A study exploring people's experiences of hearing voices over time: What are the different phases of managing voices and how might these phases affect engagement with services?

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Declaration

The thesis conforms to an 'article format' in which the middle chapters consist of discrete articles written in a style that is appropriate for publication in peer-reviewed journals in the field. Chapters one, two, three and seven present synthetic overviews and discussions of the field and the research undertaken.

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I hereby declare that this dissertation has not been, and will not be, submitted in whole or part to another University for the award of any other degree.

Signature:………………………………………………………………………

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UNIVERSITY OF SUSSEX

LEANNE BOGEN-JOHNSTON Dissertation submitted for the degree of Doctor of Philosophy: A study exploring people's experience of hearing voices over time: What are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Summary

Hearing voices (also known as auditory verbal hallucinations) can be a distressing experience. Negative beliefs about voices are associated with negative emotional and behavioural consequences. It is important to understand peoples' experiences with voices and the different stages of managing them. However, there is no conclusive empirically supported theoretical model illustrating the phases that individuals may encounter when coping with their experiences over time. Typically, research has focused upon retrospective accounts of voice hearing. The aim of this dissertation was to develop an empirically supported model of the stages of voice hearing. This was achieved by examining service users' experiences with voices over time, identifying different phases of managing voices, and exploring how these phases affected therapeutic intervention.

Chapter one is an introduction to the research in this area. Chapter two outlines the methodological processes and issues within this programme of research. Chapter three provides a systematic literature review of longitudinal studies examining distressing voices in clinical populations. Chapter four examines time one interviews and discusses the barriers and enablers to the disclosure of voices. Chapter five reports the findings from interviews with clinicians and explores the barriers and enablers to starting and continuing a conversation about voices with service users. Chapter six presents a model developed from an integration and evaluation of existing models in relation to data generated from interviews conducted longitudinally. Chapter seven summarises findings, discusses the theoretical and clinical implications, outlines the limitations of the programme of research and proposes future directions to continue the research.

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1. Introduction

1.1   Chapter Outline

The programme of research aims to examine peoples' experiences of distressing voices over time. Section 1.1. will attempt to explore what is meant by hearing voices. Sections 1.2 and 1.3 examine how and why voices become a problem. Section 1.4 discusses how voices are treated, section 1.5 why there is a need for alternate approaches, and 1.6 an argument for researching voice hearing temporally. The final section, 1.7, focuses on the programme of research presented in this dissertation.

1.2   Hearing voices

1.2.1   A Definition of Hearing Voices

Hearing voices are involuntary perceptual experiences - also known as Auditory Verbal Hallucinations (AVHs) - which take place in the absence of an appropriate external auditory stimulus whilst in a state of consciousness (Beck & Rector, 2003; David, 2004). The phenomenon is often perceived as veridical (Beavan, Read, & Cartwright, 2011; David, 2004; Honig et al., 1998), autonomous and, regardless of the voice being situated internally or externally, distinct from the sense of self (Beavan, & Cartwright, 2011a).

1.2.2   The Phenomenological Experience of Hearing Voices

The experience of hearing voices is heterogeneous and, for some populations, distressing. It is a subjective experience, varying considerably between individuals (Bell, Raballo, & Larøi, 2010) whereby the voice hearer may make sense of the occurrence in multiple ways (Longden, Madill, & Waterman, 2012). Consequently, it has been reasoned that classifying voices as AVHs is not only limiting but the phenomenon itself remains hard to define. An inclusive and empirically supported explanation, encapsulating the experiential depth and intensity described by hearers, remains elusive (Aleman & Larøi, 2008; McCarthy-Jones, 2012). The label AVH may be understood as an umbrella term that attempts to encompass the span of the voice hearing experience (McCarthy-Jones, 2012). These experiences diverge amongst hearers and include a range of perceptual properties such as the number of voices present, gender of voices, loudness of voices, voice content, voice frequency and voice duration (Bell et al., 2010; Nayani, & David, 1996; Wykes, 2004). In a phenomenological survey of 199 voice hearers, McCarthy-Jones et al. (2012) used cluster analysis and reported four sub-types of voices: 1. "Constant Commanding and

Commenting AVHs" (running commentary voices and third-person voices that were often repetitive); 2. "Replay AVH" (voices associated with memories); 3. "Own Thought AVHs" (first-person voices linked to own thoughts/voice); and 4. "Nonverbal AVHs" (voice speaks nonsensical words or makes non-verbal sounds). Most participants experienced voices from more than one cluster. Voices may also be experienced from either inside the hearer's own head or external to the body whereby the locus of the voice is sensed as either distant, near to the head, or both (Bell et al., 2010; Nayani, & David, 1996; McCarthy-Jones, 2012).

The significance and authenticity of voices that are heard within the internal space has been questioned. It has been argued that, compared to voices that are heard externally, those that are heard internally are not 'true' voice hearing experiences and should therefore be considered pseudo-hallucinations (Coplov, Trauer, & Mackinnon, 2004; McCarthy-Jones, 2012; Nayani & David, 1996). Yet, this argument fails to account for the fact that some individuals report voices occurring both inside and outside the body simultaneously. Over time the perception of the voice may also change. A view that voices are actual people in the external world may shift to a belief that voices are being transmitted by a non-human force inside the body, or that voices are in fact the person's own thoughts (Wykes, 2004). Bentall (2003) questions the clinical helpfulness of distinguishing between the experience of voice hearing as either true or pseudo hallucinations claiming that many patients, after consideration, re-assess the locus of the voice from one that is external to one that is internal. This argument becomes more salient when considering the clinical relevance of voice location and voice-related distress. Findings suggest that emotions aroused from the voice hearing experience are independent of voice location: distress arises irrespective of whether or not voices are internally or externally situated (Copolov et al., 2004; Junginger, 1986). In addition, whether the voice is considered external or internal appears to be inconsequential to the believed reality of the experience (Junginger, 1986; Junginger & Frame, 1985; Wykes, 2004). As the focus of this dissertation considers distressing voices, a distinction will not be made between externally or internally located voices, and both types of experience will be categorized under the term 'voice'.

1.2.3 The Prevalence of Hearing Voices

Hearing voices occurs across diverse populations and are found in both patient and non-patient groups (Larøi et al., 2012). Although frequently linked with psychiatric and neurological disorders, hearing voices is also experienced amongst healthy

individuals (Johns et al., 2014). Findings suggest that hearing voices is not essentially a pathological disorder (Beavan et al., 2011a). In fact, it has been advocated to be a relatively ordinary occurrence whereby voices may be considered to lie on a general continuum of human experience (Beavan et al., 2011a; Longden et al., 2012; van Os, Hanssen, Bijl, & Ravelli, 2000). Despite the suggestion that voices are somewhat commonplace, ascertaining an exact rate of the phenomenon appears problematic. A review of 17 studies of voice hearing amongst the general population found that reports ranged from .6% to 84% with a median of 13.2% (Beavan et al., 2011a).

Several authors have questioned inconsistencies between study findings (Beavan et al., 2011a; de Leede-Smith & Barkus, 2013; Tien, 1991), and have suggested that discrepancies may be due to a host of factors such as definitions of hearing voices (studies enquiring about all types of auditory hallucinations compared to studies enquiring about auditory verbal hallucinations), the focus and phrasing of the research question, under-reporting of voices, methodologies (different contexts by which data was gathered), ethnicity (studies separating responses by ethnicity), gender (studies reporting gender differences in voice hearing compared to those that do not), and exclusion criteria (Beavan et al., 2011a). For example, Beavan et al. (2011a) found that differences in exclusion criteria (e.g. voices associated with illness, intoxication, sleep) affected response rates. Studies with broader inclusion criteria reported higher rates of voices hearing.

The experience becomes more common when the definition of hearing voices is expanded to incorporate voices that occur in a host of altered states of consciousness. Posey & Losch (1983) found that, amongst a sample of 375 college students, 71% had experienced briefly hearing voices. The authors suggest five general types of voice hearing experiences: hypnagogic (transitional state of consciousness leading from wakefulness to sleep) and hypnopompic (transitional state of consciousness leading out of sleep to wakefulness); hearing one's name called; hearing thoughts aloud, hearing a voice offering support; and hearing a voice conversing. Alternatively, amongst clinical populations, voices are most commonly reported as a symptom of schizophrenia (Beck & Rector, 2003), with up to 80% of people describing experiences with voices (Aleman & Larøi, 2008). Apart from psychotic disorders, voices are also found in patients diagnosed with a variety of psychiatric conditions such as bipolar and unipolar depression (Jenner, Rutten, Beuckens, Boonstra, & Sytema, 2008; Waters, & Fernyhough, 2017). Prevalence rates are less clear amongst these disorders with

findings ranging from 11.3-62% for bipolar and 5.4-40.6% for major depressive disorder (Toh, Thomas, & Rossell, 2015).

1.2.4 First Episode Psychosis and Voice Hearing

Psychosis[1] is typically understood as an alteration in perception, thought, mood and behaviour (National Institute of Health and Care Excellence, NICE; 2014). First episode psychosis is the term used when a person experiences these symptoms for the first time (NICE, 2016). Although experiences are unique to the person, core clinical symptoms are either referred to as 'negative symptoms' (a reduction in something e.g. social withdrawal) or 'positive symptoms' (something is added e.g. hallucinations) (ibid). Typically, psychosis is preceded by a decline in personal functioning, which is referred to as a 'prodromal' period. This period is usually followed by an acute phase characterised by positive symptoms such as behavioural disturbances, delusions, disordered thinking, and hallucinations (NICE, 2014).

A meta-analysis suggested that the prevalence rate of psychosis in the general population is between 5-8% (Nesse, 2009). Although people differ in their presentation of symptoms (NICE, 2014), hearing voices is the most common type of hallucination associated with psychosis (Landmark et al., 1990).

1.3 How do Voices Become a Problem?

1.3.1 A Definition of Distressing Voices

For some, hearing voices are considered positive and enriching, while for others they are negative, frightening, and distressing (Larøi et al., 2012). In attempting to understand why some hearers' experiences with voices are negative, we need to determine what is meant by the term 'distressing voices. Although there does not appear to be a definitive explanation, voices that are distressing have generally been understood as those that are problematic for the hearer (MIND, 2013), impede functioning (Romme & Escher, 1993) and/or are disabling (Sorrell, Hayward, Meddings, 2010). Distressing voices are considered to evoke feelings of powerlessness, threat, anxiety (Romme & Morris, 2009), fear, an inability to cope, and often result in a need for care (Nayani & David, 1996).

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[1] Psychosis is an umbrella term for people diagnosed with schizophrenia and other psychotic experiences such as bipolar.

1.3.2   Voice Hearing in Patient Groups and Non-Patient Groups

As demonstrated by the occurrence of voice hearing in the general population, voices are not necessarily the result of psychopathology, nor an indicator of psychotic illness and, in fact, are not typically considered negative (Beavan et al., 2011a; Longden et al., 2012). Neither are levels of pathology displayed by the hearer necessarily associated with the levels of voice hearing intensity experienced (Longden et al., 2012). Hearing voices does not automatically indicate that the individual is in need of professional care or even that they consider themselves to be ill (Beck, 2003; Romme & Escher, 1989). This raises the question as to how patient and non-patient groups differ with regards to the voice hearing experience.

Research implies that the topographical features of voices (such as duration, location and loudness) do not diverge, and that the perceptual phenomenon appears to be similar (Hill, Varese, Jackson, & Linden, 2012; Johns et al., 2014). Yet evidence suggests that although voice hearing in non-patient groups is not typically troubling (Longden, 2012), amongst patient groups they tend to induce significant distress (McCarthy-Jones et al., 2012). In comparison to non-patients, patients report heightened fear and distress in relation to their voices, experiencing them as more negative, controlling, a disturbance to daily life and are typically less able to cope (Honig et al., 1998; Daalman et al., 2011; Romme & Escher, 1989). In addition, research indicates that between 33% and 74% of hearers experience voices that issue commands (Birchwood & Chadwick, 1997; Rudnick, 1999; Thompson, Stuart, & Holden, 1992), with a median 53% prevalence of command hallucination amongst clinical participants and, 48% reporting commands that were harmful and dangerous (Shawyer, 2003).

Taken together, the research suggests that although the physical characteristics of voices do not differ (e.g. loudness), clinical groups assess voices as more negative, more distressing, more frequent, and less controllable than non-clinical groups (Hill & Linden, 2013). These facts raise the question as to why the effect of such experiences should differ amongst voice hearing populations. If the features of the phenomenon are generally analogous amongst voice hearers, and evidence implies that hearing voices is not principally a pathological disorder and may be viewed as separate to diagnosis, then why do patient groups tend to experience voices as more distressing than those without a need for care?

1.4 Why do Voices Become a Problem?

Explanations of voice-related distress have argued that it is not the experience *per se* that may affect the hearer but the influence of other factors such as beliefs about voices (Chadwick & Birchwood, 1994), beliefs about the self (Fannon et al., 2009) and voice content (Larøi et al., 2018). Each of these cognitive factors can be negatively influenced by adverse early experience. Consequently, this section on influential factors will begin with a review of adverse experiences and trauma in early life.

1.4.1 The Influence of Trauma on Voices

Traumatic life events have been widely associated with voices in both patient and non-patient groups, and are considered a causal influence in the development of beliefs about voices (Andrews, Gray, & Snowdon, 2008; Johns et al., 2014; Lovatt, Mason, Brett, & Peters, 2010).

Compared to the general population, traumatic life events appear to be more prevalent amongst hearers (Andrews et al., 2008). Although a range of adverse life events in childhood and adulthood has been found to occur amongst both patient and non-patient groups (Andrews et al., 2008 Callcott, Dudley, Standart, Freeston & Turkington, 2011), findings are mixed as to whether the type of trauma can predict need for care (Johns et al., 2014). Evidence does, however, imply that regardless of sexual/physical abuse in adulthood, childhood abuse has been found to be a significant predictor of voice hearing, specifically commenting and command hallucinations to self-harm (Andrews et al., 2008; Read et al., 2005). Nevertheless, whilst much research suggests that childhood abuse (in particular sexual abuse) is more common amongst patients (Goldstone, Farhall, & Ong, 2012; Read, Agar, Argyle & Aderhold, 2003; Read et al., 2005) other studies have failed to find a difference between the two groups (Daalman et al., 2011; Lovatt et al., 2010). This may be due to how the individual manages and comes to terms with the trauma. For example, it has been proposed (Andrews et al., 2008; Johns et al., 2014) that traumatic life events appear to predispose the onset of voices. It is the psychological effect, such as whether the trauma remains unresolved, which fosters the development and maintenance of clinically significant voices. These factors negatively affect beliefs about voices which have been implicated with the distress and dysfunction found amongst patient populations. Findings also imply a significant dose effect of the number of traumas and heightened risk of experiencing symptoms of psychosis (Romme & Escher, 2009). Romme & Escher

(2009) assert that hearing voices is a signal of existing problems resulting from traumatic experiences.

The high prevalence of traumatic life events amongst voice hearing populations is consistent with cognitive models of psychosis (Andrews et al., 2008). Two key models of psychosis (Garety, Kuiper, Fowler, Freeman, & Bebbington, 2001; Morrison, 2001) have illustrated how traumatic events underly and shape anomalous experiences such as voices. The 'cognitive model of the positive symptoms of psychosis' (Garety et al., 2001) (see Figure 1.) is a broad model that integrates phenomenological, social, psychological and neurobiological factors to explain the formation and maintenance of the positive symptoms of psychosis (hallucinations and delusions). It describes the role of early life experiences and the effect on subsequent symptoms of psychosis.
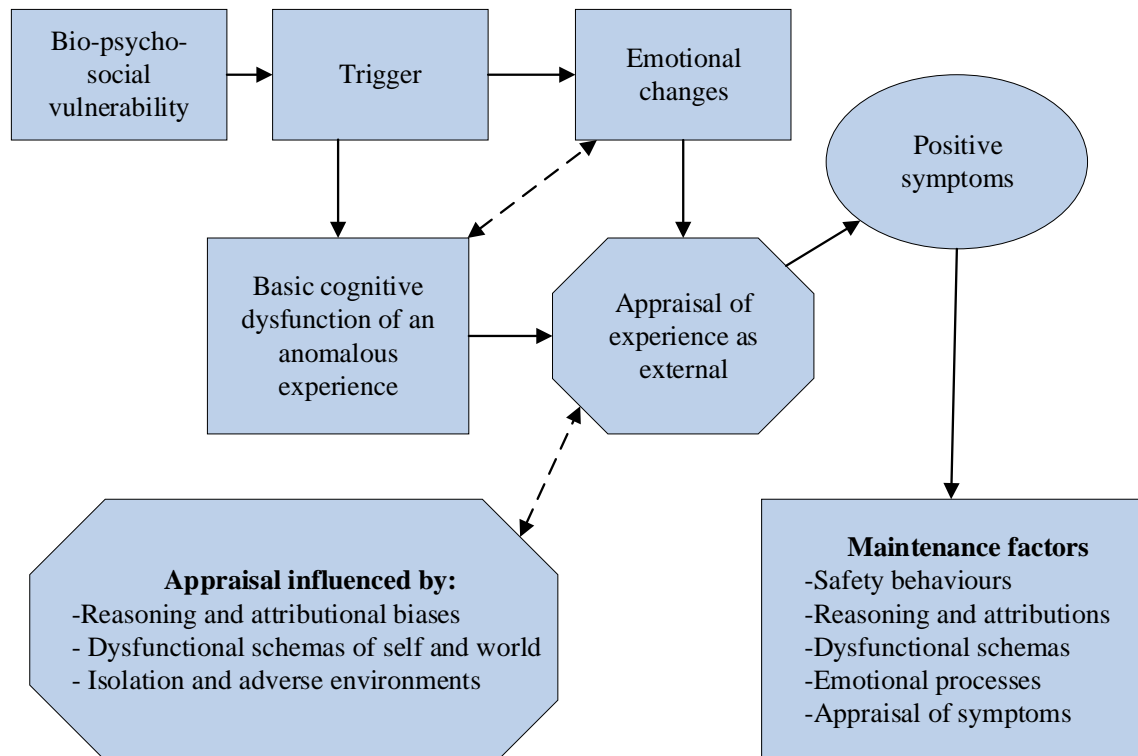
Figure 1 Cognitive model of positive psychotic symptoms (Garety et al., 2001)

The model proposes two pathways to the development of positive symptoms, with appraisal playing a central role. The first route solely describes affective changes, whereby fluctuations in emotions result in an external appraisal of anomalous experiences. This is supported by the broader literature which suggests that, within psychosis, higher rates of depression (and lower self-esteem) are associated with voices that are more distressing and have more negative content (Smith et al., 2006). The second pathway is considered more typical amongst people with symptoms of

psychosis. It builds on the work of previous literature (Frith, 1992; Garety and Hemsley,1994; Hemsley, 1993), and outlines how cognitive dysfunction, resulting from a triggering event in someone who is predisposed, may result in anomalous experiences. This pathway, and the role of cognitive dysfunction, is informed by Hemsley (1993) and Frith (1992). Hemsley (1993, p. 643) proposes that positive symptoms (such as hearing voices) occur through a cognitive incapacity to associate 'current sensory input to stored regularities.' Consequently, such experiences arise through a failure to process and filter perceptual information appropriately. The path may also be understood from the perspective of Frith (1992), whereby faulty self-monitoring (internal cognitive processes of intentions and actions) is unrecognised and attributed as external. Both hypotheses demonstrate how cognitive disturbances result in anomalous experiences (e.g. hearing voices). Emotional changes, occurring through a triggering event, also exert an influence (Garety et al., 2001).

Kuipers et al. (2006) hypothesise that traumatic life events may influence the processing of information and emotion. The model illustrates the effect of negative schemas. According to Garety et al. (2001), early traumatic events may generate a cognitive vulnerability, which manifests as 'Dysfunctional schemas of self and world'. For example, the self is considered vulnerable and others are dangerous. These negative schematic models may influence the appraisal of intrusions and attribute them as originating from an external source.

Similar to Garety et al. (2001), Morrison's (2001) 'cognitive model of positive psychotic symptoms' (see Figure 2) pays attention to the importance of early adverse experiences, as well as the role of cognition, emotion and behaviour. The model draws on cognitive theories of anxiety and panic (Clark, 1986). These theories maintain that basic, normal intrusions into awareness are misinterpreted as important. In an attempt to prevent a feared outcome, safety behaviours (e.g. selective attention) maintain the misinterpretation.

Intrusions into awareness
a) Hears voices, including a male one saying 'Hit her'
b) Experience of mind racing
c) Newsreader says 'It is really bad'

**culturally unacceptable
interpretations of intrusions**
a) The devil is telling me to harm my child
b) The devil is controlling my thoughts
c) Everyone in the BBC knows how bad I am

faulty self & social knowledge
(declarative beliefs)
Adults cannot be trusted around children
People are dangerous
I am a bad/evil person
Other people do not have unwanted thoughts
(procedural beliefs)
Scanning for danger is a good survival strategy
Hearing voices provides company
Punishing myself will control unwanted thoughts

experience
sexually abused by relative
strict religious upbringing
birth of own child & subsequent isolation

cognitive and behavioural responses
selective attention to unwanted thoughts,
others disapproval and mention of bad/evil in media
punish self for 'bad' thoughts by cutting
try not to be on own near children
avoidance of schools & nurseries

mood & physiology
anxiety
guilt
increased arousal
sleep problems

Figure 2 Cognitive model of positive psychotic symptoms (Morrison et al., 2001)

Morrison (2001) conceptualises positive symptoms of psychosis (e.g. voices) as intrusions into awareness which are misinterpreted. How the intrusion is interpreted is determined by beliefs, knowledge, and experience. Psychotic phenomena occur when the intrusion is misinterpreted. For example, hearing a voice may be misinterpreted as a demonic entity commanding that the hearer commits a harmful act. Experiences and beliefs may influence interpretations. Like Garety et al. (2001) (see Figure 1), traumatic early experiences (e.g. sexual abuse) are shown in the model to affect knowledge about the self and the world. Morrison (2001) illustrates how faulty knowledge about the self

(e.g. "I am bad/evil person") and others (e.g. "adults cannot be trusted around children") can affect the interpretation of intrusions, causing it to be misinterpreted. Trauma may influence beliefs, and it is the belief which may then result in associated distress. Both the intrusion and the (mis)interpretation are upheld by safety behaviours (e.g. selective attention), mood, physiology, cognitive and behavioural control responses. However, the model differs from Garety et al. (2001) due to the inclusion of a cultural component. Morrison (2001) argues that it is the cultural acceptability of how an intrusion is interpreted which defines it as psychotic.

Although not specific to voices, like Garety et al. (2001), Morrison's (2001) model illustrates how traumatic events may influence positive symptoms of psychosis. As previously outlined in this section, high incidence of traumatic experiences has been associated with people with a diagnosis of psychosis (Romme & Escher, 2006). While the literature suggests that different relationships between trauma and psychosis may exist (Morrison, Frame, & Larkin, 2003), Romme and Escher (1989) propose that psychosis may develop as a coping strategy in response to trauma or traumatic memories.

Morrison, Frame and Larkin (2003) assimilate Morrison's (2001) model with existing models of Post-Traumatic Stress Disorder (Ehlers and Clark, 2000) and emotional disorders (Self-Regulatory Executive Function model; Wells and Matthews, 1994). The 'integrative model of trauma and psychosis' (Morrison et al., 2003) conceptualises trauma as a causal link to psychosis. Morrison et al. (2003) present a model which describes the association in patients where trauma is considered the aetiology of psychosis and illustrate how trauma may be considered the basis of psychosis (Figure 3). As already discussed with respect to Garety et al. (2001) and Morrison (2001), previous trauma (e.g. childhood sexual abuse) may result in beliefs about the self and the world (e.g. "I am vulnerable, and the world is dangerous"). The need to protect oneself and cope with distressing intrusions gives rise to strategies of paranoia/suspiciousness and dissociation. If these strategies continue (particularly during adulthood) or are triggered by a similar event, then it is likely that they will be considered culturally unacceptable, and the person may become isolated. Verbal post-traumatic intrusions may develop which, combined with dissociation, may result in the experience of hearing voices.
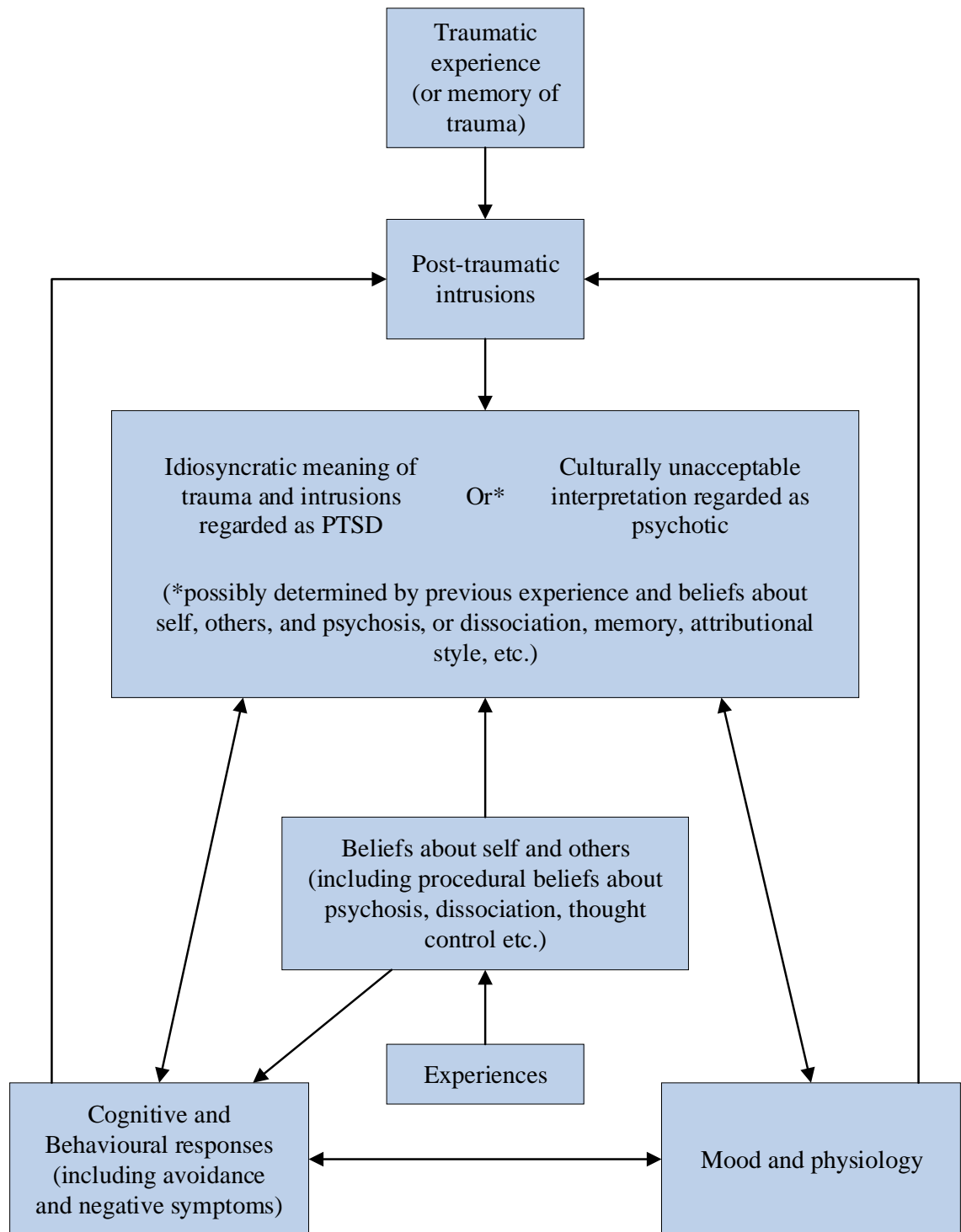
Figure 3 Integrative model of trauma and psychosis (Morrison et al., 2003)

The three models presented in this section have illustrated how early traumatic events are implicated in symptoms of psychosis (e.g. voices). The integrative model of Morrison et al (2003) has depicted trauma as central to the development of psychosis. The models have proposed that traumatic experiences may lead to faulty beliefs about the self, others and the world. Consequently, these beliefs may result in distressing interpretations of mundane events.

Considering the vital role that appraisals of voices have played in these three models, the following section shall now discuss beliefs about voices and the effect on distress.

1.4.2 The Influence of Beliefs about Voices

As suggested by differences between patients and non-patient groups, the mere presence of voices does not necessarily lead to a negative emotional response (Birchwood, Iqbal, & Upthegrove, 2005). There is accumulating evidence that the experience of hearing voices is arbitrated by cognitive processes such as appraisals and subsequent beliefs about the voices (Chadwick & Birchwood, 1994). These cognitions often play a role within the hearer's emotional and behavioural responses to their auditory verbal hallucinatory experience (Birchwood & Chadwick, 1997; Wykes, 2004; Mawson, Cohen, & Berry., 2010). For example, the broader literature has shown a relationship between cognitive appraisals of voices and distress (Mawson et al., 2010). While Romme and Escher's (1989) work with clinical and non-clinical patients implied that the hearer's capacity to cope with voices was influenced by social mediators (marriage, ability to discuss voices with others and support), it also varied according to how voices were appraised. Johns et al. (2014) suggests that, rather than voice activity as such, it is these appraisals (voices identity, relationship with voice, intent and power of voice) that determine associated distress.

In a seminal study examining a novel cognitive approach to voices, Chadwick and Birchwood (1994) found evidence of an association between beliefs about voices and an emotional response to voices. The authors observed that in all cases when a voice was considered malevolent a negative affective response (anger, fear, depression, anxiety) was triggered. Alternatively, in almost all cases (91%) of benevolent voices, a positive affective response (amusement, calm happiness) was triggered. It is important to note that in 31% of cases, beliefs about voices were at odds with the content of voices. For example, an individual may appraise the voice as malevolent despite the content of the voice being objectively positive. In these cases, voice content was not

found to directly drive the meaning associated with voices, and therefore beliefs were not a simple interpretation of the content of the voices. Birchwood and Chadwick (1997) later went on to suggest that these differences implied that beliefs about voices were the consequence of cognitive mediation, whereby the individual was trying to make sense of their voice hearing experience. However, for the majority of participants (69%), voice content was reflected in the class of belief. This suggests an association between voice content and voice appraisal. Study findings (Chadwick & Birchwood, 1994) also indicated that beliefs of 'malevolent' or 'benevolent' intent were associated with different coping strategies in terms of 'engagement', 'resistance', or 'indifference' to the voice. Hearers who considered voices as benevolent were more likely to engage with them and demonstrated a variety of coping strategies. In contrast, voices that were considered powerful, with a 'malevolent' intent were resisted. These voices induced negative, affective, and somatic responses. Compliance with voices that issued commands was found to be dependent upon the hearers' beliefs regarding the power and authority of the voice. Voices that were deemed omnipotent were associated with feelings of powerlessness. The authors concluded that beliefs concerning the voices' power, intent and identity influenced distress and behavioural response rather than the occurrence itself.

Chadwick and Birchwood (1994) applied findings from their work with voice hearers to the principles of cognitive models of distress (Beck, 1979). Beck's model theorises that distress and disruption result from the meaning that is ascribed to an event, rather than the event itself. Building upon these principles, Chadwick and Birchwood (1994) incorporate an ABC framework (Ellis, 1962) to conceptualise a cognitive model of voices (see Figure 4). The model focuses on beliefs (Bs) and how they drive voice-related distress (understood as the 'Cs' – consequences). It proposes that voice hearers cognitively appraise and construct a set of beliefs about their voices. These beliefs, in particular beliefs about voice control, intent (i.e. malevolent or benevolent), identity and power, affect the individual's emotional, somatic and behavioural responses to the experience. The authors argue that it is not just the frequency and content of voices that mediate negative affect but also the beliefs that the individual associates with them: the subjective experience of the voice and the meaning of the voice are conjoined.

A	B	C
(activating event)	(beliefs about voices)	(consequences)
Voice activity	*Power* *Identity* *Intention*	*Emotional* *consequences* *Behavioural responses*
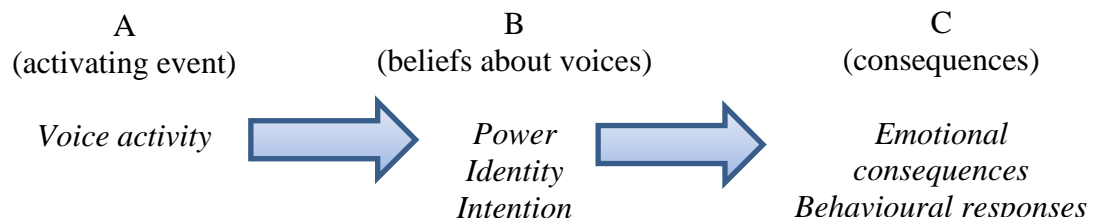
Figure 4 Chadwick and Birchwood ABC model of voice-related distress (1994) as illustrated in Strauss (2014).

Research findings have partially corroborated the work of Chadwick and Birchwood (1994). In a study replicating their research, Close and Garety (1998) found similar patterns of engagement to malevolent and benevolent voices. However, the two studies also demonstrated several differences. Unlike Chadwick and Birchwood (1994), Close and Garety (1998) found that voice content was always consistent with beliefs about voices and that voices were not always appraised as omnipotent or omniscient. In addition, Close and Garety's (1998) findings suggested that the affective response to voices was not reliant on beliefs of malevolence or benevolence but the occurrence of the voice itself. This implies that other underlying mechanisms may be implicated in voice-related distress. For example, cultural beliefs about voices (as suggested in Figures 2 and 3), may be partially responsible for shaping a person's reaction to these experiences.

The ABC model of voice-related distress (1994) has been refined to include metacognitive beliefs. Metacognitive beliefs relate to a person's beliefs that they hold regarding their thoughts- e.g., "if I struggle hard enough, I can get rid of these voices, they are controllable" or "bad people have bad thoughts about voices" (Chadwick, 2006, p.47). Although they are not specifically linked to the aetiology of voices, maladaptive metacognitive beliefs may be related to the psychological distress of the experience and need for care (Hill et al., 2012). Further research on the cognitive model has emphasised the importance of metacognitive biases as well as underlying schemata, suggesting how these factors may shape cognitive appraisals of voices (Baker & Morrison, 1998; Birchwood, Meadon, Trower, Gilbert & Plaistow, 2000).

An explanation of how voices are maintained has been proposed by Morrison, Haddock & Tarrier (1995) and Morrison and Haddock (1997).The authors propose that voices are characterised as an internal event, such as involuntary thoughts, that are misattributed as originating from a source that is external to the boundaries of the self.

An internal or external trigger leads to the misattribution of a voice as hostile whereby it is perceived to be a danger to the individual's physical ("If I do not obey I will be harmed") or psychological integrity ("I am losing my mind"). This misattribution may also be augmented by the interaction of negative emotion and physiological arousal, which produce more experiences of voices. The misattribution may result in safety seeking behaviours which can cause an increase in voices. This misattribution is considered to play a role in continuing the cycle of hearing voices (see Figure 5).

Trigger

Intrusive thought

Somatic, affective, and behavioural responses   experienced as an auditory hallucination

Appraisal of hallucination
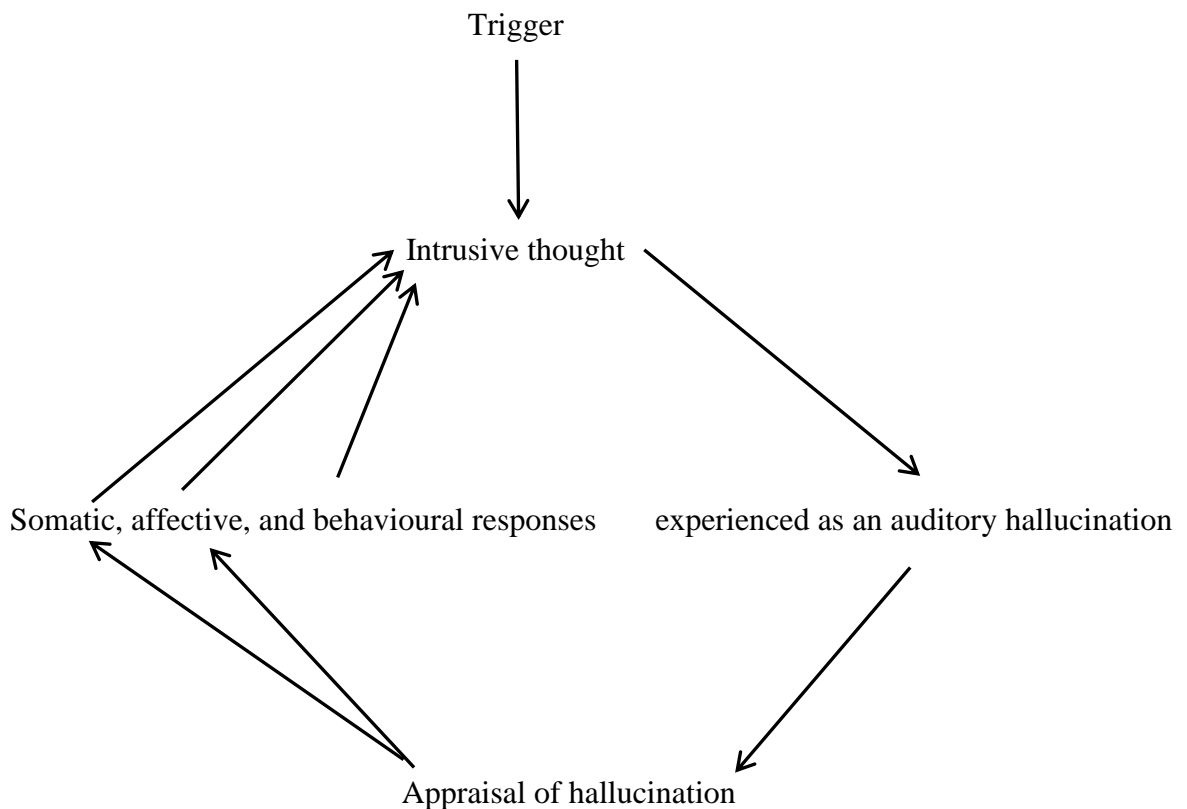
Figure 5 Model of the maintenance of auditory hallucinations (Morrison et al., 1995).

In summary, both Chadwick and Birchwood (1994) and Morrison et al. (1995) foreground the appraisal of voices. It is suggested that increased distress and struggles with voices may be a consequence of the appraisal.

The following section shall consider the effect of beliefs about the self and associations with voices.

1.4.3   The Influence of Beliefs about Self

As previously discussed, the appraisal of an experience as well as the experience itself have been associated with distress (Chadwick & Birchwood, 1994). However, the literature implies that while beliefs may be a contributory factor to voice-related distress, it does not essentially infer causality (van Oosterhout, Krabbendam, Smeets, & van der Gaag, 2013). Evidence suggests that the aetiology of voice hearing, in particular persistent voices, is multidimensional (Fannon et al., 2009). Due to the complexity of this phenomenon, it is likely that other variables, such as self-esteem, may contribute to the associated distress (van Oosterhout et al., 2013).

Recent theories have highlighted the importance of understanding the influence of self-esteem with regards to psychosis (Chadwick, Birchwood, & Trower, 1996; Close & Garety, 1998). Rosenberg (1965) defined self-esteem as the positive or negative attitude that one holds about oneself. It is a component of self-concept which is the consolidation of one's thoughts and emotions when viewing the self as the object. Low self-esteem has been implicated in the development and maintenance of symptoms of psychosis (Barrowclough et al., 2003; Bentall et al., 2014; Garety et al., 2001). Additionally, a decline in self-esteem has been associated with the exacerbation of paranoia and positive symptoms e.g. voice hearing (Erickson & Lysaker, 2012). As already discussed, the effect of self-esteem on the positive symptoms of psychosis has been illustrated in the models of Garety et al. (2001) (see Figure 1) and Morrison et al. (2001) (see Figure 2).

