research into how, if at all, voice hearers seek to make sense of the origins or maintenance of their experience. Therefore, it could be argued that there is a danger that service users’ experiences are “being colonised by professional categorisations and classifications rather than allowing users of services to theorise those experiences themselves in their own words” (Harper, 2004, p. 61).



This highlights the importance of the lived experience of people who hear voices and the need for research to explore individual's subjective understanding of this experience to contribute meaningfully to the existing body of literature (Geekie & Read, 2009). Although there are a variety of frameworks postulated for understanding hearing voices, there is a dearth in the literature regarding how useful service users find these constructions or whether it matches their experience. It is acknowledged that there is a scarcity of studies which explore voice hearer's experiences of hearing voices in general (Knudson & Coyle, 2002). This is supported by a recent literature review which claimed the evidence base is lacking qualitative research exploring the meaning or value of voices to the voice hearer (Suri, 2011). Furthermore, of the limited studies which has explored a first person perspective of hearing voices it is suggested the quality of this research warrants further improvement (Holt & Tickle, n.d).

## **2. Aims of the study**

The aims of the study are firstly to explore how, if at all, voice hearers who are distressed by this experience make sense of the origin and maintenance of their voices. Secondly, whether these understandings are perceived as useful to the voice hearer (please refer to journal paper).

The potential clinical implication of this research would be to improve services by bridging possible gaps between how people who hear voices and those working in mental health services understand and therefore approach this phenomenon. This is congruent with recent research that suggests clinicians should endeavour to consult service users more regularly and consistently regarding their priorities and preferences in relation to treatments for their psychosis (Byrne, Davies, & Morrison, 2010).

## **3. Method**

### **3.1 Methodology**

#### **3.1.1 Qualitative approach.**

When deciding upon the most appropriate methodology to investigate the phenomena under study, it is argued that one must match the method with the

aims of the research question providing a sound rationale and critical reflection of the approach chosen (Yanchar, 2006). Qualitative research is conceptualised as a discovery-oriented and exploratory method (Barker, Pistrang, & Elliott, 2002) which aims to explore how people experience and make sense of the world (Willig, 2001). One common thread in qualitative research is the explication of meaning through interpretation and inference (Madill, Jordan, & Shirley, 2000). In contrast, quantitative methods typically aim to investigate phenomenon through the manipulation of precise, controlled variables at a particular moment in time (Yardley, 2000). Although there has been a rise in the number of published research articles which have employed qualitative methodologies, there is still a relative bias towards the use of quantitative research (Rennie, Watson, & Monteiro, 2002). It has been argued that traditionally psychology has adopted a scientific discourse in its approach to research, which privileges a greater claim to truth than the people who are the subjects of study (Burr, 2003).

Qualitative methodologies are argued to contribute to the existing literature through enriching an understanding of a topic by thorough engagement with the actions of people who live these experiences (Elliott, Fischer, & Rennie, 1999). In relation to the available literature about people who hear voices, it is acknowledged that there is a small, but growing evidence base utilising qualitative methods to explore their experiences (Laithwaite & Gumley, 2007). Due to the limited literature available regarding mental health users' perceptions of the experience of hearing voices (Holt & Tickle, 2012), and in line with the research aims, a qualitative methodology, which allows the participant to theorise and describe in their own words about their experience, was chosen for this research study.

### **3.1.2 Epistemology.**

Within the heterogeneous field of qualitative research, there are various epistemological stances which inform the research process including type of method analysis utilised and approach to interpreting the data (Madill et al., 2000). The debate regarding the importance of explicitly acknowledging one's own stance in relation to ontology and epistemology upon the research process has been debated extensively elsewhere (e.g. see Darlaston-Jones, 2007). To assist

in the identification of one's epistemological stance, it is recommended that researchers ask themselves three questions (Willig, 2001, p.12-13);

- What kind of knowledge does the methodology aim to produce?
- What kind of assumptions does the methodology make about the world?
- How does the methodology conceptualise the role of the researcher in the research process?

One epistemological stance is that of social constructionism which is posited within the postmodern tradition. The theoretical assumptions underpinning social constructionism challenge the 'traditional' view that conventional knowledge is based upon an objective and unbiased observation of the world, and asserts that knowledge is historically and culturally specific (Burr, 2003). This position espouses that "all claims to knowledge, truth, objectivity or insight are founded within communities of meaning making" (Gergen, 2001a, p.2). Therefore, a postmodernist stance rejects the notion that it is possible to objectively access 'truths' or the existence of what is 'real' as this reality is socially constructed (Fopp, 2009).

Within the literature it has been acknowledged that narratives of psychosis are co-created with the participation of numerous people including; the person with psychosis, professionals, family members and members of the individual's support system (France & Uhlin, 2006). This infers that conceptual frameworks to understanding psychosis already exist within society and are reproduced within our daily interactions (Burr, 2003). However, it is suggested that these knowledge claims are merely a reproduction of socially constructed expressions of power by 'experts' such as health professionals (Cruickshank, 2012). Utilising this critical stance highlights the importance of disseminating alternative models of psychotic experiences (Boyle, 2002b) such as hearing voices and provides an alternative framework to understand this phenomenon.

A social constructionist approach recognises the research process as one of co-construction between the researcher and participant, jointly creating an interpretation of the participant's reality within a specific time and context (Darlaston-Jones, 2007). Furthermore, this viewpoint asserts that a 'second order'

of interpretation is required during the research process as in accordance with this stance there is no one observable, universal reality (Gergen, 2001b). This allows for multiple realities and interpretations which are equally valid (Ponterotto, 2005). In line with these issues and the researcher's beliefs, an epistemological stance of social constructionism was adopted throughout the research process.

### **3.1.3 Selection of qualitative method.**

Although qualitative research encapsulates a broad range of analyses, it has been suggested that there are four main methods which capture qualitative data analysis; discursive, thematic, structured and instrumental (Madill & Gough, 2008). One of the main differences between these qualitative approaches to studying different phenomena is the focus placed on the role of language. From a social constructionist perspective, language is perceived as a form of social action which has a 'performative' role (Burr, 2003). A discursive approach states that language both mediates and constructs our understanding of reality (Starks & Brown Trinidad, 2007). This is succinctly described by Parker (1992) who states "discourses do not simply describe the social world, but categorise it, they bring phenomena into sight" (p.4). Discursive psychology aims to answer questions about identity, subjectivity, how people construct versions of themselves and how they legitimise their actions (Burr, 2003). Therefore, discourse analysis aims to explore how talk is used within social interactions and does not make inferences about how people feel or think (Payne, 2007). For the purpose of this research, the aim is not to analyse the discourses individuals use to construct their experience of hearing voices or the reproduction of power, but their perception of the development and maintenance of voice hearing. Therefore a discursive approach is not the most appropriate methodology to study the research aims.

Thematic approaches to data analysis often aim to search for concepts with similar meaning within the data, intending to capture the essence of the phenomenon under investigation (Madill & Gough, 2008). Methods included in this category include grounded theory, interpretive phenomenological analysis (IPA) and thematic analysis (TA). Thematic approaches are employed when the researcher is interested in eliciting participants' understandings, perceptions and experiences of a certain phenomenon. The aim of TA is to describe patterns

across the data and it is argued to be a 'building block' of any qualitative analysis (Braun & Clarke, 2006). However, it is suggested that a distinctive feature of TA is the theoretical flexibility accorded to this method of this analysis in comparison to IPA and grounded theory which are 'theoretically bounded' (Braun & Clarke, 2006).

Within the literature, the similarities between IPA and grounded theory have often been commented upon, such as their shared focus upon human experience and their attempts to understand a phenomena from the subjective perspective of the person (Baker, Wuest, & Noerager-Stern, 1992). However, a key difference between the two methods is claimed to be the philosophical positions the methods draws upon. The theoretical origins of IPA lie within the phenomenological tradition which aims to study how people make meaning from their lived experience (Starks & Brown Trinidad, 2007). Therefore, the goal of any IPA study is claimed to be to "describe the world-as-experienced by the participants of the inquiry in order to discover the common meanings underlying empirical variations of a given phenomenon" (Baker et al., 1992, p. 1356). Comparatively, grounded theory aims to explore social processes. Barker and his colleagues (2002) articulates one of the differences concisely as, "in contrast to phenomenologists, constructionists do not see language as necessarily reflecting the individual's underlying thoughts and feelings, rather they are interested in how people use language to structure things, or to get things done"(p. 82).

Arguably, one of the distinguishing features of grounded theory in comparison to other thematic approaches is that of theory generation. This is in contrast to the claimed aim of IPA which is to describe the experience utilising the individual's frame of reference. Grounded theory is designed to facilitate the process of theory generation when there is a need to challenge existing theories or is an area that has relied on other forms of study or inquiry (Charmaz, 2006). This is evident in literature about people who hear voices where studies have mainly employed quantitative methodologies to study this phenomenon (Fenekou & Georgaca, 2010). Although there are various theories about the experience of hearing voices, there is gap in the existing literature about how service users interpret their experience of hearing voices (Knudson & Coyle, 2002).

Recently there have been various studies which have employed a grounded theory approach to study individuals' experience of psychosis (e.g. Dilks, Tasker, & Wren, 2010). The strength of this research is that it provides alternative frameworks of understanding and could potentially impact how clinicians in the NHS approach these phenomena. This is also in line with recovery oriented care approaches, which assert that subjective experiences may not only mediate the process leading to recovery but may also sustain this process (Liberman & Kopelowicz, 2005). Furthermore, grounded theory aims to explore how social processes and relationships influence interactions, patterns of behaviour and interpretations (Tweed & Charmaz, 2012). During theory development, the process of coding aims to capture action and change through the use of gerunds (Morse, 2001). This enables the researcher to explore how groups of people make sense of their experiences and define their realities through interactions with others (Cutcliffe, 2000).

The developed theory which is generated is grounded in the data, as opposed to being forced to fit an existing theoretical framework (Noerager-Stern, 2007). As explored previously, although there are various frameworks to understand the experience of hearing voices, it is unclear whether this fits with voice hearers experiences. There is a risk that service users experiences are being forced to fit existing frameworks of understanding which may not be concordant with their own (Yardley, 2000). Therefore, a grounded theory approach was deemed the most appropriate methodology for this research as this study was attempting to break new ground in relation to generating a theory grounded in voice hearers' frameworks of understanding for the development and maintenance of hearing voices.

### **3.2 Grounded Theory**

Following the recommendation of Cutcliffe (2000) that researchers need to use predominantly one method of grounded theory, from the various strands of grounded theory the author chose to use the social constructionist guidelines provided by Charmaz (2006). This constructionist paradigm asserts there are multiple, and equally valid realities and the goals of this type of research are idiographic and emic (Ponterotto, 2005). Charmaz's (2006) version of grounded

theory asserts the method as being dialectical and an active co-construction between the researcher and participants, rather than the theory being a production of an objective reality. Furthermore, Charmaz (1995) states that there is no ultimate truth and grounded theory should not be used as such, or as a prescriptive tool for practitioners, but the focus should be on the lived experience and stories of the participants. A potential strength of grounded theory is that it has the analytic power to theorise how experiences, meanings, actions and social processes are constructed (Charmaz, 2006). This methodology is also in line with the researcher's epistemological stance.

### **3.3 Participants.**

Theoretical sampling is a key feature in the grounded theory approach. It refers to the recruitment of a purposive sample which is composed of participants who best represent or have knowledge of the research topic (Bowen, 2008). The aim of theoretical sampling is to seek pertinent data to develop an emerging theory (Charmaz, 2006). Therefore, it is suggested that a 'narrow' sample be recruited from the same substantive group (Cutcliffe, 2000).

Participants were recruited who currently (or had previously) heard voices that other people could not hear, and were distressed by this experience. Eight participants in total were recruited for the study, five men and three women, aged between 25 and 63 (please refer to table 2, in journal paper). All participants received a service from the NHS in relation to their mental health difficulties. All participants were recruited through NHS Adult Mental Health Teams, although three participants identified themselves as having being involved with a local Hearing Voices Group, with two participants remaining actively involved<sup>6</sup>. One participant reported attending a 'schizophrenia self-help' group for one session.

Participants completed demographic information for the study (see Appendix A) which included; age, gender, age started to hear voices, type and frequency of NHS services they accessed, whether they accessed a peer support group and details regarding their GP and usual care team. All participants were willing to

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<sup>6</sup> One participant commented that the reason they no longer attended a HVG was due to the group disbanding

engage in at least one digitally recorded interview. No participants were asked for a second interview.

Although there is no set recommendation regarding the number of participants required for a grounded theory study, this number is consistent with the suggestion that for a Doctorate of Clinical Psychology qualitative study recruitment of 8 – 20 participants is appropriate (Turpin et al., 1997) and previous published grounded theory examples (e.g. sample size of eight and six participants respectively when utilising social constructionist grounded theory, Braehler & Schwannauer, 2012; Hirschfeld, Smith, Trower, & Griffin, 2005). Frequently, when engaging with grounded theory it is recommended that the researcher continues interviewing participants until the data is ‘saturated’ (Cutcliffe, 2000). The concept of saturation is defined by Morse (1995) as ‘data adequacy’ when no new information is obtained from data collection. However, it has been argued that saturation is widely claimed in research yet scarcely practiced (Charmaz, 2008). Dey (1999) contests the credibility of the concept of theoretical saturation and alternatively argues the utility of theoretical sufficiency. Theoretical sufficiency can be defined as when existing categories seem to cope adequately with new data without requiring extensions and modifications. Furthermore, it is suggested that the concept of saturation is in itself an artefact of how the researchers manage and focus their procedures of data collection and queries whether claims of saturation are legitimate (Dey, 1999). The argument for theoretical sufficiency complements concerns raised by Charmaz (2006) regarding published grounded theory studies and whether they in fact generate a theory. The author chose to utilise the pragmatic approach of theoretical sufficiency (Dey, 1999) as opposed to theoretical saturation for this reason, whilst acknowledging the time and physical restraints placed upon the research.

### **3.4 Ethical Considerations**

Prior to commencing the recruitment of participants, the research was reviewed and given favourable opinion by Liverpool Central Research Ethics Committee (REC) (please refer to Appendices B-D). Following this, ethical approval was sought from an Adult Mental Health NHS Trust (see appendix E) to enable recruitment of participants who accessed support through their community mental



health teams. Initially, the REC expressed some concerns regarding recruiting individuals who accessed support from Hearing Voices Groups (HVG's) which were facilitated by experts by experiences. The REC recommended that recruitment from HVG's should be restricted to groups which were facilitated by clinicians. During the process of recruitment, the author challenged this (refer to 5.5.2 for further discussion) and applied for a substantial amendment to the initial ethical approval given (see Appendix F). The substantial amendment was accepted (see Appendix G) and subsequently the author was able to recruit from all HVG's. Ethical approval was also sought from another NHS trust (see Appendix E) to broaden the pool of potential participants to recruit from.

The researcher received feedback from Trent Clinical Psychology Doctorate's Service User and Carer Advisory Panel in relation to developing the initial interview schedule and the information on the participant information sheet, effectively piloting the information with service users. Prior to any interview, the researcher discussed contingency support plans should the participant, in the unlikely event, become distressed by the process of the interview. Furthermore, details of their usual care team and GP were obtained in the demographic information sheet should an urgent referral the mental health team be required. All participants had an opportunity to discuss the study, including their right to withdraw without giving any reason, prior to providing informed consent (see Appendix H and I) to participate. Anonymity was assured, with the exception of disclosure of risk to either themselves or others that their usual care team was not aware of. All participants, with the exception of one individual, were taking medication. The researcher acknowledged the difficulties and associated side effects of medication throughout the interview process and this was taken into consideration throughout this process for the participants comfort. For example, being able to take breaks, checking for people's understanding and inviting questions throughout the interview (DCP, 2010).

### **3.5 Procedure**

#### **3.5.1 Recruitment.**

After gaining ethical approval, individuals were recruited from two main sources; individuals who access support through two NHS Adult Mental Health Services

and local HVG's were approached. The rationale for recruiting from these two groups is based upon existing literature recommendations that future research should focus on both psychiatric and non-psychiatric voice hearers (Andrew et al., 2008). However, the author encountered some difficulties in recruiting from HVG's (please refer to section 5.5.2). All participants recruited through the NHS, the researcher sent an email to all the psychologists in the region regarding the research (please refer to appendix J) with a copy of the participant information sheet attached. The participants recruited through the NHS were initially approached by their care coordinator or by their psychologist who considered issues of risk, potential impact on current treatment and eligibility to participate. The care co-ordinator or psychologist acted as the initial contact and approached potential participants during routine visits, providing them with the participant information sheet. Participants were given a minimum of 24 hours to consider the information and were asked either to contact the researcher (via the information provided on the information sheet) or to consent for the researcher to contact them. Following this, a meeting between the researcher and participant was arranged to discuss the study prior to the interview.

### **3.5.2 Inclusion and exclusion criteria.**

The following criteria were utilised for the identification of appropriate participants:

- Have previously heard voices that other people could not hear that are distressing or have been distressing in the past.
- Have been involved with the NHS/ non NHS services (e.g. hearing voices group) for at least one year.
- Be over 18 years old and above.
- Be willing to engage in at least one interview for the purposes of the study.
- Be willing to have the interview audio-recorded for the purpose of data analysis.

The following criteria were utilised in the exclusion of potential participants:

- Demonstrate any significant issues of risk to themselves, others or the researcher, as determined by the individual's care co-ordinator and/or the researcher.

- Are acutely distressed.
- Are unable to provide informed consent.
- Cannot communicate fluently in English.

### **3.5.3 Interview Process.**

Interviews are a method of data collection which have become synonymous with the qualitative tradition (Wimpenny & Gass, 2000). The use of semi-structured interviews is argued to enable some degree of structure whilst mainly facilitating the participants to explore their stories in their own words (Fassinger, 2005). This is in line with constructionist grounded theory which aims to investigate phenomena from the participant's lens (Tweed & Charmaz, 2012). An intensive interviewing approach was taken in line with Charmaz's (2006) recommendations, which refers to an in-depth nature of an interview which elicits each participant's interpretation of his or her experiences.

The data from the first interview was transcribed and analysed before any further interviews were carried out. This cyclical process of data collection and analysis enabled the author to refine and adapt the interview schedule in response to previous participant's responses, thereby emphasising "the impact of the interview process upon the data gathered...along with the explicit shaping of this material when gathered by the researcher" (Wimpenny & Gass, 2000 p.1488). The grounded theory method enables this flexibility throughout the research process, allowing the research to follow interesting leads (Charmaz, 2006). The interview schedule was refined four times in response to data analysis and the emerging theory (please refer to Appendices K-M). All interviews were conducted in a private room and lasted between 35 – 80 minutes. At the end of the interview, the researcher and participant engaged in a debriefing session, addressing any issues of concern, questions of the participants or issues of risks. All participants were asked whether they would like to receive a summary of the results once the research had been completed.

### **3.6 Analysis in Grounded Theory.**

Charmaz (2006) recommends two stages of coding before abstracting the data to a theoretical level; initial and focused coding. The interviews were transcribed

verbatim by hand. The transcript focused upon the spoken word, as opposed to a Jeffersonian transcription, as the aims of the research focused upon the meanings contained in the transcript in line with the grounded theory method (Oliver, Serovich, & Mason, 2005). Each interview was initially analysed using line-by-line coding to generate preliminary codes before the next interview took place (see Appendix N for example transcript). Coding refers to the process where attempts to define meaning of the data through analytic codes (Tweed & Charmaz, 2012). A computer package was not used during the analysis, as it is argued that such programs may create the illusion that the process of interpretation can be reduced simplistic procedures (Charmaz, 2003).

Initial codes were short, spontaneous, specific and active, sticking closely to the data and to the language used by participants (Charmaz, 2006). The aim of this was to enable the researcher to remain open to the data, rather than imposing pre-existing frameworks or concepts, whilst preserving the 'character' of the data (Charmaz, 2011). Following the initial analysis of the data, the researcher engaged in the process of constant comparative method to generate more focused coding. The constant comparative method enables the continuous contrast within and between participants experiences (Barbour, 2001) through looking for similarities and differences in the developing codes (Tweed & Charmaz, 2012).

During the process of analysis, it is suggested that the researcher should "define how, when and to what extent participants construct and enact power, privilege and inequality" (Charmaz, 2005, p.512) to abstract the data to a theoretical level. Theorising in grounded theory refers to an iterative process of progressively moving between more focused coding of the data and developing more abstract concepts, specifying the relations between them (Bryant & Charmaz, 2010). A theory's level of conceptualisation is raised by the process of comparing it to data from other substantive areas (Glaser, 1978). This process is aided through the use of memo-writing, which details the progression from description of the data to delineating properties and specificity of the codes (Tweed & Charmaz, 2012). It is argued that two important aspects involved in abstracting the data to a theoretical level is that the grounded theory is abstract of time, place, and people and that concepts have 'enduring grab' (Glaser, 2002). Therefore, theoretical coding

raises descriptive categories to abstract concepts which offer an interpretive framework to understand the relationships between the categories within the data. The end result is a grounded theory, enriching an understanding of a topic which is embedded within psychological theory (Henwood & Pidgeon, 2003).

### **3.6.1 What is a theory?**

Both the process and outcome of grounded theory is theory generation, which aims to add a new and important contribution to the existing literature base (Noerager-Stern, 2007). A common critique of grounded theory is that researchers often have difficulty distinguishing between description and theory. There is debate within the literature regarding what level of abstraction constitutes a formal theory and whether a formal theory would be of interest for the postmodern tradition (Kearney, 2007). Furthermore, it is argued that there is a lack of agreement or consistent rules governing the classification of what a theory is (Dey, 2007).

Within the natural science paradigm, a scientific theory is argued to be declared invalid only if an alternative candidate is available to take its place and research aims to test for falsification or confirmation of the theory (Kuhn, 1996). The objectives which are prioritised within a positivist theory are that of prediction, explanation, and universality seeking causes of behaviour (Charmaz, 2006). However, the approach of grounded theory was developed in response to a perceived 'crisis' in sociology regarding the limitations of deductive theory development (Rennie, Phillips, & Quartaro, 1988). The processes of grounded theory aims for theory generation, as opposed to theory verification, and as such uses different criteria to develop, define and evaluate a theory. Within the different strands of grounded theory, it is generally accepted that "...a theory must offer a coherent, contextualised explanation (versus merely a contextual description) of a phenomenon, and interrelationships among the constructs undergirding the theory must be articulated; moreover, a grounded theory must emanate directly and clearly from the data." (Fassinger, 2005 p.162). However, it is at this point which the various grounded theory methods diverges which each approach prioritising different elements of what should constitute a 'good' theory.

The definition of what a 'good' theory consists of varies from prioritising a 'conceptually dense', detailed account of the data (Corbin & Strauss, 2008) to one which emphasises the importance of parsimony and potential modifiability in the presenting theory (Glaser, 1978). Theoretical assumptions underlying social constructionism assert objectivity is impossible to achieve since each person encounters the world from different viewpoints, and the questions we come to ask about the world, our hypotheses and theories, must also arise from the assumptions that are embedded in our individual perspective (Burr, 03). Therefore, the social constructionist version of grounded theory emphasises understanding, patterns and connections within theory generation and claims theories are rhetorical, presenting arguments about the world and the relationships within it (Charmaz, 2006).