Close and Garety (1998) found that low self-esteem, negative affective response to voices and negative self-appraisals were common within a sample of 30 patients with a diagnosis of schizophrenia. The authors suggest a reciprocal relationship whereby a voice-related event triggers belief about one's core self; this activates affective and behavioural responses, which corroborate the beliefs about one's core self. Over time, as voices persist and an inability to exert control over the experience becomes evident, negative beliefs about the self (e.g. "I am weak") are further strengthened, resulting in negative affect. Close and Garety (1998) draw on the work of Seligman (1975) and propose that negative affect may lead to resignation to voices and helplessness.

Heightened levels of depression, low self-esteem and negative self-evaluative beliefs have been associated with increased voice-related distress, increased negative voice content and greater voice severity (Smith et al., 2006). In line with these findings, Fannon et al. (2009) examined the contribution of self-esteem and appraisal of voices to

depressive affect as well the mechanisms by which these components interact with regards to the voice hearing experience. A regression analysis indicated that self-esteem did not act as a moderator between beliefs about voices and depression but functioned independent to depression. Low self-esteem contributed to high levels of depressed mood in patients with persistent voices. Consequently, both low self-esteem and beliefs about voice power and control contributed to depression

The fact that self-esteem and cognitive appraisals of voices acted independently with regards to their influence on depression implied that the mechanism(s) underlying affective response to voices is complicated. It appears that depression cannot be solely attributed to a person's beliefs about voice hearing experiences. The authors argue that low self-esteem is central to understanding affective disturbances in voice hearing. In order to improve depressed mood amongst voice hearing patients, therapies should look to addressing low self-esteem. However, it is worth considering that low mood was not fully accounted for by the regression analysis. This implied that other factors may have influenced depression within the study sample (ibid).

Self-schemas have been proposed as an underlying factor in the development and influence of negative voice content. They appear to mediate between traumatic life events and what voices say (Beck & Rector, 2003; Larøi et al., 2018).

1.4.4 The Influence of Voice Content

In addition to trauma and beliefs, recent literature has considered a role for voice content. Evidence suggests that patient groups not only experience a higher frequency and duration of voice hearing incidents than non-patient groups, but that the content of the voices is more negative and personally salient (Johns et al., 2014). Negative content, such as threatening, criticising, abusive and frightening comments may trigger voice-related distress and impairment, resulting in a transition to a need for care (Johns et al., 2014; Larøi et al., 2018). For example, people who experience voices and have a diagnosis of schizophrenia typically report voice content as negative (Nayani & David, 1996). In addition, negative content has also been linked to the association between voices and the heightened risk of suicide in people diagnosed with schizophrenia (Kjelby et al., 2015). In a comparison between non-patient voice hearers and patient voice hearers (schizophrenia and dissociative disorders), Honig et al. (1998) found that, compared to 53% of the non-patient group, 100% of the schizophrenia group and 93% of the dissociative group experienced negative voices. The non-patient group reported voices that were positive and non-threatening. Alternatively, in the patient group, voices

were described as either neutral or negative, controlling, with patients also reporting heightened fear. Negative voice content has therefore been associated as a significant predictor of need for care in voice hearers (Larøi et al., 2018).

Theorists have stressed the role of content and its links to beliefs about voices and behavioural and affective responses to voices (Benjamin, 1989; Chadwick & Birchwood, 1994). Chadwick and Birchwood (1994) emphasised how people may offer voice content as proof of a particular belief. For example, evil commands were confirmed by participants as verification that their voice was evil. In addition, the omniscience of voices, knowledge of the individual's thoughts and actions, supported beliefs regarding voice omnipotence. However, beliefs about voices were not always consistent with voice content. It is suggested that, although voice content may influence voice perceptions, strongly held beliefs may influence the way voices are interpreted regardless of content (Chadwick & Birchwood, 1994; Larøi et al., 2018).

Larøi et al. (2018) argue that negative content cannot be characterised as something that induces a negative emotional response. Someone may be indifferent to a negative voice comment (e.g. "you are stupid"); whereas a neutral comment (e.g. "get a glass") may evoke distress and disturbance. Larøi et al. (2018) claim that there are two types of reactions to voices: the interpretative reaction, which deciphers the voice content and threat of the comment, and the post-interpretative reaction, how the individual responds after the content has been ascertained. According to the authors, the interpretative reaction adds to the negative content. A comment is composed of a series of words which are not inherently positive or negative. It is how these words are interpreted - positive, negative or neutral - which causes a reaction. For example, an insult may not result in upset. A person may not recognise the negative content of the comment and not interpret it as an insult. The negative content is therefore not experienced. Alternatively, it may be acknowledged as an insult, but the person does not care about the opinion of the insulter. The negative content is recognised but the person has overcome it.

Larøi et al. (2018) conceptualise mechanisms of negative content and voices within a framework (see Figure 6). The framework is an amalgamation of concepts, ranging from speculation (e.g. link between right Broca's area and negative content of voices) to empirical findings. The diagram's pathways illustrate how adverse life experiences that are not fully processed (processed in a dissociative way) are typically expressed as intrusions into awareness. These cognitions, which are personally salient

and refer to personal or social threat, are experienced as auditory verbalisations and externally attributed. Factors such as culture, past experiences and environment may influence voice content. In order to cope, people may respond in a negative manner. This style of responding may reinforce negative voice content. For example, attempting to suppress voices may result in their resurgence and increased negativity (Larøi et al., 2018; Wenzlaff, Wegner, & Roper, 1988). Similar, to Morrison (2001) and Morrison et al. (2003), Larøi et al. (2018) show a role for the influence of culture. Often, reactions to voices (increased attempts to suppress or resist voices) are influenced by cultural perceptions of voices.

   The model presented by Larøi et al. (2018) is not empirically validated but, as the authors claim, a framework for future research.
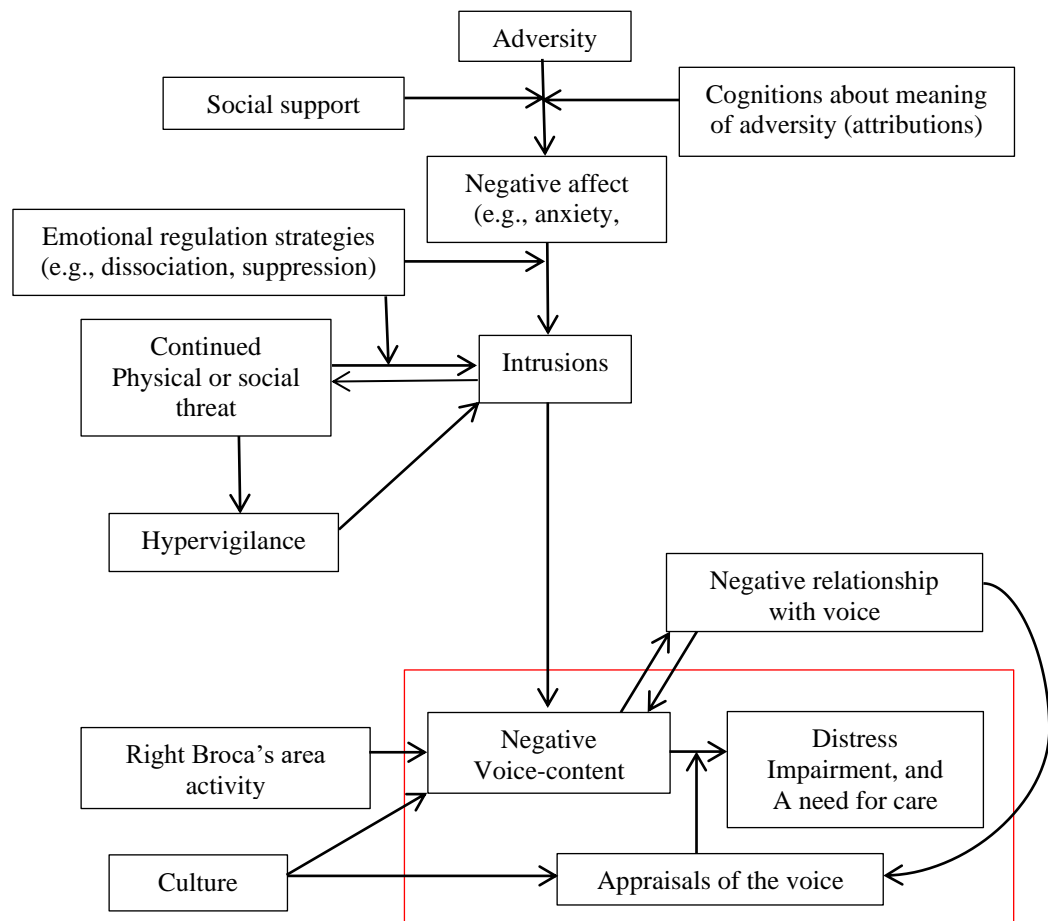
Figure 6 Proposed drivers of negative voice content (note: red box illustrates the traditional focus of the cognitive model of AVH) (Larøi et al. 2018)

1.4.5 Summary and critique

Taken together, voice-related distress appears to be influenced by a complex interaction between a number of possible variables such as trauma, beliefs about voices, beliefs about self and voice content. For example, beliefs about the self and others may be formed from early traumatic events, with negative self-schemas affecting appraisals of voices. Findings have suggested that negative schemas about the self and the world, in conjunction with the re-experience of PTSD, may act as a mediator between trauma and positive symptoms of psychosis (Gracie et al., 2007).

The models presented vary from a broad view of the mechanisms underlying positive symptoms of psychosis to a symptom-specific explanation of voice-related distress. In comparison, the models exhibit similarities and differences with respect to their focus of attention. Chadwick and Birchwood's (1994) cognitive model of distressing voices (Figure 4) does not highlight causal factors of voices but instead emphasises beliefs about voices and the relationship to consequences (association between the Bs and Cs of the model). Similarly, Morrison's (1995) model of the maintenance of auditory hallucinations (Figure 5) also focuses upon appraisals. Alternatively, models presented by Garety et al. (2001) (Figure 1), Morrison (2001) (Figure 2) and (Figure 3) outline causal factors. Garety et al. (2001) describe why people hear voices and illustrates pathways to positive symptoms. In reference to Chadwick and Birchwood (1994) ABC framework, this may be viewed as a pathway to the 'A' (activating event) of the model. However, while Larøi et al. (2018) model demonstrates a causal pathway, it also illustrates how appraisal ('Bs' – beliefs) are a mediator between negative voice-content and voice-related outcomes.

In reference to hearing voices, three models (Chadwick & Birchwood, 1994; Morrison et al., 1995; Larøi et al., 2018) related specifically to voices rather than generic positive symptoms of psychosis. Although Chadwick and Birchwood (1994) model offers the most straightforward explanation of voice-related distress, it only considers the relationship between beliefs and distress as a one-way process (Bs on Cs). It does not account for the effect of the emotional and behavioural consequences on beliefs (the effect of Cs on Bs). In addition, the model fails to account for other influences on appraisals such as voice-content.

While aspects of the models presented have been empirically supported, it appears that they have not been supported in their entirety. For instance, the cultural

association between beliefs about voices and diagnostic labels proposed by Morrison et al. (2003) (Figure 3) model, has been evidenced in a cross-cultural study of voice hearing by Luhrmann, Padmavati, Tharoor and Osei (2015). However, it does not appear that the aggregated model has been empirically supported.

This section has considered the mechanisms that may be involved in voice-related distress. The following section shall address pharmacological and psychological interventions for distressing voices.

1.5   How do we Treat Distressing Voices?

Standard interventions for people who experience distressing voices have traditionally been pharmacological with psychological therapies being used as an adjunct to these approaches (Thomas et al., 2014). As this dissertation focuses upon a psychological perspective, the following section, outlining pharmacological interventions for voice hearing, will be brief.

1.5.1   Pharmacological Treatment for Distressing Voices

Antipsychotic medication, sometimes referred to as 'neuroleptics' or 'major tranquilizers,' have been the main treatment for the symptoms of psychosis since the 1950s (Bradford District Care NHS Foundation Trust, n.d.; NICE, 2009). Initially used to treat acute psychotic states, they are now used as a treatment for long-term maintenance and relapse-prevention (NICE, 2009).

Antipsychotics work by either a) reducing the amount of dopamine in the brain or b) restoring the equilibrium of dopamine in conjunction with other chemicals in the brain. Dopamine is a naturally occurring chemical (neurotransmitter) that transmits messages mainly relating to thought, emotions, behaviour and perception (Rethink Mental Illness, n.d.). The dopamine hypothesis of schizophrenia/psychosis theorises that the positive symptoms of these conditions arise from increased levels of dopamine (NICE, 2009). Antipsychotics are used for their antagonistic blocking effect at the site of D2 dopamine brain receptors (Rethink Mental Illness, n.d.). Alternatively, in cases where people exhibit a poor response to antipsychotics, Clozapine (third generation) is used due to its higher affinity with D4 dopamine receptors and subtypes of serotonin receptors (NICE, 2009).

Anti-psychotic medication is associated with a range of issues. NICE (2002) state that all antipsychotic medications are associated with side-effects (see table 1), the clinical significance of which is dependent upon the type of drug and the individual. Due to their affinity with a number of other receptors, antipsychotics may result in a

range of adverse effects such as weight gain, sedation and sexual dysfunction. These
negative side effects may affect patient attitudes towards adhering to the antipsychotic
medication and consequently, contribute to the risk of relapse (Lambert et al., 2004;
NICE, 2009). Evidence suggests that, for atypical antipsychotics such as Olanzapine
and Risperidone, discontinuation rates may be as high as 70% (McEvoy et al., 2007). In
addition, although antipsychotics have helped a significant number of people with
voices there are still a proportion of hearers (10-33%) who fail to benefit from this
approach (Conley & Buchanan, 1997; McCarthy-Jones et al., 2015).

Name of medication	Stiffness or Involuntary movements	Sleepiness	Weight gain	Dry mouth and constipation	Sexual problems
Risperidone	++	+	++	+	++
Olanzapine	+	+++	+++	+	+
Quetiapine	+	+++	++	+	+
Aripiprazole	+	+	-	-	-
Amisulpride	+	-	+	-	++

- Very rare/not known to be a side effect

+ Only a few people will get this side effect

++ Quite a few people will get this side effect

+++ Most people will get this side effect

Table 1 Commonly prescribed antipsychotic medication and their side-effects (Bradford District Care NHS Foundation Trust, n.d.)

1.5.2   Psychological Therapies for Distressing Voices

In respect to the range of issues associated with antipsychotic treatment of
voices (as outlined in table 1), Wykes (2004) argues that an approach that is
psychologically, rather than biologically focused, may be advantageous. In particular, a
non-biologically focused method may benefit those patients whose voice hearing
experience do not respond to medication (Curson et al., 1985). In addition, NICE (2016)

recommend psychological therapy, in the form of cognitive behavioural therapy (CBT) or family therapy, for people experiencing symptoms of psychosis, including distressing voices (NICE, 2016).

1.5.2.1 The History of Psychological Therapies for Distressing Voices

Psychological treatments for voices initially centred on behavioural approaches. These approaches addressed the antecedents and reinforcers of voices and explored a range of behavioural interventions such as electrical aversion therapy, operant reinforcement techniques, graded exposure to voice triggers and relaxation techniques (Shergill, Murray, & McGuire, 1998). It was theorised that if an alternate stimulus was introduced during the voice hearing experience then it would compete with, and draw attention away from, the voice (Wykes, 2004). For example, thought-stopping practices were used such as pulling an elastic band on the wrist when a voice was heard (Allen, Halperin, & Friend, 1985). However, there was little evidence to support the effectiveness of these approaches as any gains dissipated soon after therapy ended (Wykes, 2004). According to Bentall et al. (1994), therapies based upon distraction techniques may be effective for some voice hearers, but these benefits are short-lived as treatments do not attend to the underlying cognitive disorder. Several studies examined coping strategies for voices such as listening to music, talking to others, shifting or focusing attention. Findings suggested that, while patients tend to develop their own ways to cope with voices, the effectiveness of these strategies vary and the most helpful strategies are not always used (Farhall, Greenwood, & Jackson, 2007). A review by Farhall et al. (2007) examining coping strategies for voices, indicated a positive effect when hearers were trained to use specific coping techniques e.g. auditory competition. The authors conclude that incorporating coping strategies as part of broader treatments or focusing interventions on coping enhancement appears to be generally supported.

In the early 1990s, several of these strategies were assimilated into an individually formulated training approach known as coping strategy enhancement (CSE). CSE aimed to augment self-management skills for persistent hallucinations and delusions. The approach focuses on symptom maintenance. An emotional reaction defines the symptom but also creates conditions to maintain the reaction (Yusupoff & Tarrier, 1996). CSE depends upon obtaining a detailed assessment of the modulating factors which maintain symptoms of psychosis and emotional reactions to them. This in turn is used to inform and facilitate the adjustment of an individual's coping strategies, which are evaluated for their helpfulness, consistency and limitations. Therapy aims to

enhance individual skills in managing positive symptoms of psychosis such as voices (Thomas et al., 2014; Yusupoff & Tarrier, 1996). In a controlled study (Tarrier et al., 1993) of patients with schizophrenia and hallucinations or delusions, compared to treatment as usual, participants receiving CSE showed a significant decrease on measures of symptom severity post treatment and six-month follow up. CSE has been viewed as a forerunner to the formulation-based cognitive behavioural therapies currently in use (Thomas et al., 2014).

The focus of treatment developed and expanded upon behavioural methods to include approaches that were rooted within cognitive models of psychosis e.g. Morrison et al. (2001); Garety et al. (2001); Thomas et al. (2014); Wykes, (2004). Cognitive behaviour therapy (CBT) was an accepted treatment for affective disorders. During the 1990s, studies examining CBT for the positive symptoms of psychosis (CBTp) began to emerge (Wykes, Steel, Everitt & Tarrier, 2008). In a meta-analysis of 32 studies, Wykes et al. (2008) reported a modest between-groups effect size of 0.4 for CBTp on reducing the severity of the positive symptoms of psychosis. Similarly, Zimmerman, Favrod, Trieu, and Pomini (2005) found that, in a meta-analysis of 14 studies, CBTp exhibited a reduction in positive symptoms. In addition, compared to patients with chronic psychosis, the effect was higher amongst patients with acute psychotic episodes (effect size = 0.57 for acute patients, effect size = 0.27 for chronic patients). However, Smailes, Alderson-Day, Fernhough, McCarthy-Jones et al. (2015) highlight, as positive symptoms may refer to delusions or hallucinations in other modalities, findings from these two meta-analyses cannot be extrapolated to voice-hearing.

A range of therapies emerged under the umbrella of cognitive behavioural therapy for psychosis (CBTp). As previously outlined, cognitive models theorise that it is not the psychotic experience *per se* that results in distress and poor functioning but the way it is interpreted (Morrison & Barratt, 2009). Building upon this premise, CBTp seeks to reduce distress and improve functioning through facilitating an adaptive understanding of the psychotic experience, reframing appraisals and moderating behaviour associated to psychotic symptoms (Lincoln & Peters, 2018; Morrison & Barratt, 2009).

Regarding voices, Chadwick and Birchwood's (1994) model of distressing voices was fundamental to advancing the cognitive understanding of such phenomena (Thomas et al., 2014). This was the first model (Chadwick & Birchwood, 1994; Chadwick et al., 1996) to propose a detailed treatment strategy. Rather than focusing on

voices, the primary focus of treatment was to target the meaning (identity, power and intent of voices) that was personally ascribed to voices as well as the individual's beliefs as to their control over the experience (Brockman, Kiernan & Murrell, 2015). It was considered that by targeting beliefs, affective and behavioural responses (e.g. acting on voice commands) would be reduced. In addition, self and social schemas were also linked to these beliefs as well as ways individuals related to voices (Thomas et al., 2014). The cognitive model became central to CBT for voices (McCarthy-Jones et al., 2015).

CBTp has emerged as the standard treatment for people with medication resistant symptoms of psychosis such as hearing voices (Thomas, 2015). It is also the most researched intervention. CBTp focuses on identifying connections between a person's cognitive appraisals of their voices and their emotional and behavioural responses; targeting voice-related distress, negative functioning, and compliance with voice commands (McCarthy-Jones et al., 2015). It seeks to normalise psychotic experiences, develop more productive coping strategies, look at better emotional regulation strategies, and reassess negative beliefs about the self (Smailes et al., 2015). Central to the approach is examining and testing assumptions regarding voice-related control and power (McCarthy-Jones et al., 2015).

1.5.2.2   The Effectiveness of CBTp for Distressing Voices

CBT has demonstrated medium treatment effects for symptoms of psychosis (CBTp) (Wykes, Steel, Everitt & Tarrier, 2007; Zimmermann, Favrod, Trieu & Pomini, 2005). Much of the evidence regarding these effects has come from a series of meta-analyses of RCTs (van der Gaag, Valmaggia & Smit, 2014; Wykes et al., 2007; Zimmerman et al., 2005). Van der Gaag et al. (2014) evaluated individually tailored case-formulation CBTp for delusions and hallucinations. Findings suggested a significant medium effect of CBTp on symptom reduction for auditory hallucinations compared to control interventions. This effect was maintained when only active treatment and blinded studies were included, although only a small number of these studies were included.

Despite the apparent robustness of the evidence for the effectiveness of CBTp, critics (Jauhar et al., 2014; Lynch, Laws & McKenna, 2010) have recently shown that effects are negligible and therapeutic optimism is overestimated when only blinded studies are included. Consequently, there has been much debate regarding the effectiveness of this therapy. In 2014, NICE published guidelines recommending that

CBTp should be offered as part of routine clinical practice. However, a meta-analysis published in the same year found only a small therapeutic effect of CBTp for the overall symptoms and for positive symptoms of schizophrenia. This effect was further reduced when sources of bias (data blinding, inadequate randomisation, incomplete data) were taken into consideration. The analysis also failed to find a significant effect of CBTp for positive symptoms (Jauhar et al., 2014). Evidence did not support the efficacy of CBTp for hallucinations (McKenna & Kingdon, 2014). The authors questioned the endorsement of CBTp as part of evidenced-based clinical practice.

Although findings from Jauhar et al. (2014) were discouraging, methodological concerns of a 'washing machine' approach (i.e. incorporating different populations, different therapies, and different targets of treatment) regarding selected studies within the meta-analysis have been highlighted (Peters, 2014; Thomas, 2015). For example, Jauhar et al. (2014) examined outcomes which were not always the target of therapy (Peters, 2014).

The mixed, and often disappointing, effects of CBTp may be attributable to what has been called the 'black box' character of this therapy. Due to the broad nature of CBTp there is still uncertainty as to which components are effective. Part of this problem stems from RCTs. Studies evaluating CBTp have included participants with a variety of symptoms, meaning that there are potentially different targets of therapy. CBTp study protocols have also illustrated a range of therapeutic methods, typically used within an individualised case formulation approach, making it difficult to assess which aspects of therapy are useful. Additionally, as more interventions (e.g. mindfulness) have been included, the CBTp amalgamation of therapies has expanded. Consequently, CBTp has come to embody a mixture of intervention methods, used in a variety of ways, to meet individualised needs (Thomas, 2015). The non-specific approach has meant that in order to detect outcome categories, measures have needed to be broad (i.e. the Positive and Negative Syndrome Scale (PANSS, Kay, Fiszbein, & Opler, 1987)). Such broad measures lack sensitivity and individualised outcomes may not be captured. This has contributed to a lack of clarity as to which intervention components contribute to outcomes (Thomas, 2015).

In respect to voices, psychometric measures have failed to sufficiently identify specific characteristics of the experience, instead focusing on the broader nature of the phenomenon. For example, a weakness of the Psychotic Symptoms Rating Scales – Auditory Hallucinations (PSYRATS-AH, Haddock, McCarronn, Tarrier, & Faragher,

1999), a prominent psychometric instrument employed in various trials of voice hearing, is that it only has two (out of 11) items measuring distress (Ratcliff, Farhall & Shawyer, 2010). It is unlikely that this measure is able to fully assess the impact of this dimension, which suggests a need for the refinement of psychometric measures of voice hearing.

However, taking the CBTp findings already outlined into consideration raises the question as to whether therapies are targeting symptoms of voice-related distress. This uncertainty is hardly surprising given the few trials focusing on voices (Thomas et al., 2014). Accordingly, in order to evaluate the components of CBTp, there has been a call for trials to adopt a single symptom (i.e. distressing voices) approach to psychosis (Lincoln & Peters, 2018; Peters, 2014; Thomas, 2014).

1.6   How Can the Effectiveness of Psychological Therapy be improved?

Despite evidence of an association between voice appraisal and voice-related distress, modifying negative cognitions has not been shown to be a reliable mediator in reducing distress (Mawson et al., 2010). This implies that additional underlying mechanisms are implicated. Hearing voices is a multifaceted occurrence whereby the appraisal and ensuing affective and behavioural responses may be mediated by a host of factors that are particular to the individual's experiences. Consideration needs to be given to the dynamic interplay of these factors and how underlying mechanisms may shape the phenomenological experience of voice hearing. It is therefore evident that, from a clinical perspective, directing therapy towards cognitive appraisals alone may not reduce voice-related distress to a sufficient extent; other variables need to be targeted (Mawson et al., 2010; van der Gaag, Oosterhout, Daalman, Sommer, & Korrelboom, 2012).

1.6.1   Third Wave Psychological Therapies

As CBTp for voices (CBTv) has evolved, a generation of new therapeutic approaches, referred to as "third wave" (Hayes, 2004) have been developed. While still within a broad CBT framework, most of the approaches centre upon how people respond and relate to voices, rather than changing them (Dannahy et al., 2011). Control is considered to play a key role within mental health issues. Development in thinking and practice have explored different forms of control such as reduced interpersonal control and control of one's life (Tai & Turkington, 2009; Wilson, 1999).

Consideration will now be given to some of these variables – decentred awareness; social schema; beliefs about the self.

1.6.1.1 Decentred Awareness

An area of development within therapy has been psychological interventions that are informed by acceptance and mindfulness-based approaches (Thomas et al., 2014). These therapeutic philosophies espouse non-judgemental acceptance of experiences whilst, at the same time, believe in living one's life in accordance with one's values (Hayes, 2004; Veiga-Martinez, 2008). In the case of hearing voices, Acceptance and Commitment Therapy (ACT) (Hayes, Strosahl, & Wilson, 1999) proposes that, rather than attempting to eradicate voices, the individual accepts them without judgement (Veiga-Martinez, 2008). Instead of focusing on beliefs, ACT draws attention to the relationship with voices. These interventions propose a decentred relationship with internal events (Thomas et al., 2014). The individual is encouraged to re-direct attention away from the verbal content and invasiveness of voices, while attempting to reduce unhelpful behavioural responses (Tonarelli, Pasillas, Alvarado, Dwivedi & Cancellare, 2016). Noticing voices, thoughts and feelings and accepting them as transient events is central to mindfulness and ACT therapy for voice-related distress (Thomas et al, 2014).

A recent meta-analysis (Louise, Fitzpatrick, Strauss, Rossell and Thomas, 2018) evaluated ten RCTs of third-wave CBT interventions for psychosis. Compared with control groups, third-wave approaches demonstrated a small-to-medium post-intervention (between-group) effect. These findings indicated that third-wave approaches were comparable to CBTp (Wykes et al., 2008) in the reduction of overall symptoms and depression in psychosis. Group mindfulness-based trials displayed larger treatment effects than individual ACT trials, which were found to be non-significant. However, the meta-analysis failed to find a significant between-group post-intervention effect for positive (hallucinated-distress) and negative (functioning and disability) symptoms. The authors note that third-wave approaches may be effective for general symptoms of psychosis (e.g. depression) rather than specific symptoms (e.g. voice-related distress). Findings suggest that acceptance-based therapies may not be targeting underlying mechanisms (e.g. trauma, beliefs about self, beliefs about voices, voice content) thought to be involved in the maintenance of voice-related distress.

1.6.1.2 Social Schema

In seeking to identify variables which mediate voice-related distress, attention has been drawn to the role of social schema in the interpretation of social information and subsequent responses (Paulik, 2012). Research has explored the relationship

between social rank (comparison of one's social statues or power to others) and beliefs about voices, associated distress and behavioural responses (Birchwood et al., 2000). Studies have drawn on social rank theory to investigate how voices mirror these relationships.

Social rank (Gilbert & Allan, 1994; Gilbert et al., 2001) has influenced both current models and therapies of voice hearing. Social rank theory posits that understanding of our core self develops from the social comparisons that we make. Humans have evolved mental mechanisms for identifying dominant-submissive interactions. Individuals within groups are classified (by themselves and others) as either 'high rank' or 'low rank'. These ranks regulate social behaviour and how the individual acts to others (assertively or submissively) as well as how others act accordingly. Through threat, dominant members of a group may assert power and control over subordinate members of a group. The theory proposes that, in order to survive such threats, subordinates have evolved ways of coping, typically termed as appeasement and submission (Byrne, Birchwood, Trower, & Meaden., 2007). These ranks may be viewed as dominant-subordinate cognitive schemas and contribute to the core image of our self. Consequently, perception of one's social status/rank influences one's mood and emotions (Trower & Gilbert, 1989).

The ABC model of voice-related distress (Chadwick & Birchwood, 1994) was further developed to integrate a "social mentalities" approach (see Figure 7).

Early experiences

Interpersonal experiences
Power-subordination

A	B	C
(Activating event)	(Beliefs about voices)	(Consequences)
Voice activity	*Power* *Identity* *Intention*	*Emotional consequences* *Behavioural responses*
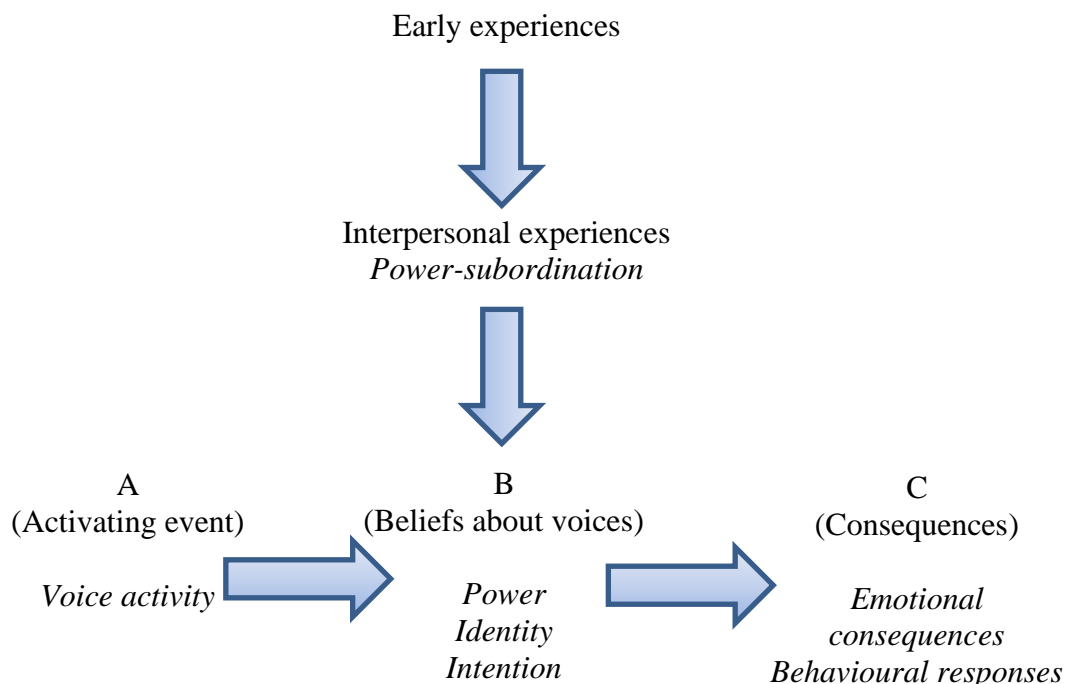
Figure 7 Cognitive model of distressing voices extended to include interpersonal schema (Birchwood et al., 2004)

Drawing on social rank theory (Gilbert & Allan, 1994; Gilbert et al., 2001) Birchwood and colleagues (Birchwood et al., 2004) propose that hearers make assessments between their own power and their voices power i.e. a relational judgement (Craig, Ward, & Rus-Calafell, 2016). Hearers who report feelings of powerlessness and inferiority with voices are more likely to have had similar experiences within previous social relationships (Birchwood et al., 2000). Negative social relationships create negative social schemata. These influence negative appraisals of voices and result in associated voice-related distress (Birchwood, 2004).

For example, a person who has been maltreated by an abusive dominant in early development will continue the dominant-subordinate social rank into adulthood, manifesting as a dysfunctional schema (Byrne et al., 2007). Consequently, the dysfunctional schema becomes a processing system that draws attention to, and interprets, social information. This information takes the form of both the social domain and the perceived voice. Beliefs regarding one's social rank (e.g. 'I am powerless'–'other people are powerful') are mirrored in the beliefs about voices (e.g. 'I am powerless'–'voices are powerful') (Birchwood et al., 2004). Although the dysfunctional schema does not explain cause of voices, it does account for the dominant-subordinate-relating style to voices (Birchwood et al., 2004; Byrne et al., 2007).

The theory that social processes (social schemas) act as a mediator between voice appraisal and distress has been supported by recent reviews (Mawson et al., 2010; Paulik, 2012). Changes in interpersonal schemas may have positive outcomes (Mawson et al., 2010). It has been suggested that therapies should aim to target social and interpersonal variables (Mawson et al., 2010; Paulik, 2012). Consequently, a group of therapies have developed out of the recognised importance of relational dynamics.

1.6.1.2.1 *Relational Therapies and Hearing Voices*

Recent research which has examined interpersonal relating and voices appears promising. As well as social-rank theory, relational therapies have also drawn on two other social theories applied to voices: Benjamin's (Benjamin, 1974, 1989) Structural Analysis of Social Behaviour (SASB) and Birtchnell's (1994) relating theory. Benjamin employed the SASB model, a method of studying different types of interpersonal behaviours, to a study with voice hearers (1989). Findings reported that voice hearers related to voices within an interpersonal framework. Benjamin suggests that hearers

form integrated relationships with voices which reflect ways of relating to others (i.e. family). Given that hearers often recognise voices as someone they know (Nayani & David,1996), plus the high prevalence of previous trauma found amongst this population (Read, van Os, Morrison & Ross, 2005), hierarchical relationships in real life are often found to be replicated between the hearer and their voice (Paulik, 2012)

Birtchnell's (1994, 1996) relating theory hypothesises that relating is comprised of two elements occurring across two intersecting axes – power (upper-lower) and proximity (close-distant). Power represents the degree of control or influence between two people and proximity represents the level of closeness between two people. The 'interpersonal octagon', theoretical structure, is formed from the transitional positions of upper/lower close and upper/lower distant. Each place is viewed as a 'state of relatedness'. No position is better than the other, but each one supports the individual in relation to others to meet specific needs (Birtchnell, 1994; Hayward, 2003).

Trials of Relating Therapy (RT) (e.g. Hayward, Jones, Bogen-Johnston, Thomas & Stauss, 2017) have examined the usefulness of Birtchnell's (1994) model with respect to the variables of power and distress in voice hearing (Hayward et al., 2017; Paulik, 2012). Evidence suggests that the manner of relating between hearer and voice is linked to different affective responses to voices. Hearer-voice relationships, whereby the voice relates in a dominant, critical manner and the hearer responds with suspicion and non-communication, have been shown to be associated with distress (Vaughan & Fowler, 2004). Therapy (RT), a symptom-specific approach, focuses on interpersonal (negative) relating as a mechanism linked to distressing voices (Hayward et al., 2017). The aim of RT is to change 'negative relating' through helping patients to develop assertiveness skills (ibid).

Avatar Therapy (Leff et al., 2013) a digitally enhanced form of relating, employs a computer-generated audio-visual Avatar of a person's voice to encourage a dialogue. Therapy centres upon targeting feelings of helplessness (reported by hearers as one of the worst aspects of voice hearing) and control (Leff et al., 2014). Leff et al. (2013). It draws upon the phenomenological findings of Nayani and David (1996) whereby engagement with voices was associated with less distress and more control. To enable hearers to engage in a dialogue with voices, individuals are assisted in creating a computer-generated audio-visual Avatar of their voice. The Avatar, which is controlled by the therapist, interacts with the patient. This allows safe 'exposure' to the persecutory voice, facilitating the hearer to talk back to their voice. Gradually, the

Avatar changes from abusive to supportive, enabling the individual to gain control over the voice. In addition, therapy draws upon associations of low self-esteem and negative voice content (Leff et al., 2013).

Empirical findings from RCTs for RT (Hayward et al., 2017) and Avatar Therapy (Leff et al., 2014) are tentatively encouraging. At post therapy, both RT and Avatar Therapy found a significant effect of therapy on the reduction of distress. This effect was maintained at follow-up for RT. However, it is worth noting that the study was a pilot RCT of 29 patients. Alternatively, while Avatar Therapy also demonstrated a large significant effect on total score of PSYRATS-AH (Haddock et al., 1999) (compared to supportive counselling), as well as a reduction regarding voice omnipotence, these comparisons (with supportive counselling) were no longer significant at 24-week follow-up.

Other approaches have focused therapy upon the perceived power differential between voice and voice hearer, and the compliance with harmful command hallucinations. Cognitive Behaviour Therapy for Command Hallucinations, (CTCH; Birchwood et al., 2004; Birchwood et al., 2018) targets beliefs about voices' power, a single mechanism associated with compliance to voice-related commands (Birchwood et al., 2004; Birchwood et al., 2018). Theoretically, CTCH draws on social rank theory (Gilbert & Allan, 1994; Gilbert et al., 200) and is by Birchwood et al.'s (2004) work regarding the compliance and appeasement of voices appraised as malevolent and powerful. Consequently, voice content plus the nature of the relationship between hearer and voice have been found to be predictive of behavioural (compliance) and affective (distress and depression) response to voices (Birchwood et al., 2011; Trower, Birchwood, & Meaden, 2004). Birchwood et al. (2011) argue that the subordinate-dominate positions between hearer and voice, whereby the hearer believes that non-compliance to voice commands risks retribution from the voice, reflects social rank theory.

CTCH focuses on weakening beliefs about voice power mechanism, enabling the hearer to resist harmful commands and reduce associated distress (Birchwood, 2014). The COMMAND (Birchwood et al., 2018) RCT, investigated CTCH with 197 participants assigned to either therapy or usual treatment. At post-therapy, findings demonstrated a between-group medium effect favouring therapy suggesting that voice power acted as a mediator of change. However, the trial was insufficiently powered to confidently rule out influences from any other non-therapy mediating variable. In

addition, the trial did not demonstrate a significant between-group effect upon voice-related distress (both groups demonstrated a reduction in distress) (ibid).

Taken together, findings suggest that relationally based therapies demonstrate significant effects during therapy. However, findings are mixed as to whether these gains are maintained once therapy has stopped.

1.6.1.3   Beliefs about the Self

One area which has been foregrounded as a potential mediator of voice-related distress, and a key therapeutic target, is self-esteem (Thomas et al., 2014; van der Gaag, van Oosterhout, Daalman, Sommer, & Korrelboom, 2012). Low self-esteem has been associated with positive symptoms of psychosis in both clinical and non-clinical populations (Barrowclough et al., 2003; Krabbendam et al., 2002). Self-esteem develops early in life, and although flexible to new experiences, can still be reactivated during negative events i.e. feelings of powerlessness (Gilbert, 1992).

Smith et al. (2006) found in a study of 100 participants with psychosis, that people with lower self-esteem and increased depression experienced greater severity of voices, as well as more voices with intensely negative content. Those with lower self-esteem were also found to be more distressed by their voice hearing experiences. Fannon et al. (2009) contend that low self-esteem plays an important role in the affective response of voice hearers. In a study (Fannon et al., 2009) of 82 participants who heard voices, both beliefs about voices and low self-esteem were found to contribute to voice persistence and depression. The authors conclude that, in patients diagnosed with schizophrenia, therapeutic interventions should target both appraisals of self and voices.

Two approaches which focus on negative beliefs about the self, compassionate mind training (CMT) and competitive memory training (COMET; van der Gaag et al., 2012), shall be considered.

1.6.1.3.1 Compassionate Mind Training (CMT)

CMT encourages awareness to negative self-relating and was developed to target heightened levels of shame and self-criticism (Mayhew & Gilbert, 2008; Tai & Turkington, 2009). It is informed by Compassion-Focused Therapy (CFT; Gilbert, 2009) which uses compassion to care for oneself and others. CMT advocates that people from traumatic, critical and shaming backgrounds, have difficulty with self-supporting and self-reassurance (Mayhew & Gilbert, 2008). It argues that shame and self-criticism act as negative internal signals, promoting submissive and negative affective responses

which, in turn, sustain chronic mental health issues (Gumley, Braehler, Laithwaite, MacBeth & Gilbert, 2010). CMT ideology centres on supporting people to identify and accept their own needs; to act with compassion and empathy towards themselves; and to develop self-supportive thoughts (Mayhew & Gilbert, 2008). Such practices are believed to promote the regulation of neural systems involved with self-soothing and contentment. These systems are involved in the modulation of threat systems which are activated during negative events such as hostile voices (Mayhew & Gilbert, 2008; Thomas et al., 2014). CMT seeks to shift people from a threat-based motivational system to a care-based motivational system (Heriot-Maitland, McCarthy-Jones, Longden, & Gilbert, 2019). In respect to voices, it encourages the individual to engage with voices from a position of the compassionate self (ibid).

Evidence suggests that compassion focused therapies are therapeutically beneficial (Braehler et al., 2013). A feasibility RCT study of 40 patients with a diagnosis of schizophrenia-spectrum disorder found that, compared to usual treatment, compassion focused therapy demonstrated a significant increase in compassion, reduction in depression and perceived social marginalisation (ibid).

1.6.1.3.2 *Competitive Memory Training (COMET)*

An RCT investigated the effect of competitive memory training (COMET; van der Gaag et al., 2012) on depression, low self-esteem and voice content in patients experiencing voice hearing. COMET was developed from theories relating to competing memory networks (Brewin, 2006). It was developed as a training protocol to increase positive self-esteem through the use of positive imagery (van der Gaag et al., 2012). The RCT aimed to decrease depression and change submissive hearer-voice relationships. Described as a technique, it sought to increase self-esteem by supporting people to retrieve positive long-term memories. The retrievability of positive memories was considered to help people experience what is already known about themselves, which could be used to change and weaken negative voice content. Changes in submissive behaviour would occur through the reappraisal of the meaning of voices and reducing emotional affect (ibid).

Findings were encouraging with respect to the primary outcome of depressive symptoms, exhibiting a medium-to-large effect which was mediated by self-esteem and the acceptance of voices, with partial mediation attributed to power and social-rank. COMET failed to achieve a significant effect on the reduction of voices or their negative content on PSYRATS-AHRS. However, this was not a primary aim of the

trial. A significant medium effect was found on PSYATS -AHRS for cognitive interpretation of voices compared to usual treatment. It is worth noting that, although a symptom specific approach, COMET did not focus on voice-related distress.

1.7 The Timing of Therapeutic Intervention

As previously discussed in this chapter, the evidence base for CBTp for distressing voices has demonstrated small to moderate effects (Smailes et al., 2015). CBTp needs to improve its effectiveness. This poses the question as to whether effect sizes for the treatment of voices can be increased. A focus on novel skills and mechanisms has shown some promise in this respect. An additional factor that may improve effectiveness is the timing of therapy. The issue of the timing of treatments has been considered most extensively within the context of early intervention for psychosis, as delays in accessing treatment have been associated with poorer outcomes (Padilla et al., 2015).

The duration of untreated psychosis (DUP), the time between emergence of first positive psychotic symptom and receipt of appropriate treatment (ibid), has been recognised as a vital marker in determining the course of the illness (Birnbaum, Wan, Broussard & Compton, 2017; Padilla et al., 2015). Longer DUP has be associated with a range of negative outcomes such as poorer personal recovery, poorer response to treatment, higher risk of relapse, poorer social and cognitive functioning, increased service use, decreased periods of symptom remission, heightened depression, chaotic and destructive behaviours, poorer physical health, less likelihood to seek pathways to treatment, less adherence to treatment, and increased treatment costs (McGlashan, 1999; NICE, 2016; Padilla et al., 2015).

Birnbaum et al. (2017) explored symptoms of psychosis and DUP. In respect to hallucinations, findings suggested a significant modest association between DUP and hallucination severity ($\rho = 0.222$; $p = 0.001$). This implied that longer lengths of DUP result in heightened severity of hallucinations at presentation. Birnbaum et al. (2017) propose that as schizophrenia pathology develops so does frequency and intensity of perceptual abnormalities. The heightened severity of positive symptoms of psychosis (e.g. hearing voices), longer DUP and relapse frequency during first year of treatment has also been linked with ten-year-non-remission (ten Velden Hegelstad et al., 2013). Similarly, Evensen et al. (2011) found that, amongst a group of EIP patients, longer DUP was associated with those whose main symptom was hallucinations. Ten Velden

Hegelstad et al. (2013) recommend that initial treatment should focus treatment on specific symptoms e.g. hallucinations.

The question then becomes, is there a critical window of opportunity for intervention for hearers that are distressed by their voices and, if so, when is the optimum time for delivery of therapy? While evidence points to the benefits of a shorter DUP, people may not be ready or able to engage with services when voices first occur. An understanding of peoples' experiences with voices over time may be valuable to helping hearers manage voice-related distress, as well as recognising the best time for therapeutic intervention.

1.7.1   Models examining the experience of voice hearing over time

Although research has implied that the relationship between hearers and voices can either remain stable or fluctuate and change (Beavan, 2011b) there is a paucity of research focusing on the experience of voices over an extended temporal period (Hayward, Awenat, McCarthy-Joes, Paulik, & Berry, 2014). Milligan, McCarthy-Jones, Winthrop and Dudley (2013a) address the question as to what is it like to live with voices over time: what are the main changes, events and stages that the voice hearer may encounter? The researchers draw on the seminal work of Romme and Escher (1989) who offered an alternative understanding of the experience of hearing voices outside of the medical model (Romme & Morris, 2009). Romme and Escher (1989) propose a three-phase process whereby individuals learn to manage and adapt to voices: the startling phase, the organisation phase and the stabilisation phase (Figure 8).
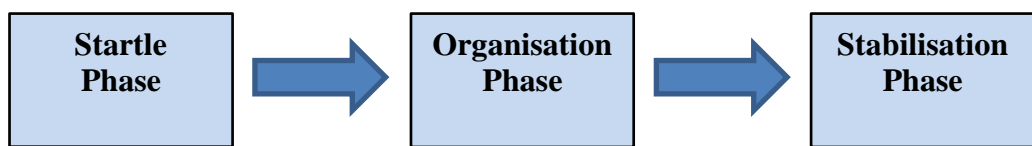
Figure 8 Diagrammatic representation of Romme and Escher's (1989) three-phase model

The first phase, 'startling phase', refers to voice onset whereby the individual is startled, frightened, overwhelmed and anxious by the experience. During this phase, people may feel powerless and confused. Typically, the onset of voices is preceded by a traumatic event. The '*startling phase'* is followed by a second phase, which the authors term as '*the phase of organisation'*; a phase that focuses on learning to cope with the experience. During this stage, the individual starts to apply and test a range of coping strategies. Initially, coping strategies may not be helpful, or only beneficial for short

periods. Types of coping may include shouting at voices, ignoring voices or/and anger. Alternatively, people may start to engage with voices and try make sense of the experience by selecting the one they wish to listen to e.g. positive voice. During this phase the hearer may start to come to terms with the experience and start to accept voices. The final stage, '*phase of stabilisation*,' is a stage of integration, where voices are assimilated into the individual's experience. Voices are understood as part of the self. They are an acknowledged as part life and, for some, may be viewed as a positive influence. The individual feels in control of their behaviour and has agency over whether to act on the advice (commands) of voices.

Romme and Escher's innovative three phase model (1989) underpins the philosophy of 'accepting voices', a position that is central to self-help approaches (e.g. methods to support the individual or/and self-help groups) (May & Longden, 2010). It has been fundamental to offering an alternative perspective of voice hearing to that of Western clinical psychiatry, whereby voices are considered a symptom of an illness (May, 2010). A limitation of the model is that Romme and Escher fail to provide empirical evidence to support the three-phases. Instead, the model was developed from the anecdotal evidence acquired from attendees at a voice hearing congress. The authors do however state that, people understand and manage their experiences in many ways and the phases suggested are three possible phases which have been used to categorise clinical experience. In a qualitative study examining participants recruited via support groups, Hayward et al. (2014) failed to find support for three distinct stages of startle, organisation and stabilisation. This was consistent with previous qualitative work conducted with patients from Early Intervention for Psychosis services (Milligan et al., 2013).

Milligan et al. (2013) examined the trajectory of voices and only found partial evidence for the three phases presented by Romme and Escher (1989). Milligan et al. (2013) interviewed six adults with psychosis who experienced voices and presented six themes associated with the course of voice hearing. The first two themes, '*Antecedent phase*' and '*voice onset*' were associated with the start of voices and negative life events preceding it. Although this is aligned to Romme and Escher's (1989) suggestion of trauma preceding voice onset, Milligan et al. (2013) failed to find evidence of a '*startle*' phase. Instead, they propose that this phase may be embedded within a phase they term '*rejection.*' During this stage, voices are rejected and there is a belief that the phenomenon will eventually 'go away'. The individual does not consider them to be

part of themselves – "they are not coming from me"- and the experience may be rationalised as the effect of drugs or originating from real people. Milligan propose a phase of '*crisis-induced change*.' This is a key stage of change that is instigated by the hearer struggling to manage the experience. Changes may be either positive (disclosure to others or/and contact with services) or negative (voices become more distressing). The theme '*discover, adjustment and coping*' describes a point of enquiry and engagement with the experience. Individuals seek to discover more about their voices, begin to adjust to them and start to find ways to cope. This phase consists of three agents of change: a) 'self' – learning about voices and how to cope with them through one's own experience b) 'others' – talking to others without negative consequences c) 'services' – change is instigated by the intervention of mental health services. Milligan et al. (2013) posit that this stage replaces Romme and Escher's (1989) '*phase of organisation*.' The final stage, is a theme which the authors labelled '*new understandings*.' It is a phase which is marked by the discarding of "voices are not me" and the belief that they will 'go away' and replaced by "voices are part of me" and an understanding that voices are long term. Voices are fully accepted. The authors argue that this phase differed to the final stage proposed by Romme and Escher (1989) of '*stabilisation*,' a phase which was not evidenced by Milligan et al. (2013) study participants.

The authors' integrated findings into a developmental model outlining the voice-hearing experience (see Figure 9).

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┌─────────────────────────┐
│   Antecedent phase      │
│ (Negative life events)  │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│  Onset of voice-hearing │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│    Rejection phase      │
│ ('go away' and 'not me')│
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│  Crisis-induced change  │
└─────────────────────────┘
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| Contact with services | Disclosure to close others | Voices become more negative |

Discovery, adjustment and coping

| Self | Others | Services |

New understandings
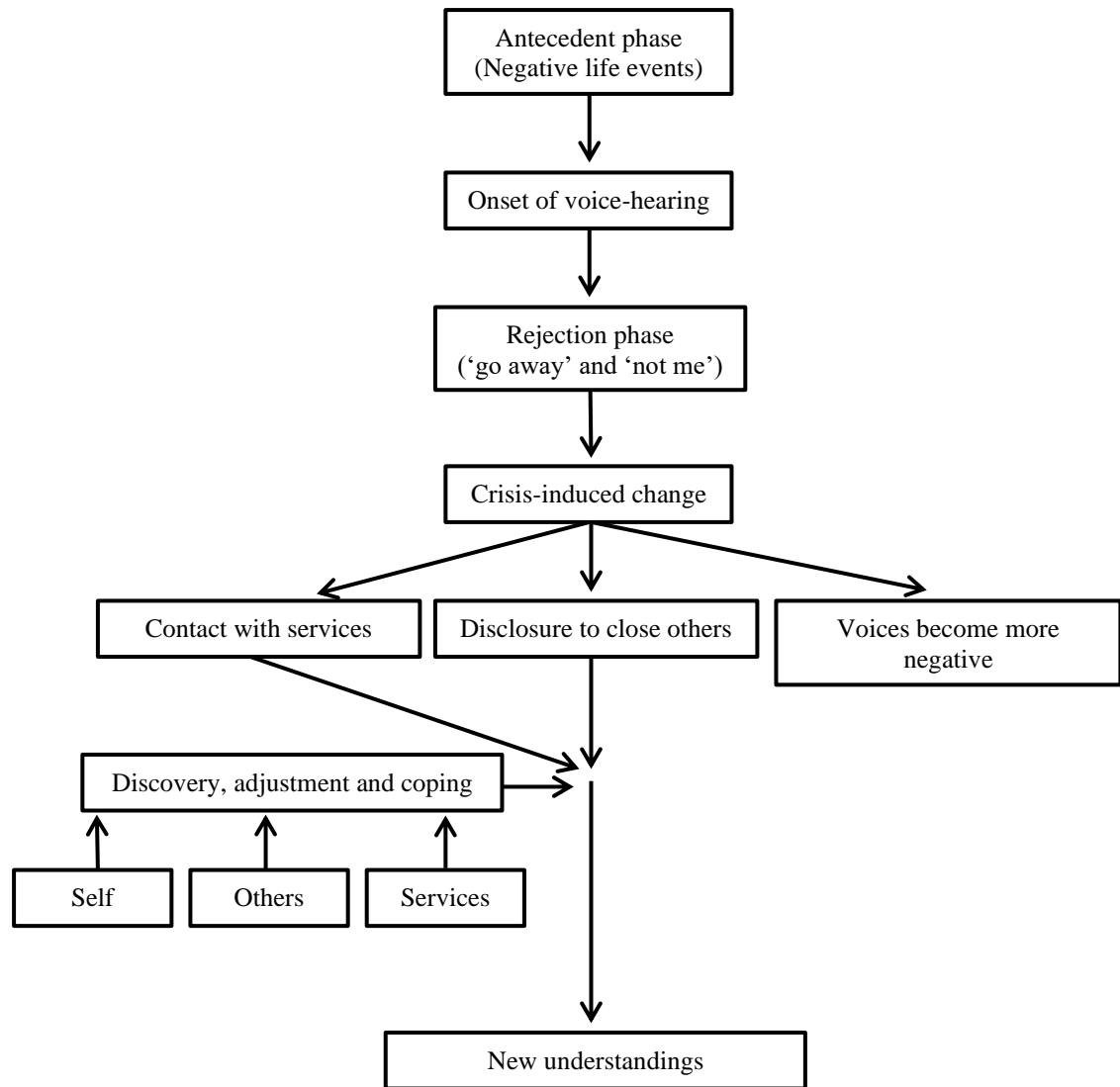
Figure 9 Developmental analysis of voice-hearing experience (Milligan et al., 2013)

The models (Romme & Escher, 1989; Milligan et al., 2013) outline a temporal course of hearing voices and suggest different stages of managing the experience. However, although Milligan et al. (2013) expand upon Romme and Escher's (1989) model, the two models fail to concur upon the proposed stages. Consequently, it appears that there is no conclusive empirically supported model outlining the phases individuals may encounter when managing the experience of hearing voices. One reason may be that research has tended to be based upon people's retrospective accounts of the voice hearing journey. Both Milligan et al. (2013) and Romme and Escher (1989) studies developed models from data collected at a single interview. Milligan et al. (2013) call for a longitudinal study examining the experience of voice hearing. The authors recommend that future research build upon themes identified in their research with EIP populations.

Through a longitudinal study with a cohort of voice hearers from EIP services, the programme of research will use a mixed-methods design to explore accounts of changes in the voice hearing experience over time. It is believed that a longitudinal study will identify current influences that retrospective studies may fail to reveal. The research will explore links between different phases of managing the experience of hearing voices, beliefs about voices and relationships with voices. It is predicted that findings may offer potential insight into how phases of voice hearing may affect engagement with therapy as well as the optimum time for intervention. For example, a meta-synthesis (McCarthy-Jones, Knowles, Rowse & Thompson, 2013b) intimated that hearers are unlikely to respond to therapeutic interventions when voices first begin. Instead, help-seeking may occur at later stages such as McCarthy-Jones et al. (2013a) proposed 'crisis-induced change' phase. Consequently, a need for a longitudinal study following voice-hearers entering EIP services has been identified.

1.8   Research Programme Focus Overview

Although voice hearing is experienced within the general population, amongst clinical groups it is often distressing and disabling (Larøi et al., 2012). Research has suggested that underlying mechanisms such as the appraisal of voices, beliefs about the self as well as voice content and traumatic events are implicated in affective and behavioural responses to the experience. Despite the development and extensive evaluation of CBT for distressing voices in the context of psychosis, the degree of benefit to patients is contested (Strauss, Thomas, & Hayward, 2015). Therapeutic development focusing upon novel skills and mechanisms appear promising. A further area of enquiry that has the potential to improve therapy outcomes is the timing of therapy. However, while research suggests that early intervention for psychosis is beneficial (Birnbaum et al., 2017; Padilla et al., 2015), it is unclear whether psychological therapy is appropriate when voices first occur (McCarthy-Jones et al., 2013b). There has been limited research of peoples' experiences of voices from a temporal perspective. Two key models (Romme & Escher, 1989; Milligan et al., 2013b) have failed to corroborate stages of voice hearing. Consequently, there is a need to examine peoples' experiences of voices temporally.

The research presented in this dissertation was designed to extend the empirical literature on voice hearing overtime. It was hoped: 1) that an empirically supported model outlining the phases of voice hearing could be developed; and 2) that the model would elucidate the optimum time for therapeutic intervention. Therefore, the

programme of research examined the following areas: 1) EIP service user's experiences with voices over a three-year period; 2) different stages of hearing voices; 3) changes in beliefs over time 4) EIP clinicians' experiences of working with voice hearers. Furthermore, it was intended that findings would be compared to existing models illustrating the phases of voice hearing.

1.8.1 Summary of Research Question - Changes over the Course of the Research Programme

Initially, it was intended that the following six, over-arching research questions would be explored in this dissertation:

1) What do we know about the course of hearing voices in clinical populations?

2) What are peoples' experiences of managing distressing voices over time – are there different phases?

3) Do beliefs about voices change over time?

4) When is the optimum time for therapeutic intervention for people who hear distressing voices?

5) How much do EIP service users report change (if any) on self-report measures of beliefs, schemata, severity and relating to voices over time?

6) What are EIP clinicians' experiences of how their clients manage voices overtime?

However, over the course of the research period, the programme of research remained flexible and, as inductive findings emerged, the focus of the original questions evolved to reflect key issues. Consequently, the research questions were incorporated into a broader set of queries which will be presented in the following chapters:

Chapter 4 – What are the barriers and enablers to the disclosure of distressing voices to family, friends, and health professionals? This question will consider the course of voice hearing from onset to help-seeking and examine factors which influence disclosure. The significance of determining how people disclose or hide non-visible health information has been examined in the disclosure decision-making model (DD-MM; Greene, 2009). However, to date, it does not appear that the model has been discussed within the context of voice hearing. Exploring how and when decisions to disclose experiences with voices are made is important to understanding the course of voice hearing, managing distressing voices and therapeutic intervention for voices.

Chapter 5 – How do EIP practitioners understand and engage with service users' journeys with voice hearing? In attempting to understand how their clients manage

voices overtime, EIP clinicians need to feel confident to discuss voice hearing. This question will seek to explore EIP practitioners' views on voice hearing and engagement with clients who hear voices.

Chapter 6 – A longitudinal study examining the phases of voice hearing over time. The focus of this chapter, integrates the central themes taken from the original research questions:

1. What do we know about the course of hearing voices in clinical populations?
2. What are peoples' experiences of managing distressing voices over time – are there different phases?
3. Do beliefs about voices change over time?
4. When is the optimum time for therapeutic intervention for people who hear distressing voices?

It will examine people's journeys with voices, beliefs about voices, identify different phases of managing voices, and how they might affect therapy.

2. Methodological Overview

2.1 Chapter Outline

The dissertation is comprised of a series of linked studies examining the different phases of managing voices. The aim of this chapter is to describe the overall methodology, outlining how data was gathered and analysed. This chapter presents the motivation for the research design. It explains the epistemological position of this dissertation and rationalises employing a mixed method approach with a primary focus on a qualitative methodology. The details of the research techniques to gather data are described. Finally, it outlines the studies presented in this programme of research.

2.2 Rationale for a Prospective Longitudinal Study

In attempting to address the research questions outlined at the end of Chapter One, it was necessary to consider the temporal elements that were required for the design of the study. Due to this time-based component, a longitudinal research design was considered suitable. Longitudinal research is an approach whereby the researcher repeatedly collects and analyses data across multiple time points (Plano Clark et al., 2015; Van Ness, Fried & Gill, 2011). There does not appear to be a clear consensus as to the minimum number of data points for a longitudinal design. Menard (2002) suggests that data should be collected over two or more points across time, whilst Plano Clark et al, (2015) argue that it should be three or more. While there remain conflicting opinions over the appropriate number of temporal points, the general purpose of longitudinal studies supporting analysis over an extended period was the main rationale for its use in this research. It allows the researcher to observe changes in the phenomenon under study from one period to another (Ruspini, 1999). However, issues with recruitment (the attraction and selection of appropriate candidates to a research study), sample size (number of study participants required to draw conclusions or make inferences (Bourgeault, Dingwall, & DeVries, 2010)), and participant attrition (participants who drop out of a study) are some of the problems that have been associated with longitudinal research designs (Plano Clark et al., 2015).

To gain insight into participants' lived experiences with managing voices over time, as well as processes of change, there were two possible longitudinal approaches that could be taken: a retrospective design or a prospective design. A retrospective approach refers to "studies in which retrospectively from the point in time when the research is carried out, certain events and processes are analysed in respect of their

meaning for individual or collective life histories" (Flick, 2018. p136). Flick (2018) argues that one of the issues of applying a retrospective design is that the current circumstances in which the event is being reported may influence an appraisal of previous events. In addition, current views may influence perceptions and evaluations of earlier experiences. Biases may also arise due to attenuated recall (Schwarz, 2007). Given these issues and given the aims of the current programme of research, it was felt that a retrospective design would not capture changes over the course of participants' experiences with voices. Another point of consideration was that participants were recruited through EIP services. As this service specialises in first episode psychosis, voice onset may have occurred near to data collection, and temporal experiences with voices may have been too brief for different phases to transpire. Subsequently, a retrospective design was not deemed appropriate for data collection with this population.

Farr & Nizza (2019) describe a prospective study design as the collection of data prior to and after a particular event. The method by which data is collected does not change, and the same approach is repeatedly applied in order to capture temporal changes in the observed issue (Flick, 2018). A prospective approach facilitates the researcher to explore experiential shifts as well as corroborate the participants' development over time. As an attempt to make sense of what ensues, changes in the participants' relationships with the phenomenon can be examined (Farr & Nizza, 2019). However, despite the benefits outlined, there are also disadvantages to this methodological design. For example, prospective longitudinal studies require substantial organisation and, as they are time consuming, typically involve extensive resources (Flick, 2018). Regarding short studies (e.g. a PhD programme) such designs can only be partially applied as sufficient time is required between data collection for change to be observed. In the current programme of research, data collection took place over a three-year period at nine-monthly intervals, so this was not considered to be an issue. Consequently, a prospective longitudinal approach was adopted as this was deemed appropriate for the questions I wished to address. A prospective longitudinal design would not only enable this research to follow the progression of participants' experiences into the future, but also facilitate the exploration of past events.

Alternatively, the focus of the interviews with clinicians was to explore their views of EIP service users' experiences of managing voices over time. This meant that

clinicians would be asked, during a single interview, to reflect upon having worked with voice hearers. A retrospective design was considered suitable for this objective.

2.3 Data Collection

The programme of research was comprised of three interlinked studies. There were three potential research methodological approaches by which data could have been collected for each of these studies: quantitative only, qualitative only, or a mixed-method designs.

2.3.1 Mixed Method Research

There does not appear to be a consensus within the literature as to the definition of mixed methods research (Mendlinger & Cwikel, 2008). In general, it may be understood as the merging of quantitative and qualitative methods which, compared to using just a single approach, enables a more comprehensive understanding of the research question (Creswell, 2005; Green, Caracelli, & Graham, 1989). Mixed method research encompasses both philosophical theories and scientific methods of investigation (Bishop, 2015). It has been conceptualised as a distinct methodology (Green, 2008) and sits alongside both quantitative and qualitative methods as a third research paradigm (Bishop, 2015; Johnson & Onwuegbuzie, 2004; Green, 2008).

Mixed method research has developed as a methodological approach that embraces the strengths of both qualitative and quantitative methods and at the same time overcomes some of the limitations of only using a single method (Creswell, Plano Clark, Gutmann, & Hanson, 2003). It has been described as a pragmatic approach that facilitates enquiry into complex research problems, allowing the investigator to fit the methods to meet the requirements of the research problem (Kettles, Creswell, & Zhang, 2011). Alternatively, purists maintain that these two approaches sit within paradigms that hold different beliefs about the social world and cannot be mixed (Firestone, 1987). Qualitative and quantitative approaches are viewed as epistemologically incompatible; it is not considered possible to synthesise two such mutually exclusive paradigms. Each paradigm holds a directly opposing view about the world, and events within the world, which also have methodological implications. Consequently, as epistemological and ontological assumptions are contradictory, purists maintain that it is only possible to uphold one or the other methodology and a monomethod approach is advocated (Kettles et al., 2011; Rist, 1977; Rossman & Wilson, 1985).

A quantitative purist standpoint maintains that social science research should remain objective, that researchers should be impassive to the object of enquiry, that bias should be eradicated, and the focus of research should be directed toward objective measurement and hypothesis testing (Johnston & Onwuegbuzie, 2013; Tashakkori & Teddlie, 1998). From the qualitative purist perspective, a constructivist standpoint is favoured. Research centres on a phenomenological paradigm which views reality as a social construction shaped by the individual's, or the groups, conception of an event (Firestone, 1987). Although debates regarding the different approaches continue (known as the 'paradigm wars' (Tashakkori & Teddlie, 1998), purists from both schools of thought agree that these two paradigms, and their respective methods, should remain separate (Johnson & Onquegbuzie, 2013).

2.3.2 Ontological and Epistemological differences between Quantitative and Qualitative Paradigms

Quantitative and qualitative methods have different epistemological, theoretical and methodological bases. The ontological position of the quantitative paradigm is 'realism' (also known as "naïve realism"). A reality, which is guided by "immutable natural laws and mechanisms" (Guba & Lincoln, 1994, p. 109) not only exists but can be captured and observed. A universal world may be understood through the laws of cause-effect (Guba & Lincoln, 1994) (see table 2). A quantitative approach sits within a dualist/objectivist (positivist) epistemological framework (Yilmaz, 2013). The world is viewed as external to the self, whereby there is only one true objective reality that is separate to the individual's cognition (ibid). As the researcher and the researched are deemed separate, both are believed to be independent of influencing, or being influenced by, the other (Guba & Lincoln, 1994).

Item	Positivism	Post-positivism
Ontology	Naive realism- "real" reality but apprehendable	Critical realism- "real" reality but only imperfectly and probabilistically apprehendable
Epistemology	Dualist/objectivist: findings true	Modified dualist/ objectivist; critical. Tradition/community; Findings probably true
Methodology	Experimental/manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/ Manipulative; falsification of hypotheses; may include qualitative methods

Table 2 Basic Beliefs (Metaphysics) of Alternative Inquiry Paradigms (Guba & Lincoln, 1994)

Alternatively, qualitative research typically rejects positivism (Howitt & Cramer, 2010). The world is viewed from a 'relativist' perspective. Reality can be captured and known but only in the form of multiple realities that are constructed. These realities are "socially and experientially based" (Guba & Lincoln, 1994. p111) and differ across time and context (Braun & Clarke, 2013). Like the realities, these constructions are fluid and changeable (Guba & Lincoln, 1994). Qualitative research is informed by a constructivist epistemology, and regards the world, and reality, as socially and psychologically constructed. Unlike the quantitative paradigm, the qualitative paradigm considers that there is an inseparable relationship between the "knower and the known" (Yilmaz, 2013. p312). There is much diversity within qualitative methods, with the 'qualitative' label encompassing a range of methodologies and associated epistemologies (Potter, 1996; Yardley, 2000). Fundamentally, pluralism is central to the qualitative paradigm (Yardley, 2000). A hermeneutical (theory and methodology of interpretation) and dialectical (comparing and contrasting opposing positions to establish a truth) methodology underpins qualitative research (Guba & Lincoln, 1994).

In between these two dichotomous ontological positions lies critical realism. Critical realism states that ontology cannot be decreased and moderated to epistemology. Critical realism argues that humans are only able to partially gain access to a deeper and greater reality (Fletcher, 2017). There is a real social world, one that we can attempt to observe and know. However, this world is viewed through a lens that is shaped by the individual's subjective and socially driven knowledge (Guba & Lincoln, 1994). It is therefore a world that is "structured, differentiated, stratified and changing" (Danemark, Ekstrom, Jakobsen, & Karlsson, 2002, p.151). It is considered that knowledge is socially influenced, and therefore exists within a different reality that is only partially accessible (Braun & Clarke, 2013). Bhaskar (1998), a proponent of critical realism, argues that the world is understood through facts and theory, but its existence is not determined by theory. For example, the world is round, and always has been, even when it was believed to be flat. According to critical realism a world does exist that is independent of human consciousness, but our socially determined theory also sits alongside this world (Danemark et al., 2002).

A limitation of critical realism is that, as a distinct ontological approach, it appears to be relatively underdeveloped. Archer et al. (2016) contend that critical

realism is difficult to define. It is a metatheory (a theory whose subject matter is a theory; Bates, 2005) that, although includes a broad alliance of social theorists, does not appear to unite them. Critical realism encompasses a succession of philosophical positions on a variety of areas e.g. ontology, causation, types of explanation etc. It does not seem to have a clear definition and has been described as a "heterogeneous series of positions" with "not one unitary framework, set of beliefs, methodology, or dogma that unites critical realism as a whole" (Archer et al., 2016, p.1). Consequently, critical realism has been poorly applied to research. As Joseph (1998, p.73) argues:

> Because the status of critical realism is not fully examined—it is more often than not simply alluded to without any distinction being made between critical realism as a methodology and its particular application.

2.3.3 Epistemological Position

This research adopts a critical realist perspective. As previously outlined (section 2.3.2), the premise of critical realism is that, while there is an objective external world independent of human consciousness that can be empirically studied and analysed, perceptions and understanding are filtered through an individual's subjective interpretation, and so what constitutes reality is also socially determined (Danermark et al., 2002).

In respect to understanding the reality of 'mental illness', Pilgrim (2014, p. 8) considers that the answer to this question exists in "context-bound events." For example, due to subjective experiences, people may behave and talk in ways that others find confusing. However, these conducts are actual events which disturb "everyday expectations of rule compliance and role achievement" and have real consequences. From a critical realism perspective, reality is not the label, or the thing, that we term as schizophrenia or depression. Instead, reality is the thoughts and perceptions that are expressed to others which result in labelling (a social transaction) (ibid, 2013).

In the context of the current programme of research, critical realism was considered appropriate to investigate peoples' experiences with voices over time. The experience of hearing voices is subjective. Certain negative events (e.g. childhood trauma) increase the likelihood of voice hearing (Escher et al., 2004). Yet, how these experiences are interpreted and understood will be influenced by personal and cultural contexts (Beavan et al., 2006; Pilgrim, 2014). Analysis may pay attention to each participant's experiential truth but at the same time, it is also acknowledged that what participants sometimes describe as real phenomena may not be real. It is an interpretive

experience, which results in a physical manifestation e.g. affective and/or behavioural response. Although the subjective experience can never be fully understood by others, the responses of the experience are real and consequently, can be observed, physically studied and therapeutically treated.

A critical realist perspective of hearing voices avoids framing the voice hearing phenomenon by diagnosis. Instead, critical realism may seek to understand the experience through "open and context-specific curiosity" (Pilgrim, 2014, p.13), a position which was felt appropriate to explore peoples' experiences of managing voices over time and understand changes in beliefs.

2.3.4   A Pragmatic Approach to using Mixed Methods

According to Johnston & Onwuegbuzie (2004), the research question is paramount. It should drive the methods of inquiry, which in turn should serve as a vehicle to obtain the most constructive answers. Consequently, the authors argue that mixed methods research provides the best opportunity to answer a range of research questions. Yet, by only focusing on the practical challenges of integrating numbers and words, it produces "uncritical and un-reflexive practices which result in poor quality research" (Bishop, 2015. p6). Therefore, equal consideration should be given to the philosophical issues that arise from the assimilation of two opposing paradigms (Bishop, 2015).

Pragmatism has been upheld as a solution to the philosophical debate concerning mixed methods research (Bishop, 2015; Cornish & Gillespie, 2009; Johnston & Onwuegbuzie, 2004; Morgan, 2014). It offers a broad, coherent, philosophy which emphasises pluralism of knowledge, appreciating the strengths of a range views and perspectives (Morgan, 2014; Cornish & Gillespie, 2009). Pragmatism differs from realism; it does not state that knowledge echoes a fundamental reality. Neither does it espouse the views of idealism, that the mind is central to knowledge; nor rationalism, "that abstract rationality is the path to reliable knowledge" (Cornish & Gillespie, 2009, p. 7). Knowledge is a means for action, operating as an arbitrator between the physical and social world (ibid). Primarily, pragmatism maintains that one should choose the methods that are best suited to addressing each specific research question (Cornish & Gillespie, 2009; Rorty, 1999).

Whilst answering the "how to" conduct research question, pragmatism also responds to the question of "why to" do research in a particular way. The pragmatic

position rejects dogmatism and limiting the choice of research. Instead, it focuses on best answering the research question and therefore legitimises the use of a range of methodological approaches (Johnston & Onwuegbuzie, 2004).

2.3.5   A Rationale for using a Mixed Methods Approach

The decision to use a mixed methods approach within this programme of research was pragmatic. The rational for using this approach, as opposed to a monomethod (single approach) will be discussed. First, the strengths and weaknesses of quantitative and qualitative research will be considered, as an understanding of the merits and limitations of these strategies supports the "fundamental principle of mixed research" (Johnson & Turner, 2003, p.299). This principle claims that researchers should mix methods and approaches in a manner that results in "complementary strengths and non-overlapping weaknesses" (ibid).

2.3.5.1   Quantitative research.

Fundamentally, quantitative research affords a framework for examining cause-and-effect relations (Mulhall, Alexander, & Le May, 1998). Quantitative research practice is well established, and this is considered one of its main strengths (Yilmaz, 2013). The methods of analysis are well-developed and, by typically ensuring that the data results are not dependent upon the researcher undertaking the analysis, generate objectivity to the study. A key strength is that the quantitative paradigm allows a standardised, objective comparison of situations or phenomena to be made (Punch, 2013). Additionally, research findings can be generalised, quantitative predictions can be offered, and hypotheses can be tested (Johnson & Onwuegbuzie, 2004).

Alternatively, many of the characteristics which are considered the strengths of quantitative research, have also been cited as weaknesses (Choy, 2014). Dudwick, Kuehnast, Jones and Woolcock (2006) argue that, by reducing research to numbers, quantitative methods are unable to meaningfully capture many important features of people and communities (e.g. identities, beliefs, perceptions). Additionally, as most questionnaires and surveys are designed in isolation from the population to which they will be administered, they may be influenced by the biases of the researcher. According to Johnson and Onwuegbuzie (2004), due to a "focus on theory or hypothesis testing rather than on theory or hypothesis generation (confirmation bias)" the researcher may not capture certain phenomena (p.19). Knowledge produced may also be too general to be applied to particular contexts or individuals (Johnson & Onwuegbuzie, 2004).

2.3.5.2   *Qualitative research.*

'Meaning' is fundamental to qualitative research. A strength of this approach is that, through exploring and interpreting people's experiences of events, and how they make sense of the world, qualitative researchers may obtain an in-depth understanding of complex psychosocial matters (Marshall, 1996; Willig, 2013. p9). Qualitative research favours methods, such as in-depth interviews and, consequently, can capture real-life experiences (Denzin & Lincoln, 2000). It is useful for depicting complex phenomena, provides a means to understanding how people make sense of 'constructs' (e.g. self-esteem) and offers a way to explore dynamic processes (i.e. recording successive patterns and change) (Johnson & Onwuegbuzie, 2004). As qualitative researchers may be sensitive to changes that arise during a study, they are able to shift the focus of the research accordingly (ibid).

Like quantitative approaches, qualitative approaches also demonstrate limitations. For example, due to small samples that are not randomly selected, findings cannot typically be extrapolated to a broader population (Dudwick et al., 2006). The nature of qualitative analysis is interpretative and may be subject to the idiosyncrasies and biases of the researcher (Dudwick et al., 2006; Johnson & Onwuegbuzie, 2004). In addition, different researchers examining the same data may conclude with different interpretations (Dudwick et al., 2006). Testing theories and hypotheses are more problematic, data collection and analyses are generally more labour intensive (Johnston & Onwuegbuzie, 2004), and "because qualitative data cannot control for other mitigating factors or establish the counterfactual, it is hard (but again, not impossible) to make compelling claims regarding causality on the basis of qualitative data alone." (Dudwick et al., 2006).

In summary, both quantitative and qualitative methods demonstrate strengths and weaknesses. Consequently, it is argued that the mixture of different methods, known as 'triangulation' (applying the strengths of a methodological approach to balance the weakness of another), can help to mitigate limitations (Rao & Woolcock, 2003)

2.3.5.3   *The decision to use a mixed methods approach.*

In relationship to the current programme of research both quantitative and qualitative methods will be considered, as well the decision to employ a mixed method approach.

Although consideration was given to using a quantitative design, it was judged inappropriate to meet the requirements of the current programme of research. To enable research findings to be generalised, quantitative research requires large representative samples (Yilmaz, 2013). However, the sample size within the current study was considered too small to ensure statistical power for a quantitative study design. In addition, participant attrition rates are generally high within a longitudinal research design. For example, in a review of 32 longitudinal studies, Plano Clark et al. (2015) found 40% or higher attrition rates. Given the high probability of attrition, it was reasoned that a quantitative paradigm was unsuitable.

Alternatively, qualitative research is directed at the individual's frame of reference of the world (Yardley, 2000). Instead of hypothesis testing on larger participant groups, qualitative researchers focus on a comparatively small number of participants' personal views and experiences (Smith, 2015. p2). Given the focus of inquiry, obtaining in-depth data from small samples, a qualitative approach was considered appropriate for data collection amongst both service users and clinicians for the current programme of research. It was also felt that in-depth one-to-one interviews may be in line with previous psychological treatments and therefore, participants may be more responsive. Yardley, (2000) proposed that the relationship and interaction between the investigator and interviewee can be aligned to traditional clinical practice such as clinician-client relationships. In particular, the reciprocal reactions (e.g. personal and ethical issues), and the effects of these reactions, that occur in the dynamic between the interviewer and interviewee are of central importance within a qualitative paradigm. Yardley (2000) concludes that qualitative methodologies provide a complementary approach to quantitative methods and can offer novel insights in areas such as health and illness.