### **3.6.2 Transparency.**

Within qualitative research, 'owning one's perspective' is encouraged to help the researcher think about their expectations and experience of the phenomena under investigation (Elliott et al., 1999). However, there is debate within the field of grounded theory regarding when it is appropriate to undergo the 'contested' literature review. It is argued that some awareness of the existing literature is required to explore whether the area of investigation has already been well developed (Willig, 2001). The notion of 'sensitising concepts' is often discussed in grounded theory in relation to the researcher's prior knowledge and suggests that, "whereas definitive concepts provide prescriptions of what to see, sensitizing concepts merely suggest directions along which to look" (Blumer, 1954, p.7.) This suggests that the researcher is required to utilise sensitising concepts to aid generation of ideas of interest and to help them become sensitised to the type of questions the research may aim to answer (Tweed & Charmaz, 2012). Furthermore, it is acknowledged that an awareness of the literature is required in order to gain ethical approval and submission of research proposals (Payne, 2007).

Cutcliffe (2000) asserts that the researcher needs to openly discuss previous experiences, knowledge and values in relation to how it has affected theory development. Glaser and Strauss (1967) claimed that "the root source of all

significant theorising is the sensitive insights of the observer himself" (p.251). Therefore, it seems appropriate to acknowledge the stance and prior knowledge which I, as the author, bring to this research. This is also referred to as theoretical sensitivity. Theoretical sensitivity is assumed to be reflected in how the theory is generated and abstracted from the data (Fassinger, 2005). This is achieved through the transparent process of memo-writing as to how the researcher generated the theory, providing a traceable audit trail throughout the process of analysis (Madill et al., 2000). Utilising guidance from Henwood and Pidgeon (2003), the author explored the various theoretical sensitivities and how this effected theory development (please refer to section 5.8.3 for further discussion).

### **3.6.3 Evaluation of research.**

Although the social constructionist stance argues that traditional positivist criterion to measures of research quality (such as reliability and validity) are inappropriate to qualitative research, it is still appropriate for the credibility of the work to be scrutinised (Madill et al 2000). Consistent with the approach used throughout data collection and analysis, the researcher utilised the evaluative criteria outlined by Charmaz (2006, p182) in relation to the generated theory (table 5). For further consideration of whether the theory generated met the criteria outlined by Charmaz (2006), please refer to the discussion section (section 5.4)

Table 5: Evaluation criteria for grounded theory studies (Charmaz, 2006, p.182)

	Criteria
<b>Credibility</b>	<ul style="list-style-type: none"> <li>➤ Has your research achieved intimate familiarity with the setting or topic?</li> <li>➤ Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data.</li> <li>➤ Have you made systematic comparisons between observations and between categories?</li> <li>➤ Do the categories cover a wide range of empirical observations?</li> <li>➤ Are there strong links between the gathered data and your argument and analysis?</li> <li>➤ Has your research provided enough evidence for your claims to allow the reader to form an independent assessment – and agree with your claims?</li> </ul>
<b>Originality</b>	<ul style="list-style-type: none"> <li>➤ Are your categories fresh? Do they offer new insights?</li> <li>➤ Does your analysis provide a new conceptual rendering of the data?</li> <li>➤ What is the social and theoretical significance of this work?</li> <li>➤ How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?</li> </ul>
<b>Resonance</b>	<ul style="list-style-type: none"> <li>➤ Do the categories portray the fullness of the studied experience?</li> <li>➤ Have you revealed both liminal and unstable taken for granted meanings?</li> <li>➤ Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?</li> <li>➤ Does your grounded theory make sense to your participants or people who share their circumstances?</li> <li>➤ Does your analysis offer them deeper insights about their lives and worlds?</li> </ul>
<b>Usefulness</b>	<ul style="list-style-type: none"> <li>➤ Does your analysis offer interpretations that people can use in their everyday worlds?</li> <li>➤ Do your analytic categories suggest any generic processes?</li> <li>➤ If so, have you examined these generic processes for tacit implications?</li> <li>➤ Can the analysis spark further research in other substantive areas?</li> <li>➤ How does your work contribute to knowledge? How does it contribute to make a better world?</li> </ul>



## **4. Results**

From the analysis three overarching descriptive categories were constructed: 'The search for meaning', 'View of self' and 'Explanations for voices'. The overarching categories and subthemes contained within these are outlined in detail below (*please refer to journal paper, figure 2*).

### **4.1 The search for meaning**

The 'search for meaning' was the overarching category, which constructs participants attempt to make sense of the origin and maintenance of the voices they hear. The search for meaning was also influenced, and at times impeded, by the individual's view of the self. Four subcategories were constructed to synthesise participants' accounts of their experiences of if, how, and what influenced their search to make sense of the origin and maintenance of their experiences of hearing voices. These subcategories, which are explored in more detail below, are: 'Personal meaning-making', 'Shared sense-making', and 'Mental Health Services'. Although the subcategory 'Blocking agents' seemed to significantly impede an individual's search for meaning of their voices, this was inextricably linked to 'View of Self' and as such will be explored more under this category.

#### **4.1.1 Personal meaning-making**

The subcategory of personal meaning-making refers to the voice hearers' active attempt to make sense of their voices individually through private enquiry. Six participants described their struggles and attempts to make sense of their experiences through engaging in personal meaning-making processes. Part of the struggle seemed to be conceptualised as the unexpected and sudden nature of the onset of the voice, as Ian described: *"I just broke into voices"*. Similarly, it seemed the characteristics of the voices further added to some participants' struggle to make sense of this seemingly anomalous experience, as Steve illustrated *"I wondered at first I thought can I hear them outside or are they inside?"* Attempts to identify who the voice may represent led some participants to develop an understanding regarding the origin of their voices. For example,

Shirley drew upon an interpersonal relational framework, attributing meaning to her voice as representing her abusive mother. However, for other participants the identification that the experience of voices was beyond the norm, *“this isn’t right this isn’t normal”* (Katie), prompted some participants to continue to search for the meaning of the voices.

During the struggle to understand the experience, it seemed that some participants asked questions either to themselves, or to the voice. Two participants, Ian and John, explained how their voices offered theories about their identities which were linked to spiritual frameworks of understanding. For example, Ian stated that his voice claimed it *“was a clairvoyant”*. This seemingly did not fit with the Ian’s understanding of his voices, claiming he did not believe in clairvoyance. The struggle to make sense of the voices seemed to lead to three participants querying frameworks of understanding which may be beyond the realm of physical knowing where other models seemingly had failed. For all three participants this led to the questioning of the possibility of spiritual theories to explain the origin and maintenance of voice hearing.

*“Well at first I thought it [the voices] was a joke by God being rational and that I thought er I guess it must be God. And er but now I’m not so sure. Yeah it might be the devil or er there might be other powers, demi-gods, who do it.”* (John)

The ‘success’ of the struggle to make sense of the experience led some participants to develop a theory for understanding their voices which they endorsed. For example, Steve explained how initially he felt confused and unsure about why his voices had started, or why they continued. He developed a framework of understanding regarding the meaning of his voices from an interpersonal perspective, following an event which led to his separation from his family. The voices were assigned a different meaning at this point, and he moved from fearing the voices to feeling comforted by them.

*“I couldn’t recognise it. I didn’t know what it were [the voices]. I honestly thought it was just my mind working overtime... And at first I didn’t understand what was happening. As time went on it’s my father’s voice that I actually hear”* (Steve)

This experience of the meaning of voices changing across time was not shared by all participants; some seemed to continue to struggle to make sense of the experience of hearing voices and their frustration of 'not knowing'.

#### **4.1.2 Shared sense making**

It seems that some participants felt unable to make sense of the origin and maintenance of their voices alone and sought support from others to aid their search for meaning. This represented a surprise finding for the researcher, and highlighted her assumption that voice hearers would have an individual understanding of why they began and continue to hear voices. However, drawing on other people and resources in an attempt to make sense of voices did not necessarily equate to an acceptance by participants of the shared sense-making process.

Four participants discussed their efforts to make sense of their experience of hearing voices through engaging in shared sense-making processes. For example, two participants, Katie and Dave, discussed how they sought information about hearing voices through the use of the internet to aid their search for meaning and three participants discussed the role of peer support groups. Others seemed to rely on mental health services to help them construct an understanding of their voices. A seemingly important link in the ability to utilise shared sense-making processes and construct an understanding of their voices was the availability of support to do this. The reasons they searched for meaning varied, ranging from wanting to increase their own awareness to wanting to see if they shared similarities with other people. This is highlighted by a quote from Dave:

*"you know if there's something wrong with you then, whether it's wrong or not, you want to know as much about it [the voices] as possible as you can"* (Dave) Two participants discussed their active involvement in peer support groups, such as a Hearing Voices Group (HVG). This seemed to serve two important functions: support from others and the comparisons made to other people with a similar experience in their search for understanding. This is illustrated by Katie's involvement in a Hearing Voices Group and the experience of 'being taken seriously' by others as a support to her.

*Because I think with the nature of the voice being in my voice it was really difficult for them [mental health professionals] to understand. It has been for other people to understand. It's only really when I joined the hearing voices group that erm I found out that only 1% of 1% of people get their own voice and then it's another figure altogether for the for whether you hear it inside your head as opposed to outside. Erm I didn't really get taken seriously until long after when I joined that group.*

#### **4.1.3 Mental health services**

Within this constructed subcategory, the role of others heavily dominated discussions about whether participants were able to utilise shared sense-making processes to aid their search for meaning. The majority of participants discussed this in relation to the impact of mental health services on the ability to search for meaning, and illustrates how the sub-category of mental health services is perceived as both a 'blocking' or 'promoting' factor.

There seemed to be contrasting views about the availability, or absence, of information from services which participants were able to access. Some participants seemed to perceive there was an absence of information, or interest, available from NHS services.

For example, five participants discussed how nobody spoke about the content of the voices with them.

*"I've never really said it to a psychiatrist because they've never really asked me" (Shirley)*

*"Most of them [mental health professionals] don't talk about it [the voices] much" (John)*

*"When you go to a psychiatrist you don't really mention anything about all the voices or anything you know. Just saying I mean it's all about you and health experience and you feel alright and that sort of thing you know?" (Ian)*

One inference could be that a lack of available information or open discussion about hearing voices restricted participants from feeling as though they were able

to actively search for meaning through shared sense-making processes. Pete described his regular meeting with his psychiatrist stating that, *"it's not what you bring up at the usual meeting"* in relation to the content and experience of his voices. Therefore, it could be interpreted that when participants sought support from mental health services to aid their meaning-making process that, at times the search for meaning was impeded, as the experience of hearing voices was not asked about.

However, some participants spoke of accessing mental health services as a promoting agent in their search for meaning. For example, two participants who had had psychological therapy reported that they had developed an understanding of the development and maintenance of their voices which they believed and endorsed. Although one participant articulated her frustration at the 'system' for only recently being able to access support from a clinical psychologist.

*"I don't really know when I started seeing Jack the psychologist do you? It must be three, four years. And he changed my life. I was very angry then with the system that I'd gone all them years before they even actually introduced the fact that. And he's changed my life you know."* (Shirley)

Participants who received support from different mental health professionals spoke finding this useful in terms of others helping support them to lead a 'normal' life, but did not talk about such support as having contributed to their understanding of voices.

Some participants discussed how seeking information about hearing voices from mental health services was frequently met by medication. This seemed linked to the participants' perception regarding their ability to search for explanatory frameworks and the utility of these explanations when utilising a medical model approach. One participant discusses his reluctance to discuss voices with professionals due to the fear that his medication will be increased.

*"It's [the voices] always been regarded simply as erm a sort of symptom of mental illness. Simple as that. It's not been regarded as anything more, that's it...And you don't really tell people what they [the voices] say. One if*

*it's a doctor they'll probably give you more medication and two they'll probably just lock you up again. So you don't."* (Dave)

Asking questions about the voices during the research interview enabled the researcher to observe sense-making regarding the voices in process, especially for individuals who stated they had no explicit theory for making sense of their experience. For example, when discussing what had precipitated the onset of Ian's voices, he identified that he had been under stress due to college exams. His experience of voices stopped for a period, and began again after a stressful period when he went back to college.

*(Ian) "Once I went back to college yeah to do that and erm did a did a well just I decided to get back on my feet again and go to college. And er yeah then it [ experience of the voices stopping] lasted about eight months actually and I broke I broke into voices again. I mean that was er yeah that was er turned into a worked work y'know I was busy at work yeah work again yeah."*

*(Interviewer) "it sounds like that the time when you've heard voices, if I'm right, it sounds like it's been at times of of stress?"*

*(Ian) Yeah yeah yeah probably was actually yeah well yeah... [I was] under pressure quite a lot really yeah."*

This highlights the important role mental health services can have as a promoting agent for the search for meaning, through asking questions about the experience of hearing voices. Another example which highlights this sense-making-in-action is during the interview with Dave;

*(Interviewer) "I'm just wondering, have you ever had any experiences in your life that seem connected to either when you started to hear voices or perhaps what the voices say?"*

*(Dave) "Mm yes. Yonks ago when our dog bit somebody and this man kept saying these disgusting words. And this ringmaster he says the same sort of man words so yeah. I've had a few things yeah. You can, or whether that's just yourself you making that up or just time and connection, but yes*

*there's definitely something there connected. .. Yeah I think I think theres something. And there's probably junkies who stoved my head in"*

The experience of mental health services, for some participants, also seemed linked to a sense of hopelessness. The majority of participants seemed to position mental health professionals as 'experts', yet their perceived failure to 'cure' the voices seemed to perpetuate the hopelessness experienced by participants. One consequence of this was the reduced motivation of the person to search for meaning due to the little futility this was perceived to have. Therefore, at times, mental health services and a biological paradigm of understanding hearing voices were constructed as a blocking agent. This was illustrated by Pete:

*"One thing they [mental health professionals] can't stop it [the voices]....I know I know they [mental health professionals] can't. Been on about 25 different medications for this and that and it just doesn't touch me. It doesn't do nothing.....It depends how long I can put up with it before I threaten to commit suicide a few times."* (Pete)

The recognised inability of medication to 'cure' the voices could be interpreted as indicating that individuals did not entirely accept a biological understanding of hearing voices.

*"In my mind I thought there would be a pill. That I would just be able to take and it [the voices] would be gone. And you know it doesn't work like that no. So I was a bit disappointed and I did think what's the point in even coming you know because they [mental health professionals] can't stop them. So I was a bit disappointed in that because I thought oh that terrible trying to tell somebody. I thought well as soon as I tell somebody they'll they'll they'll just stop it [the experience of hearing voices] and of course they haven't been able to."* (Helen)

#### **4.2 View of self**

Two subcategories were constructed to integrate participants' beliefs about the self impacted upon the development of framework for understanding the origin and maintenance of voice hearing which were: 'Blocking agents' and 'Role of the voice(s)' The view of self had a significant impact on the individual's ability to

search for meaning through inhibiting the range of actions perceived to be available to the voice hearer, due to the fear of confirmation of the self as bad or mad, as well as maintaining the experience of hearing voices through a believed inability to alter their experience. Furthermore, some participants drew on an intrapersonal framework to understand the development and maintenance of the voices they hear, with the view of self as not being 'good enough' and as seemingly confirmed by the their voices.

#### **4.2.1 Blocking Agents**

The term blocking agents refer to factors which either impeded or restricted the participants' process of meaning-making, through either an individual or shared process, to make sense of the voices they hear. Examples of blocking factors include; the perceived utility of an explanation, fear of judgement and fear of confirmation of a negative view of the self.

The perceived utility of an explanation of hearing voices was not seen by all participants as being useful, and was constructed as one potential blocking agent that impeded the search for meaning. This seemed to be inextricably linked to the hope (or lack thereof) experienced by some individuals and the contrasts of the effectiveness of an explanation in being able manage distress associated with the voices.

*"Why it won't leave me alone. Why it won't leave I don't know. I broke down and they don't know the doctors and my CPN. Or anyone else I talk to about... Nothing they can do... There's nowt I can do about it." (Pete)*

Furthermore, it could be inferred that some participants equated the utility of an understanding of the voices to being a 'cure' or 'recovery' from the voices in sense of a biomedical understanding of voices. For some participants, developing a theory to make sense of their voices was not perceived as useful unless it equated to 'stopping' the experience, which could be interpreted constructed as restricting the search for meaning.

*"I suppose you can't do anything really until they go really. I mean I er I don't think I can do anything about...I suppose that's shot your life but you have to deal with it." (Ian)*



Therefore, it seemed that the experience of drawing on shared or personal meaning-making processes and not being able to construct a meaning of the voices was frustrating for some participants and turned into a factor impeding the search for meaning. Pete explained how he had *“tried to come up with reasons over the years about what it could be”* but the difficulty in finding an understanding of the origin and continuance of his voices seemed to reduce his enthusiasm to continue the search, at times feeding into his sense of hopelessness.

There seemed to be an acceptance amongst some participants regarding their negative view of the self, and the impact that the voices have on this, that it should not be challenged.

*“It’s stupid really cause I know I’ve had them all these years and I don’t know why I just can’t accept it.”* (Helen)

One prominent blocking process seemed to be the fear of judgements from others, and from the self. This was constructed as a significant ‘blocking agent’ in the search for meaning, due to the fear of confirming the view of self as ‘bad’, ‘mad’ and somehow at fault for their experiences. Helen explained how she had only recently disclosed her experience of hearing voices, 47 years after it began, due to the fear of what others would think and do. This shows how the voices, and negative view of the self, acted as a blocking agent and prevented her from engaging in shared sense-making processes due to the fear of being judged as ‘mad’;

*“I daren’t tell anyone because I thought people would put me in an asylum or something you know. I was frightened of them and I didn’t know what they were but I just daren’t tell anybody at all because I hadn’t a clue what what anybody would say you know to me. I just thought I was going mad really you know and that. I just kept it to myself.”* (Helen)

The ‘fear of being mad’ was also voiced by Shirley who described initially not wanting to acknowledge the voices due to a fear of confirming that she was ‘mad’. It could be inferred this links both to the fear of judgement from others, but also regarding negatively evaluating the self. This illustrates the fear or perhaps the

stigma associated with mental health difficulties, and how this impacts upon people searching for explanations to their experiences.

*“it’s really hard to put put your finger on it. It’s like you know that it’s it’s up there in your head. Erm I suppose I suppose you don’t really want to know because you think you’re going mad I think. That’s that’s what it I think is the fact you think you’re going mad.”* (Shirley)

The apprehension of being judged by others did not just relate to disclosures of voice hearing, but possibly of the stigma and fear of being judged by mental health professionals. Pete illustrated this through disclosing his reluctance to discuss his experience of voices *“cause it was too embarrassing to talk to anyone about”*.

Another dimension to the constructed subcategory is the perception by some participants that it was better to ‘hide’ the experiences of voice, even to family and mental health professionals who knew about the voices. When exploring the links between how people construct an understanding of the origin and maintenance of their voices, and potentially connected events, it seemed some participants were frightened of making these associated connections to others. One of the potential reasons for this was the fear of being judged either by others or by the self. Therefore, this was constructed as a ‘blocking agent’ as it potentially restricted, slowed or halted the search for meaning for some participants. This is illustrated aptly by Shirley;

*“I knew but I didn’t want to talk about it you know so. And of course there’s lots of other things that you just want to hide them really you don’t you don’t want to talk about them to people”* (Shirley)

#### **4.2.2 Role of the voice(s).**

The meaning and power attributed to the voice by the voice hearer seemed to impact upon the individual’s view of the self, as well as the ability to search for meaning and developing a resulting framework to understand the experience of hearing voices. The role of voices, for some participants, seemed to confirm an individual’s negative view of the self.

Meanings attributed to the voices varied greatly between the participants. One common construction seemed to relate to the conflict experienced by some participants in identifying the voice. Several participants discussed the battle and confusion between whether the voice, especially the content of the voices, was generated by the self or something external and alien:

*“they [the voices] say such horrible things... they are things I wouldn’t say but how can I how can hear them in my voices and it not be me. That’s the problem... I can’t never ever strive to be the person I really want to be. I hate the person that says that them things. It’s really hard.” (Helen)*

The feelings and emotions experienced by participants, attributable to the voice, seem to feed back into the maintenance of the voices and low self-esteem experienced by the individual. One interpretation of this may be a fear felt by the participant to search for a meaning in case it confirmed the self as ‘bad’ or perceiving the voice as being generated by the self. This sense of the voices representing the complete opposite of the ideals the person hold was echoed by Dave;

*“you know it’s things you wouldn’t even you know you’d never even think about that er that appear... it’s that’s the thing always things, words you don’t like, attitudes you don’t like things like that.” (Dave)*

For another participant, the meaning and perceived identity attributed to her voice led to confusion when trying to develop an understanding. Her framework for understanding the development of her voice was attributed to her abusive mother throughout her life, and she believed the voice was still present due to the fact that her mother was still alive. The view of herself was inextricably linked to her relationship to her mother, and Shirley’s belief that she was not ‘good enough’. However, she described her confusion that the perceived identity of her voice contrasted to the meaning she attributed to her experience:

*“but erm yeah it [the voice] was her [her mother] you know. So I was always wondered why it’s male and not not female” (Shirley)*

For one participant, the meaning attributed to her voices enabled her to make sense of her experiences. Katie drew on an intrapersonal framework through

understanding her voices as being her own fears which were being vocalised above and beyond her own thoughts, in her own voice:

*"I started to hear my own voice but above and beyond my own thoughts.... what with it being my own voice it was erm quite strange. Because I think it went along with a lot of the feelings that my sort of depression were bringing up" (Katie)*

Participants commonly shared a perception that they had failed to live up to expectations either of the self or what others had placed on them due to the meaning they had attributed to the voices. This seemed to contribute to low self-esteem experienced by the person, again restricting the available possibilities for the voice hearers in their search for meaning. All three female participants discussed this in relation to their relationships with others, e.g:

*"I always wanted to be perfect. I wanted to be the perfect daughter you know. The kindest person...I just wanted to be perfect and I never could be... it just seemed like every anything I was able to do people would just make fun of me or shoot me down that it was rubbish... I always failed all the time I failed... That no matter how I try to be a good person the voices make sure that I never am" (Helen)*

The expectation of being 'perfect' and not living up to this standard seems to maintain the participant's low view of the self. One interpretation about how this may impact a person's ability to develop an understanding of their voices is that they may not feel they are worthwhile to engage in this search, as the voices seemingly confirm the negative beliefs about the self. It also illustrates how a theory of the development of the experience of hearing voices was based on an intrapersonal view of 'never being a good person' and it seems that daily experiences reinforce this sense of 'not being good enough' and are replicated in their interactions with others. For example:

*But I do believe that we can go around with a you know a certain words written on our foreheads and people just pick upon that and they know...[for me it is] Bullied. You know bully me. I'm weak bully me... That's why I try to not let people know [about the voices]. (Shirley)*

This was illustrated further by Katie when discussing how the voice used her fears against her and highlights how she drew upon an intrapersonal framework of the self not being 'good enough' to understand the development and maintenance of her voice hearing;

*"I think a lot of my fears are that I'm not good enough... You know for other people I think and I think that [the voice] went along with sort of that but that's sort of engrained in me all the time really. I don't seem to be able to get rid of that one"* (Katie)

The power and capabilities attributed to the voices seemed to impact the participants' ability to make sense of their experience, often restricting the voice hearer's perceived ability to search for meaning.