The corroboration of different approaches increases confidence regarding research conclusions (Onwuegbuzie & Leech, 2004). In addition, if findings diverge then interpretations and conclusions may be adjusted accordingly. However, the aim of mixed methods is not validation but to increase knowledge (ibid). It was therefore felt that, if used as an embedded approach (an approach that provides a supporting role to the primary methodological research approach), quantitative findings may corroborate (or not) qualitative data. In addition, it may also demonstrate clinically meaningful change in beliefs about voices, schemata, voice severity and voice relating. Clinically meaningful change signifies a change in score from atypical (e.g. a score that is typical

of a clinical population) to one that is in line with a "normal" population (Jacobson, Follette, & Revenstorf, 1984). Consequently, the research programme employed a mixed method approach. It was considered that quantitative data, collected in parallel to qualitative data, would provide a more complete understanding of the research and validate qualitive findings. Quantitative methods may support qualitative methods, which were given priority for this research.

2.3.6   Longitudinal Qualitative Research

Qualitative longitudinal research is an evolving methodology which facilitates the understanding of human experiences across time (Miller, 2015). As time is a fundamental process within Longitudinal Qualitative Research (LQR), change becomes central to the analysis. An LQR framework supports the exploration of the cause, relationship and the processes between experience, change and time (Calman, Brunton & Molassiotis 2013). How changes in experiences are interpreted and responded to temporally may be explored in-depth through LQR (Hermanowicz, 2013). Holland, Thomson, & Henderson (2006) suggest that LQR is particularly suited to studies examining areas such as changes and adaptations (e.g. traumas) and specific processes (e.g. onset of chronic illness). An LQR approach was considered relevant to exploring service users' lived experiences with voices over time.

2.3.7   Different Options to Qualitative Approaches

Qualitative researchers come from different epistemological positions which in turn will determine how data is approached. For instance, an empiricist position, which seeks to make sense of the world through systematisation and classification of observations, would adopt an approach to analysing data in accordance with this stance (e.g., grounded theory or interpretative phenomenological analysis). Alternatively, a social constructionist standpoint does not consider the world that we perceive and experience to be a true representation. Instead our perception is a reading of that world, and one that is socially influenced. Consequently, an approach would need to reflect this view e.g. narrative analysis (Willig, 2013).

The following sections will consider different approaches to qualitative analysis with respect to the current research:

2.3.7.1 *Narrative Analysis.*

Narrative psychology is concerned with the methods people use to bring structure to experience. Narratives are stories, accounts of specific experiences (Willig, 2008. p133). People use narrative construction as a vehicle to make sense of a constantly fluctuating world; to give meaning, and bring stability to disarray (Murray, 2000). Narratives are socially constructed and arise through everyday social interaction (Murray, 2003). Mattingly and Garro (2000. p1) assert that "narrative mediates between an inner world of thought-feeling and an outer world of observable actions and states of affairs." Narratives provide a cohesive framework for people to link events, make sense and draw conclusions. The narrative is an active process that attributes agency to the characters within it. Our stories not only assist us to make sense of our daily lives but also offer a structure to our beliefs about ourselves. As a result, we create narrative identities that are linked to our social relationships (Murray, 2003). Murray (2003) argues that the world that we know is constructed through our personal narratives and we are shaped by our own stories and the ones of others. Consequently, he contends that narratives have ontological status.

Through narrative analysis, narratives are framed as a creative method of investigating and explaining realities. These realities are organised and constrained in time (Esin, 2011). Narrative research pays attention to the structure and form of the story. It focuses upon the variation between the features of narratives. Key to narrative research is an emphasis on an analysis that is systematic and well-defined. Findings should offer an understanding regarding the structure, function and "social and/or psychological implications" of the narrative (Willig, 2008. p133).

The interview is the main source of data material for narrative research (other forms of data, such as published memoires, are also collected) (Murray, 2003; Willig, 2008). The aim of the interview is to facilitate the participant to provide a rich and detailed narrative description of an experience. The life-story interview has been a particularly useful tool in enabling participants to offer information regarding their life history. However, narrative analysis strives to go beyond an account of a life-history. Narrative interviews aim to understand disruptions to life and support participants to disclose information about experiences that have caused change or disruptive episodes (e.g. illness) (Murray, 2003).

Due to the temporal element, narrative analysis was considered as a potential methodology for this programme of research. However, as investigating and

discovering structures in stories are central to narrative analysis, it was felt that this approach was not appropriate for the current programme of research. In addition, narrative analysis was not suitable as a means for conducting deductive testing on existing models.

2.3.7.2   *Interpretative Phenomenological Analysis (IPA).*

IPA aims to explore and understand how people make sense of the world from a personal and social stance. Central to the approach is 'meaning' and in particular, the subjective meanings people hold for certain experiences, events, and states (Smith & Osborn, 2003). IPA acknowledges that the world is perceived in different ways, and that this is dependent upon personality, experience and motivation (Smith & Osborn, 2004). The approach draws on phenomenological methodologies. Phenomenology, developed from Hurssel's philosophy, does not focus upon abstract, general statements about the world but instead pays attention to how the world is experienced by people within specific contexts and times (Smith, 1996; Willig, 2008). Rather than an objective account, it emphasises the subjective. The phenomenological stance highlights the phenomena of the mind which arises from our engagement with the world in which we inhabit (Willig, 2008). Thus, IPA researchers are interested in the individual's lifeworld, their personal perception, experiences, and interpretations of a phenomenon or phenomena (Smith & Osborn, 2003). Through IPA, the researcher seeks to gain access to the participant's world and assume an 'insider's perspective' (Conrad, 1987 in Smith, 1996) of the object or event being studied (Smith, 1996).

The IPA analysis is viewed as an interpretation of the participant's experiences. Although the aim of IPA is to explore and make sense of the other's perspective, the role of the researcher's own conceptions plays an active part in the interpretative processes of the research (Willig, 2008). Consequently, there is a double hermeneutic, or two-stage process, to the interpretation of the phenomenon under study. While the participant is attempting to understand their experiences, the researcher is also attempting to understand the participant trying to understand their experiences (Smith & Osborn, 2003).

Although IPA can be used for broader theory or model development, the approach is more appropriate for standalone studies of experiences. Despite its flexibility, the in-depth prescribed approach would have been unsuitable for the sample size of the current research, which was larger than typically used in IPA studies. The larger sample size, plus the longitudinal methodological approach, meant that the

prescribed approach to analysis would have been unmanageable. Additionally, similar to narrative analysis, IPA would not have been suited to deductive testing on existing models.

2.3.7.3 Grounded Theory.

Grounded theory is a methodological approach that is used to examine action and interaction and their associated meanings (Frost, 2011). It is a general methodology for facilitating the generation of theory. From a theoretical stance, the aim of grounded theory is to provide a descriptive structure from which to make sense of the phenomenon being studied. It identifies, makes links and ascertains relationships between categories in order to develop theory (Willig, 2008). Theory is developed and grounded within a logical, systematic approach to data collection and analysis (Strauss & Corbin, 1994). It uses an inductive approach whereby during the research process, theory evolves from the interaction of data collection and analysis (Strauss & Corbin, 1994). Charmaz (1996) states "grounded theory methods explicitly unite the research process with theoretical development" (pp.). In addition, grounded theory challenges existing attitudes that divide qualitative approaches as only intuitive and indistinct and quantitative as rigorous and systematic (Charmaz, 1996).

Although often used qualitatively, grounded theory can be used as a mixed methods approach. It has been used in a range of areas such as clinical psychology, social work and nursing (Frost, 2011). It is appropriate for investigating "individual processes, interpersonal relations and the reciprocal effects between individuals and larger social processes" (Charmaz, 1996). Despite its suitability for analysing large quantities of semi unstructured qualitative data (Lawrence et al., 2013), grounded theory was considered not apt for a longitudinal design, as used in the current programme of research. The present study aimed to recruit two population groups, service users and clinicians, with a single set of interviews being conducted with clinicians and multiple interviews with service users. Consequently, this would contradict the grounded theory approach of constant comparison. In addition, contrary to theoretical sampling, it was intended that the sample group would remain the same over the data collection period.

2.3.7.4 Thematic Analysis.

Thematic Analysis (TA) originated as a method for coding and developing themes (Braun & Clarke, 2014). Despite several variations, Braun & Clarke's (2006) method for conducting TA is the version that is most frequently used (Braun & Clarke, 2014). This paper will now refer to Braun and Clarke's (2006) method for TA.

TA is a flexible approach that is used within a variety of disciplines, often with a health focus (Braun & Clarke, n.d.; Braun & Clarke, 2014). Its flexibility supports researchers to systematically investigate, analyse and report patterns of meaning, or themes, across data sets without being bound to a theoretical position. In this respect, TA is distinct from other qualitative analytic approaches as its sole purpose is to offer a structure for analysis (Braun & Clarke, 2013). TA does not espouse a particular theoretical position, epistemology or ontology; instead, it can be used across a variety of theoretical and epistemological methods. Consequently, within psychology, it is suitable for both constructionist and essentialist paradigms and can be applied to most research questions (Braun & Clarke, 2006; Braun & Clarke, 2013). Despite its lack of theoretical constraints, TA still has the capacity to offer a rich and in-depth description of the data (Braun & Clarke, 2006) and is suitable to use with both small and large data sets (Braun & Clarke, 2013). TA can be used as a bottom-up approach, whereby themes are identified from within the data set; a top-down approach with the data used as a means to explore theory; or a combination of both. It may be used with data in a range of ways, from a critical to experiential stance (Braun & Clarke, 2013).

Braun & Clarke (2006) provide a clear explanation of, and framework for conducting, TA. Their approach involves a systematic six-phase procedure: familiarisation with the text; development of initial codes; looking for themes; evaluating possible themes; demarcating and labelling themes; and creating the report (Clarke & Braun, 2014).

The TA method has been criticised as to its validity. It has been referred to as merely a "realist, descriptive method, and a method that lacks nuance, subtlety, or interpretative depth" (Braun & Clarke, 2014. p1). Although TA can be used within a realist or descriptive manner, Braun and Clarke argue (2014) that it is not limited to just this. Braun and Clarke's (2006) version of TA uses a robust and systematic coding framework that helps the researcher to identify patterns across the body of data. Hence, TA can support a range of research designs, from a thorough and complex analysis; research outside of academia; or more of an applied research approach (Braun & Clarke, 2014). The authors, however, have acknowledged that the interpretative power may be reduced when not applied to an existing theoretical framework. In addition, it lacks specific guidance for research requiring a high level of interpretative analysis (Braun & Clarke, 2013).

2.3.7.4.1 *Rationale for using TA.*

The current research examining service users' experience with voices over time required an approach that was flexible with regard to data collection, analysis and sample size. TA was therefore considered an appropriate method. Due to this flexibility, it was suitable for a longitudinal design, and it allowed for both a deductive testing of existing models and an inductive, experiential exploration of the data set.

2.3.7.5 Template Analysis.

Template analysis (a version of TA) is a qualitative approach for thematically organising and analysing data (King, 2004). It has been described as particularly useful for use within applied qualitative psychological research (Brooks & King, 2012). A template of codes is developed from textual data. The template is organised to denote the connections between themes which is represented within a hierarchical framework (King, 2004).

2.3.7.5.1 *Rationale for using template analysis.*

As an approach, template analysis is flexible and can be adapted to the requirements of the research project. In respect of the current programme of research, and in particular the analysis of clinicians' data, two main features specific to this method meant that it was judged a fitting approach. Firstly, template analysis emphasises across case data analysis as opposed to within case data analysis (Brooks & King, 2012). This was considered valuable in attempting to understand clinicians' views as a group. Secondly, themes can be defined prior to analysis (known as "a priori" themes) (ibid). This meant that, where appropriate, the interview schedule was used to inform the development of the template. Consequently, template analysis was used as a method to analyse clinicians' data.

2.4 Design of the Research Programme

The research programme was combined of three studies: a systematic literature review, a study with service users from Early Intervention for Psychosis (EIP) services, and a study with clinicians from EIP services. The specific methods used for each study are outlined in each chapter. However, a brief overview of the methods employed within the programme of research is explained below:

2.4.1 Ethics Approval

All study procedures were approved by the National Health Service (NHS) Research Ethics Committee (REC) London-Chelsea (REC reference: 13/LO/17/30) (see appendix 1 for ethics letter of approval).

2.4.2 Study 1: A Systematic literature Review

Study One was designed to address question one - what do we know about the course of hearing voices in clinical populations - using a systematic literature review. The study considered research examining the experience of distressing voices which also had a temporal element. The literature review synthesised and evaluated the body of literature and discussed areas for future research.

Systematic literature reviews are a meticulous method to identifying and examining the literature in a particular subject. Fink (2013. p3) described literature reviews as a "systematic, explicit, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners". They are often used within clinical practice to respond to questions under investigation (Cronin, Ryan & Coughlan, 2008). As the aim of the review is to offer an exhaustive list of studies relating to a particular topic, systematic literature reviews differ from traditional reviews in terms of rigour, critical evaluation and synthesis of the body of literature relating to a particular subject. (Parahoo, 2006). Researchers conducting the review should ensure that information is a critical evaluation, rather than a description of the information.

Both quantitative and qualitative methodologies were considered suitable for the purpose of the literature search. The synthesis of qualitative and quantitative data in systematic reviews is still in the process of methodological development (Lucas et al., 2007), and there is no consensus around a single best approach. Studies that synthesise both approaches have therefore used various methods (Lakshman et al, 2009; Lucas et al., 2007; Rosewilliam, Roskell & Pandyan, 2011). A thematic method was used for synthesis. In practice this meant that key sections (methods, results and discussions) from the quantitative and qualitative papers were entered into a spreadsheet. Matrices are a useful tool for handling quantitative and qualitative data. For example, qualitative themes can be compared to quantitative outcomes (Grant & Booth, 2009). However, Grant and Booth (2009) warn that the researcher should always consider whether the

studies are capturing the same phenomenon. A summary was created of key statistical findings. Papers were examined to identify common themes across studies and themes that were unique to specific studies (e.g., did the study only include children, duration of voice hearing, population etc). Final themes were compared to the data set for meaning.

2.4.3   Study 2: Study with Service Users from EIP Services – Embedded Mixed Methods Longitudinal Design

Study Two was designed to address several of the research questions:

2. What are peoples' experiences of managing distressing voices over time – are there different phases?

3. Do beliefs about voices change over time?

4. When is the optimum time for therapeutic intervention for people who hear distressing voices?

5. How much do EIP service users report change (if any) on self-report measures of beliefs, schemata, severity and relating to voices over time?

The study used a longitudinal mixed-methods programme of research to answer the research questions. The research presented in chapters four and six is drawn from the qualitative findings from this study.

The studies explored service users' experiences with living with voices over a period of twenty-seven months. The aim was to understand different phases of managing voices, changes in beliefs and how this may affect therapeutic intervention.

Research described in chapter four focused upon findings from time one (T1) data and examined the period from onset of voices to the time of the interview. Chapter six drew upon findings from all four time points. As described in this chapter, the study aimed to a) compare to existing models of the stages of voice hearing and b) develop an empirically supported model outlining the phases of hearing voices.

The study was an embedded mixed-methods longitudinal design, with quantitative data serving as an adjunct to qualitative findings. It was expected that as participants were within an EIP service and in receipt of treatment, that scores from clinical measures of: voice severity (Psychotic Symptoms Rating Scale - Auditory Hallucinations Scale; Haddock et al., 1999), voice and hearer relating (Voice and You; Hayward, Denney, Vaughan and Fowler 2008), beliefs about voices (Beliefs about Voices Questionnaire Revised; Chadwick et al., 2000) and schemata about self and

others Brief Core Schema Scale; Fowler et al., 2006) would show improvement over time (see section 2.4.3.2.1 for description of measures).

2.4.3.1 Participants.

Recruitment took place within Sussex Partnership NHS Foundation Trust EIP services (Brighton and Eastbourne) and Pennine Care NHS Foundation Trust EIP services (Manchester).

Twenty participants were recruited from EIP services in Sussex (n = 17) and Manchester (n = 3) (see figure 10 for a consort of participants over the four data collection points). EIP is a service for people presenting with first-episode psychosis or "at risk mental states". The service was chosen as it was considered important to explore peoples' experiences with voices as near to onset as possible. It was felt that differences between an EIP service offering care within a metropolitan borough located in the North of England (Manchester) and EIP services offering care within coastal towns located in the South East of England (Sussex: Brighton and Eastbourne) may offer different insights. The sample consisted of 12 men and 8 women aged 19–35 years ($M = 25$, standard deviation (SD) $= 4.7$, $Mdn = 24$). Age at voice onset ranged from 6 to 32 years ($M = 19$, $SD = 6.8$, $Mdn = 19$). Voice duration ranged from less than 1 to 21 years ($M = 7$, $SD = 6.8$, $Mdn = 3$) (see Table 3).

Interview T1 (May-Dec 2014) (20)
*Sussex: 17
**Manchester: 3

Drop Out (T2)
Moved to another country: 1
Doesn't wish to continue: 2
Not completed T2 –still part of study
Unwell: 1
Could not attend: 1

Interview T2 (Feb-Sept 15) (15)
*Sussex: 13
**Manchester: 2

Drop Out (T3)
Moved to another country: 1
Doesn't wish to continue: 3
Not completed T3 –still part of study
Unwell: 2
DNA: 1

Interview T3 (Nov 15-June 16) (13)
*Sussex: 12
**Manchester: 1
(T1, T2, T3 interviews completed: 12)

Drop Out (T4)
Moved to another country: 1
Doesn't wish to continue: 5
Too ill: 2

Interview T4 (Aug16 -April 17) (12)
*Sussex: 11
**Manchester: 1
(T1, T2, T3, T4 interviews completed: 11)

*Service users recruited from Sussex Partnership NHS Foundation Trust (Sussex)

**Service users recruited from Pennine Care NHS Foundation Trust (Manchester)

Figure 10 Consort of Service Users across Data Collection Period

Participant No.	Sex	Age voice onset	Years hearing voices
1	M	18	7
2	F	24	3
3	F	15	4
4	M	19	16
5	F	31	2
6	M	18	7
7	M	20	1
8	M	6	21
9	F	19	3
10	F	20	2
11	M	8	14
12	M	17	13
13	M	19	<1
14	F	22	1
15	M	20	1
16	F	24	3
17	M	13	10
18	M	7	20
19	M	22	<1
20	F	32	1

Table 3 Summary of service users

Participants were purposively sampled (Smith, 2015). This term refers to sampling whereby participants are selected according to particular criterion that are relevant to the research study. The group of participants may therefore be considered homogenous due to their common experience of a specific condition, event or situation (Willig, 2008. p.91). A benefit of purposive sampling is the opportunity to select "information rich cases for study in-depth" (Patton, 2002. p272). Rather than being directed toward making generalisations, information-rich data afford the researcher a deeper understanding of the phenomenon being studied (Patton, 2002). In the current studies, a purposive sampling method was chosen as participants needed to meet the following inclusion criteria:

- *Participants were hearing voices at the time of recruitment to the study*. This was stipulated so that participants could offer some reflections of their subsequent experience of hearing voices

- *Participants had been hearing voices (at least intermittently) for a minimum of three months prior to recruitment to the study*. This was to ensure that

participants were moving beyond an initial 'startling' phase when they may have been overwhelmed by a novel voice hearing experience.

- *Participants were 18 years of age or over*. The age was restricted to eighteen or over as voices during childhood and early adolescence are often transient (Escher, Romme, Buiks, Delespaul, & van Os., 2002a).

Participants were excluded on the grounds of:

- *Voice hearing was due to organic illness or a primary diagnosis of substance misuse*. This criterion was related to the lack of meaning that may be attributed to voice hearing in the context of organic illness and substance misuse.

Marshall (1996) argues that an appropriate sample size will depend upon the requirements to answer the research question adequately. As the current study was an embedded, mixed-methods longitudinal design, with quantitative data supporting qualitative findings, a pragmatic approach was taken to the size of the sample. This was determined by the requirements of a qualitative study design. Guidelines for TA (Braun & Clarke, 2013. p 50) suggest that sample size may be determined by the size of the study and the chosen method of data collection. For small studies conducting interviews, six-to-ten participants are recommended. However, as the current programme of research was longitudinal, participant attrition needed to be taken into account (Saldaña, 2003) and factored into the design. Determining an adequate sample size was problematic as reports regarding attrition in longitudinal studies are inconsistent (Marcellus, 2004). For example, in a review of longitudinal research of cognition in psychosis, Bozikas and Andreou (2011) found reported rates of attrition ranging from lower than 50% to 90%. Alternatively, in Simon et al.'s (2011) review of ultra-high-risk state for psychosis, attrition ranged from 0 to 64%. Qualitative studies require a flexible approach to sampling and data collection as, during the research process, the number of participants needed for the study becomes evident (Marshall, 1996). Initially, after allowing for an annual attrition rate of approximately 33%, the recruitment target was set at n = 30. However, due to the richness and volume of data, recruitment for the current studies ended at twenty participants.

A plan was developed to maximise participant retention during the 27-month data collection period. Participants were contacted on a regular basis. At each interview, participants were offered a copy of their previous interview, which was also discussed, to ensure motivation and engagement with the study. Discussions were raised regarding potential changes of contact details. In addition, regular contact was made with

participants' Lead Practitioner (clinician assigned to support patient and coordinate treatment pathway during their time in the EIP service).

2.4.3.2 *Procedures.*

EIP service teams from Sussex Partnership NHS Foundation Trust and Pennine Care NHS Foundation Trust were invited to identify service users who met the study criteria (see appendix 2 for team information sheet). Lead Practitioners (LPs) discussed the study with service users who were also provided with a participant information sheet (PIS) (see appendix 3) explaining involvement within the study. The referring team member completed a referral form (see appendix 4) confirming that the potential participant met the study inclusion criteria and was willing to discuss the research project with myself.

Service users who were interested in the study were contacted 24 hours after receipt of the PIS. Those who wished to participate were invited to meet. Lead Practitioners were informed of the date, time and place of appointment. In order that they felt at ease, participants decided where the appointment should take place. Consequently, data collection occurred at either the participant's team base or at their home. Meetings at a team base meant that, prior to the interview, the room could be arranged to create a relaxed, comfortable, and intimate atmosphere. At T1, eleven participants chose to meet at their team base, while the remaining nine chose their home. On meeting at T1, the study was discussed with the aid of the PIS. Service users were encouraged to ask questions and consider the potential implications of taking part in a longitudinal study. If they still wished to participate, and they met the study criteria, informed consent was taken (see appendix 5 for consent form). The process of informed consent was guided by Elmes, Kantowiz, & Roediger's (2011. p93) principles of ethical considerations whereby "an ethical researcher ensures that participants are fully informed as to the experimental procedure and give their consent before beginning the experiment". Once consent was completed, participants were asked whether they would prefer to complete the self-report measures first or the interview.

2.4.3.2.1 *Quantitative measures.*

The following four self-report measures were used to collect data from service users at the four data collection periods (see appendix 6 for assessment booklet):

2.4.3.2.2 *Voice and You (VAY).*

The VAY is a 28-item measure of interrelating between the hearer and their predominant voice (Hayward, Denney, Vaughan, & Fowler, 2008). Relating is

measured across four scales; two concerning the hearer's perception of the relating of the voice – voice dominance and voice intrusiveness; and two concerning the relating of the hearer - hearer distance and hearer dependence. Each item is measured on a four-point scale (0-3) generating the following range of scores for each scale: Voice Dominance 0-21; Voice Intrusiveness 0-15; Hearer Distance 0-21; and Hearer Dependence 0-27. This measure has achieved good internal consistency previously in clinical populations (Hayward et al., 2008) demonstrating Cronbach's α =.82 on five-item scale of voice hearing and acceptable test-retest reliability r $\geq$ .72 for all scales.

2.4.3.2.3 *Psychotic Symptoms Rating Scale (PSYRATS: Auditory hallucinations scale AHRS).*

The AHRS is an 11 item rating scale designed to measure the severity of different dimensions of the voice hearing experience (Haddock et al, 1999) and comprises of: frequency, duration, controllability, loudness, location, severity and intensity of distress, amount of negative content, degree of negative content, beliefs about the source of voices, and disruption to life. Each item is measured by the rater on a 5-point scale ranging from 0-4. This measure has achieved good internal consistency previously in clinical populations with Cronbach's α =.76 (Ellet et al., 2017), Cronbach's alpha unavailable in original study, Haddock et al. (1999)

2.4.3.2.4 *Beliefs about Voices Questionnaire Revised (BAVQ-R; Chadwick et al., 2000).*

The BAVQR is a 35 item self-report measure regarding people's beliefs, emotions and behaviour around auditory hallucinations. The questionnaire comprises of five subscales: beliefs about the voice's malevolence (six items), benevolence (six items), omnipotence (six items), emotional resistance (four items), emotional engagement (four items), behavioural resistance (five items) and behavioural engagement (five items) with the voice. Items are rated on a 4-point Likert scale ranging from disagree (0) to agree strongly (3). This measure has achieved good internal consistency in clinical populations (Chadwick, Lee and Birchwood,2000) with a mean Cronbach's αfor five sub-scales of voice hearing of .86 (range .74-.88).

2.4.3.2.5 *Brief Core Schema Scale (BCSS; Fowler et al., 2006).*

The BCSS is a self-report assessment of schemata centring on self and others in psychosis. It has 24 items measuring four dimensions of beliefs about the self and others: negative self (six items, e.g. "I am worthless"), positive self (six items, e.g. "I am valuable"), negative other (six items, e.g. "other people are nasty"), positive other (six items, e.g. "other people are supportive"). Items are assessed on a five-point rating

scale (0-4). This measure has achieved good internal consistency in clinical populations (Cronbach's α = .78-.88) (Fowler et al., 2006; Smith et al., 2006).

Although quantitative self-report measures are a standardised means of collecting objective data, it is worth noting that there are both advantages and disadvantages to using self-report measures. Self-reports offer access to unique participant information; they offer a means to the participants perception of the self; they are typically straightforward to administer; and facilitate the investigator to gather personally relevant variables in a single data collection period. Alternatively, they have been criticised for being subject to socially desirable responding (Paulhus & Vazire, 2007).

2.4.3.2.6 *Qualitative semi-structured interviews.*

Semi-structured interviews are particularly suited for in-depth exploration of complex and sensitive issues. They support the interviewer to clarify answers and probe further on points of interest (Barriball & White, 1994). The semi-structured interview schedule in the present study was designed in consultation with the research team who discussed topics of interest for T1 interviews (see appendix 7). As this was the first data collection period, questions were designed to support interviewees to reflect on both current and retrospective experiences of hearing voices. Although the purpose of the research was to examine participants' experiences with voices prospectively, it was also important to understand experiences with voices from the point of onset.

Consequently, the schedule included questions focusing on the following key areas:

- Participants' experiences and feelings regarding the onset of voices.
- How participants made sense of changes in hearing voices over time e.g. voice loudness, content, frequency.
- Help-seeking behaviour.
- Experience and views of therapy.
- The effect of voices over time e.g. personal impact, social impact and impact on career.
- Relationship with voices e.g. relating to voices.
- How voices were managed.
- Beliefs, feelings and hopes about voices in the future.

The schedule was guided by Braun and Clarke's (2013, p.83) recommendations to pay attention to:

1. *Opening questions* e.g. an introduction question like "tell me about yourself?" and closing questions e.g. closing or 'clean-up' question – allows participant to discuss issues that have not been raised like "is there anything else you would like to discuss?"

2. *Sequencing of questions* – refers to the ordering of questions in a logical manner. This style of questioning begins with less probing questions leading to more sensitive questions.

3. *Constructing and wording of questions* – pays attention to the careful wording of questions to build rapport. Questions should neither be too leading nor closed (questions that allow yes/no responses).

4. *Prompts and probes* – these are used to support the main question. They encourage the interviewee to expand upon specific areas and explore at a more meaningful level.

5. *Social desirability* – signifies questions that may only elicit socially desirable responses.

Rather than being prescriptive, the interview schedule was used as a guide to investigate each participant's experience. Open-ended questions allowed self-reflective and exploratory dialogue.

Subsequent interview schedules (T2, T3 and T4) established whether or not voices were still present. Theses schedules examined the time between last and current data collection period. If voices were still present, it focused on changes in perceptual experience of voices; emotional, behavioural and cognitive responses to voices; others and voices; socialising, work and/or college. However, if voices had stopped, the schedule was designed to explore how voices had stopped; emotional, behavioural and cognitive responses to voices stopping; other people's reactions to voices stopping; and effects of voices stopping on socialising, work and/or college. In addition, each participant's schedule was also informed by findings from the data from their previous interview (see appendix 8 for example). This helped to build upon, explore and understand participant's experiences with voices over time as well as verify previous findings. Personalising the interview also facilitated the development of the interviewer/interviewee relationship.

Building rapport with the interviewee, as well as ensuring that they were comfortable in discussing personal information, were considered to be essential to the success of the interview. Interviewees were informed that they could refuse to discuss a particular question or stop the interview if they became distressed. If a participant disclosed information whereby, they or someone else was at serious risk of harm, the study protocol specified that confidentiality would be breached as stated in the consent form. The participant would be informed that action would be taken and a member of their care team or an appropriate service informed.

Participants were contacted at nine-monthly intervals. It has been argued that, within longitudinal studies, researchers need to balance the time available to collect data with the risk of attrition. To try and capture change, it is essential to carefully consider the timing and frequency of interviews (Hermanowicz, 2013; Farr and Nizza, 2019). Initially, six-month collection periods were considered. However, this was re-assessed due to participant burden and manageability of data.

Prior to each subsequent meeting (T2, T3 and T4), participants received a copy of the transcript from their previous interview. Although this may have influenced the current interview, it was felt that it would ensure that participants concurred with the former interview. It also gave participants the opportunity to explore particular areas further or discuss points which may not have accurately reflected their voice hearing experiences. On meeting, key findings from the analysis of the previous interview were discussed with the interviewee. This was to offer the interviewee the chance to agree or disagree with the analysis.

All interviews were audio recorded with participant's consent. Where appropriate, notes were also taken. However, note taking was kept to a minimum as it was believed that this may compromise the rapport between the interviewer and interviewee. At the end of each interview, an entry was made into a 'reflective diary'. This helped to develop interview technique, understand changes in the interviewer-interviewee relationship over time, and explore thoughts, beliefs and feelings during each interview and their potential affect.

At each meeting, participants were given a £15 voucher as a recompense for their time. Travel reimbursement was also offered.

At T1 interviews ranged from 27.24 to 85.25 minutes; T2 interviews ranged from 30.34 to 81.12 minutes; T3 interviews ranged from 40.29 to 65.07 minutes; and at T4 interviews ranged from 45.36 to 87.10 minutes.

2.4.3.3   Statistical Analysis.

The plan for quantitative analysis was to use single case statistics (Jacobson & Truax, 1991) to identify reliable and clinically significant change on each self-report measure for each participant. At the end of data collection (fourth data collection point), each participant's data set for each measure was entered into a spreadsheet. The summed scores, plus the sub-scales, of each measure were totalled. To visualise change over time across measures for each participant, graphs were generated in Microsoft Excel (version 15.0) (see appendix 9 for graphs). Next, a formal analysis of the data was intended to determine whether changes in scores over time were clinically meaningful. In order to calculate change, the Cronbach alpha (coefficient alpha) for each measure/subscale plus its standard deviation would be entered into an online index calculator (Becker, 1999). Cronbach alpha is a measure of internal consistency, which can be used to determine the reliability of a scale - specifically, the inter-relatedness of the scale items (Tavakol & Dennick, 2011). A change score of 1.96 or above is considered reliable change (Becker, 1999).

It was anticipated that findings from each measure would then be triangulated with qualitative data findings. Triangulation is "the combination of methodologies in the study of the same phenomenon" (Denzin, 1978, p. 291) Quantitative and qualitative data findings from each participant would be entered into a mixed methods matrix (Bazeley, 2009) for comparison. However, full data sets were available for only four out of 12 participants, because: a) two participants did not wish to complete measurements because of fatigue and b) voices ceased for six participants. This rendered three of the measures (PSYRATS-AH, Haddock et al., 1999; BAVQ-R, Chadwick et al., 2000; and the VAY, Hayward et al., 2008) redundant for participants whose voices stopped as they referred to experiences over the preceding week. Consequently, a formal analysis was not conducted on the data set. Due to the success in participant retention, the results chapters focus on the qualitative data set, as this was larger and richer than the quantitative data. The small sample size was not unexpected. It was always considered that the quantitative data would be less informative than the longitudinal qualitative data.

2.4.3.3.1   *Qualitative analysis of T1 data.*

An experiential inductive thematic analysis (TA) was conducted in accordance with Braun and Clarke's (2006) six-phase guide:

1. *Transcription* – this stage focuses on the preparation of the audio (and audio-visual) data for analysis. It is not a straightforward process, decisions need to be made as to how, and what, the transcriber chooses from the recording to translate e.g. sighs and coughs. There are various styles of translation, each aligning to a particular analytic method. For TA, Braun and Clarke (2013) advocate an orthographic (Hayes et al., 2013), or verbatim, style of transcription which draws attention to spoken words and sounds. Other styles, such as Jeffersonian (Jefferson, 1992), may focus on phonetic structures of the interview. This style is more suited for methods such as conversation analysis (Jefferson, 2004). The current programme of research adopted an orthographic style of transcription.

2. *Reading and familiarisation of the transcript* – through reading and re-reading the interview transcripts, as well as listening to audio recordings, the researcher starts to become immersed in the data. This stage highlights the importance of actively engaging with the data, thinking about it critically and analytically, while questioning and exploring meaning (Braun & Clarke, 2013).

3. *Generating initial codes* – this stage is the start of the systematic analysis and begins with the creation of initial codes. Codes provide a means of identifying and labelling specific features of the data that are of interest and relevance to the research question. The data can be coded at a semantic level (reflects the content of the data and the views of the participants) or at a latent level (goes beyond the meanings ascribed by participants and offers an interpretation of the content of the data). Codes may parallel the language and ideas of the participants or be influenced by the researcher's theoretical point of reference (Braun & Clarke, 2019).

4. *Searching for themes* – at this stage, the research begins to move from codes to themes. A theme "captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p. 82). This is a dynamic process whereby choices are made regarding the creation and construction of the themes. Themes are generated from the coded data, which is reviewed for areas of similarity. Similar codes are clustered into themes that share a unifying characteristic. The resulting themes reflect clear and meaningful patterns in the data (Braun & Clarke, 2019).

5. *Reviewing potential themes* – The potential themes are appraised against the coded data and the entire data set. This is a key step for quality checking and is important

when working with large data sets. Themes are considered as to their relevance, coherence and meaning to the coded data and the data set (ibid).

6. *Defining and naming themes* – This is the process of defining and naming themes to reflect each one's focus and identity. Definitions should explain the uniqueness of a theme and offer a brief explanation of its essence and meaning. The label of a theme should be concise, informative and, ideally, memorable (Braun & Clarke, 2013).

Inductive analysis employs a process of in-depth readings of raw data to obtain concepts, themes, or a model that is derived from the researcher's interpretations of the data (Thomas, 2006). Through the inductive analysis, theory is developed from the data which is derived from the investigated area. Consequently, final themes may show little resemblance to the original interview questions (Strauss & Corbin, 1998). It is a process whereby data is coded without any attempt to shape it within a pre-existing coding framework (Braun & Clarke, 2006). In summary, the focus of an inductive approach is to facilitate the emergence of "frequent, dominant, or significant themes inherent in raw data, without the restraints imposed by structured methodologies" (Thomas, 2006. p238). The lack of existing theories regarding the barriers and enablers to the disclosure of voices lent itself to an inductive approach whereby identified themes were derived and remained closely linked to the data. Although a bottom-up approach to data analysis was taken, Braun and Clarke (2013) noted that analysis is not totally independent from the researcher's standpoint, knowledge of the subject area, and epistemology.

In line with Braun and Clarke's (2013) six-phase approach each interview was transcribed verbatim. This has been considered an important part of the analytic process in interpretative qualitative methodology (Bird, 2005). Transcripts were anonymised for any identifying material. Each transcript was read several times for familiarisation and meaning. An initial set of data-driven codes were manually generated from each transcript. Data extracts were matched to the codes. After a list of codes was completed, the next phase of the analysis consisted of searching for themes. Codes were printed onto separate pieces of paper which were then collated by the research team to generate potential themes. It was decided to use this approach as the team could work flexibly to explore the data, discuss and agree on themes as a group. As an inductive approach was adopted, working in this manner also facilitated an open interpretation of the data which was not bound by previous theory. The codes and themes were entered into a spreadsheet (see appendix 10) where the relationship between the codes, themes and levels of themes were linked, refined and separated into candidate themes. Although the

work with the findings of the data rather than be prohibited by the research question. Consequently, this allowed novel themes to emerge and research questions to evolve. The candidate themes were reviewed for internal homogeneity (data adheres together meaningfully) and external heterogeneity (distinction between themes) (Patton, 1990). The gathered extracts were read and compared against each theme to ensure that they captured the essence of the coded data. The individual themes were compared against the entire data set for validity and meaning. Themes were defined and labelled in order to represent the central idea of the theme. Themes were collated into higher order themes, themes and sub-themes. A detailed analysis was written for each theme. Themes were also considered as to the broader story of the data.

Credibility checks of the coding of three data sets were undertaken by members of the research team.

Findings from T1 data are reported in the research of chapter four**.**

2.4.3.3.2 *Qualitative data analysis of T1-T4 data.*

Due to the limited literature regarding the different phases of managing voices over time, an inductive approach to the participant data was considered appropriate. As the research was designed to extend the empirical literature of voice hearing, a combined method of inductive and deductive TA was used to analyse the data. The use of both approaches complemented the aims of the research by allowing the process of deductive thematic analysis to reflect upon existing models and novel themes to emerge from participant data through inductive coding. The interplay of both approaches supported the testing and development of existing models of voice hearing over time. The analysis was conducted in two phases as follows:

Phase 1. An inductive experiential TA was conducted at each time point for each participant. The six stages described for analysis of the T1 interviews were followed for the analysis of the T2, T3, and T4 interviews. Interviews were transcribed verbatim and anonymised for any identifying material. Each transcript was read several times and an initial set of data-driven codes were produced from the raw data for each interview at each time point. Data extracts were matched to the codes. During the initial stages of analysis, each participant's data set was explored separately from the entire body of data. The data from each time point for each participant was therefore entered onto a separate spreadsheet.

The codes from each person's time point were considered for meaning before being collated into potential themes for that data collection period. Although an

inductive approach was applied to allow novel themes at each time point to emerge, it was acknowledged that an awareness of the findings from previous data collection periods may also influence current analysis. Therefore, in an attempt to minimise this occurrence, the analysis of each transcript was conducted separate to previous findings. This allowed findings from each interview to reflect the current time period, revealed changes in participants' experiences and explored the course of similar themes over time. The candidate themes were studied for internal homogeneity and external heterogeneity. The collated extracts were compared against each candidate theme and then compared against the data set for validity and meaning. Each person's final set of themes were labelled. A summary (see appendix 11) was written of each participant's analysis illustrating their respective timeline with hearing voices. It was felt that a summary would facilitate understanding of each participant's experiences with voices over the data collection period. Each summary was compared to the original transcripts and data set.

2.4.3.3.3 *Member checking.*

Member checking refers to checking the analysis with some, or all, participants and asking for feedback on the authenticity of the findings (Braun & Clarke, 2013). Member checking had been built into the research design and participants were informed that they would be contacted. Seven participants were contacted (five were uncontactable) and six agreed to review the summary. Participants received a copy of their summary (post or email). Each participant was telephoned again, and the summary was discussed. All participants agreed that the summaries were a true representation of their experiences (see appendix 12 for participant feedback*)*

Phase 2. A deductive theoretical TA approach was used to compare participant findings from phase 1 to an amalgamated model of pre-existing recovery models of the stages voice hearing. A theoretical TA is directed by existing theory and theoretical concepts. It considers the researcher's own point of view, their knowledge of the subject area and epistemology (Braun and Clarke, 2013). A deductive approach to analysis seeks to test the data against prior assumptions, theories, or hypotheses that have been identified by the researcher. Both inductive and deductive approaches have been used in many evaluation studies (Thomas, 2006).

A systematic literature review examined existing models of the stages of voice hearing. The literature search was conducted within two electronic academic databases: PscyhInfo and Medline. The results produced 618 papers. As the aim of the study was

to explore the course of hearing distressing voices and compare findings to existing models outlining the phases of voice hearing, the following inclusion/exclusion criteria were applied:

Inclusion criteria

Studies were included if they examined a model of the stages of managing distressing voices.

Exclusion criteria

Studies were excluded if the model:

- Did not depict a temporal element
- Was not associated with distressing voices
- Did not have stages to voice hearing.

Both quantitative and qualitative methodologies were considered suitable. After exclusion criteria were applied, the remaining eleven papers were read for suitability. After further exclusion criteria a final set of three papers (qualitative studies) were included.

The three models from the papers were amalgamated (see Appendix 13 for model development) to produce a testable integrated model against the findings from phase 1 (see chapter six for model). To develop the model, each of the original models were deconstructed into their respective themes as defined by the authors of each paper. A summary of each theme, informed by the results sections of the papers, was produced. A visual representation (diagram) of the earliest model was created. Themes from the second model were compared to the diagram. Similar themes were amalgamated. Themes that differed from the diagram were integrated at the appropriate temporal phase of the diagram. The same processes of integration were applied to the themes from the third, and most recent, model. Where applicable, combined themes were re-labelled to illustrate the meaning of the new theme.

In order to generate a testable model, the process of refinement continued. Themes were amalgamated, collapsed (to illustrate the essence of a theme), refined and re-labelled. Themes were considered for meaning and whether they represented a temporal phase of voice hearing. Those which did not characterise a stage of managing distressing voices, and did not form part of a temporal progression, were discarded. The themes of the integrated model were compared to the three original models and reviewed for internal homogeneity and external heterogeneity. The model was revised until the research team was satisfied that the final model could be a) tested against

participant data and b) represented the integration of the original three models. A brief summary described each theme.

The next stage compared and evaluated the integrated model against participant data. The summary and thematic codes for each participant's data set were matched to the stages outlined by the model (see appendix 14 for example). The model stages were either confirmed or rejected. Novel stages from participant data were noted against the appropriate stage in the model. The model was adapted to represent each participant's data set. This resulted with twelve models reflecting each participant's data which were then coded. The codes from each participant were entered in a spreadsheet (see appendix 15) and grouped according to similarities across timelines. The resulting themes and higher order themes were discussed for meaning with respect to existing models and participant data. A summary, illustrating each theme, was produced.

A diagrammatic representation of the themes, expanding upon the integrated model, was developed. The purpose of the model was to depict each participant's temporal experience of voice hearing as well as factors which may have influenced this journey. The process of refinement continued and evolved through several iterations before the research team agreed that the final version represented each participant's stages of voice hearing. The model was compared to each participant's data. Sections of participant's interviews illustrated each theme. A final summary of each stage of the model was written (see chapter six for the 'Model of the stages of voice hearing).

2.4.4   Study 3: Qualitative Study with Clinicians

Study Three was designed to address the question six –
What are EIP clinicians' experiences of how their clients manage voices overtime – using a qualitative method?

The aim of this study was to explore EIP clinicians' views and professional engagement with clients who heard voices. The research described in chapter five draws on the findings from this study. This study offers an exploratory approach to understanding clinicians' views of service users' management of voices over time, changes in beliefs and how this affects therapeutic intervention.

In attempt to gain an in-depth exploration of clinicians' professional and personal views of their experiences of working with voice hearers an individual interview was conducted with each clinician. Data collection with each participant consisted of a single interview.

2.4.5 **Participants**.

Ten clinicians were opportunistically selected from EIP services. Recruitment took place across two NHS Trusts: Sussex Partnership NHS Foundation Trust (Brighton and Eastbourne) and Pennine Care NHS Foundation Trust (Manchester). It was considered that an EIP service offering care within a metropolitan borough located in the North of England (Manchester) and an EIP service offering care within coastal towns (Brighton and Eastbourne) located in the South East of England may offer different perspectives. Participant eligibility criteria was as follows:

- *To be a clinician within an EIP services*. It was required that clinicians were currently, or had experience, of working within an EIP service. This was to ensure that they had worked with an EIP service user population.

- *To have worked with people experiencing distressing voices within an EIP service*. It was necessary that clinicians had worked with people experiencing distressing voices. First, as a psychosis service, not all clinicians may have worked with people who heard voices. Second, not all service users who heard voices may have experienced them as distressing.

Participants had a range of professional training: some were trained to offer NICE approved psychological therapies; others had no formal training in the delivery of psychological therapies. The table outlines how participants chose to describe their job title - EIP practitioner, mental health nurse (MHN) or psychologist (see Table 4). The study aimed to recruit EIP practitioners who could offer a range of perspectives on the experience of hearing voices. Initially, the recruitment target was set at fifteen clinicians. However, due to the richness and volume of data, recruitment to the current study ended at ten participants.

Pseudonym	Sex	Role	Time in EIP
Ella	F	EIP Practitioner	5 years
Eryn	F	EIP Practitioner	9 years
Eve	F	EIP Practitioner	6 years
Noah	M	EIP Practitioner	6 years
Nathan	M	Mental Health Nurse	7 years
Nita	F	Mental Health Nurse	4 years
Jess	F	Psychologist	2 years
Millie	F	Psychologist	7 years
Penny	F	Psychologist	7 years
Rose	F	Psychologist	8 years

Table 4 Summary of EIP Practitioners

2.4.6   Materials

A semi-structured interview was used to explore clinicians' experiences of working and having conversations with service users about hearing voices. It was decided that this method of interview would support open, in-depth and exploratory conversations. The schedule which was designed to examine clinicians' understanding of service users' journeys with hearing voices, and how these journeys might affect readiness for, and engagement with, conversations. An initial list of questions was generated by members of the research team which were considered relevant to the area of interest. The questions were constructed to form the framework of an initial interview schedule. The schedule was further refined to ensure that questions examined clinicians' views on service users' experiences with voices over time, help-seeking, delivery of psychological therapies and recovery. The schedule was guided by Braun and Clarke's (2013) recommendations of the importance of opening and closing questions; sequencing of questions; constructing and wording of questions; prompts and probes; and social desirability (questions that may only elicit socially desirable responses). Open-ended questions facilitated a self-reflective and exploratory discussion. In order to

build rapport between the interviewer and interviewee, opening questions focused on work related demographics e.g. job title, number of years in current role, number of years working with voice hearers. The final interview guide was reviewed by the research team for meaning and relevance.

2.4.7   Procedures

All procedures were approved by the NHS Research Ethics Committee at the London Health Research Authority. Research Assistants, employed by Sussex Partnership NHS Foundation Trust, discussed the study with EIP teams in Sussex. Clinicians who were interested in participating were offered a Participant Information Sheet (PIS) (see appendix 16) and referred to the study. Three of the participants (EIP psychologists), who were work colleagues, were contacted directly by me. Alternatively, in Pennine Care NHS Foundation Trust, a presentation about the study was given by me to EIP teams in Manchester. Clinicians in Manchester were referred to the study by the Principal Investigator (Psychologist within the EIP team). All clinicians who wished to proceed, met with me at either their team base, Sussex Partnership's NHS Foundation Trust's Research and Development department or the University of Sussex. In order that they felt at ease, the interview location was decided by the participant. Interviews took place in quiet rooms which were known to the participant.

On meeting, with the aid of the PIS, the relevance and purpose of the study was discussed. Clinicians were invited to ask questions. If they still wished to participate, clinicians were asked to provide written consent (see appendix 17) to being interviewed as well as being audio-recorded. The design of the interview was semi-structured and therefore, the interview schedule was not prescriptive and acted as a guide. The same semi-structured interview was conducted with each clinician. During the interview, the information was explored which, although not part of the interview schedule, was considered relevant to the area of research. Consequently, interviews consisted of impromptu follow-up questions. To minimise potential data collection problems (e.g. digital recorders not working efficiently, poor recording quality) two recorders were used. Written notes were not taken during the interview as it was felt that this may compromise interviewer-interviewee rapport. Interviews lasted between 31 to 60 minutes. The first interview (participant 1), which was conducted with a clinician from Pennine Care NHS Foundation Trust, lasted for 38.45 minutes. The final interview (participant 10) was conducted with a clinician from Sussex Partnership NHS

Foundation Trust and lasted for 47.56 minutes. The two shortest interviews, participant 4 (38 minutes) and participant 5 (31 minutes), were conducted with work colleagues and known to the interviewer.

A reflective diary was kept during the data collection period which helped to reduce the likelihood of false recall. The diary enabled self-reflection, as well as an examination of the perceived dynamic between the interviewer and interviewee, and consequently facilitated the development of interview techniques.

2.4.8   Analysis

Each participant's interview was transcribed verbatim and anonymised for identifying information. An inductive and deductive qualitative approach was used to explore clinicians' awareness and responses to voice hearing as well as beliefs regarding therapy. A deductive approach meant that key areas relating to the original research question were explored while an inductive approach allowed for new areas of interest to emerge.

Template analysis was used to analyse clinician transcripts. Template analysis, a form of Thematic Analysis, categorises qualitative data into hierarchical clusters. (Brooks, McCluskey, King & Burton, 2013). 'A priori' themes, or features of the phenomena being studied that are of particular interest, are demarcated before the analysis takes place. During the process of analysis, the 'a priori' themes are either developed or discarded according to their usefulness in capturing meaning (Brooks & King, 2014). Consequently, through the dynamic interplay between researcher and data, a template of the analysis is constructed and modified as new themes are created (Brooks et al., 2013).

In the current study, template analysis was chosen as it allowed for an investigative non-theoretical analysis within and across the data set, thus permitting an in-depth understanding of the experience of each participant, as well as experiences across the whole sample. In addition, template analysis was used to focus the analysis on the initial research question - What are EIP clinicians' experiences of how their clients manage voices overtime? The process of the analysis was directed by King's (1998) guide to conducting template analysis. In the first instance, participant transcripts were read several times for familiarisation. The next stage consisted of the creation of the initial template. King (2012) suggests that the topic guide is a good starting point for the construction of the initial template. Key questions from the guide, prompts and

probes may be used as an initial starting point from which the template develops. The main issues in the current interview schedule were considered to focus on: help from others; help seeking and time; psychological therapy for distressing voices; experiences of therapy; and managing voices over time. Consequently, the following questions from the interview schedule functioned as higher-order codes:

     1) How have clinicians worked with people who experience voices?

     2) General experience of working with people who experience voices – what has struck clinicians about people who experience voices?

     3) What happens over time with peoples' experiences of voices?

     4) What happens over time with how people manage voices?

     5) What are clinicians' understanding of help-seeking behaviour?

Subsidiary questions and probes from the interview schedule served as potential lower-order codes.

The initial template was applied to the transcripts. The template was structurally modified in a systematic process whereby themes were re-labelled, collated together or discarded. In agreement with King (2012), an 'openness' to the analysis was maintained whereby themes which were not obviously related to the initial research question, but deemed relevant to the topic, were included. All transcripts were compared for a second time to the final template which was modified where necessary. The process continued until the final template offered a full interpretation of the data. The final version of the template was compared against the research question for meaning and significance. Although originally guided by the initial coding template, as the analysis was inductive and exploratory, the flexibility of this approach allowed for novel themes and issues to emerge from the data. The relevance and inclusion of each novel theme in respect to the research question, as well as the entire programme of doctoral research, was considered. Themes which were not clearly related to the research question but were deemed important to understanding clinicians' experiences of working with voice hearers and supporting them to manage voices were included. It was felt that these novel themes may offer interesting insights into the role played by the clinician in supporting clients to cope with voices. The final template consisted of themes derived from the initial template and novel themes that were developed through the process of analysis.

2.5 Quality control processes

In contrast to quantitative research, the standards for evaluating and conducting qualitative research are not clearly defined. Qualitative research has been criticised for not always using representative samples, employing measures that are not considered reliable, reporting non-objective findings and producing non-replicable outcomes (Yardley, 2000). In the area of health research, Mays and Pope (2000) argue that despite being widely used and accepted within health research, qualitative methods remain unclear to many health services researchers. There is much discussion as to how such methods and findings should be assessed. Consequently, many authors have attempted to argue as to what constitutes good quality and practice in qualitative research (Willig, 2013).

The quality in this programme of qualitative research studies was guided by Yardley's (2000) criteria for good quality research of sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (see Table 5). These concepts will be addressed in relation to the programme of research in the discussion chapter (chapter 7).

Sensitivity to context

Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.

Commitment and rigour

In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.

Transparency and coherence

Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.

Impact and importance

Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).

Essential qualities are shown in bold, with examples of the form each can take shown in italics (Yardley, 2000).

Table 5 Characteristics of good (qualitative) research

3. Systematic literature review

3.1   Chapter Outline

The aim of this chapter was to examine what is known about the course of hearing voices within the literature. A systematic literature review of qualitative and quantitative studies was conducted and a final twelve papers (three qualitative and nine quantitative) selected. A qualitative thematic method was used to synthesise the findings and conclusions from each of the papers. Five themes are presented: 'Adversity and voice onset', 'The course of voices', 'Managing voices over time', 'Response to voices' and 'Seeking-help.' The chapter concludes that there is no empirically supported model of the different phases of managing voices over time. Clinical implications of the findings are discussed.

3.2   Introduction

Auditory verbal hallucinations, which shall now be referred to as voices, are perceptual experiences which take place in the absence of an appropriate external auditory stimulus whilst in a state of consciousness (Beck & Rector, 2003; Anthony, 2004). The phenomenon entails a range of subjective experiences whereby the individual may perceive: a single voice or multiple voices; voices that are known or unknown; voices that are positive or negative; voices that address the hearer in either the first, second or third person (Jones, 2008). The auditory experience is often perceived as veridical (Honig et al., 1998; David, 2004; Beavan et al., 2011a), autonomous and, regardless of the voice being situated internally or externally, distinct from the sense of self (Beavan, 2011a).

Voices occur across diverse populations and are found in both clinical and non-clinical groups (Larøi et al., 2012). However, as previously discussed (chapter 1: section 1.2.3), reports vary with estimated findings of voice hearing amongst the general populations ranging from 1% (Johns, Hemsley, & Kuipers, 2002) to 84% (Millham & Easton, 1998). In clinical populations, although most commonly reported as a symptom of psychotic disorders (e.g. schizophrenia), the experience is also found in patients diagnosed with a wide range of psychiatric conditions such affective disorders (e.g. bipolar and manic depression), personality disorders and eating disorders (e.g. anorexia nervosa) (Beavan et al., 2011a; Jenner et al., 2008; Waters et al., 2017) Additionally, in comparison to non-patients, patients report heightened fear and distress in relation to

their voices, experiencing them as more negative, controlling and a disturbance to daily life (Daalman et al., 2011; Honig et al., 1998).

Evidence indicates that the phenomenological experience of hearing voices changes over time. Voices may evolve (Nayani & David, 1996) whereby, a 'dynamic developmental progression' takes place with regard to the character of the voice, appraisal of the voice and distress associated with the voice (Jones, 2008). How the hearer manages and copes with their voices may also change with the development of the experience. Romme & Escher, (1989) advocate that voice hearers journey through three potential phases of coping with voice hearing: 'the startling phase' which refers to the sudden onset of voices; the 'phase of organization' where the individual begins to select and communicate with their voices; and the 'stabilization phase', a period whereby the experiences becomes more stable and the hearer focuses on the processes of managing voices. However, Romme & Escher's (1989) proposal of a tripartite model of voice hearing was not based upon empirical research, and subsequently has been criticised for its lack of validity and reliability (Morrison, Frame & Larkin, 2003; Milligan, McCarthy-Jones, Winthrop & Dudley, 2012). In a phenomenological study examining living with voices over time, Milligan et al. (2013) only partially replicated the three phases proposed by Romme & Escher. The authors failed to find evidence of either a "startling" or "organisational" phase. Milligan et al. (2013) extended upon the suggested three phases and included "rejection" (may include "startling" phase), "discovery, adjusting, coping" and "new understandings" (suggested as a pre-"stabilisation" phase). Disparities between findings reflected the idiosyncratic nature of voices (Larøi, de Haan, Jones, & Raballo, 2010) and raised the question as to whether a common pathway of voice hearing can be demonstrated. Consequently, this suggests a need for empirically supported, longitudinal research exploring peoples' temporal experiences of hearing voices (Milligan et al., 2013).

Examining the course of voice hearing may facilitate hearers, and those offering support, to gain a better insight of what it is like to live with and manage the phenomenon over time. Knowledge of such factors, and at what stage they are likely to occur, may afford clinicians insight as to when therapeutic support should be offered. Cognitive-behavioural therapy proposes that distress is associated with the maladaptive beliefs about voices (power and control), rather than the voices as such (Byrne, Birchwood, Trower & Meaden, 2007). An awareness of why, when and how changes

in beliefs occur, and recognising these transitions with their clients, could help clinicians to support service users with voice-related distress (Milligan et al., 2013).

Research has demonstrated that the effectiveness of treatment for voices varies within clinical populations (Shergill, Murray & McGuire, 1998). This may be due to the subjective nature of the voice hearing journey, requiring different types of treatment at different stages of this journey (Thomas et al., 2014). In order to facilitate the advancement of treatment for people who experience distressing voices, it is essential that the course of the phenomenon is understood. Birchwood, McGorry, & Jackson (1997) describe a 'critical period' in psychosis, whereby symptoms stabilise 2-3 years after first onset. Exploring the course of voice hearing may increase learning about potentially significant stages of voice hearing, and any influence of these stages upon the optimising of the impact of interventions. Therefore, the aim of this review is to examine what is known about the course of hearing voices. It will consider studies that have focused upon the experience of distressing voices within a temporal framework. The review will synthesise and appraise findings from the body of available literature and highlight areas for further research.

3.3   Methods

3.3.1   Search procedure

A literature search was conducted within four electronic academic databases: Scopus, Web of Knowledge, PsychInfo and Medline. Key terms were entered to search the title and abstract of appropriate journal articles. The terms related to one of three search sets, each comprised of several search terms: 1) The "Auditory Verbal Hallucinations" (AVHs) set was comprised of the following terms: hallucination, auditory verbal hallucination, auditory delusion, inner speech, voices and hearing voices. 2) The "Diagnosis" search set: Schizophrenia, Schizoaffective, Borderline Personality Disorder, Bipolar, Depression, Autism, Asperger, Post-Traumatic Stress Disorder, Psychosis and Psychotic. 3) The "Time" search set: time, longitudinal, follow up, prospective, retrospective, cross-sectional, course, phase, over time, journey, long term, living process, stage period and trajectory. A wildcard asterisk was used to search for associated terms. The key terms were linked with 'or' and the three search sets were linked with 'and'.

3.3.2 Study selection and exclusion criteria

The foundations of CBT therapeutic conversations about psychotic experiences began in the 1960s. Studies from 1960 up to and including August 2013 were reviewed. Studies were included if they were written in the English language. Both quantitative and qualitative methodologies were considered suitable for the purpose of the literature search. Incorporating both approaches allowed for an exploration of the structures and mechanisms appropriate to the research question.

Each paper was reviewed by title, abstract and full journal article. The reference sections of the included papers were reviewed for additional relevant papers that may have been missed by the electronic search.

3.3.2.1 *Quantitative studies*

Quantitative studies were included if they examined voices from more than one time point within a clinical adult population or sub-clinical and/or clinical child population. Papers were excluded if:

a) *People had received either an organic or neurological diagnosis* - the voice hearing experiences might not be ascribed any meaning.

b) *The focus of the study was from a non-psychological perspective* – e.g. examining pharmacological interventions for voices.

c) *Non-verbal hallucinations* – the auditory experience was non-verbal e.g. music.

d) *Did not have a temporal element* – the aim of the review was to examine changes over time.

e) *Non-clinical populations* - the aim of the review was to examine distressing voices.

f) *Non-specific to voice hearing* - studies examining all types of hallucinations which did not specify voices were excluded.

g) *Studies specifically focusing on treatment and therapy interventions* - the aim was to examine changes in experience and not treatment outcomes.

3.3.2.2 *Qualitative studies*

Qualitative studies were included if they explored the experience of voices across time (or included a temporal element) within a clinical adult population or sub-clinical and/or clinical child population. Papers were excluded if:

a) *People had received either an organic or neurological diagnosis* - the voice hearing experiences might not be ascribed any meaning.

b) *The focus of the study was from a non-psychological perspective* – e.g. examining pharmacological interventions for voices.

c) *Non-verbal hallucinations* – the auditory experience was non-verbal e.g. music.

d) *Did not have a temporal element* – the aim of the review was to examine changes over time.

e) *Non-clinical populations* - the aim of the review was to examine distressing voices.

f) *Non-specific to voice hearing* - studies examining all types of hallucinations which did not specify voices were excluded.

g) *Studies specifically focusing on treatment and therapy interventions* - the aim was to examine changes in experience and not treatment outcomes.

There is much debate regarding the relevance of quality criteria for qualitative analysis to the meta-synthesis of qualitative studies, with some arguing that the application of such standards are excessively prescriptive (Barbour, 2001; Daly et al., 2007; Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Lakshman, Ogilvie & Ong, 2009). It was decided a priori not to assess the quality of studies. If studies met the inclusion criteria they were included, irrespective of their quality.

3.3.2.2.1 *Data synthesis*

The studies that were included used different approaches in quantitative and qualitative methods. Research and methods for reviewing systematic reviews of both approaches are still evolving (Lucas, Baird, Arai, Law & Roberts, 2007). Consequently, systematic reviews that synthesis quantitative and qualitative research have used alternative methods (Lakshman et al., 2009; Lucas et al., 2007; Rosewilliam, Roskell & Pandyan, 2011). It was decided that a qualitative thematic method would be used for synthesis.

In order to compare quantitative and qualitative result sections of each study, the methods, results and discussion sections of each paper were entered in a spreadsheet. These were compared for general meaning.

3.3.2.2.2 *Quantitative studies.*

Due to the inadequate numbers of randomized controlled trials, the quantitative research findings could not be meta-analysed. The topic of the findings and conclusions of each study were read several times for meaning and understanding. Each section was open coded systematically. Open coding is a procedure whereby codes are attached to the data during the process of analysis. Data is divided into meaningful segments which

is described by a single word or a few words. In line with the context, the codes were refined.

3.3.2.2.3 *Qualitative studies.*

The findings and conclusions of each paper were read several times for meaning and understanding. Each section was then open coded systematically. In line with the context, the codes were refined.

The codes from both the quantitative and qualitative studies were integrated and further refined. The codes were examined for meaning. The codes were reviewed for patterns across the entire data set which was classified into potential themes. Themes were examined and grouped into overarching themes. The final sets of themes were considered for similarities between the codes. They were compared against the review question - What do we know about the course of hearing voices in clinical populations? The integration of findings offered a holistic view of matters that were significant to the review.

3.4 Results

3.4.1 Search Results

The search produced 2550 results. After excluding 1175 duplicates a total of 1375 articles remained. After exclusion criteria were applied, the final set of journal articles included in the search was 12 (see Figure11.) and consisted of three qualitative studies and nine quantitative studies.

3.4.2 Overview of reviewed studies

A summary of the included journal articles is provided in Table 6. Three of the articles were the result of the same study (Escher et al., 2002a, 2002b, 2004). Five main themes emerged from the analysis of the result sections from the journal articles: 'Adversity and voice onset', 'The course of voices', 'Managing voices over time', Responses to voices' and 'Seeking help' (see Table 7). As there is already a large body of literature concerned with adversity and psychosis (Beards, Gayer-Anderson, Borges, Dewey, Fisher, & Morgan, 2013), the first theme will only be briefly discussed.
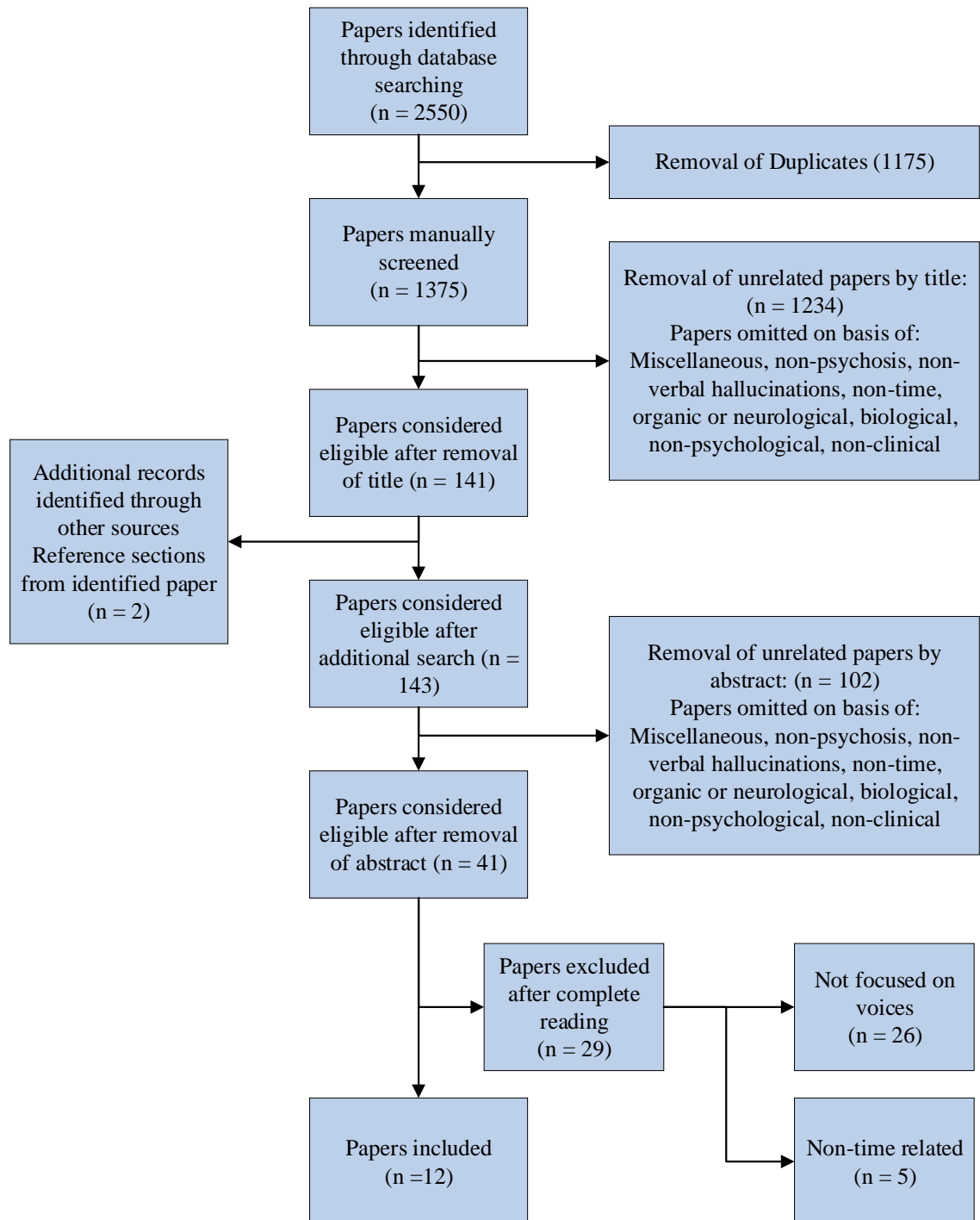
Figure 11 Prisma Flow Diagram of Literature Search

Author	Sample	Methods	Key Findings
Romme et al., 1989	People experiencing voices attending a congress (n=300)	Non empirical. Attendees reports of voice hearing experiences.	Three phases of coping with voices. Startling, Organization, Stabilization
Nayani et al., 1996	Patients experiencing auditory hallucinations (n=100)	Quantitative. Semi-structured questionnaire relating to phenomenological characteristic of hallucinations.	Pattern of increasing complexity of voices over time which related to the lessening of distress and improved coping.
Escher et al., 2002a	Children (n = 80) who hear voices. Patients and non-patients	Quantitative. Measurements of voices, voice attributions, psychopathology, stressful events, coping, dissociation and professional care taken to predict course of voices and patient status. Three-year follow-up	Sixty percent voice discontinuation over 3 years. Predictors of voice persistence: severity and frequency of voices, anxiety/depression, lack of triggers of time and place.
Escher et al., 2002b	Children (n=80) who hear voices. Patients and non-patients.	Quantitative. Measurements of voice appraisals, voice attributions, psychopathology, stressful events, coping, global functioning and professional care taken to predict delusion formation. Three-year follow-up.	Sixteen percent displayed delusional ideation over at least one follow-up period. Delusion formation associated with baseline voice appraisals/attributions, baseline anxiety/depression, baseline disorganization and stressful events.
Escher et al., 2004	Children (n = 80) who hear voices. Patients and non-patients	Quantitative. Measurements of voice characteristics, adversity, psychopathology, social network, Dissociation, global level of functioning. Three-year follow-up.	Need for care in context of the experience of voices is associated with problem behaviour; negative symptoms of psychosis; voice appraisal in terms of anxiety, depression, dissociation and frequency of occurrence.
Cspike et al., 2006	Participants diagnosed with schizophrenia spectrum disorder and hearing voices (n=46)	Quantitative. Measurements of positive, negative and general symptoms, nature, and beliefs regarding voices, anxiety and depression. Six-month follow-up.	Improvement in general psychopathology, severity and frequency of hallucinations. Beliefs about voices remained stable
Askenazy et al., 2007	Children (n=13) outpatients.	Quantitative. Questionnaire on auditory hallucinations. Measurements on traumatic events and DSM IV diagnosis. One-year follow-up.	Fifty-three percent recovered from hallucinations within 3 months (all suffered with anxiety disorders). Thirty percent hallucinations persisted over 1- year (all exhibited conduct disorders).

Chang et al., 2009	Patients who hear voices (n=40) – drug naïve first-episode schizophrenia (n=21); drug-free, chronic schizophrenia (n=19).	Quantitative. Measurements of dimensions of voices assessed prior to antipsychotic treatment and after 6-months of treatment to detect changes in underlying clusters of phenomenological variables.	Phenomenological variables of voices formed two main clusters with 6-month treatment: emotional and cognitive. Cluster structure of first episode group showed more dynamic changes than the chronic group.
Barteils-Velthuis et al., 2011	Children (n=337). Population base	Quantitative. Participants reassessed on voices, 5-year incidence and risk factors. Measures of voice ratings, substance use, cognitive ability and behaviour.	Voice persistence rate 24%; voice incidence rate 9%. Associated with problem behaviour and baseline psychotic symptoms. Persistence predicted by baseline voice severity
De Loore et al., 2011	Adolescents (n=1912). (population base)	Quantitative. Data from general health screening. Two-year follow-up. Measures on psychosis, psychopathology and depression.	Baseline – 5% adolescents reported voices: 27% present at two-year follow-up. Baseline hallucinations associated with depressed mood and psychopathology at follow-up. Voice persistence associated with risk for delusional ideation, depressed mood and psychopathology at follow-up.
Milligan et al., 2012	Patients with psychosis from EIP services who experience voices (n=6)	Qualitative. Semi-structured interview to explore voices over time.	Six themes: Negative Trigger; Voice-Affect Interactions; Rejection; Crisis-induced Change; Discovering, Adjusting and Trying to Cope; New Understandings.
Hartigan et al., 2013	Patients having heard voices for at least six-months (n=18)	Quantitative. Twelve-month longitudinal study. Measurements of relationships with voices, characteristics of voices and beliefs about voices.	Interrelating styles between voice and hearer remained stable. Trend towards a correlation between change in Hearer Distance and intensity of distress. Beliefs about voices' power and malevolent intent remained stable; trend towards beliefs about benevolence decreasing.

Table 6 Summary of the included journal articles

Theme	Sub-theme	Description
1 Adversity and voice onset		Adverse events that precede the onset of voices
2 The course of voices		Described a temporal element of hearing voices and their progression
	2a Voices over the life-course	Described the occurrence of voices over the life-course
	2b Phenomenological course of voices	The phenomenological experiences of voice characteristics over the life-course
3 Managing voices over time		The different phases of coping and managing voices over time
4 Responses to voices		Described changes in response to voices over time
	4aThe hearer makes sense and responds	The relationship between beliefs, experience, response to voices and their course
	4b Voices and secondary delusional ideation	Factors associated with development of voice related secondary delusional ideation
5 Seeking help		Referred to the point of disclosure of voices

Table 7 Summary of themes and sub-themes of the course of hearing voices

3.4.3   Theme 1 Adversity and voice onset

The papers reviewed suggest that adverse events often precede the onset of voices in both children and adults. Escher et al. (2004) report that 75% of participants recounted traumatic events or circumstances at the first voice hearing experience. Incidents beyond the individual's control, such as divorce, intra-familial violence, death of a relative (Askenazy et al. 2007), sexual abuse, long term physical illness and birth trauma, rendered feelings of powerlessness and subsequently, were associated with the arrival of voices (Esher et al. 2004). Milligan et al. (2013) label these adverse events as 'negative triggers.' In their work with Early Intervention for Psychosis (EIP) service users, they described how, for five out of six participants, difficult life events can precipitate and act as negative triggers to the onset of voices. Some hearers will experience negative triggers close to voice onset, while for others a temporal association between the negative trigger and first voice experience is less explicit. In addition, these negative triggers may be comprised of either a series of negative events or a single adverse event.

3.4.4   Theme 2 The Course of Voices

The theme "The course of voices" reflected a temporal element of hearing voices. It focused broadly on the progression of voices and included two discrete subthemes: "Voices over the life-course" and "Phenomenological course of voices".

3.4.4.1   Subtheme 2a Voices over the life-course

Taken together, the papers imply that voices may occur at any point during the life course. Studies examining voice hearing in children reported the onset of voices as young as 6.5 years (Askenazy et al., 2007). Alter natively, as demonstrated in Cspike & Kinderman's (2006) study, voices may begin during adolescents or late adulthood, with onset ranging from 12 to 52 years.

The course of hearing voices is variable. For some hearers the voices will continue throughout the lifetime. For others, voices may discontinue for a time before reoccurring or, in the case of some hearers, stop altogether. Evidence from the review indicates that this variability may be associated with the point of onset in the individual's life. Voices that begin earlier in life seem more likely to discontinue. Escher et al. (2002a) reported an influence of age amongst children, whereby voice discontinuation was associated with younger children and voice persistence with older children. The papers suggest that the majority of voice hearing in childhood tends to cease, with voices stopping before adulthood for between 60% to 76% of children and adolescents (Askenazy et al. 2007; Bartels-Velthuis, van de Willige, Jenner, van Os, & Wiersma, 2011; De Loore et al., 2011; Escher et al., 2002a; Escher et al. 2004;).

Alternatively, with voices that continue, particularly into adulthood, the probability of them discontinuing appears to decrease over time. Chang et al. (2009) found that, at six-month follow-up, voices had stopped for 48% of patients who had been experiencing voices for < 2 years (first-episode schizophrenia); whereas voices persisted for all patients whose voice hearing was >10 years (chronic schizophrenia).

3.4.4.2   Subtheme 2b Phenomenological course of voices

Evidence from the papers implies that the phenomenological experiences of voice characteristics, such as perceived 'severity', 'frequency' and 'complexity', are associated with its subsequent course. Both Escher et al. (2002a; 2004) and Bartels-Velthuis (2011) examined voice hearing in childhood and found that at follow-up, compared to participants whose voices had remitted, voices tended to continue for those whose auditory experiences were rated as more severe at baseline. In addition, Escher et

al. (2002a) also found that voices which occurred more frequently were related to voice persistence whilst those that occurred less frequently were related to voice discontinuation. Similarly, approximately 50% of Bartels-Velthuis et al.'s (2011) participants whose voices persisted also perceived them as continuous.

Over time, for some people, voices may evolve and become increasingly multifaceted, whereby the phenomenology and course of voice hearing develops in complexity. In the first instance, voices may be rudimentary with little dialogue or relationship between hearer and voice. However, if the experience continues, additional voices may be accrued whereby the character of the voice, as well as the relationship between hearer and voice, becomes more intricate (Askenazy et al., 2007; Bartels-Velthuis et al., 2011; Nayani & David, 1996). Voice content may develop in complexity with more words, more emotional expression and with a wider range of grammatical style. Evidence suggests that as voices evolve, an intimacy between hearer and voice may be fostered, leading to an attenuation of the associated distress (Nayani & David, 1996). Nayani & David (1996) found that although people with recent voice onset reported fewer and more primitive voices than chronic hearers, they also reported the experience as more distressing. Conversely, for some studies, hearing more than one voice (Bartels-Velthuis, et al., 2011) or hearing a running commentary between voices (Askenazty et al., 2007) was found to be associated with voice persistence. Yet, for others, the relationship between the number of voices and their continuation appears unclear. Though persistence was associated with those experiencing a greater number of voices (>10), it was also associated with those experiencing a single voice (Escher et al., 2002a).

3.4.5 Theme 3 Managing voices over time

The review suggests that voice hearers may encounter a developmental journey with voices, passing through different phases of coping and managing the auditory experience (Romme & Escher, 1989; Milligan et al., 2013). Romme & Escher, (1989) propose three potential phases of coping with voices: the startling phase (voice onset), the phase of organization (selecting and communicating with voices), and the stabilization phase (managing voices). Milligan et al. (2013) expand upon Romme & Escher's (1989) work and suggest six themes: negative trigger (causative); voice-affect interactions (interaction between individual and voice leading to affective changes); rejection phase (voices denied as part of self); crisis-induced change (crisis leading to

disclosure of voices to others); new understandings (taking a new stance regarding voices); and discovering, adjusting and coping. Findings from the study appear to only partially concur with Romme & Escher's (1989) three phases of coping with voices. However, differences between the studies may be due to diverse populations. Romme & Escher's (1989) findings were derived from 173 individuals from a variety of backgrounds whose voice hearing experiences ranged from weeks to years (exact range of voice duration was unspecified). Sixty percent of participants had received psychiatric care. In comparison, Milligan et al.'s (2013) 20 participants were a clinical population recruited via Early Intervention for Psychosis (EIP) services. Findings from Milligan et al. (2013) may therefore be specific to EIP. Participant ages ranged from 17 to 30 years with duration of voice hearing from 9 months to 23 years.

3.4.6 Theme 4 Responses to Voices
3.4.6.1 Subtheme 4a The hearer makes sense and responds

Meaning and understanding ascribed to the voice emerge through the individual's experience of the voice which in turn, may affect responses to voices and their subsequent course. Voices that are perceived as originating from a secondary external source such as a ghost or spirit have been found to increase the risk of voice continuation (Bartels-Velhuis et al., 2011; Escher et al., 2002a; 2002b; 2004;). In addition, a 'need for care' (receipt of professional mental health for voices) in children was not only associated with negative emotional appraisals of voices, but those in receipt of care were also more likely to appraise voices as influencing their emotional and behavioural responses (Escher et al., 2002a; 2002b; 2004). Evidence implies that this response, and subsequent course of the voice, may be linked to the individual's perceived sense of 'control' over the self in relation to voices. Voices viewed as omnipotent tend to be associated with negative behavioural responses (Escher et al., 2004; Milligan et al., 2013). Milligan et al. (2013) comment that voices believed to be powerful (negative, dominant, and highly believable) facilitate a negative affective and behavioural response such as isolation or attempting suicide. Escher et al. (2004) found an association between problem behaviour and children who believed that they were powerless with regards to their voices and unable to challenge their voices' orders.