*"Well the arguments it [the voices] puts in my head. Er at first it messed me about a lot of rubbish. Lots of rubbish like erm for example it made me do the crucifixion dance like that ... They use sensations like feelings, like fake feelings ...[I] went to a schizophrenia self-help group...But the voices came and interfered with my mind and sensations and thoughts and I couldn't take it in. And I couldn't ask questions...I'd like to know what was going on with other people who hear voices I think."* (John)

This seemed to affect how participants were able to make sense of these experiences or to develop an explanatory framework as it seemed beyond 'knowable' due to the physical, social and emotional impact of the voices on the person. Furthermore, the power inferred to the capabilities of the voice may have restricted the search for meaning due to possible fear of threat and repercussions from the voices. This is illustrated by Pete;

*"They [the voices] are saying the same things as what the others [voices] are... threatening me... determined to chop parts of me off... swear at me"* (Pete)

#### **4.3 Explanation for voices**

The majority of participants stated they were unable to make sense of the origins and maintenance of their voices, which has been demonstrated in the search for

meaning and the various factors that impact this. However, when exploring this experience further, participants seemed to make different connections to their understanding of the beginning and continuance of their voices. Some participants did not endorse any connections and at times actively rejected theories imposed on them which left them in a difficult position of feeling unable to construct a theory regarding their voices. Six subcategories were constructed to integrate participants' frameworks for understanding the origin and maintenance of voice hearing which were; 'Stress', 'Trauma', 'Attachment difficulties', 'Anxiety and depression', 'Spirituality', and 'Rejection of others' theories'.

#### **4.3.1 Stress.**

All participants discussed the impact of stress upon their understanding of hearing voices. This involved discussions about stress being both precipitant, and for some participants the attributed reason regarding maintenance, of hearing voices. Some participants had an explicit theory regarding the role of stress in their experience of hearing voices, whereas other participants did not explicitly acknowledge the role of stress but made connections between stressful events and their voices. The nature of the stressful experience varied between participants such as; transitions within the person's life, the 'battle' with the voices and specific life events.

One participant explored how the transition of becoming married, her grandfather and a close family friend dying within a short space of time as being her recognised precipitant of the voice she hears;

*"I was 18... I'd only got married, my er granddad passed away two weeks after I got married. And my brother's best friend died in a motor bike accident who I was quite close to myself. Erm so whether that started to cause the break down I don't really know. Erm plus my mum's always been really overpowering."* (Shirley)

Another participant discussed work related pressure shortly prior to hearing voices;

*"Well pressure at work at college I suppose. At the time you see final year exams yeah."* (Ian)

Most participants explored the constant battle they were engaged with the voices and how this contributed to their experience of stress. Similar themes which were constructed included the inescapable presence of the voices, persistence of the voices and the voices wearing you down. Dave referred to the voices as ‘spoilers’ when they wear him down emotionally.

*“with these spoiler things they are not because you’re feeling quite. You think hang on I’ve acted and behaved almost human today and er all of a sudden you get these clowns [the voices] shouting and balling at you”*  
(Dave)

#### **4.3.2. Trauma.**

Four participants, two males and two females, discussed the role of trauma in their experience of hearing voices, which ranged from; sexual abuse, , domestic violence, bullying and physical assault. Trauma was perceived as being distinct from the subcategory of stress due to the underlying threat of danger to the individual. Furthermore, a distinction was made between physical abuse (sustained abuse by someone known the individual) and physical assault (an isolated incident perpetrated by strangers). Whilst all participants acknowledged the role of trauma on their experience of hearing voices, two participants identified the experience of trauma explicitly as an explanatory framework for understanding the origins of their experiences of hearing voices.

*“And as I said there’s probably junkies who stoved my head in... The brick pretty well took me out so they [the people who assaulted him] made a bloody mess of me. And after that I thought oh hang on you know this [the voices] isn’t right... [the voices] could have been right from the crisis and maybe I just thought. I’m really good at sticking things to the back of my mind. Brilliant at it. I don’t brood on things or anything and maybe it [the assault] popped it’s ugly head up.”* (Dave)

Both female participants spoke of other re-victimising experiences which have occurred throughout their life and the impact this has on the view of the self as well as their reluctance to trust others. Furthermore, this seemed to serve as a maintenance process for the voices though confirmation of what the voices said.

This is illustrated by Shirley, who spoke of her experience of being physically abused by her mother and sexually abused by her brother, went on to describe other life experiences that replicated her early experiences.

*“At school I was badly bullied. I left school went to work I was badly bullied, I left that work placement to another work place badly bullied” (Shirley)*

#### **4.3.3. Attachment difficulties.**

The subcategory ‘attachment relationships’ was constructed as distinct from ‘trauma’ as individuals described how this had impacted on their view of the self, as it was inferred from the data that some participants developed their view of the self based upon their relationships with others. All three female participants discussed the difficulties in relation to their relationship with their early attachment figures as framing their experiences of voices. One male participant, Steve, also discussed the impact of his relationship with his parents as precipitating his anxiety which he felt ‘fed’ into his experience of hearing voices.

The experience of being separated from the main attachment figures seemed to be significant within this subcategory. For example, Steve spoke of how his separation from his family and their severing of contact with him as contributing to appraising his voices differently. He explained how he used his voices as a source of comfort as he identifies the voice as his father and as demonstrating his father’s attempt to stay in contact with him. Helen attributed the origin of her voices as arising from being separated from her mother when she went to nursery, and the fear that she would not return.

*“I first went to nursery I never forget that day...I was terrified. Absolutely terrified and I remember mum leaving me and and I just I felt absolutely as though she’d you know. I was totally on my own do you know what I mean...it [voice said] er mainly things like you know she doesn’t care about you anyway you know and er you’re not good enough you know she doesn’t love you and all that sort of thing that’s why she’s left you there and all that sort of thing you know..” (Helen)*



All female participants discussed the perception that they were not 'good enough' and were critical towards the self, attributing the development of this view to their early relationships with their attachment figures. This is illustrated by Katie;

*"I mean a lot of the things in my subconscious have been drilled into me by my dad. Erm I've had some I don't know my dad's not a bad person but he's got a way of. He's got some certain rules and things that he thinks should be and if I don't adhere to that then sort of I'm not good enough and I think a lot of my fears are that I'm not good enough."* (Katie)

Furthermore, two participants' mothers had histories of mental health difficulties. This experience was constructed differently by each participant, with one discussing the difficulties of the insecure attachment with her mother whereas Katie spoke of her fear of watching her mother's 'illness' growing up. Again, this seemed linked to the view the individual had of themselves. One consequence of this seemed to be linked to the desire to be 'normal' and the comparison of themselves to their parental figures.

*"I'd felt for a long time when I was younger that I needed a family erm and when I got with that particular guy I'd got all the family that I wanted. Sort of his family was really accepting of me and you know put me on a pedestal...My big episode came pretty much from losing that family sort of situation. Erm but that's pretty similar really to my mum and I see elements of myself in my mum that I don't think are normal."* (Katie)

#### **4.3.4. Anxiety and depression.**

The majority of participants explored the role of anxiety and depression in their experience of hearing voices. The experience of anxiety and depression was seen as co-morbid and intertwined with the experience of hearing voices, as well being cited as a maintaining role of the voices, which distinguishes this from the subcategory of stress although it is acknowledged the two are closely linked.

Two participants directly attributed the role of depression and anxiety as the origin of their experiences of hearing voices. Mainly participants attributed the experience of this to the maintenance of their voices. A significant factor within this seemed to be the direct experience of the voices and how that affected the

voice hearer. For example, Dave describes how “*the psychosis can really really get you down you know very bad voices.*” Furthermore, for some participants, this seemed to feed in to the hopelessness they experienced in relation to their experience of hearing voices.

#### **4.3.5. Spirituality.**

The framework of spirituality or of mystical external, experiences was discussed in four participant’s accounts in relation to the voice’s content. Interestingly, only one participant stated the role of spiritual forces in the development or maintenance of their experience of hearing voices, a theory which seemed to be offered by his voices. The questioning of the possibility of the role of the paranormal in voices seemed to be raised when participants struggled to make sense of their experiences as other ‘physical’ ways of knowing could not provide adequate explanatory frameworks.

One participant, John, explored a previous mystical experience he encountered;

*“It might be connected. I was at University when I was nineteen and I. Around about my nineteenth birthday I had a mystical experience. And I felt that everything was alright. And er I was light and could see things better.”*  
(John)

Although he attributed this as a positive experience, this contrasted to his experience of hearing voices. Three participants’ discussed the content of the voices in relation to spiritual frameworks and the theories offered by the voices.

*“Well at first I thought it was a joke by God (pause) being rational and that I thought er I guess it must be God. And er but now I’m not so sure. Yeah it might be the devil or er there might be other powers, demi-gods, who do it.”*  
(John)

Although not all participants recognised a spiritual frame of reference as being useful to them in understanding voices, it was acknowledged that this was a ‘popular’ explanation amongst other voice hearers.

*“Some people get very very you’ll find throughout mental health you know service users community one of our er most successful group which is*

*spiritualist er they meet in a church. You will find that a lot and lot of people think that they are being talked to by God er and things like that” (Dave)*

#### **4.3.6. Rejection of others’ theories.**

The majority of participants seemed to actively reject the theories of hearing voices offered by others, including mental health professionals and ideas offered by the voices. Other participants were not aware of, or did not understand, the clinicians’ understanding of their voices. Two participants spoke of feeling rather dismissed by mental health professionals due to the perception that their voices were ‘just thoughts’ and so were not ‘dangerous’.

*“But I was told it was a voice not to worry about by one psychiatrist because it was a voice within my head and not outside my head...And he said that because it was in my head it was my own thoughts...I disagreed.”*  
(Shirley)

When asked directly what participants theories regarding the development and maintenance of their voices, the majority stated they were unsure. Some participants articulated their frustration at ‘not knowing’ why the voices came or remained there as it was more difficult to ‘fight’ the voices.

#### **4.4 Theoretical coding**

The overarching descriptive categories, outlined above, provide an insight into how participants view their situation during their process of making sense of their voices. Charmaz (2006) asserts the value of ‘moving beyond’ the data through asking questions of how and why participants construct meanings, focusing upon the social processes, to abstract the data to that of a theory. This enables the researcher to explore what ‘seems’ present, yet is unarticulated through explicating the larger social context within which the phenomena is embedded (Clarke, 2005). Furthermore, the constructionist approach to grounded theory emphasises the importance of exploring variation within the studied phenomenon and the social processes enacted (Charmaz, 2011). Through abstracting the data in this manner, the resultant grounded theory highlights the wider significance of these socially situated experiences (Henwood & Pidgeon, 2003). Three theoretical categories were constructed to understand whether and how participants

generate an understanding of their experience of hearing voices; 'Meaning making processes', 'Sense of agency' and 'Stigma'.

#### **4.4.1. Meaning making processes**

Participants seemed to draw mainly upon three main frameworks to explore the development and maintenance of their experience of hearing voices. These were; 'inter-personal', 'intra-personal' and 'para-personal' (*please refer to the journal paper for definition of terms*). The ability to engage with meaning-making processes is effected by the person's sense of agency (*please refer to section 4.4.2*) as well as the stigma perceived by the person (*please refer to section 4.4.3*).

Drawing upon inter-personal frameworks to aid meaning making processes helps to explain how some people conceptualise the origin and maintenance of hearing voices. The role of inter-personal theories in the experience of hearing voices has been documented elsewhere in the literature. For example, individuals who reported feeling distressed by hearing voices often perceived their voices as powerful, persecutory and dominant, whereas in comparison view the self as inferior and subordinated (Birchwood et al., 2004). It has been suggested that the attributions frequently made about the experience of the voices is replicated in people's social relationships positing themselves a lower social rank to others and the voices (Gilbert et al., 2001; Birchwood et al., 2000b).

The experience of inter-personal trauma or attachment difficulties, as experienced by many participants, may lead to the development of beliefs as others as threatening and powerful which subsequently influences the view of the self (Mawson et al., 2011). Resulting appraisals made by the voice hearer, both of the voices and of other social relationships (Birchwood et al., 2000b), are affected thereby impacting upon meaning making processes engaged with by the individual. Furthermore, drawing upon stress-vulnerability models (e.g. Zubin & Spring, 1977), it could be argued that inter-personal stress has a significant role in both the development and maintenance of hearing voices.

The role of inter-personal processes within the meaning making process is closely linked to the individual's intra-personal developing framework. As indicated above,

view of the self is connected to inter-personal relationships (Mawson et al., 2011) as it relates to other people's expectations and fear of being judged negatively if these are not met. This is internalised as we build internal working models of the self based on our interactions with others (Bretherton & Munholland, 1999). The theory of attachment could potentially help build an understanding of the inter-personal processes within the experience of hearing voices, as well as the replication of these attachment in subsequent relationships, and the development of beliefs about the self (Berry, Barrowclough, & Wearden, 2007). Intra-personal processes can help us understand why some individuals may or may not seek understanding of their voices. One potential reason could be through fear of re-confirmation about negative beliefs of the self. An implication of person-based cognitive therapy is to assist the person to move away from the view of the self which is entirely experienced through the lenses of the voices (Chadwick, 2006).

It is suggested by the author that individuals who enact 'para-personal' meaning-making processes to make sense of their experience of hearing voices may encounter hopelessness in relation to their voices. The psychological theory of learned helplessness in human behaviour (Abramson, Seligman, & Teasdale, 1978) can help us to understand this concept further. This theory suggests a flow of events where the experience of failure produces an expectation of 'uncontrollability' that is independent of the person's actions and is generalised to future experiences, generating the perception of helplessness through reducing motivation of the individual (Witkowski & Stiensmeier-Pelster, 1998). Therefore, in situations where the person perceives neither they, nor anybody else, can help to solve the problem, the individual experiences 'universal helplessness' (Abramson et al., 1978). In relation to the experience of hearing voices, some individuals may perceive that the 'experts' from mental health services, nor the self, as being able to 'cure' the voices therefore attempts to search for meaning is attributed as futile.

#### **4.4.2. Sense of agency**

It is suggested through the interpretation of results that the sense of agency the person was perceived to feel they have affects their ability to seek out, and draw upon, different meaning making processes. The implications regarding the powerless some people feel in being able to make sense of their voices draws

upon the broader social arena, situating the theory in a wider context (Clarke, 2005). The developed theory suggests that several social processes as contributing to, as well as re-enactment of dominant pejorative discourses regarding 'mental illness' and 'incompetence' (Corrigan, 1998), a person's sense of agency. The label of 'mental ill' affects how the person is viewed, as well as how their future behaviour will be responded to, with the consequence being placing the individual in various double-bind and contradicting situations when conceptualising their experience of distress (Burr & Butt, 2000). The double bind occurs through the contrast between Western cultural individualistic assumptions regarding autonomy and responsibility (Blackman, 2000) and the label of mental illness which assumes incompetence. This effectively 'dis-ables' the individual, they are unable to increase their sense of agency in relation to meaning making of their experience of hearing voices leading to sense of hopelessness. This is highlighted in the passage below regarding the conceptualisation of 'non-human agents' of control;

"If behavior and/or experience somehow resisted understanding and management under the auspices of willful human action or reasonable human reaction, it was then ascribed to specific kinds of non-human agents deemed capable of wresting control of people's actions or experience in particular kinds of ways" (Weinberg, 1997, p. 229).

#### **4.4.3 Stigma**

The enactment of meaning making processes occurred within the context of the stigma associated with the label of mental illness, which impacts the individual's frame of reference for understanding their voices, as well as the available support to access this information from. This is affected by the dominant discourses surrounding mental health (as discussed in section 4.5.2).

The role of gender and gendered meanings of 'mental illness', within social processes of stigma should also be considered. When exploring mental health difficulties, it is suggested that gendered expressions of meaning making are enacted; with men relating difficulties to financial and work responsibilities, and women relating it to relational stress (Schon, 2009). This suggests that available frameworks for understanding the development of hearing voices may be

constrained by gendered assumptions. Furthermore, the impact of stigma is assumed to effect the help-seeking behaviour of the individual (Corrigan, 2004). This may further impact the individual's ability to search for an understanding of their voices.

Further influences impacting the experience of stigma upon a person's perceived ability to engage in meaning making process are the services within which the person engages with. For the participants within this study, the mental health services represent the significant institution which they sought support from. It could be suggested that the perceived lack of interest in the content of voices from mental health services, rather focusing upon the 'plausibility' of the belief (Harper, 2004) could impact the individual's perceived ability to make sense of the development and maintenance of their voices. Therefore, the conceptualisations available to mental health service users will be constrained by the dominant professional frameworks (Harper, 2004) (please refer to section 5.2 for further exploration).

## **5. Discussion**

### **5.1 Developing a grounded theory**

This study sought to explore how, if at all, people construct an understanding of the origin and maintenance of their experience of hearing voices and how useful individuals find these frameworks. The author found it useful to think about the 'essence' of the generated theory through a one sentence summary;

*Participants attempted to construct an understanding of their voices through drawing on three main frameworks (inter, intra and para-personal), but the relative 'success' of this pursuit, and potential usefulness of an understanding, is effected by the sense of agency, stigma and hope(lessness) perceived by the individual.*

This study highlighted participants' attempts to search for meaning, but the utility of this was often linked to the hopelessness they experienced, and relatively few participants held an explicit theory of the development and maintenance of their voices. The failure to adopt a meaningful framework to understand the experience of hearing voices has been argued to prevent the voice hearer to progress to the organisation phase of their relationship with their voices, which is claimed to

decrease the levels of anxiety experienced by the voice hearer (Romme & Escher, 1989). This illustrates the potential clinical utility of assisting individuals to make sense of their experiences of hearing voices.

The majority of individuals who participated in this study viewed themselves negatively and powerless in relation to their voices. The sense of hopelessness seemed to affect the perceived utility of an explanatory framework. This study seemingly links with a recent study which explored processes in developing positive experiences with their voices (Jackson et al., 2011). The preliminary grounded theory suggested a sense of control was pivotal in helping the voice hearer develop a personally meaningful narrative about the voices, which was thought to help reduce the fear experienced by the individual (Jackson et al., 2011). A similar finding was reported in a group of Clairaudients, in which the process of attributing personal meaning to the voices helped decrease the initial distress experienced when the person first started hearing voices (Taylor & Murray, 2012). One suggestion from this research illustrates the importance of the ability of the voice-hearer to engage in a meaning-making process that enables them to ascribe a personal understanding of their voices. The clinical implication of this highlights the need for services to engage in person-centred collaborative processes between voice hearers' and professionals to derive a shared understanding of the voice hearing experience.

The data from the current study suggests that the imposition of one theoretical framework onto the experience of hearing voices was of little utility to the participant and at times actively contradicted their own understanding. Therefore, it may be possible that service users are encouraged to engage in the application of coping strategies that are not congruent with their own understanding of the voices. This is supported by Romme and Escher (2000) who assert that individuals with an explanatory framework of their voices often utilised tailored coping strategies for managing distress which were consistent with their understanding of their voices.

One theoretical category which was constructed to impact upon the individual's enactment of meaning making processes and the available support to access this information was within the context of stigma. Stigma was constructed as acting in



an inhibitory fashion in the person's perception of being able to engage in a meaning-making process. There is a wealth of research which has documented the role of stigma for people with a diagnosis of mental health difficulties. The HVN has arisen in response to the need to provide a space for voice hearers to talk about this experience freely, to raise awareness of voice hearing and to support individuals who want to seek understanding of this experience (HVN, 2012). The main premise of the HVN is that each voice-hearer is entitled to their own individual, unique explanatory framework (Blackman, 2000).

It is claimed that HVGs are both widely accepted and are received positively by service users and therapists alike (Ruddle et al., 2011). Interestingly, an evaluation of a support group for people who hear voices suggested that the experience of sharing information about their voices without the perception or threat of judgement from others was valued by group members (Martin, 2000). This lends further support to the theorised role of stigma in meaning-making processes and how through decreasing stigma may help the perceived accessibility to seek understanding of the experience of hearing voices. It is also asserted that to reduce stigma experienced by the voice hearer, the frameworks utilised by the individual needs to be accepted by others (Lysaker, Yanos, & Roe, 2009). This highlights the importance of mental health professionals in accepting and respecting an individuals' frame of reference for understanding their voices (BPS, 2000).

## **5.2 Clinical implications of research**

One benefit of using a grounded theory approach is to help us learn how people who experience the studied phenomena define their realities through understanding what challenges they encounter (Charmaz, 2011). It is the problems which people encounter that frequently become the source of the generated theory (Charmaz, 2011). Therefore, one implication of using a grounded theory method for this research is to provide mental health professionals with alternative understandings of service users actions, beliefs and frameworks than those which are necessarily available in mental health settings (Charmaz, 1990). This could help improve communication between service users

and mental health professionals, through a shared understanding of the person's reality.

Despite the increasing body of literature which illustrates the importance of developing a shared understanding of the experience of hearing voices, it seems that it is not currently a standard feature of mental health care. A study which investigated psychiatrist interactions claimed that their patients often tried to discuss the content and meaning of their psychosis, yet it seemed the psychiatrists partaking in the research were uncomfortable and reluctant to explore this (McCabe, 2002). This is supported by the data from this study which indicated many people had not had the opportunity to explore the experience of their voices. Interestingly, the two participants who had seen a clinical psychologist both had developed a meaningful narrative to their experiences of their voices and had an explicit framework in which to understand their voices. It is questionable whether all mental health professionals would currently feel comfortable or confident in engaging with this recovery-oriented process. A recent study indicated that nurses often lacked confidence in feeling able to discuss the meaning and content of voices with the voice hearer (Coffey & Hewitt, 2008).

It is suggested then that the current challenge to mental health services is "to practice in a manner that is creative and acknowledges the strengths of the individual" (Jones & Coffey, 2012, p. 57). It is argued that mental health services may need to foster and 'hold' hope for the individual at times when they may struggle to do this (McCarthy-Jones, 2012). This identifies a need within mental health services, with a focus on staff training to increase their confidence in being able to discuss alternative frameworks of understanding voices, highlighting an area for future research. However, it is important to explore the potential dilemma this may place professionals in. That is the challenge of how professionals are able to take, and utilise effectively, multi-explanations for the experience of hearing voices whilst simultaneously providing a containing experience for the individual.

During the construction of categories in data analysis, the role of medical professionals as experts was raised by some participants. Participants placed mental health services within the expert role, which came fuelled with

expectations regarding treatments and 'cures'. This ultimately seemed to perpetuate the hopelessness experienced by the individual. However, the context of individuals seeking help must be considered in relation to this. It is claimed that if voice hearers are seeking help from mental health services in relation to the distress they are experiencing, they may still be searching for and trying to develop an understanding of their voices (McCarthy-Jones, 2012).

This research raises numerous questions about how practically the process of meaning making to understand the voices should be approached. It raises the question of how services can offer something that is helpful to the service user, without imposing their own professional 'expert' viewpoint. Furthermore, this begs the question whether any, or a range of, explanatory frameworks should be offered if it is not a developed construction of the person's problem. When thinking about the needs of the service users, and that people often access mental health services when they want help, it questions what they would find useful. This highlights an area warranted for future research.

### **5.3 Relevance to clinical psychology**

This study has significant implications for the field of clinical psychology. One implication of this research is the utility of psychological formulation to help people engage meaning-making processes regarding their experience of hearing voices. The aim of psychological formulation is to develop a joint understanding of a person's difficulties (Sivec & Montesano, 2012). It is acknowledged that there are different levels of intervention which can be targeting within psychological formulation, ranging from a 'disorder-specific' to 'case level' formulation (Stephens, unknown). Furthermore, psychological formulations can draw upon different theories of understanding. The ability to draw on various models could be argued to be able to meet the need of service users when developing an understanding their experience of hearing voices, as opposed to imposing one theoretical framework. Psychological formulation possibly provides one solution in the challenge presented to mental health services (as discussed above).

In relation to the experience of hearing voices it has been suggested that formulation, at both the historical and maintenance level, can help an individual develop a 'plausible' understanding of their voices (Morrison et al., 2004).

Furthermore, it is suggested that insights gained regarding the role of insecure attachment can significantly inform the process of formulation through exploring the development of social cognition and the impact of this on interpersonal relationships (Berry, Barrowclough, & Wearden, 2007). This supports the results constructed from this study, which illustrated the role of interpersonal frameworks some participants drew upon to develop their understanding regarding both the origin and maintenance of their experience of voices.

It could be argued that the process of attributing meaning to the experience of hearing voices holds much promise and provides alternative ways to intervene therapeutically, such as the development of meaning which supports the wellbeing of the service user (Chadwick, 2006). This may have an impact on the voice hearers view of the self and their relationship in the social world (Dilks, Tasker, & Wren, 2008), which was indicated by the present study to effect the perceived utility of an explicit framework to understand the voices. However, it is currently unclear within the literature how service users experience the role of formulation. One study indicated that participants varied in their response to the experience of formulation, although therapists viewed this process positively in helping them engage and understand their client (Chadwick, Williams, & Mackenzie, 2003). This highlights an area warranted for further research. Furthermore, the role of attachment and how this impacts upon interpersonal relationships should be considered during the therapeutic relationship as well as within the formulation. Previous research indicates that attachment style affected, and at times disrupted, the therapeutic relationship (Berry et al., 2008).

#### **5.4 Evaluation of research**

In line with the methodology adopted throughout the research process, the developed grounded theory research has been evaluated against Charmaz's (2006, p.182) guidelines of; credibility, originality, resonance and usefulness (please refer to table 5, section 3.6.3). The concept of theoretical sufficiency will also be discussed in order to evaluate the claims generated by this study.

#### **5.4.1 Credibility.**

This research has achieved an 'intimate familiarity' with the phenomena under study, the experience of hearing voices, through the cyclical process of data collection and analysis. All interviews were transcribed and analysed by hand, using initial and focused coding before abstracting the data to a theoretical level. This enabled the researcher to become immersed within the data.

However, due to the time limitations of the study and relatively small sample size, it could be argued that the claims made by the research are modest but is supported and generated from the data. This study could be improved from recruiting individuals from different religious and ethnic backgrounds, as well as individuals who do not receive support from the NHS who hear voices. This may broaden the range of empirical observations within the constructed categories.

The use of the constant-comparative method ensured that systematic comparisons were made within and between the data at all stages of data analysis. Furthermore, it helped promote similarities and differences across the data set which developed strong logical links between the data and resultant constructed categories. The use of memo-writing procedures (please refer to Appendix O for an example memo) further evidences the progression of strong links between the data and developing analysis.

The developing theory does cover a wide range of observations and is grounded within the data. This is evident through the use of participant quotes when illustrating and evidencing the descriptive codes. The use of interview transcripts throughout the paper enables the reader to make an independent assessment of the claims made by the research.

#### **5.4.2 Originality.**

To the author's knowledge, the categories offer new insights into how mental health services users attempt to search for meaning of their experiences of hearing voices and the challenges encountered by individuals during this process. It further offers a new conceptual rendering of the data as it illustrates the different factors which affect a person's perceived ability to develop a framework to understand their voices, and how useful a potential explanatory model is to the

individual. Although the scope of the research was modest, it does offer significant implications for the field of clinical psychology and mental health professionals. The developing theory challenges existing ideas about mental health service users as 'passive' recipients of experiences and regarding the utility of imposing one theoretical framework. Furthermore, this research builds on the current emphasis on developing a shared understanding of the development and maintenance of voice-hearing (BPS, 2000) and suggests ways in which this can be achieved.

#### **5.4.3 Resonance.**

The wide range of experience within the studied phenomena is encapsulated during the process of analysis and through the constructed categories. The results aimed to incorporate the sometimes differing views and perspectives of participants to portray to fullness of the experience of hearing voices. When abstracting the data to a theoretical level, the 'taken-for-granted' meanings were explored to situate the theory in a wider cultural frame. This was aided through explicating the researcher's theoretical sensitivities (Henwood & Pidgeon, 2003, please refer to section 5.8.2 for further discussion) and how this affected the developing interpretation. This resulted in exploring how current institutions, such as mental health services, may unintentionally foster or maintain hopelessness experienced by the individual regarding the utility of an explanatory framework. Therefore, during the process of analysis, links were made between individual participants as well as the wider organisations and society which voice hearers exist within. The developing theory was not tested with participants to see if this made sense to them, or offer further insights about their lives, and perhaps highlights an area which this study could improve upon.

#### **5.4.4 Usefulness.**

This research offers interpretations that have clinical implications on mental health professionals and their interactions with service users, specifically that voice hearers seemingly draw on three main meaning-making processes in an attempt to make sense of their experiences. One implication of this research is the importance of being aware, and open to, differing frameworks to understand the experience of hearing voices as well as the importance of supporting an individual

to help develop such an understanding. Furthermore, it illustrates the factors which impact a person's perception regarding the utility of an explanatory model. It could be argued that the developing theory is useful and is something which can be used by people in their every-day worlds.

#### **5.4.5 Theoretical sufficiency.**

It was the aim of this grounded theory study to achieve theoretical sufficiency (Dey, 1999) as opposed to theoretical saturation. The concept of theoretical sufficiency indicates “the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications” (Dey, 1999, p.117). A difficulty encountered during this research project was the recruitment of individuals during the time constraints of the study (please refer to 5.5.2 for further discussion). Furthermore, it was not possible to pursue extensively every avenue that arose from each interview within these time constraints. In an attempt to manage the confines of the study, the interview schedule was adapted to maintain the focus on if, and how, people constructed their understanding of the maintenance and origin of their experiences of voices (please refer to Appendices L-O to show adaptation of interview schedules). By the final interview (eighth), the author was not identifying new categories or broadening the range of categories to incorporate the new data. It could be argued that due to this, some level of theoretical sufficiency had been achieved. Although it could be argued that should the author have pursued extensively all lines of enquiry that arose during data collection and analysis, it is likely that new categories or properties of categories would have been constructed.

#### **5.4.6 Arriving at theory?**

Charmaz (2006) has referred to a common critique of ‘the unfilled promise of theory generation’, alluding that many studies which claim to utilise the grounded method fail to move beyond the level of description. The debate regarding what constitutes a theory has been discussed previously (refer to section 3.6.1). Given the assumptions held by a social constructionist position in relation to theory generation, which should aim to emphasise understanding and patterns in the data (Charmaz, 2006), the current research could be argued to have gone some way into developing an interpretative theory. It has provided a new understanding

of how people attempt to make sense of their experience of hearing voices, and the factors which impact this. Furthermore, an imaginative interpretation was constructed through employing the constant comparative method. This was achieved through reaching beyond, whilst simultaneously being tied to the data, and abstracting the data to a theoretical level. Through achieving this, it could be argued that this study has gone beyond merely describing the data.

However, the author acknowledges the modest claims of the data and does not claim to have generated or constructed a whole theory due to the limitations of the study (outlined in section 5.5). Rather, the current study offers a preliminary insight into the experiences of mental health service users in their attempt to engage in a meaning-making process in relation to their experience of hearing voices. It is suggested that qualitative research progressively contributes to a complex, emerging understanding of a studied phenomenon through a series of complimentary pieces of research (Chin et al., 2009).

## **5.5 Limitations of study**

### **5.5.1 Sample size.**

The most notable limitation of this study is the limited number and range of participants recruited for the research. Although the aim of theoretical sufficiency (Dey, 1999) was argued to be achieved, the recruitment of individuals from a relatively narrow background may have constrained the results of the study. All participants were of White British ethnicity. Information was not gathered regarding their religious or spiritual views, which highlights an area that the study could have improved upon. This potential illustrates one 'blind spot' of the researcher, which was identified during the process of analysis. Efforts were made to recruit further participants in an attempt to broaden the study within the available time limits but no further participants were forthcoming. To improve upon the current study, it is recommended that further research explores individuals who hear voices and are distressed from this experience from a wider range of cultural, religious and spiritual backgrounds.



### **5.5.2 Recruitment difficulties.**

Previous research has suggested the potential utility of researching the experience of people who do not seek help from mental health services (e.g. Andrew et al., 2008). Although the author attempted to incorporate this to broaden the range of experiences studied, through trying to recruit through various HVGs, there were some problems encountered when trying to do this. Firstly, an initial difficulty presented at the level of the ethics committee. The REC was uncomfortable in permitting the author to recruit individuals who attended a HVG facilitated by an 'expert by experience' restricting recruitment from only clinician led HVGs (please refer to Appendix B).

The author challenged this perception, requesting a substantial amendment to her ethical approval to incorporate all HVG's (please refer to Appendix F). However, this left the author with a limited time period in an attempt to recruit individuals from HVGs once the substantial amendment had been approved. Furthermore, it was difficult to establish contact with some groups. An area identified for further research would be to explore if, and how, people who attend HVG's seek to make sense of the development and maintenance of hearing voices and whether this process is similar or different to mental health service users. It may also be useful to explore further the positive experiences of people who hear voices (Jackson et al., 2011).

## **5.6 Conclusions**

Therefore, in conclusion, this study offers a unique and distinct contribution to the current literature which is significant to the field of clinical psychology and the wider mental health culture. Although some individuals in this study did not have an explicit theory regarding the development and maintenance of this experience, the attempt to attribute meaning to their experience of voices was evident. Participants searched for meaning of their voices through different frameworks, but the relative 'success' of this pursuit, and potential usefulness of an understanding, is effected by the sense of agency, stigma and hope(lessness) perceived by the individual. It highlights the importance of helping people engage in meaning-making processes to help individuals understanding the experience of hearing voices, as well as the potential challenges encountered by the service

user. Furthermore, it illustrates the various frameworks which service users draw upon when trying to make sense of their voice. One implication from this study highlights the important role of psychological formulation in generating a collaborative and shared understanding of the voices.

## **5.7 Future research**

The present research was exploratory and has delivered a preliminary insight into the experience of service users attempts to make sense of the development and maintenance of their experience of hearing voices. Consequently, this research has generated a wide range of potential areas that warrant future research;

- To explore the effect of increased training for mental health professionals upon their confidence to explore alternative frameworks to understand the experience of hearing voices.
- Exploration of if, and how, people who attend HVG's seek to make sense of the development and maintenance of hearing voices and whether this process is similar or different to mental health service users.
- Exploration of individuals who hear voices and are distressed from this experience from a wider range of cultural, religious and spiritual backgrounds.
- Explore if people value the experience of developing a shared framework to understand the origin and maintenance of their voice hearing.

## **5.8 Reflection**

I engaged in a process of reflection throughout the research process, from the initial conceptualisation of the research idea to the end stages of this project. The following section aims to illustrate the different reflections I have engaged with by including excerpts from my reflective diary and through the process of memo-writing. This includes some of challenges I encountered during the research process and how I have managed this.

### **5.8.1 Researcher versus clinician.**

Throughout the research process, I grappled with different dilemmas. A recurring dilemma I kept re-visiting was the distinction between working as a clinician and

as a researcher, reflecting a difficult relationship which is acknowledged within the literature and specifically qualitative research (Goldfried & Wolfe, 1996). The similarity between the two roles, of clinician and researcher, is illustrated in the following quote;

“The therapeutic relationship and the research interview appear on the surface to have something in common. In both there is a telling of experiences by one participant, while the other listens with a view to making sense, interpreting, reframing and understanding the narrative” (Hart & Crawford-Wright, 1999, p. 205).

Whilst engaging within the interview process with participants, I was frequently aware of a ‘pull’ to adopt a clinician role. One factor potentially affecting this was the research question I was asking, as I was asking people to share their understanding of their voices and their theories about this experience. It could be suggested that the research interview in this instance shared many similarities with an initial assessment interview prior to someone engaging in psychological therapy.

One example, when I felt this ‘pull’ and queried my ethical obligations within my role as a researcher, was during a disclosure made by a participant. He had a known history of (and was currently engaging in) self-harm, previous suicide attempts and both his father and his care team were aware he had access to knives. During the process of the interview the participant revealed his team were only aware of three knives he had in his personal possession, but he actually had six, and referred frequently to the self-harm he engaged with. After completing a risk assessment of the situation, during the debriefing process after the interview, and establishing the participant was not in any immediate risk, I was left with the uncomfortable position of whether I should disclose this to his care team or respect the prior agreed confidentiality of the interview.

I sought supervision with my academic supervisor regarding the matter, raising the ethical dilemma I felt in my dual role as a clinician and as a researcher, and the difficulty I felt due to my perception of the less distinguished boundaries in the researcher relationship in comparison to the therapeutic relationship (Hart & Crawford-Wright, 1999). We agreed that in this instance the participant’s

confidentiality should be respected. This decision was based on the knowledge that participant was a known risk to the team, they were aware of knives in his possession as well as his self-harming behaviour, he was accessing a day-centre service with his support worker later that day and he was seeing his community psychiatric nurse the following day. However, the uncomfortable tension between my dual roles remained.

I became increasingly aware of how the stories of participants, and frequently that of trauma, affected me. I managed this affect through the use of my reflective diary, supervisions and through pacing the interviews ensuring I completed no more than two interviews within the same day (Field & Morse, 1995). Despite this, I acknowledge it was disheartening to encounter so many individuals who seemed resigned to their experience of hearing voices and feeling utterly hopeless about the future.

### **5.8.2 Researcher positioning.**

It is suggested that a common ethical dilemma within qualitative research is the role of the researcher and their ideals, morals, professional standards and personal values when engaging with the research participants (Laine, 2000). In my role as a researcher, I was aware of my 'biases' and the difficulties this presented during the research process. For example, I acknowledge that I view certain aspects of the biomedical approach to hearing voices critically. All the participants who I interviewed were recruited through, and regularly accessed, support from mental health services. At times, I struggled with the medical conceptualisation that many participants seemed to accept unwittingly. This is captured below in an excerpt from my reflective diary following an interview with a participant;

*"I think I am beginning to realise the potential naivety of the research question I am asking. My preconceived ideas are being illustrated in that I assumed that people would have some understanding of their experiences, or some theories or questions about their voices. Yet I am encountering individuals who do not seem to have had an opportunity to think about the possible reasons of why their voices started or remain here. I am surprised at how many individuals refer to perception that you should not discuss*

*your experience of hearing voices at the 'usual' meeting with their psychiatrist or members of your care team. Some individuals seem quite unaccustomed to even talk about their voices. This in itself is interesting, that people do not have any theories and that people seem very hopeless regarding the future. Perhaps I should be focusing on the process of how people try to develop meaning, even if this is not the 'end product' or outcome ”*

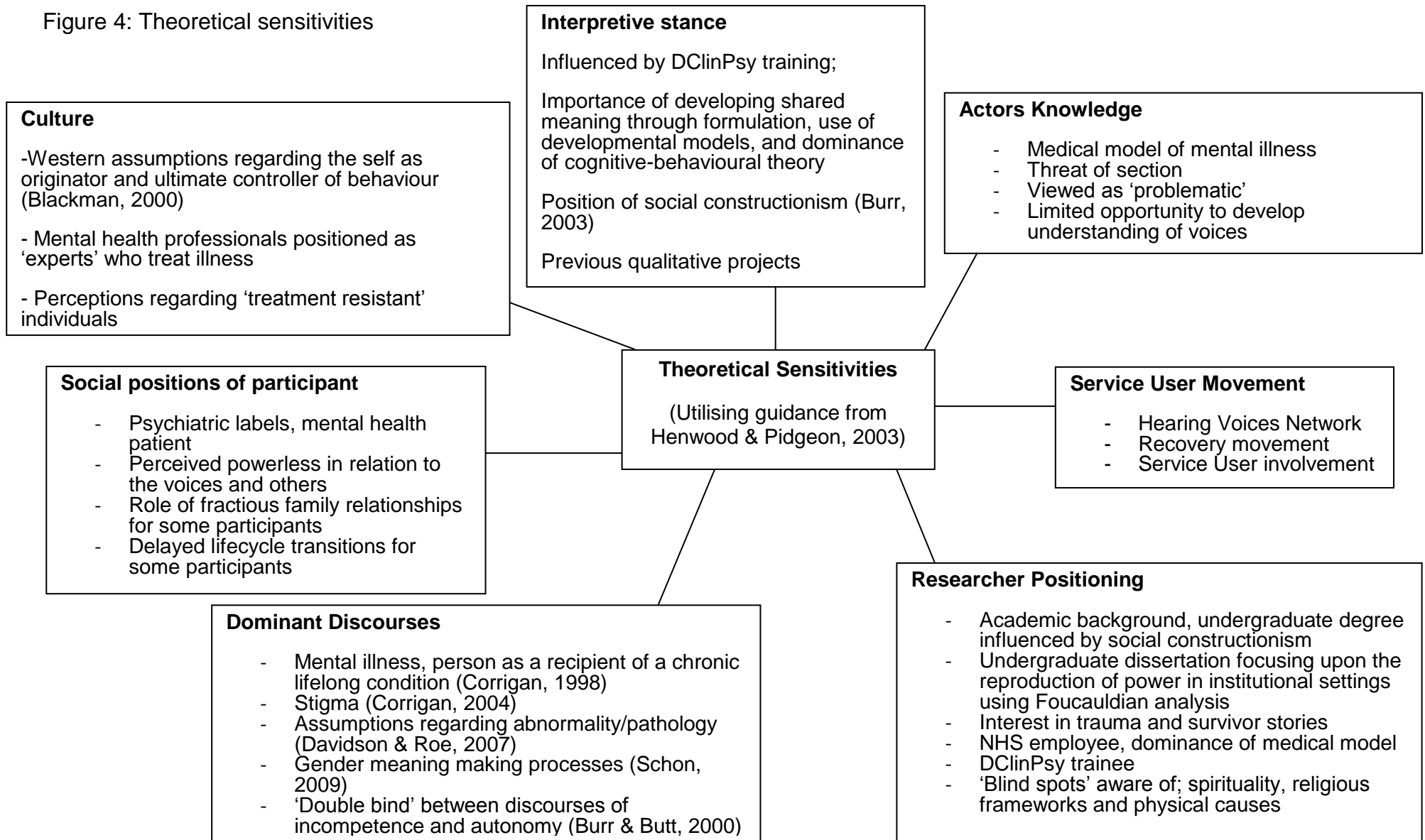
However, reflecting on the process my potential biases or 'blind spots' may have constrained the stories told by the participants. It also made me reflect upon the naivety of my research question, that firstly people would hold a theory about their experience, and that people would separate the origin and maintenance of their voice hearing. This lead me to think explicitly about the processes which people engaged with when 'struggling' to make sense of their voices and how this impacted the development of an understanding.

### **5.8.3 Memo writing.**

Within grounded theory, reflexivity is captured through memo-writing and through the researcher monitoring their analytic decisions which documents the abstraction of the data to a theoretical level (Fassinger, 2005 please refer to an example of memo-writing in Appendix P). Through engaging in memo-writing procedures I was able document all thoughts, insights and queries I had about the data, making my role within the construction and interpretation explicit. Furthermore, by documenting the composite of interpretative practices and the influences upon the research process, it is suggested these theoretical sensitivities helps the researcher abstract the data to a theoretical level (Henwood & Pidgeon, 2003 see figure 2). However, a frustration I encountered was the continual process of raising further questions and demands. Through engaging with a methodology which prescribes no one universal 'truth', I had to sit with the (at times uncomfortable) feeling that there was no one 'right' answer to the question. It seems at times my role as clinician, and the dominance of the scientist-practitioner model as well as the importance ascribed to evidence-based practice, contrasted with the epistemological stance of social constructionism. During the research process, and data analysis, I became more comfortable with

‘owning my perspective’ (Elliott, Fischer, & Rennie, 1999) through acknowledging the role I had in constructing the data.

Figure 4: Theoretical sensitivities



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## **Appendices**

## Appendix A: Participant Demographic Information sheet

Please answer the following questions as accurately as possible. The data you provide will remain strictly confidential.

1. Age

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2. Gender (Please circle)

Female

Male

Transgender

3. Do you experience hearing voices that other people do not?

Yes

No

4. At what age did you first experience hearing voices?

---

5. Are you currently receiving support from NHS services?(please circle)

Yes

No

6. If yes, how frequently are you in contact with them? E.g. one a week, once a month etc

---

7. If you answered yes to Q.5, which services do you have regular contact with? (please circle)

GP

Crisis Team

Care co-ordinator

Occupational Therapist

Psychiatrist

Psychologist

Community Psychiatric Nurse

Assertive Outreach

Early Intervention

Community mental health team

Other NHS service

If you ticked 'Other' NHS service please provide further details below

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8. How long have you received services from the NHS?

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9. Are you currently taking any medication? If yes, please specify what medication you are currently taking.

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10. Have you been involved with any peer support groups previously? If so, please detail which group and how long you have been involved for.

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11. Please give the details of your GP:

GP Name:

Address:

Telephone Number:

12. If you have a care co-ordinator, please provide their details below:

Care Co-ordinator name:

Address:

Telephone Number:

13. Have you ever been detained under the Mental Health Act?(please circle)

Yes

No



If yes, please provide some brief details:

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14. Is there any other information about yourself that you think is important for us to know prior to inviting you for interview e.g. any physical disabilities

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If you would like to add any other information or if there is not enough room to complete your answers, please feel free to use the back of this sheet.  
Thank you for taking time to complete the above questions.