The literature suggests that beliefs pertaining to the voices' influence over emotional and behavioural response tend to remain stable over time (Cspike & Kinderman, 2006; Hartigan, McCarthy-Jones & Hayward 2013). Amongst adult voice

hearers, studies found that, regardless of changes in voice frequency, severity, distress or disruption, beliefs endured with respect to voices' intentions (Cspike & Kinderman, 2006) and their 'malevolence' or 'omnipotence' (Hartigan et al., 2013). Even when the characteristics of voices change it seems that beliefs do not fluctuate. However, findings do imply that voices that are believed to originate from the self, afford a sense of agency whereby the hearer is able to decide how they wish to respond to voice-related commands. Romme & Escher (1989) found that over time, those hearers who shifted to an internal explanation (voices are me) were able to choose between accepting and rejecting the advice of their voices.

3.4.6.2 *Subtheme 4b Voices and secondary delusional ideation*

Voices evoke emotional states whereby the individual's appraisal of the experience may result in mood disorders such as anxiety and depression (De Loore et al., 2011; Escher et al., 2004; Milligan et al., 2013). This appraisal can affect the course of voice hearing with heightened levels of anxiety and depression acting as predictors of whether voices continue or discontinue (Askenazy et al., 2007; Escher et al., 2002a; 2004). In addition, in an attempt to explain abnormal perceptual experiences with voices, hearers may develop secondary delusional ideation (e.g. voice is caused by a ghost). Findings suggest that anxiety and depression (as well as disorganisation, stressful life events, appraisal of voice, perceived location of voice and identity of voice) are associated with the formation of such delusional ideations (Escher Romme, Buiks, Delespaul & van Os, 2002b).

The literature implied that, for those whose voices persist, there is an increased risk of developing a secondary delusional belief system (beliefs arising from an interpretation of the phenomenon and its effects). De Loore et al. (2011) found that children and adolescents whose voices continued after a two-year follow-up were more liable to report the formation of secondary delusions than those without voices. Similarly, Nayani & David (1996) report that chronic voice hearers (>1 year) were more likely to present a delusional construction as to the meaning and purpose of voices (e.g. a government conspiracy) than hearers whose voice onset was more recent (≤ 1 year). Taken together these findings suggest that, as voices continue, the sense that individuals assign to their experiences develops in complexity over time.

3.4.7   Theme 5 Seeking help

The review suggests that people may encounter a juncture within the course of hearing voices, whereby the experience, which may have been kept a secret, is disclosed to family, friends and professional mental health services. Disclosure can lead to a range of positive or negative changes in the voice hearing experience, resulting with the hearer divulging experiences and seeking help from mental health services (Milligan et al.2013). According to findings, these services may provide support through promoting feelings of safety; support in the environment; ego-strengthening; working through problems at the root of the voices (Escher et al., 2004), facilitating coping with voices and improving self-confidence (Milligan et al., 2013).

According to Escher et al. (2002a), professional health care may not be associated with whether or not voices continue. The authors found that although 50% of children whose voices discontinued received professional care, 50% whose voices persisted also received professional health care. In addition, after assessing which form of care may be the most successful, with respect to child development as well as voice discontinuation, receipt of 'no professional care' was found to be the most effective followed by 'professional care with supplementary care' with no supplementary care such as homeopathy; therapy from paranormal healers (focus on restoring harmony between energies; and haptonomy (physical contact between therapist and patient). The provision of 'Professional mental health care only' did not appear to be as effective as 'no professional care' or 'professional care with supplementary care.' However, Escher et al. (2004) note that the findings may be accounted for by the fact that some of those who received 'professional mental health care only' also experienced other mental health problems such as ADHD and learning difficulties.

3.5   Discussion

The purpose of this review was to consider what is known about the course of voice hearing over time. The results from twelve papers which examined the phenomenon from a qualitative, quantitative or mixed methodology were appraised. Taken together, the studies suggest that the path of hearing voices is heterogeneous; one that may be influenced by factors such as life events, help from others, other mental health illnesses, cognitive responses, emotional responses, and behavioural responses. Voices may continue or discontinue however, for hearers whose voices persist, it

appears that for some the phenomenological experience evolves and the likelihood of voices ceasing decreases overtime.

Five themes associated with the course of hearing voices were generated and suggested an influence of: adversity in relation to voice onset; age of onset and duration of voices in relation to the likelihood of discontinuation and evolving complexity; changing experience and reactions to voices through different phases of coping; the appraisal of voices and associated emotional and behavioural responses; and the breadth of help offered by mental health professionals.

The findings from the review can be compared to the broader literature. Consistent with previous research, social adversity that occurred in childhood (Varese et al., 2012) or adulthood (Beards et al., 2013) tended to precede the onset of voices. However, as suggested by Larøi et al. (2010), the subsequent journey with voice hearing was idiosyncratic and influenced by various factors. The review supported existing arguments that age of onset, frequency and duration of voice hearing affect the likelihood of voices continuing or discontinuing (Johns et al., 2014; Daalman et al., 2011). For example, voices that begin earlier in life were more likely to discontinue. Rubio et al. (2012) claim that hearing voices is typical in the developmental pathway of childhood and that voices only continue for a subgroup of hearers. The findings of the review indicated that for voices that continue into adulthood, the prospect of them ceasing decreased over time. These findings raise the question as to whether there may be a critical period during the course of the experience when voices are more likely to become established and less likely to discontinue. Given that the prolonged length of duration of untreated psychosis is linked to poorer outcomes (Boydell, Gladstone & Volpe, 2006), the offering of therapy at an early stage of voice hearing may be indicated.

The suggestion that the course of hearing voices is mediated by the appraisal and beliefs individuals maintain about voices is in line with cognitive models of voice hearing (Chadwick & Birchwood, 1994; Morrison, 1998). How voices are appraised appears to reflect the individual's self-perceived power or powerlessness in relation to the phenomenon. This sense of powerlessness, and inability to cope with voices, has been shown to mirror beliefs regarding one's social schemata, and is often reflective of adverse circumstances (Paulik, 2012). Evidence suggests that maladaptive responses to the experience may therefore stem from a sense of helplessness which is maintained by perceptions of the voice as omnipotent (Mawson et al, 2010). Voices that are believed

to originate from an external source and are experienced as threatening and controlling tend to result in feelings of distress (Johns et al., 2014). Our findings suggested that negative metacognitive beliefs about voices remain stable over time and also facilitate the development of secondary delusional ideation. Consequently, therapeutic intervention may be necessary to influence these beliefs and reduce their influence upon the maintenance of distressing voice hearing experiences (Hartigan et al., 2014).

Romme & Escher, (1989) and Milligan et al. (2013) propose a recovery pathway whereby hearers encounter changes with the experience of hearing voices. Both models imply a journey of exploration and discovery as hearers search for different ways of coping with the phenomenon. Milligan et al. (2013) expand upon Romme & Escher's proposed three-phases and suggest five themes associated with the trajectory of voice hearing. Despite both representing a recovery pathway of voice hearing, the models only partially concur. Firstly, as evidenced within the broader literature (Beards et al., 2013; Varese et al., 2012), negative life events acted as a precursor to voice onset within the Milligan et al., model. Although Romme and Escher do not incorporate this stage within their recovery model, the authors cite adverse events as a trigger for distressing voices. Secondly, Milligan et al. were unable to substantiate Romme & Esher's 'startling' phase but advocate that it may be part of a wider 'rejection' of voices - a stage that incorporates the fear and confusion associated with the onset of persecutory experiences such as voices (Boyd & Gumley, 2007). Finally, Romme & Escher suggested that individuals whose voices persist move towards a final stage of 'stabilisation', whereby voices are assimilated into everyday life. Milligan et al.'s (2013) model does not evidence 'stabilisation' but proposes a pre-cursor stage (new understandings) where attitudes towards voices are more ambivalent. Taken within the wider literature, these findings suggest that, over time, hearers can build a stable and consistent relationship with voices. However, reaching this stage entails a process of acceptance, enquiry and a change in reactions and responses to voices (Fenekou, & Georgaca, 2010).

The review indicates that there is no conclusive empirically supported theoretical model as to the phases individuals may encounter when managing the experience of hearing voices. This may be attributable to a reliance upon retrospective accounts of the voice hearing journey. Therefore, when attempting to identify the different phases of coping and managing voice hearing, there is a need for research to examine this matter within a longitudinal methodological framework. The findings

suggest that further investigation is needed in order to understand the course of hearing voices.

3.5.1 Limitations

The aim of the review was to undertake a comprehensive appraisal of the literature examining voice hearing in conjunction with a temporal element. Due to the dearth of literature a decision was made not to exclude studies on the grounds of quality. Therefore, a number of the studies included in this review presented methodological issues and, consequently, findings are limited.

One limitation of this review concerns the variation in sample size and, in particular, quantitative studies with a small sample size: Askenazy et al. (2007), Chang et al. (2009), Csipke & Kinderman, (2006) and Hartigan et al. (2013). The plan of analysis was let down by small sample size. This point is demonstrated through Askenazy et al.'s (2007) research whereby, due to the small data set, descriptive findings are presented. A small sample indicates that a study may be underpowered and therefore is unlikely to detect significant changes within the data.

A second limitation relates to the fact that there does not appear to be a collective definition of the term 'persistent voices.' Studies included in the review investigated factors associated with voice continuation and discontinuation. De Loore et al. (2011) classify 'persistence' as hearing voices at both baseline and follow-up. Similarly, and Askenazy et al. (2007) defined 'persistence' by the presence of voices at baseline and follow-up. Alternatively, Bartels-Velthuis et al. (2011) distinguish 'persistence' by voices present during the year prior to baseline and (intermittently) at least one other year during the follow-up period. While 'persistent' voices do not seem to be clearly defined by Escher et al. (2002a).

Three of the papers (Escher et al., 2002a; Escher et al., 2002b; Escher et al., 2004) resulted from the same study and were therefore subject to the same methodological weakness. For example, one weakness of the study was the heterogeneity of the sample with regard to age. Due to the wide age range between the participants, differences within developmental cognitive abilities (ref) may have acted as cofounding variables within the analysis of the data. This would have been a methodological weakness of all three papers.

3.6 Clinical Implications

The literature that was reviewed implied that individuals negotiate a complex

path with voices. This voice hearing journey may be influenced by numerous associated factors which influence the onset and experience of the phenomenon. An empirically supported model illustrating different stages of hearing voices would facilitate both hearer and clinician to determine the optimum time for psychological intervention. In addition, given that a recovery model would outline changes in the voice hearing pathway, the appropriate psychological intervention could be used to target a particular stage. For example, during the initial stages of the pathway brief, low intensity interventions such as: Coping Strategy Enhancement (method which teaches coping skills for positive symptoms of psychosis) (Tarrier et al., 1990) may be apt to foster ways of managing voices; or Compassion-focused therapies (CBT therapy focusing on teaching skills and characteristics of compassion) (Mayhew & Gilbert, 2008) could be used to help self-esteem, anxiety, depression and shame with adverse events. Alternatively, just starting a discussion on the individual's experiences with voices may be appropriate to the stage. Over time, as hearers' progress, targeted cognitive behavioural therapies (Haddock et al., 1998) may be used to work with the negative appraisal of voices, to help feelings of empowerment and diminish voice-related distress (Johns et al., 2014). Overall, it would be clinically beneficial to understand at which stage, and how ready, the hearer is to receive a particular psychological intervention.

3.7   Future Research

It is evident from the review that there is a dearth of studies examining the course of hearing voices from a longitudinal methodological framework. Given the reliance on retrospective accounts, which may be subject to bias and unreliability, further research should engage individuals as close to voice onset as possible.

In working with younger adults, key periods of the voice hearing journey may be explored affording a richer understanding of the evolution of voices. Further research is required to explore the course of hearing voices with populations derived from EIP services. This would consider methodological issues such as data derived from retrospective reports and allow for a longitudinal design. Milligan et al. (2013) suggest that a longitudinal qualitative study is needed with EIP service users to understand why and how the various transitions occur through the hearers' journeys with voices.

In conjunction with the themes identified within this review, findings from a qualitative longitudinal study with EIP participants identified areas of importance for future research. A valuable research question would focus upon whether or not voice hearers enter different phases of managing voices, and if they do, what these phases

signify? Is there an optimum phase for individuals to engage with therapeutic interventions? The literature review examined responses to voices; how appraisals and attributions may affect the individual and the course of their experience. By employing qualitative methods, research could explore how the belief system develops over time and how this may be associated with the increasing complexity of the voice hearing experience.

A study working with service users over time would explore people's journeys with voices and may elucidate different phases of managing voices. Findings could facilitate the development of an empirically supported model illustrating these phases. Such a model may provide further insight as to when (and type of) psychological therapeutic intervention is required. For example, how can clinical services support 'adversity and voice onset?' What can be done to encourage 'seeking help?' Does understanding the 'course of voices' help hearers with 'response to voices' and 'managing voices over time?'

4. "That little doorway where I could suddenly start shouting out": barriers and enablers to the disclosure of distressing voices

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4.1 Abstract

Hearing distressing voices is a key feature of psychosis. The time between voice onset and disclosure may be crucial as voices can grow in complexity. This study investigated barriers and enablers to early voice disclosure. Interviews with 20 voice hearers underwent Thematic Analysis. Beliefs about the effect of disclosure on self and others acted as a barrier and enabler to voices being discussed. Voice hearing awareness should be increased amongst young people, the public and care services. To support earlier disclosure measures need to increase skill amongst those likely to be disclosed to.

Keywords: hallucinations, voice hearing, psychosis, schizophrenia, disclosure.

4.2 Introduction

The Duration of Untreated Psychosis (DUP) is the time between the emergence of the first psychotic symptom and the start of effective treatment (Padilla et al., 2015). Longer DUP is associated with poorer outcomes, and shorter DUP with better outcomes (Padilla et al., 2015). Consequently, there is a need for early detection of first-episode psychosis to reduce DUP (Penttila et al., 2014; Yung et al., 2007).

Psychotic disorders are typically preceded by low-level signs of psychosis, a prodromal at-risk mental state (ARMS) (Yung and McGorry, 1996). Due to fears of 'going mad' and negative reaction from others, ARMS individuals often delay disclosure and help-seeking (Byrne and Morrison, 2010). Those who progress to first-episode psychosis may still not seek help as they (and others) may not recognize symptoms of psychosis, deny warning signs of illness, or fear involvement with mental health services (McGlashan, 1999). Stigma, shame and a lack of mental health literacy are barriers for people seeking help for mental health problems (Bay et al., 2016; Gulliver et al., 2010). Furthermore, people tend to be unaware that voice hearing is a primary symptom of psychosis (Bay et al., 2016).

Although hearing voices is a common and often distressing symptom of psychosis (Aleman and Larøi 2008), many are reluctant to disclose voices at initial onset (Milligan et al., 2013). During the 'startle phase' when voices first occur, the hearer may not confide in others due to confusion about their experiences, the content of their voices or concerns about others' responses (Beavan et al., 2011a; Boyd and Gumley, 2007). Disclosure of voice hearing is often met with negativity and considered a sign of 'madness' (Romme et al., 2009). Negative stereotypes may be internalized, eliciting fear and apprehension of the stigmatizing costs of mental illness (Vilhauer, 2017).

Feared negative responses from others and internalized self-stigma may result in the hearer choosing to keep voices a secret (Boydell et al., 2006; Vilhauer, 2017). Milligan et al. (2013) proposed that help-seeking tends not to occur until the individual encounters a crisis regarding their experience with voices. During the time between onset and disclosure, voices may increase in complexity, with the hearer becoming progressively entrenched in the experience (Yung et al., 2007), intensifying the risk of delusional ideation and general psychopathology (De Loore et al., 2011). It is therefore important that help is sought as near to the onset of voices as possible, that barriers to

early disclosure are understood, and that processes underlying the development of voices and delusions are explored.

The present qualitative study explored voice hearing in patients with first-episode psychosis from Early Intervention for Psychosis (EIP) services. Exploration of our research question - what are the barriers and enablers to the disclosure of distressing voices to family, friends and health professionals? – can inform both theories of disclosure (e.g. Disclosure Decision-Making Model; Greene, 2009) and interventions designed to promote early disclosure.

4.3 Methods

4.3.1 Design

This study was part of a longitudinal mixed-methods project examining people's journeys with hearing voices over time, identifying different phases of managing voice hearing, and how these affect therapy.

In this study, we explored data from time one (T1) interviews designed to capture hearers' experiences of voices from time of onset. We employed a qualitative inductive approach to explore the disclosure of distressing voices among EIP service users. Due to the limited literature in this area, an inductive approach was appropriate for gaining a deeper understanding of: why, when and how hearers decided to disclose voices; barriers or enablers to disclosure; and processes of seeking help. We took a critical realist perspective which argues that an external world independent of human consciousness exists, but that perception and understanding of it is socially determined (Danermark et al., 2002). Analysis paid attention to each participant's experiential truth but acknowledged that participants sometimes described as real phenomena that may not have been real. Thematic Analysis was appropriate for exploring how understanding of these phenomena may have changed over time.

4.3.2 Participants

Participants were 20 purposively selected EIP service users in Sussex (n=17) and Manchester (n=3). EIP services are for people with first episode psychosis or 'at risk mental states'. They have a philosophy that focuses on managing symptoms rather than diagnosis and work within diagnostic uncertainty (Baird et al., 2012). Inclusion criteria required that service users were currently experiencing voices and had been doing so for at least three months. Service users were excluded on the grounds of organic illness or if

voices were the result of substance misuse (as determined by EIP service practitioners). The sample consisted of 12 men and 8 women aged 19 to 35 years ($M = 25. SD = 4.7$; $Mdn = 24$). Age of voice onset ranged from 6 to 32 years ($M = 19, SD = 6.8; Mdn = 19$). Voice duration ranged from less than 1 year to 21 years ($M = 7, SD = 6.8; Mdn = 3$).

4.3.3   Procedures

All procedures were approved by the relevant NHS Research Ethics Committee. Prior to interview, clinicians discussed the study with service users and offered them a participant information sheet (PIS). The first author contacted service users (only those that had given permission) 24 hours after receipt of the PIS. Interviews were arranged at either NHS premises or at participants' homes.

After obtaining written informed consent, participants completed semi-structured interviews conducted by the first author. Open-ended questions allowed self-reflective and exploratory dialogue that generated new questions specific to each interview. The interview schedule reflected the aims of the broader study: to understand people's journeys with distressing voices over time. The research team discussed key areas of interest for the T1 schedule which focused on voice onset to current interview. Of relevance to this article were questions on: first voice experience; changes in experience; meaning and understanding ascribed to voices; seeking help; experiences of therapy; effects of voices; relationship with voices; and managing voices. Interviews lasted between 27 and 85 minutes and were digitally recorded.

4.3.4   Analysis

Inductive Thematic Analysis (TA) was conducted following Braun and Clarke's (2006) six-phase guide: 1) transcription; 2) reading and familiarization of transcript; 3) coding; 4) searching for themes; 5) reviewing themes; and 6) defining and naming themes. TA permitted an in-depth understanding of participants' voice hearing experiences with an exploratory non-theoretical approach. Although theories exist regarding barriers and enablers to disclosing stigmatized health conditions (e.g., Greene, 2009), the aim of the T1 interviews was not to test hypotheses, but to apply an inductive, bottom-up approach where themes emerged through participants' accounts of their experiences with voice hearing.

Interviews were transcribed verbatim and anonymised. Under the supervision of the research team, the first author coded each transcript systematically. The team

reviewed the codes for patterns across the entire data set, which through a process of comparison and discussion, were classified into potential themes and entered into thematic tables and diagrams. The thematic tables and diagrams were reviewed independently and as a group, and once consensus had been reached, themes were re-examined for links and grouped into higher order themes. The final set of themes was compared against the research question for meaning and significance.

Several attempts have been made to define quality in qualitative research: whereas there may be agreement about the broad issues, it is unlikely that any one set of criteria will be applicable to a diverse range of qualitative methods (Mays and Pope, 2000; Tracy, 2010; Yardley, 2000). Our approach to analysis was guided by Yardley's (2000) call for qualitative research to demonstrate sensitivity to context, commitment to rigorous analyses; transparency and coherence of methods and analysis; and an interest in research impact.[2]

4.4 Findings

Analysis identified three higher order themes and their sub-themes. Each is described and illustrated below.

4.4.1 Theme 1. Effect of Disclosure on the Self

Participants gave much consideration to the pros and cons of disclosure. This often entailed a process whereby the presence of voices had to be acknowledged (What problem?), which also meant coping with the embarrassment of being a voice hearer and identifying as someone who has mental health issues (I feel too ashamed). In many cases, seeking help was not initiated until it became necessary and voices could no longer be endured alone (Reaching desperation).

4.4.1.1 Subtheme 1a. What problem?

Part of the process of discussing voices involved acknowledging that a problem existed. In some cases (7/20), denial of voices, or that voices were an issue, was a less fearful option than admitting to a socially stigmatized experience. However, as the distress and a battle with voices continued, accepting their presence could no longer be avoided. Participant 17 came to realise that in order to obtain relief they needed professional support, and that meant disclosure:

I'd been kind of running away from it, you know. Trying to ignore it for so

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[2] For an expanded version of the methods section please refer to Chapter 2, 'Methodological Overview'

long and I just didn't think that I could do that anymore. It's one of the
reasons why I decided to, to get help a couple of years ago. But I struggled
with it for quite a long time before I actually admitted that there was a
problem. [P17]

Even when voices were acknowledged, if the experience did not significantly
affect everyday life, then disclosure was not considered essential. Hearing voices
intermittently was not recognized as a problem that required professional help. Voices
were accepted as something that occasionally interfered with life, and needed no further
enquiry:

Was [hearing voices] a problem then, or not?
I wouldn't have said so. I said now and again it became a problem like when
it did distract me but not like now ... It didn't have a big massive impact on
my life really. [P16]

However, as voices became more insidious and their frequency increased, P16
realized that voices were not trivial and were starting to become a major part of her life.
Similar to other participants, her need to discuss them changed, as they could no longer
be kept as a private experience: "it became really bad". Voices were now an occurrence
that she could neither disregard nor live with.

For a few (2/20), voices alleviated the isolation of their social lives. Despite their
negative voice content, voices were a constant companion that could relieve loneliness;
the absence of this companion was a greater fear than the anguish caused by its
presence. This acted as a barrier to voice disclosure. Remaining silent and existing
within a dysfunctional relationship with voices was preferable to disclosing and risk
losing them:

I never really had many friends. Probably like one or two friends. And [the
voice] was constantly there so I regarded it as a friend. Even though it was
horrible it was there. And I say, I found myself talking to it and yeah, just I
felt scared you know. I felt it, like it, it was there with me, like having your
best friend with you constantly. Yeah, it's that, I don't really, I just felt scared
of losing it. [P18]

4.4.1.2 Subtheme 1b. I feel too ashamed.

Participants (5/20) described how their understanding and perception of voices
was either a barrier or enabler to disclosure. For some, beliefs about what it meant to
hear voices evoked feelings of shame. The self-stigmatization of identifying as 'crazy'

meant that hearing voices was an embarrassing experience best concealed:

Did you tell anybody?

No! No, I felt really ashamed 'cause you know when you think "ah, you're hearing voices" you felt a bit crazy and mental you know. So I kept it for myself for a very long time. It's not 'til erm, I told. I didn't tell my mu- I didn't tell my family for months, and months, and months. I kept it to myself. [P9]

For other participants, awareness of self-stigmatization and others' stigmatization prompted them to challenge unhelpful common beliefs and to begin a process of enquiry of finding opportunities to talk about voices:

I felt the need to talk about it because there's a lot of stigma around it and I was internalizing the stigma about it. So I felt like I had to sort of say "Well it doesn't mean I'm a psycho." So I try and explain it to people and see what they thought it was as well. [P10]

4.4.1.3 Subtheme 1c. Reaching desperation.

As voices continued, a vital point in the journey was reached: hearers felt that they had no other alternative but to disclose their experiences, enabling them to seek professional help and support from others. Despite feeling ashamed, participants (10/20) reached the point of desperation whereby they needed to disclose negative feelings associated with voices. In some cases, talking about these experiences became paramount and facilitated discussions with others. For example, for P9 low self-worth, shame and helplessness reached a stage whereby voices no longer acted as a barrier to disclosure:

That's when I had to sort of tell them because I couldn't hold it in anymore, like I had to tell someone. Even though like you do feel like really ashamed and like beaten. [P9]

Some participants were so intimidated by their voices that this became another barrier to disclosure. Yet, for P9, taking the risk of revealing her experiences when an opportunity arose was a chance she could not miss. In spite of her voice screaming threats, P9 too needed to scream for help:

[The voice] was shouting at me at this point. Sort of saying like "Shut up! Don't say anymore. What are you doing?" sort of thing. But, I just literally couldn't help it. I felt like I had that little doorway where I could suddenly start shouting out. Sort of telling people what was going on. [P9]

Over time, as resources to cope with voices became depleted, and voices' negative effect on self-worth and lifestyle could no longer be tolerated, participants were ready to seek help. For example, P4 was homeless, and tired of unemployment and the constant battle with voices and their consequences for his life. Worn down, and in need of self-respect, he had had enough and decided it was time to discuss his voices:

> *Why do you think you mentioned it then?*
>
> Just because I'd heard, had enough of, of liv-living with like the way I was living you know, homeless. Ob- you know obviously hearing voices and not able to hold down a job you know...
>
> *Why do you think changed, it, you started to react to them more?*
>
> Well, I've just got older and, and , and my, you know my mental, mental and physical resources aren't, aren't as power- powerful as strong as they used to be ... Just wanna put an end, just wanna put a, put an end, an end to t-to the to the insults you know. Just wanna … I just wanna, just wanna have respect. [P4]

The monotony of living with voices on a daily basis, and the associated negative feelings, led to suicidal thoughts for some participants. Questioning what a life with voices meant resulted in desperation whereby disclosure or suicide were weighed against each other and considered as the only available options:

> I just thought "There, there must be something better than waking up and feeling like this every day. Like, there must be. This, this can't be sort of it, really. Like this can't be what life is?" So I was just like "maybe I should [disclose voices]" I think it was like a final step really. I thought "You know what? I will see what happens. If it doesn't work out then I'll know, that if it doesn't work out, and therefore I'll think" I was thinking that I would end my life. [P14]

4.4.2   Theme 2. Effect of Disclosure on Others

In weighing up whether voices should be revealed, many interviewees considered the potential impact of disclosure upon others: the needs of others ('Concerns about others'); and the reactions of others (How will they respond?).

4.4.2.1   Subtheme 2.a. Concerns about others.

Some participants (5/20) worried that disclosure of voices would cause anguish to, and place a burden on, significant others in their lives. Consequently, revealing

voices was not always a feasible option:

> *Did you tell anybody about it?*
>
> No!
>
> *Why not?*
>
> I wanted to help myself. I wanted to get rid of it myself instead of putting
> the burden on other people. [P12]

Most participants disclosed their voices to significant others such as parents or partners, but only after a period of time. However, P19's sense of responsibility to his family meant that they were entitled to know about his voices at onset:

> I think I left it about an hour after it [voice onset] ... I sat upstairs by
> myself trying to make sense of things, trying to figure out what was going
> on. Then just decided: "No! Nothing's working." Sort of called my mum,
> my dad; went straight down the urgent treatment centre at the hospital and
> got some, got seen...
>
> *Right! So very quickly you told everybody about it.*
>
> I, I figured especially my mum, my dad, my partner was out at the time but
> I did get hold of her and tell her. Especially they're, they're the most three
> important people to me so they're the people who need to know what's
> going on. [P19]

4.4.2.2   Subtheme 2.b. How will they respond?

Anticipation of how others may react affected most participants' (13/20) decisions to disclose. Other people's experiences, understanding and attitudes towards mental health issues functioned to either discourage or encourage participants' willingness to reveal and discuss their voices. In some cases, the decision not to disclose was bound within a history of family mental health issues and related stress. Awareness of these existing stressors influenced interviewees' reluctance to share their experiences, resulting in a belief that disclosure would add to family pressure and that voices needed to be managed alone:

> *As you got a bit older with your voice, why did you not tell anybody?*
>
> I really don't know ... I just thought like, well my dad, my sister's suffered
> with mental illness ... I knew that I didn't want to put any more pressure on
> my dad ... I think I felt a bit scared. I thought of my dad going through all
> that with my sister I didn't want to put any more pressure on him. So again
> it was that thing of not worrying anyone else, sort of deal with it on my

own. [P18]

Alternatively, growing up within a family culture of mental health problems where voices were accepted and integrated within family norms meant that P15 was at ease discussing his experiences:

> *How were your family when you told them?*
>
> Yeah, they're f- we had family fully of, a fam- our family history full of people with mental illness. So my mum's mum heard voices. Her dad heard voices and I think her aunties heard voices. So it's not you know, they weren't too shocked. They were a little bit like "for God's sake here we go again." [P15]

However, believing that he would be judged negatively, P15 was not willing to talk about voices with those who had not had similar experiences. He felt that other people who had not faced mental health issues would be prejudiced towards someone who experienced voices. Deeming himself vulnerable to their lack of understanding, P15 felt uncomfortable with exposing voice hearing to his friends:

> *Why do you not tell your friends?*
>
> 'Cause I don't, I think they'd think I was barking [mad]. Yeah!
>
> *How do you think they would react?*
>
> Erm, not very well I don't think. No! [P15]

4.4.3   Theme 3. Help-Seeking

When they reached the point of wanting help from others, hearers needed to have someone to talk to. In a few cases (3/20), social circumstances influenced beliefs about the availability of others and whether disclosure was a viable option:

> I never said anything 'cause I never had nobody to tell really. Like at what, and I was, a partner or anything like that. I wasn't close to my family. My mum and dad had just been divorced and it was just, there was so much going on I didn't feel I was able to talk to anybody at the time. [P16]

Help from others was not the norm for some participants, because of past experience and/or gender stereotypes. Despite struggling with his voices, P18 was uncomfortable sharing personal experiences. He had never been shown how to, or acquired the language to, express his feelings:

> I just found it hard to deal with on my own but all my life I've sort of tried to deal with things on my own ... I know my dad's the same. He never, he

never wants to sort of ask for help and I've never seen my dad ask for help
so I don't know. It's like I never really spoke about anything as well
because I never saw my dad, my brother or my granddad sort of show any
emotion. So I never saw them crying. I never saw anything. So I just
thought "it's not a man" sort of, no "a male sort of thing to do." So I just
kept it all in. [P18]

Even when wanting to seek help, the disorientation and fear that rose from their
experiences with voices left some participants feeling confused and unable to determine
who they could talk to or where they could get support:

I was a bit confused. Confused and frightened. I didn't know who to turn
to. [P14]

4.5   Discussion

Concerns about how talking about voices might affect the hearer and significant
others influenced decisions to disclose. Hearers did not always acknowledge voices; if
voices were acknowledged, struggles with voices were not always recognised. Some
participants described a cognitive shift regarding disclosure; a process that moved from
denial (barrier) to acceptance that voices were present and distressing (facilitator). If the
perceived benefits of hearing voices (e.g., companionship) were considered to outweigh
the perceived benefits of disclosure, then this transition was delayed. However, even if
voices were acknowledged and help wanted, stigma often affected whether voices were
revealed. The majority of participants reached a stage whereby beliefs concerning the
adverse effects of disclosure were outweighed by the adverse effects of remaining
silent.

The second higher order theme addressed the role that others play in disclosure.
Participants' beliefs about the effect that revealing voices would have on family and
friends influenced their decision. Voices were viewed from opposing perspectives: a
liability that should not be shared; or something that, if remained undisclosed, was a
betrayal to significant others. Experience of family and friends' attitudes towards mental
health also affected decisions: positive approaches encouraged disclosure whereas
negative experiences evoked concerns and reluctance.

A third theme illustrated how seeking help could be complex and more than just
a decision to disclose. Hearers were not always accustomed to asking for support or
confident that they could express their experiences. In addition, not everyone had a
trusted other to confide in. How these themes relate to the disclosure of voices within

this study can be seen in Figure 12.
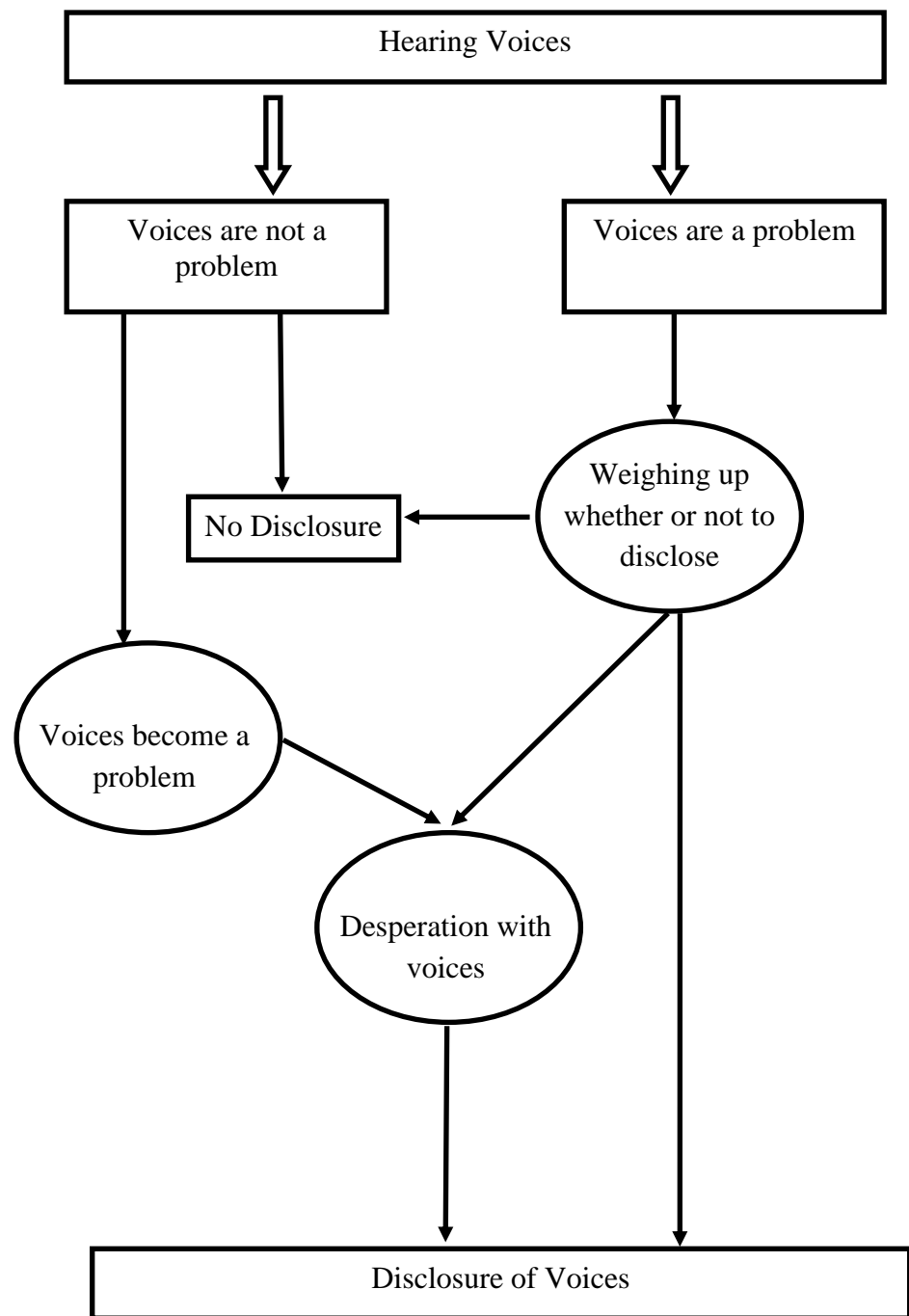
Figure 12 Disclosure of Voice Hearing

As in previous studies, participants were generally reluctant to disclose voices: delays in seeking help were associated with denial (McGlashan, 1999), misinterpretation of symptoms (Phillips et al., 1999) and fear of stigmatization (Compton et al., 2008). Our results partly concur with previous findings that fear of being judged negatively is related to not disclosing (Bay et al., 2016; Sickel et al., 2016). Alternatively, Bril-Barniv et al. (2017) found that, for some, mental health disclosure was a proactive decision, attributed to an effort in encouraging social change. Similarly, the present study showed that, in certain instances, the motivation to disclose cantered upon confronting negative perceptions and exploring the meaning of voices with others. These differing approaches may reflect broader styles of recovery from psychosis: "integrators" seek to understand psychotic experiences and draw upon others' support, whereby those who "seal over" may reject the existence or severity of the illness (McGlashan, 1987).

Milligan et al. (2013) proposed a "Rejection" phase whereby voices are denied by the hearer as part of themselves. The present study expands upon this phase and suggests that, even if voices are accepted as part of the self, hearers may deny their negative effect, deny that their presence indicates a serious mental health issue, and reject that this needs to be addressed. Consistent with cognitive models of voices (Morrison, 2001), the idiosyncratic nature of any rejection of voice hearing experiences was influenced by how hearers interpreted their experiences. Similarly, Milligan et al. (2013) discussed a period of "Crisis-induced Change," where a key negative event with voices results in either a positive or negative change. Although our findings partially concur with this theme, positive change (disclosure to others) was not due to a significant event but the cumulative effect of living with the distress of voices over time (c.f. de Jager et al., 2016).

Perceptions of others' reactions to disclosure were also influential. Boydell et al. (2006) found that young service users (with first episode psychosis or schizophrenia) often hid symptoms from family to avoid worry. Although several participants in our study echoed this point, those growing up in a social context where mental health issues were accepted found disclosure easier.

For some participants, disclosure of voices did not occur despite treatment for other mental health issues. This suggests that mental health stigma is hierarchical, with schizophrenia and psychosis symptoms carrying the most stigma. Whereas public awareness of depression, anxiety and eating disorders has improved, schizophrenia and

hearing voices are often associated with danger, leaving hearers unwilling to discuss voices (Ruddle et al., 2011). Delays in disclosure raise questions as to why health professionals may not detect or discuss voices sooner. Health professionals can lack confidence to discuss voice hearing, and feel limited in their capability to adequately support hearers (Coffey and Hewitt, 2008).

The observation that hearers decided to disclose when the cost of non-disclosure was considered greater than the cost of disclosure corroborates theories of disclosure regarding stigmatized conditions (Greene, 2009; 2014). Reservations around voice disclosure and help-seeking may have long-term effects upon the progression of the hearer's experience with voices. Disclosure models of stigmatized health conditions tend to focus upon post-diagnosis disclosure whereby first disclosure has already occurred, but we examined voice hearers' decision-making processes prior to first disclosure of a symptom. The present findings also suggest that, amongst some hearers, acceptance that voices are distressing, and that support is required is an antecedent of the disclosure process. Consequently, our data offers insight into the processes of first disclosure among people who live with a stigmatized health condition. In addition, through focusing on a single symptom (hearing voices), this study adds to the literature on the disclosure of mental illness (Bril-Barniv et al., 2017).

4.5.1 Implications

The findings indicate a need to explore and challenge barriers to disclosure. There is also a need for strategies that focus on a) facilitating hearers to disclose voices at onset and b) encouraging positive responses from individuals who receive disclosure. As these issues operate within a multi-social context, we advocate a multi-dimensional approach targeting children and young people, the public, primary, secondary and tertiary care services.