## Appendix B: Initial letter from the REC committee



### National Research Ethics Service

#### NRES Committee North West - Liverpool Central

3rd Floor  
Barlow House  
4 Minshull Street  
Manchester  
M1 3DZ

Telephone: 0161 625 7818

16 September 2011

Professor Nadina Lincoln  
Professor of Clinical Psychology and Consultant Clinical Psychologist (Honorary)  
University of Nottingham  
International House, Floor B, Jubilee Campus  
Wollaton Road, Nottingham  
NG8 1BB

Dear Professor Lincoln

**Study Title:** How do mental health service users explain the origins and maintenance of their voice hearing: A grounded theory approach  
**REC reference number:** 11/NW/0629

The Research Ethics Committee reviewed the above application at the meeting held on 07 September 2011. The Committee thanks Lucy Holt for attending to discuss the study.

#### Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter		18 August 2011
Evidence of insurance or indemnity		26 July 2011
Interview Schedules/Topic Guides	1.0	13 July 2011
Investigator CV	Professor Nadina Lincoln	22 August 2011
Investigator CV	Dr Anna Tickle	11 July 2011
Investigator CV	Miss Lucy Holt	18 August 2011
Letter from Sponsor		18 August 2011
Other: Patient Demographic Sheet	1.0	13 July 2011
Participant Consent Form: Non NHS	1.0	13 July 2011
Participant Consent Form	1.0	13 July 2011
Participant Information Sheet: Non NHS	1.0	13 July 2011
Participant Information Sheet	1.0	13 July 2011
Protocol	1.0	13 July 2011
REC application	3.2	22 August 2011

This Research Ethics Committee is an advisory committee to the West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

### **Provisional opinion**

The Chair welcomed Lucy Holt to the REC and thanked her for attending to discuss the study. Miss Holt agreed to the presence of the observers for the discussion of the application.

Miss Holt explained for the Committee that the non NHS sites are based on the Hearing Voices network which offer peer support and can be very useful. They are sometimes used by service users who feel this support is not available on the NHS.

The Committee asked whether the facilitators have training and Miss Holt said it would depend as two groups are clinician led and two are not. However they have expertise via their experience. She told the Committee she has not contacted specific sites as yet but they are likely to be charitable or NHS.

The Committee asked how it would be handled if someone became distressed in the group and Miss Holt said that the clinician would be able to handle this. She will present the research initially and will discuss with the facilitator or as part of the consenting process regarding asking for permission to contact the GP or care team. If the participant is significantly distressed they will be referred to the mental health service. If they are not registered with the mental health service Miss Holt is aware of contacts to whom she can refer.

The Committee asked when the tapes would be destroyed and Miss Holt said this would be done after 7 years. The Committee asked whether this could be done after transcription and Miss Holt said she would check this.

The Committee asked for changes to the participant information as below

Miss Holt confirmed that she will assess capacity before interviewing.

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair and Dr Tume.

### **Further information or clarification required**

- a. the Committee would like to know whether the tapes can be destroyed following transcription rather than after 7 years. The correct information should be included on the Participant Information Sheet.
- b. The Committee would like confirmation that the groups will be clinician run
- c. The Committee would like to see the Participant Information Sheet revised to
  - i) Under "benefits" revise the second sentence of the first paragraph to "These personal experiences may help to educate professionals.
  - ii) Include contact details for Kevin Browne in case of complaints
- d. the Committee would like to see the Consent Form revised to omit point 5

**If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Carol Ebenezer whose contact details are on this letter.**

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 January 2012.

#### **Membership of the Committee**

The members of the Committee who were present at the meeting are listed on the attached sheet.

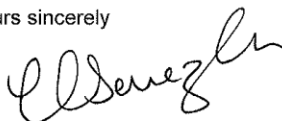
#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**11/NW/0629**

**Please quote this number on all correspondence**

Yours sincerely



**Professor Sobhan Vinjamuri**  
**Chair**

Email: carol.ebenezer@northwest.nhs.uk

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.*

*Copy to: Mr Paul Cartledge  
Miss Corinne Gale, Derbyshire Foundation NHS healthcare trust*

**NRES Committee North West - Liverpool Central**  
**Attendance at Committee meeting on 07 September 2011**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Julie Brake	Specialist Diabetes Nurse / Vice Chair	Yes	
Miss Carmel Dersch	Lay Member	Yes	
Mr Derek Hollingsbee	Pharmacist	Yes	
Mr Frank Killen	Lay Member	Yes	
Miss Karen Knowles	Biomedical Scientist	Yes	
Mrs Jennifer Newman	Lay Member	Yes	
Dr Stephen Pennefather	Consultant Anaesthetist	Yes	
Dr Lyvonne Tume	Lecturer Practitioner of Paediatric ICU	Yes	
Professor Sobhan Vinjamuri	Consultant in Nuclear Medicine	Yes	
Dr Helen Wong	Statistician	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Diane Catterall	Assistant Co-ordinator
Mrs Carol Ebenezer	Committee Co-ordinator
Professor Donald Kelly	Observer
Kimberley Saint	Observer

## Appendix C: Researcher's reply to the REC committee



University of Nottingham  
International House – B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG8 1BB  
30<sup>th</sup> September 2011

Dear Carol Ebenezer,

**Study title:** **How do mental health service users explain the origin and maintenance of their voice hearing: A grounded theory approach**

**REC Reference Number:** **11/NW/0629**

Thank you for your response to my recent application for ethical approval and the comments from the REC committee about the proposed study. I have made the following amendments in line with the recommendations made by the REC committee:

- When recruiting from the Hearing Voices Network, I will only approach groups which are clinician led as opposed to groups which are facilitated by 'experts by experience'.
- The participant information sheet has been amended to include details of Kevin Browne (in case of complaints) and revised the information as suggested under 'benefits'. Please see the attached participant information sheets (Final version 2.0 dated 30.09.2011) in which the altered sections are highlighted.
- Point 5 on the consent form (Final version 2.0 dated 30.09.2011) has been omitted.

In relation to the query raised by the committee regarding whether the audio tapes of the interview can be destroyed after transcription, I have consulted the University of Nottingham Code of Research Conduct and Research Ethics. It states on page 3, point 4.2.2 that, "Data must be retained intact for a period of at least seven years from the date of any publication which is based upon them. Data should be stored in their original form – i.e. tapes/discs etc should not be deleted and reused, but kept securely as outlined." Therefore in line with University of Nottingham policy, the tapes will be kept for a period of seven years securely as outlined in the research protocol. This is stated on the participant information sheet (Final 2.0, dated 30.09.2011).

Furthermore, the lead NHS R&D contact for this research has changed from Corrine Gale to:

Wendy Henson  
Head of effectiveness  
Derbyshire NHS Healthcare Foundation Trust  
Bramble House, Kingsway Hospital

Derby  
DE22 3LZ  
Email: [wendy.henson@derbyshcft.nhs.uk](mailto:wendy.henson@derbyshcft.nhs.uk)

If there are any further queries please do not hesitate to contact me. I look forward to hearing from you.

Yours Sincerely,

Lucy Holt  
Trainee Clinical Psychologist

## Appendix D: Confirmation of ethical approval



### **National Research Ethics Service**

**NRES Committee North West - Liverpool Central**

3rd Floor  
Barlow House  
4 Minshull Street  
Manchester  
M1 3DZ

Telephone: 0161 625 7818

12 October 2011

Professor Nadina Lincoln  
Professor of Clinical Psychology and Consultant Clinical Psychologist (Honorary)  
University of Nottingham  
International House, Floor B, Jubilee Campus  
Wollaton Road, Nottingham  
NG8 1BB

Dear Professor Lincoln

<b>Study title:</b>	<b>How do mental health service users explain the origins and maintenance of their voice hearing: A grounded theory approach</b>
<b>REC reference:</b>	<b>11/NW/0629</b>
<b>Protocol number:</b>	<b>ref: 11055</b>

Thank you for your letter of 07 October 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Dr Tume.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### **Non-NHS sites**

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to the North West Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England



*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		18 August 2011
Evidence of insurance or indemnity		26 July 2011
Interview Schedules/Topic Guides	1.0	13 July 2011
Investigator CV	Professor Nadina Lincoln	22 August 2011
Investigator CV	Dr Anna Tickle	11 July 2011
Investigator CV	Miss Lucy Holt	18 August 2011
Letter from Sponsor		18 August 2011
Other: Patient Demographic Sheet	1.0	13 July 2011
Participant Consent Form	2	30 September 2011
Participant Information Sheet	1.0	13 July 2011
Protocol	1.0	13 July 2011
REC application	3.2	22 August 2011
Response to Request for Further Information		07 October 2011

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

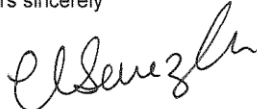
Further information is available at National Research Ethics Service website > After Review

**11/NW/0629**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely




**Professor Sobhan Vinjamuri**  
**Chair**

Email: carol.ebenezer@northwest.nhs.uk

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Mr Paul Cartledge  
Miss Corinne Gale, Derbyshire Foundation NHS healthcare trust

## Appendix E: R&D approval confirmation

Derbyshire Healthcare 

NHS Foundation Trust

Mental Health Research Unit  
Kingsway House  
Kingsway  
Derby  
DE22 3LZ

Tel: (01332) 623579

Fax: (01332) 623576

Email: [Rubina.Reza@Derbyshcft.nhs.uk](mailto:Rubina.Reza@Derbyshcft.nhs.uk)

30 November 2011

Professor Nadina Lincoln  
B19 International House  
Jubilee Campus  
University of Nottingham  
Wollaton Road  
Nottingham  
NG8 1BB

Dear Professor Lincoln

I am writing to inform you that the Derbyshire Healthcare NHS Foundation Trust Clinical Research Committee has reviewed and approved the following study:

**Title:** How do mental health service users explain the origins and maintenance of their voice hearing: A grounded theory approach (11/NW/0629)

**Area:** Adult community Mental Health Teams

**Start date:** 01/12/2011    **End date:** 13/10/2012

As part of our monitoring requirements, we will ask you for a progress report six months after the start of your study, and every six months as applicable. We will also ask you for a short summary of your research findings once the study is complete to assist in the dissemination process within the Trust.

You can now proceed with your study in accordance with the agreed protocol and the Research Governance Framework. Please notify us immediately of any adverse events or changes to the protocol.

If you require any further information please do not hesitate to contact me.

Yours sincerely



Rubina Reza  
Research and Clinical Audit Manager

On behalf of Dr John Sykes and the Clinical Research Committee

Trust Headquarters, Bramble House, Kingsway Site, Derby DE22 3LZ Tel: 01332 623700 Fax: 01332 331254  
Chief Executive: Mike Shewan Chairman: Alan Baines FCA



Nottinghamshire Healthcare   
NHS Trust

*Positive about integrated healthcare*

**Research Management and Development Department**  
**Institute of Mental Health**  
**University of Nottingham Innovation Park**  
**Triumph Road**  
**Nottingham**  
**NG7 2TU**

E-mail: emma.pearson@nottshc.nhs.uk  
Direct Line: 0115 748 4320

Our ref: AMH/01/08/12  
2<sup>nd</sup> Aug 2012

Miss Lucy Holt  
University of Nottingham  
I-WHO, International House B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG8 1BB

Dear Miss Holt

#### **Letter of access for research**

**Study title: Hearing voices: Service users perceptions of origin and maintenance**  
**REC Ref: 11/NW/0629**

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. This letter confirms your right of access to conduct research through **Nottinghamshire Healthcare NHS Trust** for the purpose and on the terms and conditions set out below. This right of access commences on **02/08/2012** and ends on **30/11/2012** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to **Nottinghamshire Healthcare NHS Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Nottinghamshire Healthcare NHS Trust** you will remain accountable to your employer **Derbyshire Healthcare NHS Foundation Trust** but you are required to

The Resource, Duncan Macmillan House, Porchester Road, Nottingham NG3 6AA  
Chair: Dean Fathers, Chief Executive: Professor Mike Cooke CBE



follow the reasonable instructions of your nominated manager in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Nottinghamshire Healthcare NHS Trust** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Nottinghamshire Healthcare NHS Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Nottinghamshire Healthcare NHS Trust** premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

**Nottinghamshire Healthcare NHS Trust** will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes,

you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Shirley Mitchell', with a circular flourish at the beginning.

Shirley Mitchell  
Head of Research Management and Governance

**cc:**  
Derbyshire Healthcare NHS Foundation Trust

positive

Nottinghamshire Healthcare **NHS**  
NHS Trust

*Positive about integrated healthcare*

**Research Management and Development Department**  
**Institute of Mental Health**  
**University of Nottingham Innovation Park**  
**Triumph Road**  
**Nottingham**  
**NG7 2TU**

E-mail: emma.pearson@nottshc.nhs.uk  
Direct Line: 0115 748 4320

Our ref: AMH/01/08/12  
Your ref: 11055  
Date of letter: 01/08/2012

Miss L S Holt  
University of Nottingham  
I-WHO  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG18 1BB

Date of NHS permission for research: 1<sup>st</sup> August 2012

Dear Miss Holt

**Study title:** Hearing voices: Service Users Perceptions of Origin and Maintenance

**Chief Investigator:** Professor Nadina Lincoln

**REC Ref:** 11/NW/0629

**List of sites where NHS permission for research has been given:** Nottinghamshire Healthcare  
NHS Trust – Adult Mental Health Services

Thank you for submitting your project to the Nottinghamshire Healthcare NHS Trust's R&D Department. The project has now been given NHS permission for research on behalf of:

Dr Peter Miller: R & D Lead, on behalf of Nottinghamshire Healthcare NHS Trust

Although NHS permission for research has been given for this study it does not guarantee that independent contractors such as GPs, dentists, optometrists and community pharmacists will be able to take part in your study.

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version Number
Interview schedule	1.0 13/07/2012
CV	Nadina Lincoln, Anna Tickle, Lucy Holt
Sponsor letter	18/08/2011

The Resource, Duncan Macmillan House, Porchester Road, Nottingham NG3 6AA  
Chair: Dean Fathers, Chief Executive: Professor Mike Cooke CBE





Demographic Sheet	1.0 13/07/2011
Consent Form	2.0 30/09/2011
Information Sheet	3.0 12/07/2012
Protocol	2.0 12/07/2012
R&D form, SSI form	

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP [ONLY if applicable], and NHS Trust policies and procedures available <http://www.nottinghamshirehealthcare.nhs.uk/contact-us/freedom-of-information/policies-and-procedures/>

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D Office should be notified within the same time frame of notifying the REC and any other regulatory bodies. All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

Yours Sincerely



Shirley Mitchell  
Head of Research Management and Governance

CC:

CI: Professor Nadina Lincoln

Sponsor: Paul Cartledge



Mental Health Research Unit  
Kingsway House  
Kingsway  
Derby  
DE22 3LZ

25 July 2012

Tel: (01332) 623579

Fax: (01332) 623576

Email: [Rubina.Reza@Derbyshcft.nhs.uk](mailto:Rubina.Reza@Derbyshcft.nhs.uk)

Lucy Holt  
University of Nottingham, I-WHO  
Jubilee Campus,  
Wollaton Road  
Nottingham  
NG8 1BB

Dear Lucy

The Derbyshire Healthcare NHS Foundation Trust R&D department acknowledges the receipt of the substantial amendment notified to us on 21/06/2012 as this does not affect recruitment from this Trust:

**Title:** How do mental health service users explain the origins and maintenance of their voice hearing: A grounded theory approach (11/NW/0629)

**Area:** Adult community Mental Health Teams

**Start date:** 01/12/2011 **End date:** 13/10/2012

As part of our monitoring requirements, we will ask you for a progress report six months after the start of your study, and every six months as applicable. We will also ask you for a short summary of your research findings once the study is complete to assist in the dissemination process within the Trust.

You can now proceed with your study in accordance with the agreed protocol and the Research Governance Framework. Please notify us immediately of any adverse events or changes to the protocol.

If you require any further information please do not hesitate to contact me.

Yours sincerely



Rubina Reza  
Research and Clinical Audit Manager

On behalf of Dr John Sykes and the Clinical Research Committee

## Appendix F: Request for a substantial amendment



University of Nottingham  
International House – B Floor  
Jubilee Campus  
Wollaton Road  
Nottingham  
NG8 1BB  
12<sup>th</sup> June 2012

Dear Chair of Committee,

**Study title:**                      **How do mental health service users explain the origin and maintenance of their voice hearing: A grounded theory approach**

**REC Reference Number: 11/NW/0629**

I am writing to the committee regarding significant challenges I have encountered whilst trying to recruit participants for the above study within the required deadline for the completion of this research. I am requesting the committee consider amendments to my initial proposal outlined below, in order to address these challenges by widening the recruitment pool.

There was some concern raised by members of the committee at the time of gaining ethical approval regarding the recruitment of individuals from hearing voices groups (HVGs) which were facilitated by 'experts by experience' as opposed to groups which were clinician led. Following this, the committee asked for confirmation that recruitment of participants would only focus on HVGs that were facilitated by clinicians, which I provided in my response (dated 30.09.2011). However, I feel that perhaps I failed to convey the Hearing Voices Network (HVN) philosophy and purpose adequately to the committee and would like to take this opportunity to expand on this further. Additional information regarding HVN can be accessed at <http://www.hearing-voices.org>. I have also attached the HVN group's charter to help clarify the HVN philosophy further.

The HVN includes groups in a range of settings, including: independent community groups; voluntary sector organisations; mental health teams; inpatient units; secure mental health units; prisons. Hearing Voices Groups are based firmly on an ethos of self- help, mutual respect and empathy. They are peer support groups, involving social support and belonging, not therapy or treatment. They provide a safe space for people to share their experiences and

support one another. Due to the experiences of some members in the group, the content discussed in the group may include distressing information. Individuals who access HVGs use the groups to seek support and manage their distress. A central tenet of the HVN ethos is the recognition of the importance of HVGs being user-centred and user-led. Consequently, I have had great difficulty finding HVGs that are clinician—led. Of the four clinician-led groups that I was aware of, two have since disbanded and one is currently in the midst of reorganisation of the group due to low member numbers. I have managed to contact a fourth group but the facilitator also has personal experience of hearing voices as well as being a clinical psychologist. It will not be possible to recruit sufficient numbers of participants from this group alone.

Furthermore, I applied to the REC primarily because the study aims to recruit participants who access NHS services. It was my understanding that University ethical approval would be sufficient regarding the recruitment of participants through HVGs if they were not facilitated by NHS clinicians and would like to check whether my understanding of this is in line with the committee's position on this.

Due to the reasons highlighted, I would be very grateful if the committee could reconsider their initial decision regarding the recruitment of participants from HVGs and grant permission to extend recruitment to all HVGs as opposed to only clinician-led groups. In line with my current proposal, I would aim to interview participants prior to the running of a HVG. While I maintain that it is highly unlikely an individual will experience distress as a result of the interview, the aim of meeting prior to a group meeting is to reduce any potential distress the participant may experience through being able to seek support from the group immediately following the interview. I also believe that being interviewed at the location of the group will provide an environment to participants that they inherently know to be safe and supportive, which could minimise the likelihood of them feeling anxieties in relation to going to an unknown place in order to be interviewed. The group, therefore, will be used in accordance to HVN aims which is to provide a safe space in which to share experiences and support one another. The HVG would not be asked to manage distress beyond what they would reasonable expect. Their usual procedures would be followed should anyone require support additional to the group.

In a further attempt to increase the number of potential participants I can recruit, I am also requesting a further amendment regarding the sites from which I can approach. I have received approval from an *Adult Mental Health NHS Trust*<sup>7</sup> which confirms I am able to recruit from all adult community mental health teams within that trust (please see attached letter dated 30.11.2011). I am

---

<sup>7</sup> Letters in italics represent where the name has been changed

requesting for this to be extended to Adult Mental Health Teams within *another NHS Trust* and two Service User Involvement centres within this NHS Trust, which have managers employed by the Trust. I have outlined the changes to my initial application, highlighted them, and have attached them to this letter. I have also made a slight amendment to the Participant Information Sheet, stating that 'Liverpool Central Research Ethics Committee' has granted approval for the study as opposed to '*NHS Trust*'. To summarise, I am requesting the committee to consider the following amendments;

- Extending recruitment of participants to all HVGs as opposed to solely clinician led HVGs
- Extending recruitment of participants by enabling recruitment of individuals who access services from another *NHS Trust*

Thank you in advance for the committee's consideration of my request. I look forward to hearing from you.

Yours Sincerely,

Lucy Holt

Trainee Clinical Psychologist

## Appendix G Approval of substantial amendment



**Health Research Authority**  
**National Research Ethics Service**  
**NRES Committee North West –Liverpool**  
**Central**

3rd Floor  
Barlow House  
4 Minshull Street  
Manchester  
M1 3DZ  
Telephone: 0161 625 7434

20 June 2012  
Lucy Holt  
University of Nottingham, I-WHO  
Jubilee Campus,  
Wollaton Road  
Nottingham  
NG8 1BB  
Dear Professor Lincoln

**Study title:**

**How do mental health service users  
explain the origins and maintenance of  
their voice hearing: A grounded theory  
approach**

**REC reference:**

**11/NW/0629**

**Protocol number:**

**ref: 11055**

**Amendment number:**

**3.2**

**Amendment date:**

**13 June 2012**

Amendment to the Protocol.

The above amendment was reviewed by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Email from sponsor		19 <sup>th</sup> June 2012
Hearing Voices Group Charter		
Participant Information Sheet	3.0	12 <sup>th</sup> June 2012
Protocol	2.0	12 <sup>th</sup> June
Notice of Substantial Amendment (non-CTIMPs)	3.2	13 <sup>th</sup> June
Covering Letter		12 <sup>th</sup> June

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**11/NW/0629: Please quote this number on all correspondence**

Yours sincerely

**Mrs Julie Brake**  
**Chair**

E-mail:  
anna.bannister@northwest.nhs.uk  
Enclosures:

*List of names and professions of  
members who took part in the review*

Appendix H: Informed consent sheet

**CONSENT FORM**  
**(Final version 3.0: 12.06.2012)**

**Title of Study: How do mental health service users explain the origin and maintenance of their voice hearing: A grounded theory approach**

**REC ref:** 11/NW/0629

**Name of Researcher:** Lucy Holt

**Name of Participant:**

**Please initial box**

1. I confirm that I have read and understand the information sheet version number 3 dated 12.06.2012 for the above study and 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 from the study at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be digitally recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I give my full informed consent to participate in the above study. ☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

## Appendix I: Participant Information Sheet

### **Participant Information Sheet**

Final Version 3.0 12.06.2012

#### **Study title: How do mental health service users explain the origins and maintenance of their voice hearing?**

I would like to invite you to take part in a research study. My name is Lucy Holt, I am a trainee clinical psychologist, and I am interested in the experiences of people who hear voices. Before you decide whether or not you would like to participate you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please feel free to ask me if there is anything that is not clear.

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

The purpose of this study is to listen to service users' experiences of hearing voices. This includes asking about reasons you think you began to hear voices and why you think you still hear voices.

#### **Why have I been invited?**

The research is asking people to take part who currently (or have previously) hear voices that other people could not hear, that have been or are distressing to hear.

I am hoping to interview approximately 10 people in this research. If a large number of people show their interest in participating in the study, then participants will be selected at random.

#### **Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights or care.

#### **What will happen to me if I take part in the study?**

If you are interested in taking part, you will be asked to complete two forms: a consent form and a form which provides some information about yourself and your experiences. Part of this information will include providing contact details for your GP. I will answer any questions or concerns you may have about the research process before you agree to take part. You would be asked to meet with me, the researcher, for approximately one hour to take part in a recorded interview. The interview will either take place at a NHS base or at the base where the hearing voices group is held. This time is flexible and depends on how long you feel able to be interviewed.

If you hear voices during the interview you are able to stop the interview at any point if you feel distressed or alternatively are able to take a break from the interview. During the interview I will ask you about your experiences of hearing voices, about what you think led to you hearing them and why you feel you still experience this. There are no right or wrong answers, I am interested in hearing your thoughts about your own



experience of voice hearing. The interview will be recorded using an audio-recording device. You may stop the recording at any point in the interview.

The interview is recorded so that I can listen to your interview again in order to carefully understand your experiences and type this into a computer. The recording will not be listened to by anyone else. All the information discussed will be anonymised, which means it will not have your name or any other identifiable information. You can stop the interview and withdraw from the study at any time. It may be possible that you will be invited to attend a second interview to explore your experiences further.

If you would like a copy of the summary of the research findings, then please advise me at the time of the interview.

### **Expenses**

If you decide to attend the interview, your travel expenses for this journey will be reimbursed, up to £10. This will be based on the cost of public transport (receipts must be provided) or own vehicle costs (diesel/petrol) based on the mileage travelled and submission of valid receipts as approved by the University of Nottingham

### **What are the possible disadvantages?**

It is possible that some of the topics we discuss may be difficult or distressing for you to talk about. You do not have to talk about anything you are not comfortable talking about. If you are asked a question that you do not want to answer, you can say that you do not want to answer it. You can take a break if you wish and you can choose to finish the interview if you find it too uncomfortable. You will be given time at the end of the interview session to explore the feelings you have after discussing your story and alternative support will be sought if necessary. You are encouraged to contact your usual care team if you wish to seek additional support. If you become acutely distressed during the interview and show signs of needing further support, then your GP or care co-ordinator will be contacted by the researcher. If you give consent to participate in the study, you are giving consent for the researcher to contact the GP or care co-ordinator if you become acutely distressed.

### **What are the possible benefits?**

It is hoped that by taking a personal perspective in this research, it will give you an opportunity to describe your story. These personal experiences may help to educate professionals. There might not be any direct personal benefit of you taking part in this study. However, the interview will give you a chance to think and talk about your experiences in confidence. The information learned from this study may impact the services available in the future for people who hear voices.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Their contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints. Details can be obtained from your hospital.

### **Will my 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.

If you join the study, some parts of your data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for 12 months after the end of the study so that I am able to contact you about the findings of the study (if you advise me that you would like a summary of the results). All other data (research data) will be kept securely for 7 years which will include the audio tape of your interview. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data which will only be used for the purpose of this proposed study.

However if you disclose that you have or are likely to harm yourself or others the researchers have a duty of care to report this for your safety. Other circumstances when confidentiality may be broken is if you disclose that you have been harmed by somebody else, are at risk of being harmed by somebody else, or if you talk about criminal activity. If you are accessing NHS mental health services this information will be passed on to your care co-ordinator. If you are not currently accessing NHS services, then before the interview you will be asked for the details of your GP, who this information will be shared with. Except in extreme circumstances, the researcher would always speak to you before sharing this information with anybody else.

The recordings will be stored in a locked cabinet. The recordings will be transcribed by the researcher, this means they will type up what was said in the interview word for word.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights or care being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

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

It is hoped that this research will be published in a journal and will form part of a qualification in Clinical Psychology. Please advise me at the time of the interview and provide your contact details if you would like to be provided with the summary of the findings.

### **Who is organising and funding the research?**

This research is being organised by the University of Nottingham and is being funded by the student and the University of Nottingham.

### **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 Liverpool Central Research Ethics Committee.

### **Further information and contact details**

For further information about the study please contact Lucy Holt, researcher:

Tel: 07407 623049  
Email: [lwxlsh@nottingham.ac.uk](mailto:lwxlsh@nottingham.ac.uk)  
Post: I-WHO University of Nottingham,  
International House B floor  
Jubilee Campus  
Wollaton Road  
NG8 1BB

You can also contact the supervisor of the research: Dr. Anna Tickle, Academic Tutor:

Tel: 0115 846 6646  
Email: [Anna.Tickle@nottingham.ac.uk](mailto:Anna.Tickle@nottingham.ac.uk)

or Professor Nadina Lincoln, Faculty of Medicine & Health Sciences  
Tel: 0115 951 5315

Thank you for taking the time to read this information. If you require any further information about the study please do not hesitate to get in touch. If you decide to take part in the study, please contact me. I will be happy to discuss any further questions you have. You will also be required to sign a consent form, agreeing to take part, which you will be given a copy of for your records.

Yours Sincerely,

Lucy Holt

Trainee Clinical Psychologist

## Appendix J: Email sent to psychologists

Dear Name of Psychologist,

My name is Lucy Holt, I am a second year trainee clinical psychologist on the Trent Doctoral Training programme. I hope you do not mind me contacting you regarding my research.

I am currently trying to recruit participants for my study which is hoping to explore people's experiences of hearing voices, specifically why people believe they started to and continue to hear voices. This research project is being supervised by Dr Anna Tickle. To achieve this, I am trying to recruit individuals who hear voices and interview them about their experiences. In terms of my recruitment pool, I am trying to recruit individuals who access NHS services as well as individuals who access support from Hearing Voices Groups (HVGs). I have been through the process of gaining ethical approval and have received a favourable opinion from the Research Ethics Committee (REC) as well as Derbyshire Healthcare Foundation Trust and Nottinghamshire Healthcare Trust R&D departments (see attached documents). This enables me to recruit potential participants from adult mental health teams across Derbyshire and Nottinghamshire.

I am emailing you to ask for help in the recruitment of participants. I appreciate you are really busy and would be grateful for any help you could provide. I thought it might useful to describe the study briefly (this information is also stated in the information sheet attached). The aim of the research is to generate an alternative theory of the origins and maintenance of hearing voices which is grounded in the data elicited from participants who hear voices and access support for hearing voices.

If participants decided they would want to take part in the study it would involve meeting with myself for roughly a period of 1-2hours (although it may be less than this) and discuss their experience of hearing voices with me. The interview will be recorded using a Dictaphone so I can transcribe the discussion verbatim. To consent to take part in the study, participants will be asked to provide details of their GP and care co-ordinator as well as giving permission that if they were

to become acutely distressed during the course of the interview, then I would discuss this with their usual care team.

Participants will be eligible to participate in the study if:

- Have previously heard voices that other people could not hear that are distressing or have been distressing in the past.
- Have sought support for hearing voices
- Be over 18 years of age or over.
- Be willing to engage in at least one interview for the purposes of the study (due to the possibility that the participant may be asked for a second interview dependent upon the outcome of data analysis).
- Be willing to have the interview audio-recorded for the purpose of data analysis.

Individuals will be excluded from the study if they:

- Demonstrate any significant issues of risk to themselves, others or the researcher, as determined by the individual, their care co-ordinator and/or the researcher.
- Are acutely distressed or too distressed to engage in the interview as judged by the researcher or if the participant states this.
- Only hears voices under the influence of drugs or alcohol.
- Are unable to provide informed consent.
- Cannot communicate fluently in English.

I wondered whether it would be possible for you to hand this information sheet (attached to this email) to people who hear voices and who may be interested in taking part in my research. If the person indicates to you that they are interested and give permission to be contacted by phone, would it be possible for you to contact me (by phone or email) to indicate that someone is interested and then I will arrange to come to your base to gather the contact details of the person.

From this I will contact the individual to discuss the research and if they want to participate I will arrange the details for this.

I appreciate that you are really busy and am very grateful for any help that you may be able to provide. Please contact me if you have any questions or comments.

Thank you in advance for reading this email,

Yours Sincerely,

Lucy Holt

Trainee Clinical Psychologist

## Appendix K: Interview schedule version 1

### Interview Schedule

#### *History of voice hearing*

- Can you tell about when you first started hearing voices that other people could not?

Prompts: Age, events going on around this time, what were the characteristics of voice/s

- At first, how did you make sense of why you were hearing voices?

Prompt: Why did you think you started to hear voices?

- What was your relationship like initially with your voice(s)?

Prompts: How did you feel about them?

- Have you told family or friends that you hear voices? If not, why not?
- If you did tell other people that you hear voices, what were other people's reactions?

Prompts: Family, friends, significant others

#### *Current experience*

- What is your relationship with your voice/s now?

Prompt: has it changed? If so, how? Characteristics similar? More voices? Content of voices? Distressing/comforting?

- What is your understanding now of why you started to hear voices?

Prompts: Has it changed from your initial way you made sense of them, if so why?

- What is your understanding of why you still continue to hear voices?
- If the voice/s have changed over time, why do you think this has happened? How do you make sense of this?
- What do you think has influenced your view about why you hear voices?

#### *Services*

- Can you tell me about the current services you are engaged in the NHS/HVG?
- Have mental health professionals' views about the reasons why you hear voices been similar or different to your understanding of why you hear voices? If so, how?
- How has this influenced your relationship with mental health professionals?
- How do you feel about the services available to those who hear voices?

Prompts: NHS, HVG, peer support

- Is there anything that you would like to add that you feel is relevant to this interview?

## Interview Schedule

### **History of voice hearing**

- Can you tell me about when you first started hearing voices that other people could not?

*Prompts: Age, events going on around this time, what were the characteristics of voice/s, what was going on for you at the time when you started to hear voices?*

- At that time why did you think you started to hear voices?
- Have you had any experiences in your life that seemed connected to when you started to hear voices or what the voices say to you?
- If they were related, how do the voices you hear relate to that experience?

*Prompts: What was the connection for you between that experience and hearing voices?*

- Have you told family or friends that you hear voices? If not, why not?
- If you did tell other people that you hear voices, what were other people's reactions?

*Prompts: Family, friends, significant others*

### **Current experience**

- What is your understanding now of why you started to hear voices?

*Prompts: Has it changed from your initial understanding, if so why?*

- Why do you think you still hear voices?

*Prompts: What is keeping the voices going? Why do you think the voices are still here/haven't gone away?*

- Have the voices changed over time? If so, why do you think this has happened?
- What do you think has influenced your view about why you hear voices?

*Prompts: where have you got information about why people hear voices? Do you agree with the information you read/hear about people who hear voices?*



*Does your understanding of why you hear voices fit with what you have heard?  
If not, how is it different?*

## **Services**

- Can you tell me about the current services you are engaged in the NHS/HVG?
- Have mental health professionals' views about the reasons why you hear voices been similar or different to your understanding of why you hear voices? In what way?
- How have these (similarities or differences) in your views influenced your relationship with mental health professionals?
- How do you feel about the services that are available to those who hear voices?

*Prompts: What do you feel would be useful/ what has been useful in supporting you What has been unhelpful/ would be unhelpful?*

- Is there anything that you would like to add that you feel is relevant to this interview?

Interview schedule

**History of voice hearing**

- Can you tell me about when you first started hearing voices that other people could not?

*Prompts: Age, events going on around this time, what were the characteristics of voice/s, what was going on for you at the time when you started to hear voices?*

- At that time why did you think you started to hear voices?
- Have you had any experiences in your life that seemed connected to when you started to hear voices or what the voices say to you?
- If they were related, how do the voices you hear relate to that experience?

*Prompts: What was the connection for you between that experience and hearing voices?*

- Have you told family or friends that you hear voices? If not, why not?
- If you did tell other people that you hear voices, what were other people's reactions?

*Prompts: Family, friends, significant others*

**Current experience**

- What is your understanding now of why you started to hear voices?

*Prompts: Has it changed from your initial understanding, if so why?*

- Why do you think you still hear voices?

*Prompts: What is keeping the voices going? Why do you think the voices are still here/haven't gone away?*

- Have the voices changed over time? If so, why do you think this has happened?
- What do you think has influenced your view about why you hear voices?

*Prompts: where have you got information about why people hear voices? Do you agree with the information you read/hear about people who hear voices?*

*Does your understanding of why you hear voices fit with what you have heard?  
If not, how is it different?*

## **Services**

- Can you tell me about the current services you are engaged in the NHS/HVG?
- Have mental health professionals' views about the reasons why you hear voices been similar or different to your understanding of why you hear voices? In what way?
- How have these (similarities or differences) in your views influenced your relationship with mental health professionals?
- How do you feel about the services that are available to those who hear voices?

*Prompts: What do you feel would be useful/ what has been useful in supporting you What has been unhelpful/ would be unhelpful?*

- Would it be helpful if people gave you ideas about why you hear voices?
- Have services made any difference to your experience of hearing voices?
- Is there anything that you would like to add that you feel is relevant to this interview?

## Interview schedule

### **History of voice hearing**

- Can you tell me about when you first started hearing voices that other people could not?

*Prompts: Age, events going on around this time, what were the characteristics of voice/s, what was going on for you at the time when you started to hear voices?*

- What reaction did you have when you first started to hear voices?

*Prompts: What did you think it was? Did you recognise it as voices or did you think it was something else? How did you perceive or experience the voices?*

- When it first started, did you have any thoughts about why you were hearing voices?

*Prompts: Why did you think they were there? At that time what did you think had prompted the voices? What, if any, function/purpose did you think the voices served?*

- Have you had any experiences in your life that seemed connected to when you started to hear voices or what the voices say to you?
- If they were related, how do the voices you hear relate to that experience?

*Prompts: What was the connection for you between that experience and hearing voices?*

### **Current experience**

- If you still hear voices, why do you think this is?

*Prompts: What is keeping the voices going? Why do you think the voices are still here/haven't gone away? What, if any, function/purpose do you think the voices may have?*

- Have the voices changed over time? If so, why do you think this has happened?

*Prompts: Relationship with the voice(s), number of voice(s), content, tone*

- In comparison to when you first started hearing voices, have you changed in how you respond to the voices? If so what effect, if any, has this had?

*Prompts: How have you changed in your response to their voices? Why did you change the way you responded to the voices? If you haven't changed how you respond, why?*

- What is your understanding now of why you started to hear voices?

*Prompts: Has it changed from your initial understanding, if so why? Do you have any thoughts now about why the voices started at that point in your life?*

- What do you think has influenced your view about why you hear voices?

*Prompts: where have you got information about why people hear voices? Do you agree with the information you read/hear about people who hear voices? Does your understanding of why you hear voices fit with what you have heard? If not, how is it different? Have you met other people who have found hearing voices a distressing experience?*

## **Services**

- Can you tell me about the current services you are engaged in the NHS/HVG?
- Have mental health professionals' views about the reasons why you hear voices been similar or different to your understanding of why you hear voices? In what way?

*Prompt: How has this affected your relationship with services?*

- Have services made any difference to your experience of hearing voices? If so, what has that been?
- What difference, if any, do you think it would make (or did make) to have a clear understanding or explanation about why you may hear voices?
- Is there anything that you would like to add that you feel is relevant to this interview?

# Appendix O: Example of transcript coding

Transcript	Initial Coding
<p>1. Interviewer: Here let's have a look. Right that seems like that's recording now and that's okay. Okay then. So can you tell me about when you first started to hear voices that other people couldn't hear.</p> <p>2. Participant: Well it was along while ago like as I said I was 18 you know I mean your talking about what 30 years ago. Erm (sighs) I think it started because I went I had a really bad depression uhm and not long been married. I'd only got married, my er granddad passed away two weeks after I got married. And my brother's best friend died in a motor bike accident who I was quite close to myself. Erm so whether that started to cause the break down I don't really know. Erm plus my mums always been really overpowering.</p> <p>3. I: Right.</p> <p>4. P: And she's been the main problem in my life. I've suffered quite a lot of abuse from her erm so. Er but they Max [husband] couldn't take time off work then at that time.</p> <p>5. I: Mm.</p> <p>6. P: I didn't really he didn't really know I don't think how bad it actually was,</p> <p>7. I: Yeah.</p> <p>8. P: So I trundled off to my mums which was probably the worst place to go.</p> <p>9. I: Right.</p> <p>10. P: Erm and I stayed there for about a fortnight so. Doctor was worried about the tablets I had.</p>	<p>Was 18</p> <p>Had bad depression</p> <p>Just married</p> <p>Granddad passed away</p> <p>Friend passed away</p> <p>Overpowering mother</p> <p>Mother main problem</p> <p>Suffering abuse</p> <p>Husband unaware of problems</p> <p>Went to mum's</p> <p>Worse place to go</p>

11.I: Yeah.	
12.P: And er I think that's when it all started really. And they haven't really left me properly since.	Voice constant since
13.I: Right.	
14.P: Sometimes there much louder and worse than others. It's only one voice, it's always been the same voice, I don't have lots of voices.	Change in intensity of voice One voice
15.I: Right.	
16.P: I have one and it's male. And yeah and then er and then er I can remember that erm it er because it still does it now but it's more under control. It's me personally person erm becomes very strong.	Same male voice Under more control now Strength of voice
17.I: Right.	
18.P: And it tries to take over really. But I was told it was a voice not to worry about by one psychiatrist because it was a voice within my head and not outside my head.	Voice tries to take over Reassured by psychiatrist Voice within head
19.I: Right.	
20.P: And he he said that because it was in my head it was my own thoughts.	Thought as opposed to voice
21.I: What what do you think about that?	
22.P: I disagree.	Disagreed
23.I: You disagree? Okay. So it sounds like you started to hear voices when you were 18 and it sounds like an awful lot was happening at that time. And unfortunately you erm experienced some bereavements and some quite tragic as well erm with with the motorbike.	
24.P: Yeah.	

25.I: Quite unexpected it sounds like.	
26.P: Yeah.	Unexpected bereavement of friend
27.I: And it sounds like that your mum has been quite overpowering in the past. And what, if any, connection do you make between that and kind of hearing your voices?	
28.P: Erm I think because David [brothers best friend] died in a bike accident and my granddad passed away. We knew my granddad was dying.	Two bereavements Knew Granddad was dying
29.I: Yeah.	
30.P: Erm he people plus my grandma said that he would never make it to the wedding.	
31.I: Right.	
32.P: Erm and the build up of actually being erm. I'd gone to live without my mum basically and I was living my life.	Build up Living without mum Living my life
33.I: Mm.	
34.P: Erm I suppose couldn't quite cope with not having that situation. I used to poke you didn't I like that for him to hit me. But he's never touched me in his life you know and he never would but erm . It was it was really hard to understand why he's there.	Could not cope Tried to provoke husband Hard to understand why husband stayed
35.I: Mm yeah.	
36.P: When you've lived with abuse it's very are it's a very hard thing to live behind.	Living with abuse
37.I: Mm.	Hard to leave abuse behind
38.P: With lots of people they are unlucky and they carry it for the rest of their lives from one person to another if you know what I mean?	Circle of abuse
39.I: Yeah.	



40.P: I was lucky enough to find Max. Erm we've been together 32 years, it's 30 years this year we got married you know so.	Feels lucky to have husband
41.I: Wow congratulations.	
42.P: Thank you. So yeah it's er yeah. I think it was a really big thing that all of a sudden and I er and she wasn't there you know and I didn't need her.	Sudden big thing Not needing her mother
43.I: Mm.	
44.P: Anymore. And then erm I started drinking quite heavy.	Drinking heavily
45.I: Right.	
46.P: And I drank quite heavy for about five years and then we decided we were going to have a baby. And then that stopped really.	Drank heavily 5 years Decided to have baby Stopped drinking
47.I: And and if you don't mind me asking can I ask some questions about your relationship with your mum?	
48.P: Yeah.	
49.I: Because it sounds like from what you said she was quite overpowering and quite abusive.	
50.P: Yeah.	
51.I: When.	
52.P: She's still alive.	Mother still alive
53.I: She's still alive? And it sounds like you still have a relationship with her?	
54.P: No.	No relationship with mother
55.I: No you don't ok.	Broke off relationship
56.P: Broke it off about a year and a half ago but she's been poorly and she's. Well we got	Mother's ailing health

<p>more or less got all of us we went about two three weeks ago. My brother from Sweden came over er my other brother and me. And we decided we wanted her in a nursing home. Very horrible where she lives and she smokes and drinks all the time.</p> <p>57.I: Okay.</p> <p>58.P: Can't take young children in there. But she chose to stay.</p> <p>59.I: Right.</p> <p>60.P: And my big brother he gave in within an hour. So er yeah you know we didn't win that fight.</p> <p>61.I: Okay so it sounds like your one of three?</p> <p>62.P: Yeah.</p> <p>63.I: And erm growing up with your mum it sounds like that was a really difficult time. And when you talk about abuse do you mean things that she used to say to you or do you mean physically or was it both of that?</p> <p>64.P: At the time I actually didn't realise what was happening till I got married.</p> <p>65.I: Right.</p> <p>66.P: I knew that er other friends mums weren't like my mum. Er and it wasn't the actual er physical abuse it was erm I can't think of the word. Mental.</p> <p>67.I: Yeah.</p> <p>68.P: Abuse that affected me for the rest of my life. Er and it wasn't the physical erm and erm you know she used to locked me in a cupboard and that was be a lot worse than if she'd have beat beat me I think. Erm and she was very cruel but I was by the time I can</p>	<p>Mother smokes and drinks</p> <p>Chose to stay</p> <p>Not winning that fight</p> <p>Did not realise it was abuse</p> <p>Mother being different Powerful mental abuse</p> <p>Long lasting effect of abuse Locked in a cupboard Cruel unusual punishment</p>
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<p>when it got that dominating I actually didn't really realise I was having voices at first. I didn't connect it at all. And like I said I had a massive breakdown when I was carrying my son. There's not much I can remember about beginning of that at all.</p> <p>77.I: Mm right.</p> <p>78.P: Er all I know is I was really poorly wasn't I. Erm and I had to go to the hospital psychiatric bit there. And they started they induced me early actually to get the baby out.</p> <p>79.I: Right.</p> <p>80.P: So that they could start me on electric therapy. And erm that did help for a time and then things would just go back down again and it carried on like that. Where I'd climb up the ladder and then slowly come back down. But the voice would be more aggressive.</p> <p>81.I: Right.</p> <p>82.P: That's how I felt more er more dominant the poorer or. You'd get headaches with it er painful headaches. I'm not quire. It's hard to explain because you can't really always remember what when you get really poorly you can't really always remember that bit.</p> <p>83.I: Mm.</p> <p>84.P: It's er it's er yeah it gets jumbled up.</p> <p>85.I: Yeah.</p> <p>86.P: It's it's not something you can always remember you always remember right at that moment when you become that ill. It's er but I do know that it slowly becomes more dominant and more louder and more more annoying.</p> <p>87.I: Yeah.</p>	<p>voice</p> <p>Massive breakdown when pregnant</p> <p>Was really poorly</p> <p>Psychiatric care when pregnant</p> <p>Induced baby early</p> <p>ECT</p> <p>'Dips' in mental health</p> <p>Voice becoming more aggressive</p> <p>Dominance of voice</p> <p>Link to wellness</p> <p>Headaches</p> <p>Difficulty remembering periods of 'illness'</p> <p>Difficulties remembering</p> <p>Voice gaining dominance and strength when poorly</p>
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88.P: Really. Whereas I find it as an an annoyance now erm sometimes because when I lie in bed that's what I can hear.	Voice as an annoyance
89.I: Yeah.	
90.P: But it's like I can't always what it's saying now.	Difficult in understanding content of voice
91.I: Right so like hearing the noise but not necessarily being able to distinguish the words?	Knowing it's the voice
92.P: Yeah yeah I know it's him, his voice. I mean you know this voice. I mean I don't know who it is or it's never pleasant but it's it's like yeah I can put it where I can't actually hear what it's saying. It's like turning the volume that low on your radio you still hear music a tiny bit but can't work it out.	Never pleasant Turning the volume of voice down
93.I: Mm. And do do you erm do you link the content of what the voice says so what the male voice says. Do you link anything of what he says to perhaps any experiences that you've had?	
94.P: Erm I believe myself erm but I've never really said it to a psychiatrist because they've never really asked me. That erm it was the fact that the he-he wanted me to die because I wanted to die basically. And when I do get to them situations where you know I've had a bit of er a drop I can't remember was it Christmas time? Something like that. And again it it you know yeah.	Psychiatrist never asked beliefs about voice Believes voice wanted her to die Getting drops in mood
95.I: And that's when he's more powerful and more dominant?	
96.P: Yeah.	
97.I: And more annoying because it's and that's when he's saying those things.	
98.P: When you're at your lowest really.	Voice attacks when most

99. I: Mm okay. So it sounds like you started hearing voices the voice when you were 18 and all these changes were happening.	vulnerable
100. P: I can't really remember that but I can.	Cannot remember time when started hearing voices
101. I: It sounds like you started to remember you started to er if your thinking back that the first big sign when you can really him being there was then you were admitted to the mental health ward when you were pregnant with your son.	
102. P: Yeah yeah.	
103. I: Had you noticed any differences when you were pregnant with your daughter? Of the voice? Or is that still quite hard to rememeber?	
104. P: Erm I can't really remember much about erm all with my second daughter all I can remember is trying to be superwoman more or less. Trying to get everything done and be perfect. I was pregnant you know and er I'd been very ill when I was been pregnant actually with Felicity.	Trying to be superwoman Trying to be perfect Being ill during pregnancy
105. I: Right.	
106. P: Erm I had chicken pox when she was about 4 weeks pregnant with her.	Chicken pox when pregnant
107. I: Gosh.	
108. P: And then I got shingles on my lungs while I was pregnant so very ill with that. I was in hospital with that. And erm yeah I always blamed myself really for what happened because they wanted me to be in a nursing home with her which was Smithhouse back then. That's where you went.	Ill when pregnant Hospitalised Blaming self
109. I: Like a mother and baby place?	