Family involvement is key to facilitating pathways to care (Morgan et al., 2006), highlighting the need for education around initial symptoms of mental health issues and the necessity for early intervention (Boydell et al., 2006). We agree with Mueller et al. (2016) that educational programs encouraging a positive, informed and de-stigmatizing outlook towards mental health issues should be implemented in schools. The introduction of such a program at a time when children are beginning to comprehend rules of social desirability may help to reduce the stigma associated with hearing voices. An educated understanding of mental health problems from an early age could also

enable young people to recognize symptoms of psychosis, encourage self-enquiry into one's mental health, and support those distressed by voices to make informed choices about help-seeking.

If hearers feel confident of receiving a positive response from others, then they may be encouraged to disclose voices nearer to onset. The success of large scale campaigns aimed at de-stigmatizing mental illness is uncertain (Clement et al., 2013). An alternative approach is the "Headspace" model, which focuses on engaging young people with mental health services through integrated and coordinated specialist youth and carer-friendly services that address mental health, physical health, work/study, or substance misuse (Malla et al., 2016; McGorry et al., 2007). An online support service also allows young people to access professional help and advice (Malla et al., 2016; McGorry et al., 2007). The findings from this study suggest that public awareness of voice hearing could be promoted through a model similar to the Headspace model.

Because many people find it difficult to talk about symptoms of psychosis (Department of Health, 2012) it is essential that primary care practitioners feel confident discussing these experiences with patients. Evaluating the training needs of GPs may help to address uncertainties around detecting and discussing voices.

It is important that EIP practitioners recognize and are able to discuss service users' voice hearing experiences. Conventional approaches have typically discouraged enquiry into the experience of voice hearing, preferring to focus the hearer towards a more objective reality (Coffey and Hewitt, 2008). Enhancing therapeutic skills may build confidence and help practitioners to engage with clients distressed by voices. Coffey and Hewitt (2008) argue that mental health practitioners should be educated to deliver specific techniques for voice hearing such as supportive (validating patient's self-knowledge and responsibility) and catalytic (encouraging new self-understanding) interventions. Evidence suggests that brief Cognitive Behavioral Therapy for psychosis (CBTp) delivered by experienced therapists can reduce the distress caused by the symptoms of psychosis (Hazell et al., 2016). The provision of training to deliver CBTp adapted to focus on voice hearing could help to build practitioner confidence in talking about voices, facilitate the identification and disclosure of such experiences, and help to meet the challenges faced by service users in accessing appropriate therapies.

4.5.2 Limitations

There are several limitations to the study. First, participants were recruited from a small, select sample of EIP service users, so findings might not be extrapolated to hearers who have not discussed voices with others. Research should explore the disclosure of voice hearing in more diverse groups of hearers (e.g. online data collection and hearing voices groups). Second, themes that were generated by the authors and interpretations of the data may be subject to personal preconceptions, but using multiple analysts mitigated this. Third, participant accounts of the period between voice onset and point of disclosure were retrospective and may have been influenced by attenuated recall or current circumstances. Research should seek to recruit service users as near to voice onset as possible.

4.6 Conclusion

The processes of deciding to disclose voice hearing experiences and seek help are complex, with hearers considering the effect of disclosure upon themselves and significant others. In seeking to reduce the time between onset and treatment for distressing voices, interventions should seek to raise awareness and skill among people most likely to be the recipients of disclosure.

4.7 Summary of Chapter 4

This chapter explored the results of T1 semi-structured interviews, which investigated the experiences of distressing voices, from the time of onset to the date of interview, among 20 users of EIP services. Although, the chapter examined several 'enablers' the central argument focused on highlighting difficulties voice hearers encounter when disclosing or trying to discuss their voice hearing experiences. Barriers and enablers were categorised using three higher order themes and their sub-themes: 'effect of disclosure on the self', 'effect of disclosure on others' and 'help-seeking'.

The evidence presented shows how the disclosure of voices could affect self and others. Initially, struggles with voices were not always recognised or acknowledged. Service users, within this study, demonstrated that they shifted from denial of voices to acceptance that voices were present, and that they were struggling with them. Past experiences of family and friend's attitudes towards mental health appear to affect whether participants were willing to discuss voice hearing experiences. Even when a decision to disclose voices occurred, help-seeking was complex, with participants lacking confidence or knowledge to access support.

These findings are supported by the wider body of literature. Delays in disclosure were associated with denial (McGlashan, 1999), misinterpretation of symptoms (Phillips et al., 1999), and fear of stigmatisation (Compton et al., 2008). The work expanded upon previous models of voice hearing (Milligan et al., 2013), which have also suggested that typically, there is a reluctance to disclose voice onset. Considering that the duration of untreated psychosis has been associated with poorer outcomes (Padilla et al., 2015) it was felt important that EIP practitioners recognise and are able to discuss voice hearing experiences with service users.

Given that people who hear distressing voices may delay disclosure for a number of reasons, it would be prudent to explore EIP practitioners' perceptions of service users' experiences. As gatekeepers to treatment, it is important to better appreciate if, and how, practitioners understand their possible role in facilitating disclosure as this may affect how voice hearers are supported through the intervention process. The next chapter turns to look at this issue through the lens of a qualitative study.

5. How do Early Intervention for Psychosis Practitioners engage with Service Users' experiences of voice hearing?

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Contributions:

Conceptualisation: LBJ and MH

Methodology: All authors

Data Collection: LBJ

Data Analysis: LBJ

Initial Draft: LBJ, MH and RdV

5.1 Abstract

Hearing voices is a common and distressing symptom of First-Episode Psychosis. Early Intervention in Psychosis (EIP) practitioners can play a key role in supporting service users to disclose and explore this experience. This study investigated how EIP practitioners work with service users who hear voices. Ten practitioners were interviewed, and interviews were analysed using template analysis. Two themes that offer novel insights are presented within this paper: "starting a conversation about voices" and "continuing the conversation about voices". Starting and continuing a conversation about voices was considered important but not all practitioners were confident in this respect. To support conversations, a standardised interview guide for voice hearing could be introduced. Practitioners may benefit from training to work with voice hearing experiences and the opportunity to deliver brief symptom-specific therapy.

Key words: Early Intervention, psychological therapy, hallucinations, voice hearing, psychosis.

5.2   Introduction

Hearing voices (also known as auditory hallucinations) is a distressing and disabling experience that is commonly reported by service users experiencing a first episode of psychosis (National Institute for Health and Care Excellence (NICE), 2016). A meta-analysis of randomised controlled trials of Cognitive Behavioural Therapy for psychosis (CBTp) has shown significant between-group effects on psychosis symptoms, including voice hearing (Van der Gaag et al., 2014). Consequently, NICE recommend that CBTp should be offered to everyone experiencing psychosis (NICE, 2014). However, despite this recommendation, CBTp is rarely offered to psychosis patients (Royal College of Psychiatrists, 2018). Various initiatives are being developed to increase access to CBTp (including briefer forms of CBT [Hazell et al., 2018] and briefly trained therapists [Hayward et al., 2018]), but the impact of such initiatives is likely to be in the medium-long term. In the meantime, the importance of informal conversations about voice hearing experiences can be valued and foregrounded, as having a conversation about this subjective experience, whereby the hearer learns to explore and engage with voices, appears to mitigate voice-related distress (Craig et al., 2018; Hayward et al., 2017; Romme et al., 2009).

Romme et al. (2009) argued that mental health practitioners should support the voice hearer to engage in an open and non-judgmental conversation about their voice hearing experiences. With specific reference to EIP practitioners, NICE (2016) guidelines suggest they should be competent to engage with service users' psychological needs, have the ability to build trust and support open and non-judgemental conversations about symptoms of psychosis (including voice hearing experiences). However, there seems to be at least two barriers to having such conversations. First, a recent qualitative study with Early Intervention for Psychosis [EIP] service users indicated that hearers find it difficult to disclose their experience of hearing voices and were reluctant to discuss their experiences with practitioners (Bogen-Johnston et al., 2017). These difficulties were attributed to feeling of shame, intimidation by voices, concern for others and uncertainty about the likely responses of others. Second, many practitioners may avoid talking about voice hearing experiences with service users due to anxiety and a lack of confidence (Coffey and Hewitt, 2008; McMullan et al., 2018). This lack of confidence was attributed to the dominance of the medical model, concerns about making things worse and the limited meaning of voice hearing experiences. Over time, if voice hearing experiences are not explored and

access to CBTp is limited as a consequence, voice complexity may increase and recovery processes may be impeded (Nayani & David, 1996; Yung et al., 2007).

Given the apparent discrepancy between NICE recommendations, the difficulties of service user disclosure and the possibility of limited practitioner confidence, it is important to understand how EIP practitioners engage with service users' experiences of hearing voices, and the breadth and purpose of any conversations. This qualitative study assessed EIP practitioners' experiences of working with service users who hear voices. Examination of our research question – how do EIP practitioners understand and engage with service users' journeys with voice hearing? – can inform understandings of the gaps that can exist between policy, service user preferences and clinical practice.

5.3 Method

5.3.1 Participants

Ten practitioners from EIP services were interviewed. The sampling process was opportunistic but designed to include EIP practitioners with a range of professional backgrounds (i.e., psychologists and non-psychologists). EIP services are a multidisciplinary community mental health service which provide treatment and support for people experiencing psychosis for the first time or are "at risk" of developing psychosis (NICE, 2016). Practitioners were recruited through two NHS Trusts and had a variety of professional training; some were trained therapists who offered formal NICE-recommended psychological therapies such as CBTp; others had no formal therapy training. See Table 8 for a summary of participant characteristics.

5.3.2 Materials

The semi-structured interview schedule was designed to examine practitioners' understanding of service users' journeys with hearing voices, and how these journeys might affect readiness for and engagement with conversations. A semi-structured interview was utilised to explore practitioners' experiences of working and having conversations with service users who heard voices. The interview included questions examining practitioners' views on help-seeking, delivery of psychological therapies and recovery.

Pseudonym	Sex	Role	Time in EIP
Ella	F	EIP Practitioner	5 years
Eryn	F	EIP Practitioner	9 years
Eve	F	EIP Practitioner	6 years
Noah	M	EIP Practitioner	6 years
Nathan	M	Mental Health Nurse	7 years
Nita	F	Mental Health Nurse	4 years
Jess	F	Psychologist	2 years
Millie	F	Psychologist	7 years
Penny	F	Psychologist	7 years
Rose	F	Psychologist	8 years

Table 8 Summary of EIP Practitioners

5.3.3 Procedure

All procedures were approved by the NHS Research Ethics Committee at the London Health Research Authority. Practitioners were approached by the first author and were offered a Participant Information Sheet. After providing written consent, the practitioners completed the same semi-structured interview conducted by the first author. Interviews lasting between 30 and 60 minutes were digitally recorded, transcribed verbatim and anonymised. The first author met with the fourth author regularly during data collection to reflect upon each interview and to consider key conversation points for subsequent interviews. A reflective diary of each interview facilitated conversations and reduced the likelihood of false recall. The diary enabled self-reflection, and an examination of the perceived dynamic between the interviewer and interviewee.

5.3.4 Analysis

We employed both an inductive and deductive qualitative approach to explore practitioners' awareness and response to voice hearing as well as their beliefs regarding therapy. We took a critical realist stance which claims that independent of human consciousness an external world exists, but that our perceptions of, and beliefs about, this world are shaped by social influences (Danermark et al. 2002).

The first author coded the transcribed interviews. The second author conducted a credibility check of this coding on three randomly selected transcripts: no major discrepancies were identified. Data were analysed in accordance with King's (1998) procedures for using Template Analysis - a structured analytical technique that is also flexible enough to meet the needs of a specific study (King, 2012). We chose this approach as it allowed for an investigative non-theoretical analysis within and across the data set, thus permitting an in-depth understanding of the experience of each participant, as well as experiences across the whole sample. The first and second author produced an initial template (list of codes) using predefined codes from the interview schedule. The template was developed through three rounds of analysis. The research team met as a group to review the final version of the template which was compared against the research question for meaning and significance. Although it was initially guided by the

coding template, the analysis was also inductive and exploratory, thereby allowing novel themes and issues to emerge from the data. [3]

5.3.5　Quality and rigour

Assessment of the credibility of the analysis was guided by Yardley's (2000) guidelines for qualitative research which suggested four criteria: sensitivity to context (reading of relevant literature and conversations with mental health practitioners); commitment and rigour (procuring an adequate sample size and analysis guided through principles of Template Analysis); transparency and coherence of methods (use of reflexive diaries to reflect upon relevant influences on data collection and analysis); and impact and importance (increase understanding of the enablers and barriers to conversations about voice hearing experiences).

5.3.6　Reflexive Positioning

The first author worked as a researcher in an NHS clinic for voice hearing. The second author was the study supervisor and university lecturer. Both the third and fourth authors were supervisors on the study and clinical psychologists with experience of working with voice hearers. The third author had experience of working within an EI service. The authors consider open, in-depth conversations about voices to be beneficial for service users distressed by these experiences and that practitioners should feel able to facilitate such conversations. This view may have influenced the analysis by directing our attention toward service user/practitioner conversations about voices. We are aware that, as three of the authors work within an NHS Trust, we have preconceived ideas as to the different conversations that psychologists and non-psychologists might have with voice-hearers. For example, variations in training may not only affect confidence but whether voices are viewed through a medical or biopsychosocial paradigm. These opinions may have affected our development of the final themes. However, as noted in the methods section, the template was applied consistently, and there was good agreement between the first author (who worked in an NHS setting) and the second author (who as a non-clinical academic). Although our themes were discussed with the second author [who is not affiliated to the NHS] we are aware that the position of the other three authors may have prejudiced their development.

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[3] For an expanded version of the methods section please refer to Chapter 2, 'Methodological Overview'

5.4   Results

Nine themes were generated by the analysis: six were identified deductively from the coding template, and three were identified inductively during the process of analysis (see table 9).

1	How have practitioners worked with voice hearers?
1a.	Working in EIP Services: Practitioners' roles in EIP and their understanding of the EIP model.
1b.	How I work: Practitioner-service user therapeutic relationship.
2	What has struck practitioners about people who hear voices?
2a.	Challenges of Voices: Difficulties associated with hearing voices.
2	Cause of Voices: Beliefs about the cause of voices.
2c.	Voice Content: What voices say
2d.	Differences in Voice Hearing: Differences in types of hearers, diagnosis and distress
3	What happens over time with peoples' experiences of voice hearing?
3a.	Changes in the self over time: The emotional and functional effect of voices over time
3b.	Changes in the self over time: How and why voices change over time.
4	What happens over time with how people manage voices?
4a.	Control and power: Hearers' beliefs regarding the voices control.
4b.	Coping with Voices: How hearers cope with voices.
5	Practitioners' understanding of help-seeking behaviour.
5a.	Who initiates help? Who first seeks help for voices, how and why?
5b.	Barriers to help-seeking: What stops hearers from seeking help for voices.
6	Starting a conversation about voices: Initiating a conversation about voices and their disclosure
7	Continuing the conversation about voices: Practitioners and service users having further conversations about voices
7a.	Voices are not always the main concern: Whether voices are service users' main concern.
7b.	Importance of having a deeper conversation: Why a deeper conversation about voices was important
7c.	Confidence to work with voices: How comfortable were practitioners working with voices
8	Practitioners' expectations of recovery
8a.	What is a good outcome? What is a recovery outcome for service users?
9	Practitioners' ideas on future support for hearers.
9a.	Psychoeducation: Mental Health education for young people.
9b.	What needs to be done clinically: How Mental Health teams can support voices hearers.

Table 9 Themes identified from the analysis with EIP Practitioners

This paper presents two themes that offer novel insights: 'Starting a conversation about voices' and 'Continuing the conversation about voices'. The two chosen themes are explained and illustrated below.

5.4.1   Theme 6. Starting a Conversation about Voices

Disclosure of voices was an important part of the journey with voices, but, for this to occur, a conversation about voice hearing experiences needed to be started. There were mixed views as to how conversations were initiated. One participant stated that - "it's certainly about [the service user] being asked the question in the first place" [Penny, psychologist]. As they worked in a specialist service for psychosis, four practitioners presumed that this would have naturally occurred:

> We often are aware they're hearing voices, we've asked them the questions ...
> They're [EIP] quite specialist services and that's kind of what we're going for and asking.

> Penny [Psychologist]

Two practitioners found that service users were extremely candid about the disclosure of voices. For example, Nita noted "I do find that people do usually openly talk about what they hear." Alternatively, in Eryn's experience, starting a conversation about voice hearing was not always easy for service users. Despite wanting to disclose voices, she found that many service users were unable to find a language to express their experience.

> I don't know if it's necessarily a reluctance [to disclose voices] or kind of just not knowing how to, how to describe their experience and, and how to, how to kind of say that.

> Eryn [EIP Practitioner]

Prior engagement with other mental health services seemed to exert an influence on the likelihood of conversations about voices. It appeared that, outside of EIP, mental health practitioners did not always enquire about whether service users were experiences voice hearing. A lack of enquiry and subsequent conversation suggests that, even within mental health services, conversations about voice hearing experiences may be considered unnecessary and/or too difficult.

Penny expressed her surprise that conversations about voices were not always initiated by all mental health practitioners. This suggested that service users may be

invited to start a conversation in EIP about an experience that had previously been ignored by other Mental Health Services:

> I can think of some people I've worked with who've, who've had contact for long periods of time with mental health services and feel that no one's asked them about voices. And that's something I've kind of heard a few times from people: that no one's actually, specifically asked if they hear voices. So, therefore they haven't disclosed...
>
> Penny [Psychologist]

It was noted that EIP's routine use of standardised assessment procedures often brought attention to voices for the first time. Preliminary conversations could be stimulated and guided through the practitioner's use of measures such as the Positive and Negative Syndrome Scale [PANSS] (Kay, Fiszbein, and Opfer, 1987); with the framework of this diagnostically-oriented assessment tool enabling practitioners to begin a conversation about voices and service users to find a channel to discuss and bring awareness to these experiences:

> Until they're actually asked directly those questions, they'll kind of mention the voices but they won't really go into much detail. I, they're, they're first presenting they'll just say "Oh yeah, well I have heard a voice" but until we actually pick it apart it's just kind of a voice and they kind of don't make it into more than they have to. You know they don't explain it very well because they don't understand it I think.
>
> Ella [EIP Practitioner]

However, the value of having a structured conversation (e.g. guided by the PANSS) was still dependent upon a service user's readiness to disclose voices. Even after years of working with a practitioner, and openly responding to voices in front of them, some service users had not reached a stage where they were able to admit to being someone who heard voices. This denial meant that practitioners had to call upon their training to build trust with service users and support them along a pathway to disclosure. Nevertheless, an established therapeutic relationship did not always guarantee that an open and exploratory conversation would take place:

> Using our engagement skills and that to try and tease out what is going on. But cert, even with some that I see, I've been seeing for two or three years, they don't like to talk about it even though we can sense they're hearing voices from their

looking away or responding.

<div align="right">Nathan [Mental Health Nurse]</div>

This point was echoed by one psychologist's work with hearers who, in their experience, never directly spoke about voices. Even within EIP, by the time service users began psychological therapy they may still not have had an open conversation about their voice hearing experiences with other EIP practitioners. Consequently, through subtle enquiry, it was the responsibility of the practitioner to make sense of whether voices were present:

> People don't say "I'm hearing voices so that's why I've come to a -" almost never ... Yeah, no! People will talk about the belief they have about the voice and you sort of by kind of talking and questioning somebody you can understand that actually they're, you know, to all intents and purposes, they will appear to be talking about a, a voice hearing experience.

<div align="right">Millie [Psychologist]</div>

5.4.2   Theme 7. Continuing the Conversation about Voices

The theme "Continuing the conversation about voices" referred to whether the initial disclosure of voices continued into a more meaningful exploration of these experiences. Three sub-themes emerged as interviewees considered the value of talking about voices, whether focusing on them was a key concern for service users, and their confidence and ability to have a deeper conversation with service users about hearing voices.

5.4.3   Subtheme 7a. Voices are not always the main concern.

There were mixed opinions between practitioners about whether service users were particularly concerned about hearing voices. These differences seemed to be influenced by the forms of contact that practitioners had with service users. According to non-psychologists (who were likely to see service users over an extended time period and assist with a variety of problems), hearing voices was a typical cause of initial referral to EIP. As EIP was a specialist service for psychosis, three non-psychologists argued that hearing voices was therefore a prevalent symptom of this client group:

> ... It's [voices] definitely one of the, the, one of the main symptoms that people are referred into our Early Intervention service.

<div align="right">Nita [Mental Health Nurse]</div>

Alternatively, three psychologists (who were likely to see service users over a limited time period and focus upon a specified problem) believed that voices were not the primary concern, or even a typical symptom, for most service users. As Millie argued "I don't think voice hearing is very common in Early Intervention. We get a lot more people with, you know, paranoia and no voice hearing." According to psychologists, paranoia was the main symptom of psychosis that EIP service users presented with. If neither service user nor psychologist foregrounded voices then only the most pressing issues, or those that were believed to be the most significant, were explored. Consequently, conversations about voices may be curtailed by the level of importance that the practitioner and/or service user attribute to this experience:

> It just isn't a main thing quite often, or that they have voices, but they also have, you know, massive paranoia, or they also have other you know and it just kind of, quite often isn't the main thing people are bothered about.

> Rose [Psychologist]

5.4.4   Subtheme 7b. Importance of having a deeper conversation.

Practitioners spoke of the significance of having an in-depth conversation about voices. Despite Penny and Rose arguing that voices were not typically a main concern for service users (see sub-theme 7a), they also thought that the therapeutic relationship offered a supportive environment for service users to explore voice-related emotions and beliefs. Penny claimed that a deeper conversation helped hearers gain a sense of agency over the emotional response, and the effect of voices on their life, as well as introducing them to the possibility of higher intensity therapy:

> I think on the whole people find it a, a positive experience to be talking about voices and to be starting to think about having some options that therapy, as therapeutic options to, to help kind of manage certainly their distress around voices and also prove their kind of functioning ability to, to get back to a normal, normal kind of life.

> Penny [Psychologist]

For Rose, talking about voices meant that service users were able to express their experiences in a safe relationship. Having open, non-judgemental conversations about voice hearing normalized these experiences. Service users became accustomed to their voices and, with support, they began to get to know them. This rendered the voices less frightening. Rather than feeling alone, service users realised that voices were not

unusual and were something that could be spoken about. Subsequently, with support and time, service users became accommodated to the experience and voices became less distressing:

> In our service people tend to get less frightened by them [voices] because they either get used to them anyway or they do some work around them; and then kind of yeah, get kind of more familiar with them, or even just when they realise it can be quite a common experience, and it can kind of be understood and listened to, heard by people, that kind of tends to make people less frightened...
>
> Rose [Psychologist]

Two non-psychologists also reflected upon the importance of having a detailed conversation about voices. However, to have an in-depth conversation, practitioners needed to be aware of, flexible and able to work with diverse styles of service user engagement. Noah compared different types of service users: those who wanted to make sense of hearing voices, and those who wanted to forget their experience of hearing voice. When asked which approach was better he deemed:

> ... people who kind of want to engage in looking at kind of the meaning within those voices. Who are, who are more reflective? Who kind of are more open to kind of talking about the experience do better? I think for those who don't engage in that kind of work, I find that the kind of anxiety and fearfulness maintains itself more.
>
> Noah [EIP Practitioner]

5.4.5   Subtheme 7c. Confidence to work with voices.

Two interviewees considered EIP practitioners' confidence to work with voices. Opinions regarding mental health training, particularly around voices, differed according to the interviewee's job role. Rose had trained as a clinical psychologist and found working with voices more straightforward than other symptoms of psychosis such as unusual beliefs. She believed that with rudimentary symptom-specific (voices) training, practitioners' felt more confident to work with these experiences than other mental health issues:

> We often struggle more with knowing how to help with different symptoms than we do with voices. Voices seem a bit, you know once you've kind of done some basic training around it most practitioners feel quite confident doing that work

whereas they might struggle more to know what to do with their client's unusual beliefs for example.

Rose [Psychologist]

Nathan's training had differed to that of Rose's. He did not support her view and felt that voices represented "a less normal range of experience than an unusual belief." Nathan had trained to deliver CBT, however he still lacked confidence to work with voices within a psychological framework. Nathan not only doubted his ability as a therapist but also his belief in a psychological model for voices; which, in his opinion (and echoing a more medical paradigm), could have a negative effect on these experiences. Despite training, he still did not believe that he was competent to deliver voice-related therapy:

> I feel confident it's a good thing to talk about the voices and explore them, but a little less confident of doing that in, in the structured way that I've seen or read about. I don't feel as confident that, I don't know if that's me as a clinician or, or whether just not as convinced by that evidence for the voices ... I'd probably say it's something I don't feel too skilled in and feel slightly fearful of (breathes in) I suppose I do have a slight fear of making them [the voices] worse for people.

Nathan [Mental Health Nurse]

Nathan's uncertainty suggested that not every practitioner's training needs relating to working with voices had been met. Differences in training had resulted in a disparity within the EIP team of how practitioners approached, viewed and worked with voice hearing experiences. Nathan argued that increased practitioner confidence and the standardisation of approaches within teams would only be facilitated if all practitioners were trained together:

> I've been through courses that tackle these areas but I don't think enough, I think more time needs to be given to that particular area ... and I think if we were trained collectively as a team rather than sending me off to do another course, all collect-so we all talk in that way, all thinking in that way, it changes att-attitudes like perceptions and how we all work…

Nathan [Mental Health Nurse]

5.5   Discussion

This study explored practitioner perspectives and experiences in relation to the voice hearing experiences of EIP service users. Three inductive themes emerged. Two novel themes offered insights into the process of starting and continuing conversations

with service users about voice hearing, and the influences upon the nature and timing of these conversations.

The first theme examined the practitioner role in starting a conversation about voices. This was not always a straightforward process due to previously reported barriers to having these conversations from the perspective of service users (Bogen-Johnston et al., 2017) and practitioners (Coffey & Hewitt, 2008; McMullan, Gupta & Collins., 2018). Our findings suggested that even within EIP services (a specialist service for the treatment of psychotic experiences), practitioners were not always comfortable about having these conversations. There were differences of opinion as to how conversations were initiated; while some believed that service users readily talked about voices, others argued that it was the responsibility of the practitioner to start a conversation. The use of structured assessment tools (e.g. PANSS) offered service users and practitioners a common language to start a conversation about voices. This may suggest that conversations about voices could be initially stimulated by the systematic use of a symptom-specific assessment tool such as the Auditory Hallucinations Interview Guide (AHIG)(e.g. Trygstad et al., 2014).

The second novel theme examined the role practitioners played in continuing a conversation about voices. Practitioners believed that talking about voices was important. However, the specific role of a practitioner in continuing a conversation was somewhat dependent upon their confidence and training, understanding of voices and beliefs about whether voices were a concern for service users. This finding is consistent with previous research that found varying levels of practice and confidence amongst nursing staff (Coffey and Hewitt, 2008). Griffiths et al. (2019) maintain that practitioners should work from a position of curiosity, offering service users an open and non-judgmental space to discuss issues. Our study suggested that not all practitioners perceived themselves to have the necessary ability and confidence to work with voice hearers in this manner.

There are several limitations to this study. First, participants were recruited from a small sample of EIP practitioners across two services, so findings cannot be extrapolated to EIP practitioners more generally, or to practitioners from other mental health services. Future research should seek to recruit practitioners from a broader range of EIP services and explore similarities and differences across services. Second, the generated themes and interpretations of the data may be subject to personal preconceptions. This was mitigated to some extent by employing a systematic approach

and multiple analysts. Third, interviews were directed at practitioner experience of service users' journeys with voices over time and not specifically on understanding the support provided by practitioners to voice hearers. Future research should focus on the barriers and enablers for practitioners supporting voice hearers. Furthermore, future research should examine how practitioners can continue conversations about voices after service users have completed a course of psychological therapy.

The findings from this study suggest that both the practitioner and service user could benefit from support to engage in conversations about voices at the earliest appropriate time. Disclosure can be difficult for some service users and it is important that practitioners not only facilitate disclosure but are able to subsequently continue a conversation about these experiences. The systematic use of an interview guide such as the Auditory Hallucinations Interview Guide (Trygstad et al., 2014) would support disclosure by offering practitioners and service users a shared language and a structure to explore these experiences.

Continuing these conversations about voice hearing experiences may benefit from being supported by the provision of symptom-specific training for practitioners. Such training could initially focus upon the fundamental skills of non-judgemental listening and the expression of curiosity, and the specific use of these skills in the context of voice hearing experiences. Subsequent training could focus upon the delivery of brief and targeted therapy for voices, such as Coping Strategy Enhancement (Hayward et al., 2018) or Guided Self-help CBT (Hazell et al., 2018) – with ongoing supervision provided by psychologists. These interventions of lower intensity may generate sufficient distress reduction for some service users, and prepare other service users for high-intensity therapy informed by a longitudinal formulation and delivered by psychologists (as expert therapists).

5.6 Conclusion

EIP practitioners suggested that starting and continuing a conversation about voices was important. However, not all practitioners were confident to have such conversations. To support conversations about voices, a standardised interview guide that focuses on voice hearing could be introduced. Practitioners may also benefit from training and ongoing support to work with service users who hear voices, as well as the opportunity to deliver brief symptom-specific therapy.

5.7   Summary of Chapter 5

This chapter presented a qualitative study containing 10 semi-structured interviews with practitioners working in EIP service, exploring their views and experiences of users who hear distressing voices. The need to examine and better understand practitioners' responses and engagement with voice hearers is identified within the wider literature (Coffey & Hewitt, 2008). Although the analysis revealed nine novel aspects to these experiences, which were briefly presented (table 9), the chapter concentrated more specifically on two of these themes: 'starting a conversation about voices' and 'continuing a conversation about voices.' The rationale for this focus rested on the realisation that, while all practitioners understand the value of discussing voice hearing, not all practitioners were confident in their ability or skills to initiate and manage ongoing discussions about distressing voices or, indeed, even see it as part of their role. The significance of this finding was argued to warrant closer inspection as it speaks to an issue that has been acknowledged within existing studies but that has, to date, been given little attention. Griffiths et al. (2019) argue that, while it may be beneficial to offer service users the chance to have open and supportive conversations about voices, practitioners differ with regard to their views on whose job it is to provide such spaces. In addition, the importance of conversations is corroborated by findings that will be presented in chapter 6 where it is highlighted that many service users would welcome more opportunities to have open and informal dialogue about their voice hearing.

In considering these two different, but related, aspects of having 'conversations', what the evidence in this chapter has shown is that conversations are not simple processes but are a complex mix of factors. Practitioners may feel that they are not adequately armed with the knowledge and skills to begin a conversation or, because of lack of experience, they are not comfortable having conversations. At the same time, Chapter Four showed how service users themselves can be reluctant to talk candidly about their voices, which may contribute to the undermining of confidence the clinicians expressed.

The next, and final, empirical chapter moves to examine how EIP service users manage distressing voices over time. This builds upon the findings from the previous two chapters by examining the different stages of voice hearing and how service users come to make sense of their experiences through therapy and with the support of others, including EIP practitioners.

6. "It's just a bit like a rollercoaster". A longitudinal qualitative study exploring a model of the phases of voice hearing.

Chapter six is under review with the journal Psychosis as: Bogen-Johnston, L., de Visser, R., Strauss, & Hayward, M. (under review). "It's just a bit like a rollercoaster". A longitudinal qualitative study exploring a model of the phases of voice hearing.

Contributions:

Conceptualisation:	All authors
Methodology:	LBJ, RdV, MH
Data Collection:	LBJ
Data Analysis:	LBJ
Initial Draft:	LBJ, MH and RdV
Reviewing and Editing:	All authors*

*Plus comments from peer-reviewers during the review process

6.1 Abstract

Background: Existing models of the phases of hearing distressing voices have relied upon data from cross-sectional designs and the retrospective accounts of hearers. There is a need for a longitudinal study to examine the phases of voice hearing over time.

Methods: A longitudinal, mixed-methods design was used. Stage 1 – semi-structured interviews were conducted at nine monthly intervals at four time-points with voice hearers (n = 12) from Early Intervention in Psychosis Services. Data were Thematically Analysed. Stage 2 - findings were mapped onto an integrated model of voice hearing. Results Stage 1 analysis generated higher-order themes: 'Common Pathway', 'Voices Stop', 'Voices Continue but Beliefs Change', and 'Voices Continue but Beliefs do not Change'. Stage 2 analysis generated a preliminary revised model of voice hearing over time with three novel sub-group pathways.

Conclusions: An integrated model of the phases of voice hearing over time can be expanded to include three novel sub-group pathways. Beliefs about voices influenced the course of voice hearing. Changes in beliefs were associated with acceptance, meaning-making and recovery: whereas beliefs that did not change were associated with ongoing voice-related distress. Findings highlight the importance of therapeutic conversations in supporting hearers to explore their experiences with voices

6.2 Introduction

The experience of hearing voices (auditory hallucinations) can cause significant distress and disability. In the context of psychosis, the National Institute for Health and Care Excellence (NICE) recommend psychological therapy, including Cognitive Behavioural Therapy (CBT) and family intervention, for patients distressed by hearing voices (NICE, 2016). Despite the proliferation of studies that have evaluated the effectiveness of psychological therapy for distressing voices (Thomas et al., 2014), and the recent and encouraging focus upon single-symptom therapies in psychosis (Lincoln & Peters, 2018), less attention has been paid to the optimal time for these therapies to be offered to patients. The seminal model that may be useful in this respect was developed by Romme and Escher (1989) nearly 40 years ago. They drew upon anecdotal data to propose a three-phase model of voice hearing: 'startling' phase (voice onset), 'organisation' phase (choosing when and which voices to communicate with) and 'stabilisation' phase (more continuous way of managing, and deeper understanding of, voices is established). There have been recent attempts to refine and elaborate this model through the inclusion of additional phases (Milligan et al, 2013) and divergent recovery typologies (de Jager et al., 2016) (see Figure 1 for an integration of the three models).

In a qualitative study, Milligan et al. (2013) found partial evidence to support Romme & Escher's three phases with an extended a six-phase model of the experience of hearing voices: 'antecedent phase' (negative life events); 'onset of voice-hearing'; 'rejection phase' (voices are not me and will go away); 'crisis-induced change' (positive or negative change with voices); 'discovery, adjustment, coping' (learning, adjusting and coping with experience); and 'new understandings' (voice accepted as part of self and will continue). The model of recovery proposed by de Jager et al. (2016) suggests two typologies: 'turning toward/empowerment' (normalising and integrating voices, developing skills and transformation of identity) and 'turning away/protective hibernation' (seeking resources to survive experience, emphasis on medication). However, these studies have been limited by their reliance upon cross-sectional designs and solely retrospective accounts of hearers, leading researchers to call for longitudinal research that can offer an in-depth analysis of the change processes that voice hearers might experience over time (Hayward et al., 2014; Milligan et al., 2013).

This study aimed to address these limitations by examining voice hearing across multiple-time points to empirically validate and refine a preliminary model of the

phases of voice hearing over time. Further clarity about how distressing voices evolve over time will facilitate clinical decision-making about the most appropriate times to offer evidence-based psychological interventions. Voice hearers have suggested that therapeutic conversations about voices should begin as early as possible (Hayward et al., 2014), but what does 'early' mean in relation to the phases of voice hearing, and how might subsequent trajectories influence the offer of psychological interventions if voices continue to cause distress?

6.3   Methods

6.3.1   Design

This study was part of a longitudinal (retrospective and prospective) mixed-methods project exploring the different phases of voice hearing over time within Early Intervention for Psychosis (EIP) services.

Participants were interviewed at nine-monthly intervals at four time points across a three-year period. Due to the limited literature in this area, an inductive approach to data analysis (Stage 1) was appropriate for gaining a deeper understanding of the different phases of voice hearing. A subsequent deductive approach (Stage 2) was used to map the emerging findings from the analysis onto the integrated model (see Figure 13).

A critical realist view was taken which contends that an external world independent of human consciousness exists, however perception and understanding of it is socially determined (Danermark, 2002). Analysis considered each participant's experiential truth, but also acknowledged that what participants sometimes described as real mental phenomena may not have been objectively real.
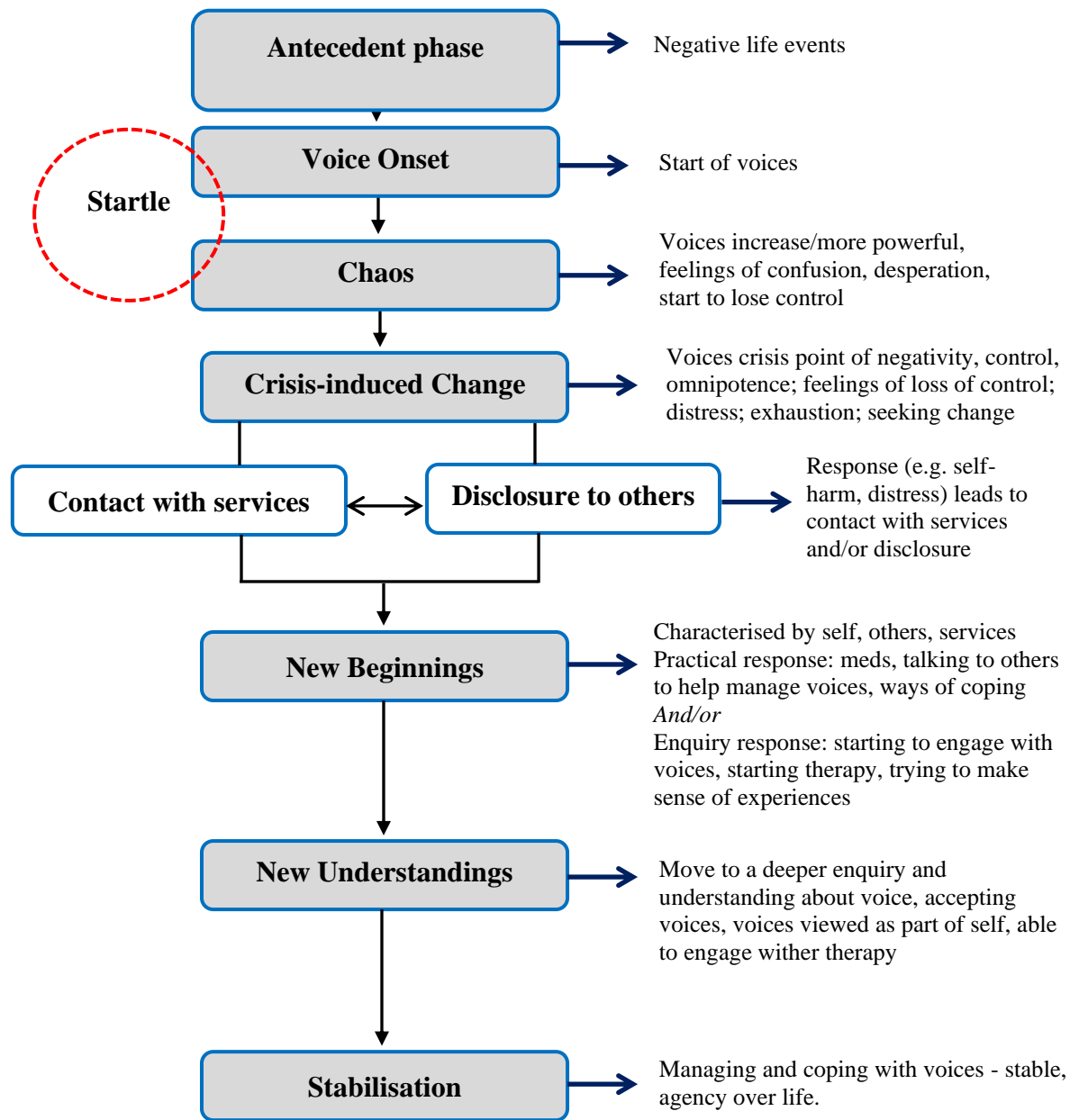
Figure 13 An Integrated Recovery Model

6.3.2 Participants

Twenty participants were purposively recruited from EIP services in the South of England (n=17) and in the North of England (n=3). EIP services specialise in first-episode psychosis or 'at risk mental states' and were selected to facilitate recruitment of hearers, where possible, who were close to the onset of voices. However, many clients in EIP services have heard voices for a number of years before entering the service. This study aimed to recruit a sample that was sufficiently large to capture the heterogeneity of voice hearing experiences, but also small enough to be manageable for a longitudinal study. A sample size of six is considered sufficient to yield a rich data set (Smith and Osborn, 2003); however, the longitudinal nature of the study suggested that it was necessary to allow for participant attrition (Saldaña, 2003) and a sample size of 20 was deemed adequate. Inclusion criteria required that patients were currently hearing voices and had been doing so for the past three months (verified by referring clinician and participant). Patients were excluded if voice hearing resulted from organic illness or substance misuse. In order to protect participant anonymity, pseudonyms were used and identifying information changed.