110. P: Yeah.	
111. I: Yeah.	
112. P: That's where you went to Smithhouse. And we went and this lady put is in this front room to wait with Felicity er Helen didn't they our other little girl at the time. First born that one. And er it was horrible it was like stuffed beds and all that in there and nothing else was there. I can remember it and it was like it was just cold and horrible and she just said I've just got to go get somebody. And by the time she had gone and come back I had made my mind up to go.	Mother and baby home  Horrible home Cold and horrible Made mind up Left mother and baby home
113. I: Mm.	
114. P: That's all it took was. Perhaps if they'd have took me straight in and not seen that room and met the people I might have stayed and that. And I think that y'know if I'd have stayed then things probably would have been picked up more.	Should have stayed Possibility problems would have been exposed more
115. I: Right.	
116. P: But erm I did all the normal things for two and half years when I had her.	Doing all the normal things
117. I: Mm.	
118. P: And I did all the cleaning right didn't I and looking after them right and em.	Doing all the normal things
119. I: I was really interested when you said you know I was like a superwoman, I had to be perfect.	
120. P: Yeah.	
121. I: And was that in your eyes that you had to be perfect?	
122. P: Yeah.	Had to be perfect

123. I: Or was that any other influences?	
124. P: I'd got to hide everything else. I knew it was there. I knew there was something wrong, I knew something was but I don't think it was just the post natal depression by then was it. It was other things and it just got worse and worse. Until one day it crept up on me and bit me erm.	Had to hide everything Knowing something was wrong Post natal depression Getting worse Crept up and bit me
125. I: Mm. So it sounds like something that was always there and you were you were doing everything. You were being a superwoman, you were cleaning and you know with your kids but it sounds like as well you feel that part of that was a post natal depression?	
126. P: They said it was post natal depression.	Professional label of postnatal depression
127. I: What did you think? Did you feel like that?	
128. P: Erm yeah I do believe I had post natal depression yeah.	Had post natal depression
129. I: Okay.	
130. P: But I don't think it was just post natal depression either. I think I was already depressed before I gave even birth to her really.	'Not just that' Depressed prior to giving birth
131. I: Right.	
132. P: And when I gave birth to my first daughter because there's only 15 months between them.	
133. I: Right okay.	
134. P: I think it was already there by then. I think it was with me for a very long while.	Depression being with her for a long time
135. I: Mm. And if you don't mind me asking, how was your relationship with your mum at this point? Because I remember you saying that your mum didn't want you to move out or get	



<p>married.</p> <p>136. P: Still dominant. She erm she didn't want us me to have any more babies did she. And that caused problems. That's what cause the post natal depression in my eyes.</p> <p>137. I: Right.</p> <p>138. P: Erm because I got pregnant er of course not too long after having Felicity and daren't tell her you know. Daren't tell her I was having this baby and er I always thought that she was the way I was because I'd had girls. Because she always wanted me to have boys. The girls weren't any good boys it was only boys that were any good. Erm and that's one reason that they started me off early when I went into the hospital. Not just for the erm electric treatment erm but to get this baby out you know boy. Cause they knew what it was but they didn't want me to find out at the hospital.</p> <p>139. I: Right.</p> <p>140. P: Erm because they weren't sure which way I'd go. And of course I was having a boy. Erm I quite I can remember being quite really happy about the fact that I was having a boy and actually being able to tell my mum that. But it didn't make any difference.</p> <p>141. I: Right.</p> <p>142. P: I thought it would. Erm I was always wanted to please her really wasn't I. And then erm my children went on the at risk register because of what happened with Felicity. I don't know whether you want me to tell you the actual story of what happened.</p> <p>143. I: If you feel comfortable.</p>	<p>Dominant mother</p> <p>Mother's judgement on pregnancy</p> <p>Connection – mother's judgement causing depression</p> <p>Fearful to admit pregnancy</p> <p>Girls weren't any good</p> <p>Only boys that were good</p> <p>Induced labour</p> <p>Others not wanting her to know the sex of baby</p> <p>Unsure 'which way' she would go</p> <p>Being happy having a boy</p> <p>Being happy to tell mum</p> <p>Made no difference</p> <p>Wanting to please others</p> <p>Children went on risk register</p>
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144. P: Well the reason the breakdown came out was erm we was home. Max was at work and it was tea time and my phone was say on the wall there and the settee here. And she was screaming and screaming and screaming. And erm sh laid on the settee and kicking away kicking her arms up. I can remember it as if it was you know now.	Breakdown Baby screaming incessantly
145. I: Yeah.	Vivid memory
146. P: And I went to put my arms around her more or less. I wanted it all to end. Erm but I was stronger than my mum and I didn't. I picked up the phone and rang the nursery and within minutes and I mean minutes they had everybody there police.	Wanting it all to end Being stronger than her mum Phoned the nursery
147. I: Mm.	Everybody came
148. P: Hospital doctor, Max. I can remember it happening really fast.	Happened really fast
149. I: Mm.	
150. P: And I was just sort of relieved in a way I think because I didn't do er. I suppose I expected myself to be my mum.	Feeling relieved Expected to be same as her mum
151. I: Right.	
152. P: Because I always thought I saw my mum as her mum. Because my grandma was just as evil. Erm so yeah I always I suppose I expected myself to be like that, but that's at that time at particular time I realise I was stronger than that. I didn't need to be like her at all. I gave her not not I'd not committed any abuse on them had I. Er I didn't even believe in smacking you know.	Family scripts of evil women Expected to conform to be like her mum Being stronger Not needing to be like her mum
153. I: Mm.	Did not abuse others like she
154. P: So erm but at that particular time I don't know whether it's because I saw the phone or	had been abused

<p>something clicked. I didn't do what I was going to do you know so.</p> <p>155. I: It must have been a really brave thing to do at that time because it sounds like it was really quite overwhelming.</p> <p>156. P: Yeah. I can remember like yesterday. I can't really remember going to the case conferences though at the er children.</p> <p>157. I: Right.</p> <p>158. P: That on the at register. But my son wasn't even though he was a baby.</p> <p>159. I: Right.</p> <p>160. P: It was only the two girls that went on it for six months I think it was.</p> <p>161. I: Okay.</p> <p>162. P: Well they decided they didn't want me to have more babies. Erm and then they was having talks what have you about and this went on for quite a long while. And then we decided we wanted another baby and we wouldn't let anyone stop us.</p> <p>163. I: Mm.</p> <p>164. P: And I got pregnant with Liam. That's my fourth child, my last.</p> <p>165. I: Mm.</p> <p>166. P: I was six months pregnant before I told my mum.</p> <p>167. I: Right wow.</p> <p>168. P: I mean you're talking about a woman who had been married then you know for a long while. I didn't have my first baby until I was 23, I'd been married for five years. Erm not being able, being too frightened to tell her I was pregnant basically.</p>	<p>Revelation</p> <p>Vivid memories</p> <p>Son not on risk register</p> <p>Two girls on risk register</p> <p>Pressure from professionals to not have more babies</p> <p>Not letting anyone stop us</p> <p>Becoming pregnant</p> <p>Withheld pregnancy from her mother for 6 months</p> <p>Comparison of 'woman' and child</p> <p>Justification of pregnancy</p> <p>Frightened to share pregnancy</p>
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169. I: Sounds like she was a very powerful very powerful figure.	
170. P: In my mind.	Powerful in her mind
171. I: Mm.	
172. P: Not in anybody elses.	No one else viewed her mum as powerful
173. I: But for you it felt very powerful and it sounds like you felt a need to kind of hide that until the last possible moment really.	
174. P: I've always felt really angry because this went on for years. I mean I'm talking years of erm in and out of hospital. She always blamed my daughter for it Felicity. I mean she was a crier. I do believe that Felicity knew from the beginning that I had post natal depression.	Feeling angry Years going in and out hospital Blame placed on her daughter Child knew she had post natal depression
175. I: Yeah.	Babies know
176. P: I do believe babies know. I mean she was two and half by the time I came out.	Blame placed on her daughter by her mum
177. I: Right.	Scared to disagree
178. P: So my mum always blames Felicity for me going in and out of hospital. I never had the balls really to tell her it wasn't Felicity you know. I mean it was what she had done to me really you know. It wasn't just myself it was what she did erm. And I wouldn't let Max say anything to her erm. So that went on and off for years. And I was really cross because then I er I can't remember how long it must have been it's probably been three or four years I don't know. They introduced the fact that I could see a psychologist.	Connection – feels it was influence of mum Not letting others confront her Feeling angry
179. I: Right.	Began seeing psychologist recently
180. P: By this time your talking you know 30, 40, 45 ish I don't really know when I started seeing Jack the psychologist do you? It must be three, four years. And he changed my life. I	

<p>was very angry then with the system that I'd gone all them years before they even actually introduced the fact that. And he's changed my life you know.</p> <p>181. I: And what do you think helped about that?</p> <p>182. P: Jack?</p> <p>183. I: Yeah.</p> <p>184. P: Erm. He taught me really I suppose that it was her that was doing all the wrong things. And it was the way she behaved that was wrong.</p> <p>185. I: Right.</p> <p>186. P: It wasn't me that was being wrong you know being wrong about that. I mean I didn't allow myself to get angry or anything did I Max. But you know I wouldn't allow it. Of course he taught me that anger was alright in the right circumstances, it was alright to be angry. It was alright to relax. It was alright to go and stay in the bath it was you know. It was all those things you know there were things that were alright that I was doing. Not everything was wrong that I was doing. I honestly thought I couldn't do anything right. I was brought up with that. I was brought up with the fact that anything I did was wrong really.</p> <p>187. I: Mm. Because it sounds like to me, and please tell me if I've got his right or not, but it sounds like that you've always had quite a powerful influence in terms of your mum perhaps telling you that you couldn't do things right. And that sounds quite similar to the voice that you experience? So the male voice sounds quite powerful and dominant.</p> <p>188. P: Yeah.</p> <p>189. I: It seems to share a few characteristics between how you describe your mum.</p>	<p>Changed my life</p> <p>Was angry with the system</p> <p>Attributes change to psychologist</p> <p>Realisation that mother was wrong</p> <p>Wasn't wrong</p> <p>Not allowing self to be angry</p> <p>Learnt it's okay to show some anger</p> <p>It was okay to relax</p> <p>I was not doing everything wrong</p> <p>Felt could not so anything right</p> <p>Voice shares characteristics with mum</p>
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190. P: Yeah. That's why I never understood why it was male.	Confusion of gender of voice
191. I: Mm okay. And has your understanding changed at all? Because it sound like you were in hospital when you were having your son but it sounds like it was a long time before you were able to see a psychologist but you had other services in between.	Expectation voice should be female
192. P: Yeah.	
193. I: So how you understand your voices your voice now, has that changed from when you were younger?	
194. P: I can't really remember er I was too frightened to tell anybody about it. But I know when all that happened with Felicity between me touching the phone and ringing and them coming. I don't remember much about how I got to hospital or anything. I had a psychotic break.	Frightened to tell others Had a psychotic break
195. I: Right.	
196. P: And I I can't I didn't really tell anybody about the voice until some years after you know some years after that. Uhm when they became stronger and worse again. So I've had about er I think it's five lots of electric shock treatment which was lots of erm I think it was six to twelve at the time. I can't remember how many courses you had of it. So I had a lot of memory loss.	Not telling others about the voice for years Voice becoming stronger and worse 5 separate ECT treatments Side effect ECT memory loss
197. I: Right as a side effect of the electric.	Cannot remember giving birth to son
198. P: I can't even remember giving birth to Ian [son] which is the worst thing in the world.	
199. I: Right.	
200. P: And yeah so I had quite a lot of that. But then I went to have my electric shock	Worst thing

<p>treatment done at the hospital at the mental hospital. I can't remember what it's called now or I was intake at the time. I was actually in the hospital.</p> <p>201. I: Right.</p> <p>202. P: Erm and for some reason they couldn't get me round. They've never explained or anything but they couldn't get me round. It took me too long to get me round and then they wouldn't allow it again.</p> <p>203. I: So that was after the electric treatments the last time you had it?</p> <p>204. P: Yeah I was there and they couldn't wake me up and couldn't get me round but no one's ever said why.</p> <p>205. I: Right.</p> <p>206. P: And that was it they said you couldn't have anymore of that. I found it quite helpful but I suppose that's because I like my memory being blocked out (laughs).</p> <p>207. I: So that that was quite helpful but it sounds like it had other side effects.</p> <p>208. P: Yeah.</p> <p>209. I: It sounds like.</p> <p>210. P: Blocking out it started blocking out.</p> <p>211. I: Yeah so almost the benefit and difficulty of that was the memory blocking?</p> <p>212. P: Yup.</p> <p>213. I: But not being able to choose which bits it was?</p> <p>214. P: I don't think it's really beneficial to anybody.</p> <p>215. I: No.</p>	<p>Inpatient stay</p> <p>Difficulty in waking following ECT</p> <p>Lack of explanation</p> <p>Restriction of further ECT</p> <p>No one explained why</p> <p>Found ECT helpful</p> <p>Link – effects of blocking memory</p> <p>Blocking out</p> <p>Both benefit and difficulty</p> <p>Feels ECT is not beneficial to anyone</p>
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<p>216. P: I mean they say that it is but it's not actually doing the job it's supposed to do. Because they are trying to say it lifts your mood but the only reason it is lifting your mood is because it's blocking out everything. And then eventually you start to unfold it again it all happens again.</p> <p>217. I: Mm.</p> <p>218. P: The best thing they ever did for me was Jack [psychologist] and I can't understand why they didn't offer me it earlier. I mean it was him that taught me to live with the voices, that they might not ever go you know.</p> <p>219. I: Was that different to the message you received earlier?</p> <p>220. P: Yeah I mean it's er more or less. I can't really remember when I actually told the psychiatrist when I've got voices. I can remember when that was. I can't remember what period of time that was. So I can't really say to you whether it, I know it wasn't when I had Ian.</p> <p>221. I: Right.</p> <p>222. P: Erm I was in a ward, so it was a period you know of time.</p> <p>223. I: Yeah.</p> <p>224. P: When I started to go to that hospital erm that I actually told somebody that something wasn't wasn't right. I wasn't even I didn't really know if it was actually erm voices. It was quite a shock for them to actually say that back to me. What's happening to you is that your hearing voices. I couldn't quite grasp it.</p> <p>225. I: Mm.</p>	<p>Not doing the job it is supposed to</p> <p>Lifting mood through blocking memory</p> <p>Begin to unfold again</p> <p>Frustration not offered psychology earlier</p> <p>Learnt to live with the voice</p> <p>Acceptance voice might remain</p> <p>Cannot remember telling psychiatrist about voices</p> <p>Inpatient stay</p> <p>Telling someone</p> <p>Unsure what it was</p> <p>Feeling shocked when informed it was hearing voices</p>
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226. P: Even though I know that sometimes I'd lie in bed at night and it would keep me awake. I didn't actually grasp the fact the concept that that's that's what it was.	Voices keeping her awake at night
227. I: Did you have any idea before someone said, so someone has obviously said it's hearing voices.	Struggle to comprehend concept
228. P: Yeah.	
229. I: Before that did you have any kind of idea what you thought it might have been?	
230. P: It's it's hard (sighs) it's really hard to put put your finger on it. It's like you know that it's it's up there in your head. Erm I suppose I suppose you don't really want to know because you think your going mad I think. That's that's what it I think is the fact you think your going mad.	Difficult to pinpoint Knowing 'it' is there Not wanting to know Fear of going mad
231. I: So almost a worry.	
232. P: It's not the sort of the thing you want to tell everybody.	Not wanting to tell others
233. I: Yeah and almost a worry to tell? It sounds like almost a worry to kind of understand what it is because that might mean that you?	
234. P: I know that on that day that I really remember the voices starting was when Felicity was on the settee.	Vivid memory of voices
235. I: Yeah.	
236. P: And it some reason I picked the phone up but it was telling me that it was time for me to go. That's more or less what it said a lot of the time it was time for me to go. You know. It would ask me if I was tired. Was I tired. You know and I'd be thinking yeah I'm tired so tired of all the, it's time for me to go you know you've got to do something about this now. You	Voice saying 'it's time to go' Repetition of message from voice Voice urging action



245. I: Yeah.	Voice just there
246. P: But when it does it does still come back. You know it still you know it does come back. Like I say at Christmas I had a period of time where I wasn't very well. I can't remember whether it was before or after but. I can remember that I wasn't well and that's you know. Like I say I can drop I can be perfectly alright and then. He wants to win doesn't it. You see that's what way become where it becomes a fight because you know not it's not real it's not real up there. But when you've got somebody going on and on and on and on and on and on and on. I mean it's like you getting on at your boyfriend or partner about wanting a certain bar of chocolate from the shop and will they go. And what do you do, you go on and on until you get this bar of chocolate. And that's what they this is what the voice does.	Voice still comes back Christmas  Voice wants to win Becomes a fight Real versus unreal Going on and on Persistence of voice Voice wearing you down
247. I: Mm. It sounds very persistent.	
248. P: Yeah. When you've got that in your head it makes you tired it makes you tired. It makes you physically like I can't be bothered anymore.	Makes you tired Physically cannot be bothered
249. I: Yeah.	
250. P: Just get it get it over and done, can't cope. Just want to go. I mean go by die you know. When I die it's not going to be there anymore. In fact it's worse I suppose when your not very well you'd rather not cope with the voice then cope with the actual thing that's happening to you.	Cannot cope Want to go, want to die Rather not cope with the voice than the situation
251. I: So almost everything else seems quite overwhelming that in some ways the voice.	
252. P: Wins.	Voice wins the fight
253. I: That it wins in that sense?	

254. P: And you have to learn to not to allow the voice to win. I mean I used to self-harm a lot, I mean you can tell. And erm that's I mean that's been cut right down hasn't it. So you know for years.	Have to learn not to let voice win Used to self-harm
255. I: So that sounds.	
256. P: Jack working with me really. Allowing me to do it if I needed to do it. It wasn't the wrong thing to do. It was to release the pain I mean I call it pain cause I call it pain.	Being allowed to do it Not the wrong thing
257. I: Yeah.	Self-harm as release of pain
258. P: It wasn't the wrong thing to do. It was alright to do that it was alright to scream it was alright to get angry. Nobody had ever told me it was alright you know before. And that's when it started to help. That's when I started to notice a difference.	Being comfortable expressing emotions Being told it is not wrong
259. I: Right.	Link- began to notice a difference with the voice
260. P: And I was phoning my mum every day, probably twice a day. Erm and it dwindled down to maybe once every few days.	Reduction in contact with mum
261. I: Mm.	
262. P: Erm still seeing her at that time a lot. You know when the children were young it was every weekend really.	Seeing mum every weekend with children
263. I: Yeah.	
264. P: And and then it slowed down to once a week I'd ring her. Maybe once a month I'd go. And then it dwindled down to the fact that I wouldn't go at all for her more than once a month. In my own mind, Jack's never told me don't go, my CPN has never said don't go.	Slow reduction of contact Own decision
265. I: Mm.	

266. P: But it's your decision what you do. And the less I had to do with her. It was really hard. I mean you know the year and a half was quite hell at the beginning as well.	Hard decision Hell at beginning
267. I: Yeah.	
268. P: Because she's still there, everyday you wake up your all your stuff but she's still there in your head. And I had to understand that the reason she was there because she was that that dominant person and the reason my dad wasn't there because he he died when he was 56. And I'll never forgive you know the world really for taking my dad, such a good person and leaving her behind. The reason dad wasn't there was because I was content with it. Content with my Grandma Hannah which was my dad's mum.	Still there in your head Mum there because she was domineering Angry about father's death Content with dad, reason it's not him
269. I: Yeah.	
270. P: And the reason I wasn't with my mum is because she's always been. I wasn't content, I was always fighting for her affection. Wanting her to cuddle me wanting her to touch me. So I didn't need to do it with my dad. And I didn't know that nobody had ever taught me that.	Always fighting for her mum's affection Wanting to be cuddled by her mum
271. I: Because you had it with them?	
272. I: Yeah.	
273. P: Yeah and I didn't need to fight for it, it was there you know. And erm I just carried on fighting and fighting with that. And I still see her in my mind now erm everyday but its erm. I think it did me really good because of course I went to see her a few weeks ago. She was supposed to be ill. And there was this little frail old lady there you know.	Just had to fight for it with mum Carried of fighting for affection  Frail old lady now
274. I: Right.	
275. P: And erm I always said I wasn't going to go again. She told me she didn't want me at	Told not to go to her funeral



287. P: No.	Unsure what makes voice worse
288. I: Are there anything that helps with the voices that makes it less likely that he's going to be there or less powerful?	
289. P: Only me really yeah. Because like I say when your having the er electro treatment it's only covering it. Pills only cover it really. I mean I came off anti-depressants that's right that's why I was ill cause we tried to come off the anti-depressants.	Role of self in recovery 'Covering' treatments
290. I: Right.	
291. P: Jack don't really believe in them you see and my CPN does you know. So I came off them. We gave them quite a period of not being on them and erm. [noises outside] I can't concentrate sorry, that gentleman's struggling.	Debate between professionals regarding medication
292. I: It's okay yeah.	
293. P: Forgot completely where I was.	
294. I: We were talking, you were saying about erm about the medication that perhaps Jack isn't the biggest fan of medication.	
295. P: Yeah yeah yeah. So I tried for a period of time but then I started to erm to erm dip quite badly. And erm I left it and left it as long as I could and I tried anti-depressants and it picked me up again.	Stopped anti-depressants Began to tip Recommended medication
296. I: Right.	
297. P: I suppose really Jack was a bit shocked at that and I suppose I was because they'd not always helped.	Shock to self and psychologist
298. I: Yeah.	

299. P: Erm but I do think you know that sometimes medication certain medications can completely cover them cover it.	Some medications 'cover' problems
300. I: Right so it sounds like you've had a bit of mixed experience with medication?	
301. P: Through life yeah. I mean it's been a long while you know. And when the doctor gave me them medications when I was 18, it knocked me out.	Long time on medication Feeling knocked out
302. I: Right.	
303. P: Completely I was asleep all the time you know. Erm I feel all they were doing were pulling the curtains around it but not quite. It took them all those years to give me Jack you know, somebody to actually open the curtains and make you look.	Feeling lethargic Medication pulling curtains around problem Opening the curtains
304. I: Mm.	
305. P: You know so I suppose the voice was very controlling really because I was allowing it to be.	Making you confront the problem Allowing voice to be controlling
306. I: So you felt it was controlling because the curtain was always drawn?	Role of self in recovery
307. P: Mm.	
308. I: And it sounds like that some medication has been quite useful but it didn't let you it didn't let you look at the voice and?	
309. P: Yeah and what was happening around me.	Medication restricting addressing voice and situation
310. I: Mm okay. So it sounds like seeing Jack has been a big a big turning point it seems.	
311. P: Yeah.	
312. I: But before that what do other professionals that were involved with you, what did they think? Why did they think you were hearing voices?	



313. P: The thing like I said the only explanation I got was erm the voices is perfectly already because it was in your head not out your head. That's it.	One explanation from professionals
314. I: And that was something you didn't agree with?	Voice was okay because it was in the head
315. P: Erm no.	
316. I: No. So it sounds like you've been accessing services for quite a while. Was that the main explanation or was that the only explanation that perhaps?	
317. P: No no no you've got diagnosis as such you know. So. Clinical depression and er personality disorder. Is that right Max? That was it. Just labelled then aren't you. They're not all brilliant. I mean I've had some brilliant nurses I mean before my CPN I had Pete, he took me places to do things and stuff. And my new CPN, I think it was my CPN really that fought to get me Jack you know so. It's the psychiatrists because they don't really bother. You don't always get good psychiatrists you know. Just in it for the money some of them you know. They just move you along sometimes. There's been good ones.	Diagnosis Clinical depression and personality disorder Being labelled through diagnosis Positive experiences of professionals Mixed experience of psychiatrists
318. I: Yeah yeah.	
319. P: I mean they've got a lot of people to see because they have to move about don't they as well. They don't just stay in one place these days. You know you can have one psychiatrist and they are gone in 6 to 8 months you know. Er yeah never had anyone really explain to me, sit down and explain anything to me at all, never.	Large case load Temporary nature of psychiatrists No explanation of voices
320. I: Do you think that would have been useful back then?	
321. P: Yeah.	Would have been useful
322. I: So before kind of seeing Jack.	

323. P: Yeah.	
324. I: So you feel that would have been useful yeah. Okay. So do you feel that services have made a difference to your experience of hearing the voice?	
325. P: Yeah.	Services has made a difference to experience of hearing voices
326. I: And it sounds like that's a fairly recent change?	
327. P: Yeah.	
328. I: So before Jack would you say that.	
329. P: And my CPN.	Role of psychologist and CPN
330. I: And your CPN, of course and she fought for you to see Jack. But before that did you find services, were they useful for you?	
331. P: Yeah my nurse was brilliant erm you see I never it wasn't just Pete's fault either I suppose at the time. I never I never really said much about things. I didn't want to I didn't even want to involve me mum really. I mean the thought that because things are not always been there in my head that I remember. Because I didn't want to know.	Not wanting to talk about voice Not wanting to involve mum Not wanting to know about voice
332. I: Yeah.	
333. P: You know I knew but I didn't want to talk about it you know so. And of course there's lots of other things that you just want to hide them really you don't you don't want to talk about them to people.	Knowing but not wanting to talk about voice Wanting to hide voice from others
334. I: Yeah.	
335. P: So.	Not wanting to talk to others
336. I: It sounds like erm that a few individuals have been really really helpful.	

<p>337. P: Some psychiatric nurses at the hospitals have been brilliant.</p> <p>338. I: Right so when you've been staying in the hospitals the nurses there were brilliant.</p> <p>339. P: Yeah.</p> <p>340. I: That's nice to hear.</p> <p>341. P: I wouldn't be here without them put it that way. But definitely nurses I've had some good ones and I've had some atrocious ones.</p> <p>342. I: Mm. I was going to ask have there been any experiences while you've accessed services that had led to the voices being more powerful?</p> <p>343. P: Oh yeah. My dad dying.</p> <p>344. I: Right.</p> <p>345. P: Max told them not to tell. He rang the hospital, I was actually in you see.</p> <p>346. I: Right.</p> <p>347. P: And he rang the hospital I don't really know what happened. I think he must have told them that he was on his way and that my dad had died and not to say a word to me. I remember the psychiatrist on call at the time getting me in the office and the psychiatrist just came out with it. And I thought they were lying me. I mean wasn't well anyway I can remember not being well erm there's not much about it that I can actually remember whether it was real even now. I know I kicked him. I told him stop fucking lying to me.</p> <p>348. I: Mm.</p> <p>349. P: And course I don't know whether it was then, only Max that probably knows whether it was then or the day after that I hung myself in the toilets there. Do you remember? Er.</p>	<p>Certain individuals being helpful</p> <p>Wouldn't be here without support</p> <p>Mixed experiences of nurses</p> <p>Father's death</p> <p>Asked services not to inform her of her fathers death</p> <p>Husband wanting to share news of her fathers death</p> <p>Psychiatrist going against wishes</p> <p>Felt others were lying</p> <p>Feeling angry</p> <p>Attempted to hang self</p>
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350. I: Gosh.	
351. P: The support was absolutely atrocious I suppose. They put me I mean it wasn't it was	Atrocious support from services
352. me. It was my fault. Because I'd got a male nurse because I was 24 obs I was on 24 hour observations.	On constant observations
353. I: So kind of like someone?	
354. P: I've got to have someone with me all the time anyway.	Constant observations
355. I: Yeah.	
356. P: I can remember it well. I don't remember what I used I can't even remember if I took my bra off or took shoelaces out my shoes but I can't imagine having shoelaces in your shoes. When your suicidal your not normally allowed that. And I talked this male nurse to waiting outside the toilets for me. And it was a roof like this funnily enough. It's amazing what they can hold and you know and I jumped off the toilet. Erm and the feeling I actually went on a picnic with my dad.	Cannot remember details of suicide attempt Ligature around the roof Jumped off the toilet Imagining being on a picnic with her father
357. I: Right.	
358. P: And my two children you know. And it was the feeling it was fantastic you know it was wonderful. And the next thing I remember I'd been cut down and I was on a bed you know. It wasn't it wasn't really the nurse I talked him into it going to the toilet but your not supposed to close the door. And that's all it took really it didn't take me long.	Feeling fantastic Remember being cut down
359. I: Mmm.	Not taking long
360. P: I can remember thinking you know that er were lying to me and of course when Max come it would have to all happen again. All happen sort of again that it wasn't real.	Remember thinking staff were lying to her

361. I: Oh gosh.	Having to re-experience news
362. P: And of course it went on well weeks for you didn't it. I didn't really understand that he was dead. I couldn't believe that they actually were telling me the truth. I know I went to the funeral didn't I. It was one of the worst losses probably in my life.	Having to re-experience news Did not believe staff Worst loss of her life
363. I: Gosh and it sounds like you've experienced quite a lot of loss.	
364. P: Mm.	
365. I: And especially when you were 18 in such a short period of time, gosh.	
366. P: Yeah. I can't remember how old I was when he died. How old was I. I don't even know how old he'd be now. He wouldn't be more than 74 now. Quite old but horrible I'd suppose but I honestly believed that that psychiatrist enjoyed telling me. He wasn't even my psychiatrist at the time and I, it's funny he probably didn't but that's how it felt.	Believed psychiatrist enjoyed telling her Felt it was vindictive at the time No personal connection to psychiatrist
367. I: That's how it felt at the time.	
368. P: That they were trying to hurt me.	Feeling staff were intentionally trying to hurt her
369. I: Mm okay. And I remember you mentioned that you went to a hearing voices group. Can I ask what was that like?	
370. P: Can't even remember really.	Cannot remember hearing voices group
371. I: Right.	
372. P: Right. I think I only went around 4 times didn't I. Er I didn't it didn't last long because it started to dwindle down. It did me good. I can remember going to the theatre once all together with our partners and whoever you know. That was nice. It was it was er a few of my friends and I know one had got schizophrenia.	Positive experience of hearing voices group Inclusion of partners

373. I: Mm.	Diagnosis
374. P: And others was some cause some of them were different like me they just were classed differently for some reason just classed differently because we just hear voices you know. It's not the same as people who are schizophrenic as they see it you know.	Classification of voices Diagnosis Difference in diagnoses
375. I: Right.	
376. P: Yeah I suppose you know in some cases with some of the psychiatrists and erm some of the psychiatric nurses and that they don't see it the same. But it's a bit silly because it can do exactly the same thing. They don't see it as dangerous as much.	Different conceptualisation by professionals, similar experience Viewed as less dangerous
377. I: So.	
378. P: So a lot of that I can remember a lot of that helped because it came out and you know people were talking about. Well I think I brought it up the difference why weren't we seen as being a problem as much.	People talking about voices Helpful Not seen as problematic
379. I: Yeah.	
380. P: As you know I can remember that. Other than that I can't remember much about going.	Difficulty remembering hearing voices groups
381. I: So it sounds like that you feel that if you'd been given a different label, if you'd been given like a diagnosis of schizophrenia.	
382. P: Yeah or something yeah.	
383. I: That perhaps people would have responded to you differently?	
384. P: Yeah and helped me with my voices a lot quicker.	Impact of diagnosis on support
385. I: Right.	

386. P: Because I didn't want to talk about it with anybody. But because nobody ever bought it up apart from really my CPN, I mean my previous CON didn't did she. I mean I would hide anything I would. I mean you know, I'd hide how I'd felt an hour ago so.	Not wanting to talk about voice No one else wanting to talk about voice
387. I: So it was almost like erm if no one asked you about it then you wouldn't mention anything because it was something you wanted to keep hidden?	Hiding emotions from others
388. P: Its like even now if my CPN will come erm and she erm I can't always say you know that I don't want her to leave. I'll write it down because I can't actually ask for help a lot of the time.	Finding it hard to talk about emotions Finding it difficult to ask others for help
389. I: Right.	
390. P: I can't physically I don't physically want to ask so I have to sometimes write things down.	Writing things down as opposed to talking
391. I: Mm.	
392. P: And I can cover but I've learnt to cover things so easy. Erm I think it was to do with being abused as a child because my brother abused me sexually when I was about 4 and he was about 8. I think it was a case of living a lie, yeah covering it. But you know out there. You know my mum would I always had the best clothes you know er because that was my mum's way of hiding the fact she was a poor mother I always believed. Erm and I hardly ever did PE so I've always hated sports really because I hardly ever did PE. Erm and she would write me notes for this that and the other because she wouldn't want me to be seen.	Have learnt to cover feelings Sexually abused as a child by brother Living a lie Covering emotions Looking 'fine' on the outside Mother actively conspiring in living the lie
393. I: With because.	
394. P: With being naked I suppose yeah erm. So I learnt to live a lie.	Hiding physical abuse

395. I: Yeah.	Learning to live a lie
396. P: To lie to the world. And I carried on that for the rest of my life basically. Yeah I am alright yeah I am okay and then that's you know. I mean that's its been hard erm pressure from going to yes I am okay and then just dropping and everything goes completely wrong to being able to write it down.	Lying to the world Continuance of living the lie Pressure Hiding emotions
397. I: Mm.	
398. P: Or being able to say you know.	
399. I: That I need a bit of support now.	
400. P: Saying I mean I can say it now because I'm not worried can you help.	Not being worried about asking for help
401. I: Yeah.	
402. P: I couldn't I can't even say it now. I wouldn't be able to say it to Jack or I have to write it down. I can't physically ask because I feel like I've gone wrong somewhere I suppose.	Finding it hard to ask for support Feeling of going wrong
403. I: So it sounds like that if your to ask for help that would be a bad thing.	
404. P: Yeah that I've lost. That I've not done my job properly.	Feeling that she's lost
405. I: That you've lost.	Not doing my job properly
406. P: Yeah not done my job properly.	
407. I: Yeah. So it sounds like that actually not being able to tell people about what you experienced, it sounds like the connection you make to that is not being able to tell other people anything at all?	
408. P: I didn't.	
409. I: So it sounds like you had to hide what about your brother all the horrific things that	



<p>your brother was doing to you. And it sounds like you had to hide what your mum.</p> <p>410. P: I don't talk about it now. I don't I mean my mum a bit more with things that came along as I got older that I couldn't really quite focus on.</p> <p>411. I: Yeah.</p> <p>412. P: But the main thing I have to say it wasn't the beatings or anything it was the actual mental abuse. That can be a lot worse sometimes in some cases.</p> <p>413. I: Mm.</p> <p>414. P: And that led me up to being bullied.</p> <p>415. I: Right.</p> <p>416. P: And of course I felt school at school I was badly bullied. I left school went to work I was badly bullied, I left that work placement to another work place badly bullied. But I was luckily enough to find my husband Max cause that can sometimes led to where you find a man or a woman is a bully you know.</p> <p>417. I: Mm.</p> <p>418. P: I was lucky. I was. I probably wouldn't be here now if it wasn't for Max. Because if I'd have found that destroying behaviour at home as well.</p> <p>419. I: Yeah.</p> <p>420. P: I probably wouldn't have made it.</p> <p>421. I: Gosh.</p> <p>422. P: But I do believe that we can go around with a you know a certain words written on our foreheads and people just pick upon that and they know.</p>	<p>Not talking about abuse</p> <p>Only spoke about mum when older</p> <p>Mental abuse being worse</p> <p>Experience of being bullied</p> <p>Badly bullied at school</p> <p>Badly bullied at work</p> <p>Continuance of bullying</p> <p>'Lucky' exception of husband</p> <p>Circle of abuse</p> <p>Positive support of husband</p> <p>Contemplation of different possibility</p> <p>Would not have made it</p> <p>Labels being carried with people</p> <p>People knowing about your</p>
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423. I: What do you feel that word is for you?	weaknesses seeming visible
424. P: Bullied. You know bully me. I'm weak bully me. Sometimes my children bully me don't they sometimes.	Bully me Children bully me
425. I: It sounds like sometimes that your worried that because you've had those experiences that other people can pick up on that.	
426. P: That's why I try to not let people know.	Link- why hide feelings because others will bully you
427. I: Yeah. So actually hiding it has another function as well? Protection?	
428. P: I don't hide it, I don't mind people knowing that I've got mental difficulties mental er issues. I'm not ashamed of the fact of that at all. I don't go round hiding my scars. They can think what they like about that. I just don't want anybody knowing it's not just that I can't actually physically just tell people that you know that erm you know the kids now know certain bits about their grandma.	Not ashamed of mental health difficulties Differences between something being visible and 'mental'
429. I: Right.	Difficulty talking about experiences
430. P: But I think they were always clued up ojn the idea that she wasn't that great a grandma did they. Erm and erm you know things about what happened with my brother I will probably never ever talk about I will never talk about it. Because as far as I'm concerned the people who need to know, know they don't they know enough not to need to know anything else.	Not wanting to talk about sexual abuse People who need to know, know enough
431. I: Yeah.	
432. P: Because I don't need to bring it back. I can leave it back there. I'm sure it's not going to affect me in the future you know. Well I hope it's not going to affect me in the future. Erm	Leaving it in the past Not letting it affect the future

<p>and like I said it's not the physical abuse with my mum it never was about that. It was about you know I really for the rest of my life, up to now till probably a year and a half ago all I wanted her to do was love me.</p> <p>433. I: Yeah.</p> <p>434. P: So all I ever tried to do was make her love me. You can't make someone love you. You can't make somebody love you. They either do or they don't. If they don't well some people are cruel about that aren't they so.</p> <p>435. I: Mm. Gosh it just sounds like you've had so much.</p> <p>436. P: I suppose it does when you hear it all at once (laughs) in a quick conversation.</p> <p>437. I: Yeah it.</p> <p>438. P: I've had a good life. I've got four lovely children I've got nine lovely grandchildren and two more on the way.</p> <p>439. I: Wow. And is there anything else that you want to add that you feel is relevant to what we have been talking about?</p> <p>440. P: The only thing I can add is people in certain situations that are psychiatrists and have anything to do with mental illness shouldn't pull curtains over. Because it will still come out in the end. There's no use masking somebody's illness. You need to be able to underlying it because it will just get worse and fester. And that's what I would like to see changed.</p> <p>441. I: So you think that could be useful for other people?</p> <p>442. P: Mm. There's a lot of people with mental illness out there that are beautiful people. I've</p>	<p>Wanting her mother's love</p> <p>Trying to make her love me</p> <p>Cannot make someone love you</p> <p>Having a good life</p> <p>Professionals 'pulling the curtains' around problems</p> <p>Not masking illness</p> <p>Needing to approach underlying problem</p> <p>Wanting change in services</p> <p>Beautiful people</p>
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<p>met some beautiful people. Yeah. You don't have to see them every day or every week or ever month. You can see them in the street three months down the line no different to when you saw them last you know. Beautiful people.</p> <p>443. I: Mm.</p> <p>444. P: When we used to be hospital we used to look at the staff room and we used to say we are the ones that are normal. It's them down there that aren't. You know. Because not everybody with mental illness is evil and bad. It doesn't work like that. There's a lot of good ones out there. And a lot of them have you know passed on because they are not willing to open the curtains on that person.</p> <p>445. I: Mm.</p> <p>446. P: You know I mean I was in hospital when a man he committed suicide by throwing himself in front of a bus outside the hospital. I don't know if you ever saw that or heard the story?</p> <p>447. I: Oh gosh no.</p> <p>448. P: Well I had been put on a different ward that night and he came in while I was there. Lovely little lovely round face and a beard and a tash. Rosy cheeks I can remember him.</p> <p>449. I: Yeah.</p> <p>450. P: Erm and he was always smiling. He didn't speak he just smiled because he'd only just come in I supposed he was very very depressed but nobody to look you know.</p> <p>451. I: Behind the curtain?</p> <p>452. P: Erm and he didn't actually get his thingy when he got there. You know where they</p>	<p>No change in people</p> <p>Staff as abnormal, not service users</p> <p>Perception of mental illness linked to evil and bad people</p> <p>Consequences of pulling the curtains around a person</p> <p>Man committed suicide</p> <p>Was very depressed but not to look at</p>
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<p>have to go and interview him and then it was quite late. So it was their fault I know they erm probably got sued for what had happened. And the next morning he got up and he smiled at me and I smiled at him. You know thinking well he seems a really lovely lovely person. He didn't talk and I said I hope your alright but he didn't talked he just smiled. Walked straight out of the hospital and straight under a bus.</p> <p>453. I: God.</p> <p>454. P: You know. Because you know that's what I did that's what I did.</p> <p>455. I: Mm.</p> <p>456. P: And then that it frightened me because that's what I do.</p> <p>457. I: Yeah.</p> <p>458. P: And a lot of people with mental illness do that and if everyone else is going to go round drawing curtains on them then nothing will come out and people will die.</p> <p>459. I: That's great thank you. I'll just press stop.</p>	<p>Staff's fault</p> <p>Thinking he's a lovely person</p> <p>Smiling on the outside</p> <p>Committed suicide</p> <p>Resonance with her experience</p> <p>Felt frightened</p> <p>Lot of people with mental illness hide their emotions</p> <p>People will die if underlying problem not addressed</p>
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## Appendix P: Example memo writing

### Example of Memo-writing after interview 7

#### **Memo Title: Gender, relationships and experiences of voices**

All female participants so far have discussed difficulties in their relationships with their mothers. Participant 3 and 5 explore the 'fight' for their mother's affection and all three female participants discuss the perception they are 'not good enough' which in part they attribute to their relationship with their parents through being told this during childhood. Both participants 3 and 6 discuss their mother's mental health difficulties and relative absence of their mother during their upbringing. Male participants, so far, have not discussed their early attachment relationships, only one male participant (4) discusses his father but in relation to the antagonism he feels towards him currently due to his dependence on him. Why is there a contrast between male and female's accounts so far regarding the role of parents in childhood and how participants believed this affected the development of voices? Is there a connection between gender, attachment and view of the self or of expectations of gender? Or is this potentially related to 'family scripts' which are handed down from previous generations regarding what it is to be female? What stories are being passed down?

Schon (2009) explored gendered meanings of 'mental illness' within her study. When categorising illness, she argued it is emphasised more in relation to gender. This separation being for men it is related more to work and financial responsibilities, in comparison for women it is related more in terms of relational stress. In terms of 'personal responsibility', the author argued men displayed 'action orientation' in their narrative and talked about being active agents in developing their illness. Contrasting this, women spoke more as being receptors of stress to which they been exposed.

Think in relation to participants who gave the experience of 'stress' as an explanatory framework and whether this is evident in the data;

Male participants: 2, 6 explicitly mentioned stress in relation to work and finances, participant1 stated he was unemployed at the time.

Female participants: 3, 5 and 7 discussed relational stress.

Contrasts in the data: Male participant (6) discussed the role of violent interpersonal trauma, unprovoked beating, in theories of the development of hearing voices.