6.3.3 Procedure

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by an NHS Research Ethics Committee (approval number: 13/LO/1730).

Written consent was obtained from all participants. Participants completed a series of semi-structured interviews conducted by the first author. Open-ended questions allowed self-reflective and exploratory dialogue. The research team discussed key areas of interest for the time 1 (T1) schedule which focused on voice onset to T1 interview. Time 2 (T2), time 3 (T3) and time 4 (T4) interview schedules were informed by the findings of each participant's previous interview. Interviews were digitally recorded, transcribed verbatim, and anonymised.

6.3.4 Analysis

A two-stage analysis was guided by Braun and Clarke's (2006) six phases for

Thematic Analysis (TA). TA facilitates an in-depth understanding of participants' voice hearing experiences with an exploratory non-theoretical approach. The flexibility of this approach facilitated the development of a theoretical model of the phases of voice hearing. An inductive, bottom-up approach where themes emerged through participants' accounts of their experiences with hearing voices was deemed appropriate for Stage 1 of the study.

At Stage 1, interviews were transcribed verbatim. The codes of each participant's interview were reviewed for patterns across their entire data set (at each time point and classified into potential themes). Each participant's data set was entered into a separate thematic table. Guided by the thematic table, the first author wrote a summary of each participant's set of interviews which the research team reviewed and compared to existing themes. To ensure respondent validation, participants were offered the opportunity to discuss the summary findings with the first author.

A deductive approach was used in phase 2 to test the fit of accounts to the integrated model. The fit of each participant's data comparison against the integrated model was compared across the body of data, re-examined for links and grouped into higher order themes. The final set of themes was compared against the research question for meaning and significance. The higher order themes were developed by the research team into a revised model of the phases of voice hearing over time.

Quality checks were guided by Yardley's (2000) call for qualitative research to exhibit sensitivity to context (reading of relevant literature and discussions with patients, commitment to rigorous analyses (procuring an adequate sample size and analysis guided through principles of TA); transparency and coherence of methods (reflexive diaries to reflect upon relevant influences on data collection and analysis) and impact and importance (increase understanding of the optimum time for therapy).

6.3.5   Reflexive Positioning

The first author worked as a researcher in an NHS clinic for voice hearing. The remaining three authors were supervisors on the study. The second author was a university lecturer. The third and fourth authors were clinical psychologists with experience of working with voice hearers. Three of the authors were aware of existing models of the stages of managing voices in the literature, which may have influenced the analysis and development of the final model. However, one of the authors, a non-expert in relation to the voice hearing literature, was not aware of these models until

post data collection and after the start of the analysis. As three of the authors work within an NHS trust, examining the effect of cognitive behavioural therapies for voice hearing, we acknowledge that existing views may have prejudiced our focus on beliefs about voices. The research team benefitted from consultation with Lived Experience Experts at the design and analysis stages, ensuring that the study was orientated towards and relevant to perspectives of people who hear distressing voices.[4]

6.4   Results

Twenty participants agreed to be interviewed at T1, 12 men and 8 women aged 19 to 35 years ($M = 25$. $SD = 4.7$; Mdn = 24). Eighty-five percent of participants identified as white British, with 10% identifying as white other, and 5% as mixed race. Forty percent of participants were in paid employment (full-time or part-time) with 5% in voluntary employment, 5% self-employed, 5% in education, and 45% unemployed. Age of voice onset ranged from 6 to 32 years ($M = 19$, $SD = 6.8$; $Mdn = 19$). At T1, voice duration ranged from less than 1 year to 21 years ($M = 7$, $SD = 6.8$; $Mdn = 3$). Fifteen participants (75%) agreed to an interview at Time 2, 13 (65%) at Time 3, and 12 (60%) at Time 4. Participants were included in the analysis if they had completed at least three interviews.

6.4.1   Stage 1 – Themes from a Developmental Analysis of the Phases of Voice Hearing

Four higher order themes were generated through the analysis and are reported below.

6.4.1.1   *Common pathway.*

The first higher-order theme referred to a shared pathway common to all participants, extending from pre-onset to receipt of help, and beginning with an 'antecedent stage' that included negative events preceding voice onset. These events happened either close to onset or many years previously. Twelve participants spoke of an adverse event, or a series of adverse events, that happened before voices were first experienced, including physical and sexual abuse, bereavement, physical and emotional illnesses, bullying, exam anxiety, and childhood trauma.

At 'voice onset', participants were often startled and frightened. Five participants normalised the experience and believed that it was temporary – "I was a bit

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[4] For an expanded version of the methods section please refer to Chapter 2, 'Methodological Overview'

scared but I just thought 'oh, it's where I'm tired and maybe it's the meds I'm on"
(Eva). Others were confused and could not explain it: two participants could not
remember voice onset, and three had it to originate from an external source:

> I think back then I did think it was [deceased friend] himself. Somehow,
> somehow he's, he's in my head; some bizarre way like.

> (Joss)

Subsequent experiences had a sense of 'chaos' as voices increased in frequency
and confusion and distress escalated; there was a sense of voices taking control and
increasing in dominance. Participants tried to manage and cope with voices, but often
these strategies were often negative and ineffective (e.g. self-harm). As hearers tried to
make sense of their experiences, delusional beliefs evolved. At voice onset, Eva had
assumed her voice was due to tiredness but as it continued this belief changed: 'I
thought it was like a, like a monster or a demon or something inside me'.

Voices were viewed as powerful and omnipotent: "I felt they were really, really
you know ever so powerful over me" (Kirsty). Consequently, participants felt helpless
and believed that they were at the mercy of their experiences. For Joss, her voice had
seized control of both her body and mind. She felt dissociated from her physical self
and possessed by the voice which made her act in ways that were out of character. Joss
described feeling powerless as it drove her to self-harm:

> I don't have any control of me anymore. Like there'd be stuff that I'd be watching
> and I'd be a bit like "What are you, what are you doing?" …Because he got me
> self-harming and I was a bit like "Why, what on earth are you doing?" Cause
> like, in my eyes self-harming had always been something ridiculous. Like, I'd
> think "Why would somebody do that?" And then when I saw myself doing it I
> was a bit like "What!" Yeah, just shocked and sort of felt a bit like: "Oh God,
> what's next?" … it was like I was watching myself from a window.

> (Joss)

This period of chaos was followed by a 'watershed', as voice power, control and
negativity reached a peak and were no longer tolerable; participants did not have the
resources to cope with these experiences anymore. Six participants described suicidal
thoughts (due to voices) which one, Ian, acted on - "I just got to that point where I
thought 'I'm never gonna get rid of it.'" This was a time when the effect of voices
resulted in either their disclosure ("I sat upstairs by myself trying to make sense of
things, trying to figure out what was going on; then just decided 'no, nothing's

working!' Sort of called my mum, my dad; went straight down the urgent treatment centre at the hospital' – John), others noticing changes in behaviour ("Well my, my mum heard me like talking to them" – Chloe) or destructive behaviour ("I got to about twenty, when I set light to the car, the voices would sort of peak" - Aaron)

This watershed led to 'change through help' as participants benefitted from the help of: mental health services ("I know that CBT was a massive, a massive thing" – Ian; "I've been doing really well recently with the voices are not so loud. I think the medication I'm taking is really kicking in now" – Aaron); other people ("It was explaining it all to you [first author] as well that really helped because it helped me really express it, because I'd never talked to anybody about it before, not in such depth…" – David); and the self ("When they're shouting at me I just write down what they say. And it's, I don't know, it feels really good because it's like I'm letting out some anger. And I can just sort of read all that back and I just think "that's a load of rubbish!" And I just get a bit of paper, screw it up an' chuck it in the bin" – Eva).

'Change through help' signified the end of a common pathway as participants divided into three sub-groups: 'voices stop', 'voices continue but beliefs change', or 'voices continue but beliefs don't change'.

6.4.1.2   *Voices stop.*

For six participants, the benefits gained from 'change through help' continued until voices ceased. Prior to voices stopping, beliefs about voices began to change. Although the majority of participants attributed voices stopping to medication, three participants felt that discussing and exploring their experiences also played a significant role – "I think it was the changing of my beliefs in what did happen and my rationalisation, and obviously the medication as well and the CBT" (Fliss). Voices did not return for these three participants.

After voices stopped, participants reflected upon the experience and tried to make sense of what had happened. They discussed their fears of voices returning as well as thoughts (which were mixed) on how the experience had changed them:

> It's changed my understanding of myself really because yes, I believe, it's one of those things, I believe I'm stronger than I was because of the experience I've been through. I suppose it's the same with anyone going through any problem really. You start with it, you battle through it, you come out the other side and you can appreciate that yeah, I have had to do certain things differently to get to this place, so for better or worse this is the person I am now. So it is as, I do

believe it's definitely changed me to come through and I don't think it's changed me for the worse at all.

(John)

For three participants the voices returned and led to further 'changes through help'. For Beth, this meant self-help "no! If I've kicked this before then I can kick it again. I don't want to go back on the medication. I want to kick it myself. And that's what I did".

6.4.1.3 *Voices continue but beliefs change.*

A further theme reflected a process of belief modification despite the continuation of voices. The origin of beliefs changed for three participants from an external explanation to an internal understanding ("they seem part of me now if that makes sense" - Eva). The balance of power between self and voice also began to alter with all three participants believing that, at times, they were in control –"I think on good days I have a little bit more control over him" (Joss).

Belief modification facilitated the taking of a 'A different stance" on voices as the focus shifted from waiting for voices to stop to accepting that they were part of one's life. This had been an important change for Eva as it had allowed her to engage with therapy and focus on ways of managing voices instead of expecting therapy to cure voices:

I think because before I went in and obviously had the therapy session with [therapist] I sort of came to terms with it a bit more "like okay! It's happening. I'll do what I can." Whereas before I was literally like, thinking "right, somebody fix it!" Like I expected somebody to just magic a wand I guess, whereas when I went in to start the therapy it was a bit more like "I've accepted okay, I have him in my head and I just want to learn, deal, ways of dealing with it" I guess. I didn't really go into therapy thinking "this is gonna cure it."

Through CBT, Eva and Joss were able to acquire a more in-depth understanding of their experiences – "It sort of made me think of my voice in like a different way, which really helps because it just sort of changed my outlook on, on, on this voice "(Eva). It was a time whereby participants' regained control and agency over their lives ("I just feel like that my life is not controlled by my voice anymore. It's controlled by what I want to do and then the voice is secondary. So it feels like I make the decision…' – Aaron).

However, despite beliefs changing, as part of their journey, voices could also become more distressing. All three participants experienced a time(s) when voices increased in their perceived control and power. For Aaron and Joss, this period was associated with a negative event - "It can be from a trigger, like one of my times because my dog died" (Aaron). At these times, help was sought through services, others and one self – " I wanted to prove to myself I could do it" (Aaron).

Despite concerns regarding a possible return of voices - "I do get a bit scared because it's like 'oh God, is, is he gonna come back to like being here every day?'" (Eva) – participants accepted that voices were part of their lives - "I'm always gonna have the voices. They [EI services] said that to me, that I'm always gonna have relapses - it's like that's the way it goes" (Aaron). However, after reflecting upon their past experience, the participants believed that it was something that they would be able to overcome ("I feel stronger than the voice now. So I feel like I can tell him to like go away. Like "leave me alone"!" – Eva).

6.4.1.4 *Voices continue but beliefs do not change.*

A final theme was generated from the data of three participants whose voices remained but understanding of them did not alter. An external explanation of voice origin persisted as well as a belief that voices were omnipotent. Over time, Kirsty became more entrenched in her belief that voices were part of a political conspiracy that had control over her:

> …it seemed to be political at the time. Like they wanted me to be a spy or something because they never would show their faces but they always communicated silently through my body [Interview 1]

> …they've told me the mission. All, all along the mission that I have to do for them to stop giving me schizophrenia is to have a, instead of be abused in my head is be abused in the real world [Interview 4]

Participants believed that voices were in control and had the power to affect their lives ("Oh they've got so much [power]. Yeah, they can ruin, ruin me you know, whenever they want to" – Kirsty). For Kirsty and Chloe, the voices had become more distressing over time as their negativity and power increased.

> I think they're worse than when we first met. They've gotten worse over time…They, they're more powerful… They, they say more negative things. They didn't used to be that negative.

> (Chloe)

For this group of participants, opportunities to discuss their beliefs about voices were limited and, when this did occur, were often unhelpful:

Do you talk to them [mental health team] about it [voices]?

They, they don't talk about it with me.

So they don't talk about voices with you?

No, they just say every time - "we have a different opinion to you. We think it's a chemical imbalance."

Participants seemed to fluctuate between voices becoming more negative and 'changes through help', as help was sought at times of crisis but any changes were not sustained.

6.4.2   Stage 2 Developing a Revised Model of Voice Hearing over Time

The themes developed in stage 1 were mapped onto the integrated model of voice hearing over time to generate a revised model (see Figure 14). A preliminary revised model corroborates and expands upon the integrated model. Specifically, three sub-themes highlight the idiosyncratic journeys beyond a common pathway which implied that recovery was not a linear or universal experience for the participants.

Prior to accessing help, a "common pathway" was followed by all participants. The preliminary revised model subsequently divides into three pathways representing different experiences of voice dis/continuity that appeared to be influenced by beliefs about voices. Two of the pathways involve the changing of beliefs about voices. For both the "Voices continue but beliefs change" and "Voices stop" pathway, belief modification seemed to play a role in the recovery process, irrespective of the continuation or dis-continuation of voice hearing experiences. By contract, the "Voices continue but beliefs do not change" pathway describes the journey of participants who do not seem to experience belief modification, and consequently felt trapped in a cycle of voice negativity and accessing help.
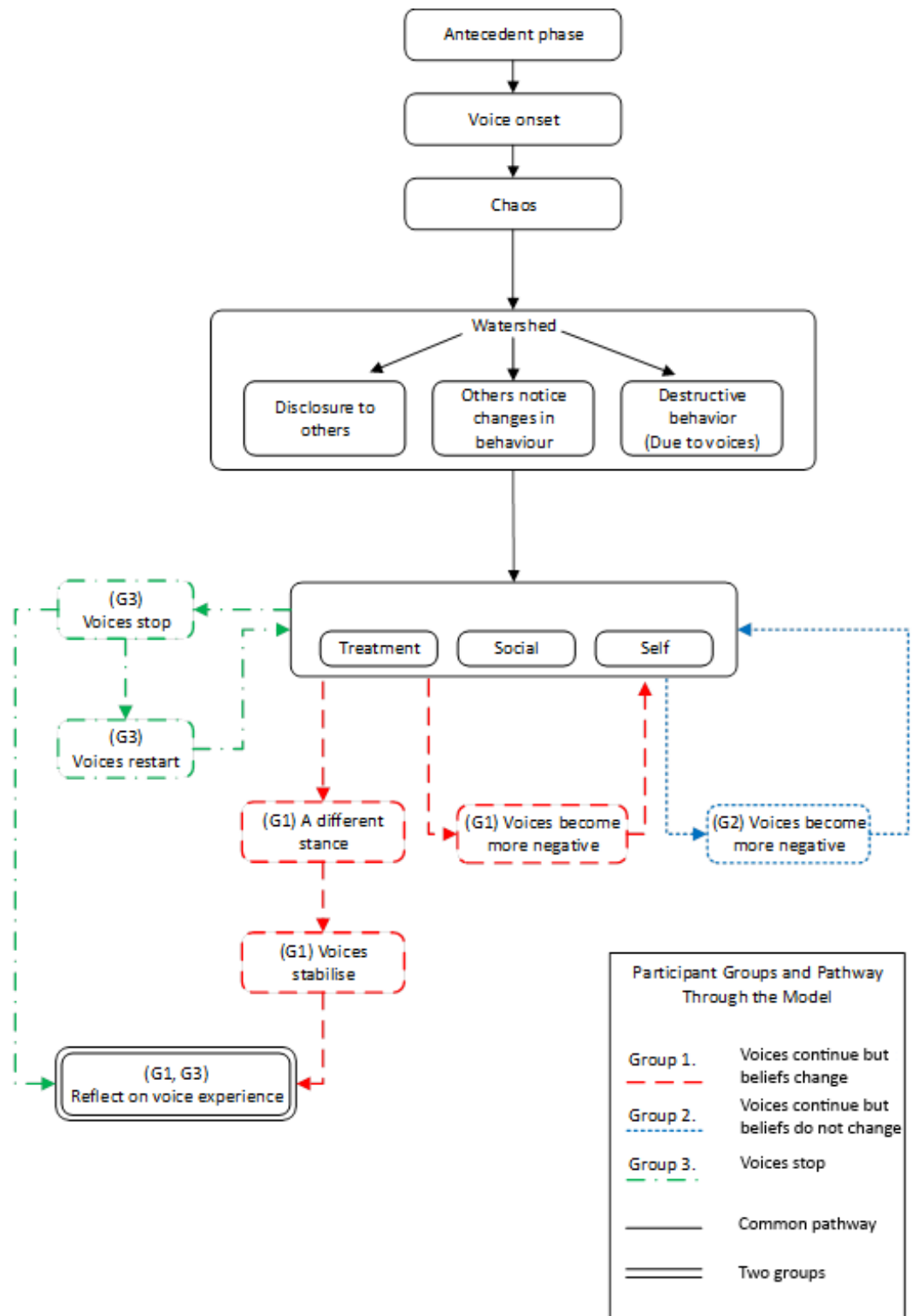
Figure 14 A Revised Model of Voice Hearing over Time

6.5   Discussion

This study aimed to compare findings from a longitudinal (retrospective and prospective) study of a cohort of patients distressed by hearing voices with existing models of voice hearing over time (de Jager et al., 2016; Milligan et al., 2013; Romme & Escher, 1989).

Four higher-order themes emerged from the analysis of the accounts of twelve participants who were interviewed over a three-year period. The analysis proposed a "Common pathway" that was experienced by all participants – whereby a journey was travelled from voice onset through to disclosure and the accessing of help that was necessitated by a worsening of voices. Subsequently, pathways diversified in a manner that seemed to result from an interaction between voice continuation/dis-continuation and belief modification. The 'common pathway' was developed from participants' retrospective accounts. The three novel pathways emerged during the period of data collection. The pathways did not appear to differ systematically according to time since onset of voice hearing. Although the duration of the 'common pathway was more protracted for those with longer-term recall than those who were in the early stages of voice hearing and help-seeking, this pathway did not differ according length of time.

Within the "Voices stop" pathway, participants experienced a cessation of voice hearing experiences. Despite the likelihood of voices stopping after a first episode following the establishment of an anti-psychotic medication regime (Sommer et al., 2012), participants attributed this cessation to a variety of sources - medication, therapy and the opportunity to discuss voice hearing experiences. Cessation prompted a time of reflection and sense-making that facilitated the modification of beliefs about voices and the accessing of further help if voices returned. For participants whose voices continued, the modification of beliefs (or lack thereof) seemed to play a role in what happened next. Both groups experienced stages of heightened voice negativity resulting in an increased need for help. For the participants whose "Voices continue but beliefs change", a process of enquiring facilitated by CBT and supportive discussions with significant others enabled re-evaluation and modification of beliefs about voice omnipotence, control and origin. Participants within this group changed from a passive response style (accepting voice comments and commands) to a more active response style (challenging voice comments and commands) to voices. Alternatively, those who's "Voices continue but beliefs do not change" remained in a cycle of intensifying voice negativity and the continued need to access services. Unlike the group whose

voices continued but beliefs changed, this group did not have access to supportive non-judgemental conversations about voices.

The integrated model of voice hearing (see Figure 13) has been expanded to include three novel sub-group pathways (see Figure 14). The preliminary revised model corroborates the existence of the significant challenges that can be faced by patients prior to disclosure (Bogen-Johnston et al., 2017). Following disclosure, beliefs about voices seem to exert an influence, with modification being associated with acceptance, meaning making and recovery (whether voices continue not), and a lack of modification being associated with ongoing struggles with voices. Several [5] participants ascribed changes in beliefs about voices to CBTp based therapeutic intervention. Through therapy, participants questioned the control and power of voices, and for those whose voices continued, learnt to re-address the imbalance. Outcomes implied that therapy (as an adjunct to medication) influenced the recovery pathway. Beliefs regarding voice origin (external or internal), omnipotence and omniscience have been prominent within the empirical literature (Birchwood & Chadwick, 1997; Chadwick & Birchwood, 1994) and their modification is a central aim of CBT (Smailes et al., 2015). Our findings suggest that the exploration and evaluation of the accuracy of these beliefs may be an important part of therapeutic conversations about voice hearing experiences that occur after disclosure. Whilst the preliminary revised model of voice hearing over time does not identify the precise timing of these conversations and how formal they need to be, there is no suggestion within the data that these conversations would benefit from being delayed after disclosure. Whilst patients may not be 'ready' for formal psychological therapy immediately following disclosure, therapeutic conversations that encourage patients to explore and evaluate voice hearing experiences may lay the foundations for subsequent belief modification. However, engagement with these conversations may be influenced by both the recovery style of the patient and their willingness to explore voice hearing experiences (de Jager et al., 2016) and the ability and confidence of clinicians to start and continue a conversation about voice hearing (Coffey & Hewitt, 2008).

Whilst we accept that the preliminary revised model cannot be generalised beyond the experience of this study's participants, we propose that it offers insights that can augment the existing voice hearing literature. The preliminary revised model builds upon previous recovery models and suggests three novel pathways. The identified pathways offer new insights into hearers' trajectories with voices and are the

groundwork for future clinical research. Research examining the suggested pathways may further clinical understandings between the relationship of voice appraisals, readiness for therapy and the timing of therapy.

6.5.1   Limitations

This study had a number of limitations. Firstly, participants were engaged with Early Intervention in Psychosis services and therefore findings cannot be extrapolated to patients who hear voices beyond a first episode of psychosis or people who have never accessed mental health services. Future research should explore the preliminary revised model with differing populations of voice hearers and seek to triangulate qualitative and quantitative data. Secondly, participant views prior to engagement with services were retrospective and reflections may have been influenced by attenuated recall. Future longitudinal research could address this issue by deploying novel methodologies (e.g. experience sampling methodology) which, supported by digital technologies, could capture data 'in-the-moment'. Thirdly, differences in duration of voice hearing meant that, with respect to the early course, some participants were reporting more distant experiences than others. However, despite the heterogeneity, time since onset did not affect course of voice hearing. Fourthly, our analysis did not reach the point of saturation, suggesting that some possible experiences of voice hearing over time may not have been captured by this study. Future studies could adopt methodologies (e.g. Grounded Theory) that could be more comprehensive in this respect. Fifthly, a limitation of this study was the lack of diversity within the sample. We did attempt to partly address this problem by recruiting from two EIP services: a metropolitan borough located in the North of England (Manchester) and coastal towns located in the South East of England (Brighton and Eastbourne). However, the sample was limited, for example in terms of age, ethnicity and geography. Consequently, future research should explore the utility of the preliminary model in samples that are more diverse.

7. General Discussion and Conclusions

7.1 Chapter Outline

The programme of research set out to explore peoples' experiences of hearing voices over time with the aim of developing a model which would illustrate different stages of managing voices and the optimum time for therapeutic intervention. This final chapter will discuss how the focus of the research evolved from 'the timing of therapy' to the value of having 'conversations' about voices at varying levels of intensity. A summary of the qualitative findings from each of the studies is considered with respect to the development of the aims of the research. Novel findings from the studies are explored within the context of theoretical contributions. The clinical implications of these findings are reflected upon, and recommendations aimed at supporting EIP clinicians to start and continue informal conversations about voices are offered. The limitations and strengths of the programme of research are discussed, and a summary of the overall findings are presented in the conclusion. Final reflections regarding the programme of research will be considered

7.2 Summary of Findings

A summary of the key findings, structured around each chapter, will be presented.

7.2.1 Understanding the Importance of Various Temporal Dimensions of Voice Hearing from a Systematic Literature Review

In chapter three a systematic literature review was conducted. The review identified 12 studies (three qualitative and nine quantitative) that met the search criteria. A synthesis of the selected studies implied that the course of voice hearing is complex and is subject to the influence of a range of associated factors. The age of onset and duration of experience was found to affect the likelihood of voices stopping. These findings suggest that there may be a critical period during the course of the experience which determines the probability of voices continuing or discontinuing, as well as the development of a secondary delusional belief system. This stresses the importance of interventions being offered early. Additionally, the significance of having an informal conversation about voices prior to reaching the 'critical period' was also highlighted. Findings from the review emphasised the need to examine the course of hearing voices using a longitudinal (retrospective and prospective) methodological framework.

7.2.2   Barriers and Enablers to the Disclosure of Distressing Voices

Chapter four explored the qualitative data from 20 services users' T1 semi-structured interviews. The aim of the study was to examine peoples' experiences of managing distressing voices from onset to the current data collection period. The key finding of the study highlighted the complexities of disclosing distressing voices, and the barriers to seeking help and discussing these experiences with others.

Participants described the difficulties of disclosing distressing voices. Decisions to disclose these experiences were influenced by the perceived effect that this would have on the hearer and others. Consequently, the benefits and costs of disclosure were weighed-up and delays in help-seeking were affected by this decision. Barriers to accessing help were associated with denial, misinterpretation of symptoms and fear of stigmatisation. Voices were not always acknowledged or, if they were, the associated distress and adverse effects recognised. For some participants, a cognitive shift from denial (barrier) to the acceptance that distressing voices were present (facilitator) needed to occur before disclosure took place. Personal experiences of family and friends' attitudes towards mental health also affected decisions to talk about voices: positive approaches facilitated discussions whereas negative experiences acted as barriers. Typically, participants reached a point where the negative effects of remaining silent outweighed concerns of disclosing and asking for support. However, help-seeking was complex with participants not always knowing how to access services or having the confidence to discuss their experiences with others. Even if participants were receiving treatment for other mental health issues, voices were not always readily discussed, and disclosure was often delayed. To encourage earlier disclosure, these findings suggested that interventions should focus on increasing awareness and skill among those most likely to be disclosed to.

7.2.3   Practitioners Vary in their Confidence and Capacity to Engage in Conversations about Distressing Voices

Chapter five presented the findings from interviews with 10 EIP clinicians. The aim of the research had been to examine clinicians' experiences of how their clients managed voices overtime. However, two themes, 'Starting a conversation about voices' and 'Continuing the conversation about voices', offered novel insights. The aim of the research was re-focused to exploring practitioners' engagement with clients' experiences of voice hearing. A key finding of the study was that not all practitioners were comfortable or confident to have a conversation about voices.

Although participants considered talking about voices important, there were differences of opinion regarding the initiation and continuation of these conversations. Opinions varied as to who was responsible to start a discussion about voices: service users or practitioners? Structured assessment tools, such as the PANSS (Kay, Opler, & Fiszbein, 1987), enabled both practitioners and service users to start a conversation, providing a common language to explore voices and support difficulties when talking about these experiences. It was felt that conversations about voices should continue; however, this was dependent upon several factors such as practitioner confidence to discuss voices, training to work with voices and understanding of the experience. Some participants felt that these conversations did not occur as voices were not a primary concern for EI service users. The findings from the study indicated a need for interventions that can support practitioners to work with voice hearing experiences.

7.2.4 Similar and different routes to recovery

Chapter six explored the findings from 12 service users' semi-structured interviews, conducted over a three-year period, which were then compared to existing models of voice hearing over time. A preliminary revised model of voice hearing over time was developed. The aim of the research was to examine the different phases of managing voices, changes in beliefs about voices and 'the timing of therapy'. However, as the research evolved, the focus moved away from timing of therapy to the benefits of having 'conversations' about voices at different levels of intensity. The importance of different types/levels of conversations was a key finding of the study.

All participants described a 'common pathway', from pre-onset to the point of accessing help due to a worsening of voices. After disclosure, the 'common pathway' broadened into three novel pathways, which appeared to result from an interaction between voice continuation/dis-continuation and modification of beliefs. Voices stopped for some participants ("Voices stop" pathway) and this was attributed to a range of sources – medication, therapy and the opportunity to discuss voices informally. The cessation of voices provided a space for reflection and meaning making which assisted modification of beliefs about voices. For the remaining participants, voices continued but became less distressing when beliefs about voice omnipotence, control and origin were re-evaluated. This sub-group ("Voices continue but beliefs change"), ascribed belief modification to CBT and supportive discussions, which had facilitated a process of enquiry. There was also a shift from a passive response style (accepting voice comments and commands) to a more assertive style of responding (challenging voice

comments and commands) to voices. The third pathway ("Voices continue but beliefs do not change"), illustrated participants who remained in a cycle of increasing voice negativity and need to engage with services. Despite wishing to discuss their experiences, this group did not have access to supportive non-judgemental conversation. Although recovery style (sealing over or integration) may have influenced decisions to engage in therapy, or have a conversation about voices, it is unclear if it influenced the trajectory of a participant's pathway. These findings suggest the need for different types/levels of therapeutic conversations which support patients to make sense of voice hearing experiences and lay the foundations for subsequent belief modification.

7.3 The Novel Findings and Theoretical Implications

There are four key contributions from this research to the existing literature: 1) 'model of the stages of voice hearing', 2) the influence of beliefs about voices on the three different pathways outlining recovery, 3) the benefits of conversations about voices and 4) barriers to having conversations about voices. I will discuss each of these points in turn.

7.3.1 Model of the Stages of Voice Hearing

The categories outlined within the 'model of the stages of voice hearing' presented in this dissertation build upon existing models of voice hearing over time (de Jager et al., 2016; Milligan et al., 2013; Romme & Escher, 1989). The aim of the program of research was to develop an empirically supported model, outlining the phases of managing distressing voices, which would elucidate the optimum time for therapeutic intervention. Evidence suggested that there was not an empirically supported model of voice hearing over time which had been tested within a prospective longitudinal design.

7.3.1.1 *Model Development and the Interplay of Deductive and Inductive Themes*

The expanded model presented in this dissertation was developed from the analysis of primary and secondary data. Deductive themes (stages of voice hearing), which emerged from the amalgamation of existing models of voice hearing (de Jager et al., 2016; Milligan et al., 2013; Romme & Escher, 1989) were formulated into an integrated model. The model, and the individual deductive themes, were compared to findings from a longitudinal design of participants' experiences of hearing voices. In testing the model and its component themes, it had been necessary to consider: 1) whether the 'Integrated model' and themes reflected participants' experiences of voice

hearing over time and 2) if stages of voice hearing, as reflected by participants' inductive findings, were missing from the integrated model.

During the development of the integrated model, it had been important to pay attention to the interplay between deductive and inductive themes. The final, expanded model - 'The model of the stages of voice hearing' - illustrated the considered blending of themes from existing theory (deductive) and newly emerging data (inductive). Deductive themes were found to a) reflect the same meaning as inductive themes or b) partially reflect meaning - inductive findings expanded upon deductive themes. Alternatively, inductive themes, were not always represented by the original integrated model. Careful consideration was given to the incorporation of inductive themes within the model.

The relationship between deductive and inductive themes are characterised by the following two pathways ('The Common Pathway' and the 'Voices Continue but Beliefs Change' pathway) of the expanded integrated model - the 'Model of the stages of voice hearing:'

The Common Pathway

Antecedent phase – this theme (stage of voice hearing) represented both deductive (present in original integrated model) and inductive (emerged from participant data findings) data. The essence of this theme was similar in deductive and inductive findings.

Voice Onset – this theme (stage of voice hearing) represented both deductive (present in original integrated model) and inductive (emerged from participant data findings) data. The essence of this theme was similar in deductive and inductive findings

Chaos – this theme (stage of voice hearing) represented both deductive (present in original integrated model) and inductive (emerged from participant data findings) data. The essence of this theme was similar in deductive and inductive findings

Watershed – this theme (stage of voice hearing) demonstrated the interplay between the deductive (present in original integrated model) and inductive data (emerged from participant data findings). Inductive data findings expanded upon the 'Crisis-induced change', 'Contact with services' and 'Disclosure to others' themes from the 'integrated model.' The 'Watershed' theme incorporated three sub-themes: 'Disclosure to others', 'Others notice changes in behaviour' and 'Destructive behaviour

(due to voices)'. These themes emerged from the assimilation of novel findings from participant data and deductive themes from the 'Integrated model.'

'Treatment', 'Social' and 'Self' – these sub-themes (stages of voice hearing) demonstrated the interplay between the deductive (present in original integrated model) and inductive (emerged from participant data findings) data. These three sub-themes correspond to, and expand upon, the 'Integrated model's' theme 'New beginnings.'

Voices Continue but Beliefs Change Pathway

A different stance – This theme (stage of voice hearing) represented both deductive (present in original integrated model) and inductive (emerged from participant data findings) data. Inductive data expanded upon the deductive theme of 'New understandings.'

Voices stabilise – This theme (stage of voice hearing) represented both deductive (present in original integrated model) and inductive (emerged from participant data findings) data. Inductive data expanded upon the deductive theme of 'Stabilisation.'

Reflect on experience – This was a novel inductive theme that did not correspond to the themes (stages) of the 'Integrated model.'

7.3.1.2   The Pathways of the Model of the Stages of Voice Hearing

The 'Model of the stages of voice hearing' illustrated the potential role of beliefs as a moderating factor in how voices can change over time by separating experiences along three distinct pathways: 'Voices stop', 'Voices continue but beliefs change' and 'Voices continue but beliefs do not change'. These three groups, which represented the recovery (or non-recovery) pathways of participants' experiences of hearing distressing voices, can be considered with reference to the broader literature.

The 'Voices stop' group concurs with evidence that, in first-episode psychosis, a range of treatments facilitates recovery and increase the likelihood of positive symptoms stopping (Addington, 2008; Lally et al., 2017; Sommer et al., 2012). However, approximately 80% of people who respond to treatment appear to relapse within five years (Brown, Kim, Mitchell, & Inskip, 2010). This pattern was demonstrated within the current study, with voices re-occurring for three out of six participants ('Voices stop' group). In comparison, the two groups whose voices endured ('Voices continue but beliefs change' and 'Voices continue but beliefs do not change') also correspond to the literature and demonstrated that, even with treatment, a proportion of individuals continue to experience distressing symptoms of psychosis

(Addinton, 2008). The findings that half of these participants learnt to live with and accept voices, 'Voice continue but beliefs change', maps onto the literature examining the processes of recovery (Romme & Escher, 1989; Romme et al., 2009; Romme & Morris, 2013). The current programme of research expands upon the literature by illustrating three recovery pathways linked by a 'common pathway'.

The four pathways presented in the model offer novel insights into the similarities and differences of managing voices. The 'common pathway' stage of the model provides further understanding into peoples' journey with voice hearing prior to treatment. Whilst previous research has typically focused upon recovery with voices that continue (de Jager et al., 2016; Milligan et al., 2013; Romme & Escher, 1989), the current model presents three different pathways outlining the processes of recovery (voices stopping or continuing) and non-recovery (voices still distressing). Peters (2014) argues that clinical research should investigate differences between types of patients and their different outcomes from different therapies delivered at different stages. Although the 'model of the stages of voice hearing' is preliminary and cannot be extrapolated beyond the participants within this programme of research, it may lay the groundwork for future clinical enquiry examining these queries.

7.3.2 The Influence of Beliefs about Voices

A factor that appeared to mediate these pathways was the appraisal of voices. The modification of beliefs was associated with a recovery pathway (whether voices continued or not), and a lack of modification associated with continued struggles with voices. As discussed previously in this dissertation, beliefs about voices are prominent within the literature which has emphasised the importance of the appraisal of voices and associated distress (Birchwood & Chadwick, 1997; Chadwick & Birchwood, 1994). Cognitive theories have asserted that the development of the symptomology, and the ensuing emotional and behavioural responses, are mediated by the meaning and beliefs attributed to the experience. Consequently, supporting individuals to examine biases in information processing which maintain maladaptive appraisals of voices may decrease levels of distress (Chadwick & Birchwood, 1994; Garety et al., 2001). Consistent with this literature, recovery was supported by opportunities to re-evaluate the accuracy of beliefs about voices ('voices stop' pathway and 'voices continue but beliefs change' pathways). Where this opportunity was lacking, recovery was less apparent ('voices continue but beliefs do not change' pathway). These divergent pathways seem to offer

novel understandings due to their temporal relationship with an initial pathway that was common to all participants.

Changes in beliefs regarding the perceived control of voices also appeared to be associated with changes in the manner of responding to voices. Beliefs that one was in control, and not the voice, exhibited a shift from a passive to assertive response-style. In the context of the wider literature, interpersonal theories have examined hearer-voice relationships with therapies (e.g. relating therapy) focusing on supporting hearers to respond to voices from an assertive position (Birchwood et al., 2004; 2014; Hayward et al., 2017; Leff et al., 2013).

7.3.3   The Benefits of Conversations about Voices

Although the model does not identify the exact timing for therapeutic intervention, it does highlight the significance of having 'conversations' at varying levels of intensity. The timing of therapeutic intervention (pharmacological and/or psychological) for psychosis has been significant within the literature with arguments stressing the importance of early intervention (Birnbaum et al., 2017; Millan et al., 2016; Padilla, 2015). The National Institute for Health and Care Excellence (NICE; 2016) have recommended that, within two weeks of referral, people experiencing first-episode psychosis receive a NICE approved care package. Consequently, within this programme of research, the move away from timing of therapy to the importance of conversations about voices was unexpected. The value of having supportive and exploratory conversations was stressed by both service users and clinicians. As previously discussed (Chapter Six: section 6.4.1), one participant partially attributed voices stopping to having had the chance to explore experiences through the interviews conducted within the present programme of research. Although the recognition of the benefit of conversations about voices outside of formal therapy is not new (e.g. within Hearing Voices groups) (Dillon, 2009; Oakland & Berry, 2015), the need for mental health services to offer hearers different types and levels of intensity of conversation was a novel finding. Participants appeared to benefit from supportive conversations which seemed to play an important role in challenging unhelpful beliefs about voices. As already stated within this dissertation, whilst the preliminary revised model of voice hearing does not focus on exact timing, or intensity, of therapeutic intervention, there was no evidence within the data that conversations about voices should be delayed.

7.3.4   Barriers to Having Conversations about Voices

Findings from the programme of research indicated that there were barriers to having conversations from both service users and clinicians. While service users described a range of factors which inhibited disclosure and conversations about voices, it was also evident that clinicians varied in their reports of their confidence to initiate and facilitate these conversations. The existence of barriers to working with distressing voices within an Early Intervention for Psychosis service (EIP) was unexpected. Previous research has suggested that mental health staff (outside of EIP services) may be limited in their provision of mental health care for people experiencing distressing voices (Coffey & Hewitt, 2008). Coffey and Hewitt (2008) found differences of opinion between service users and community mental health nurses (CMHNs) regarding the level of involvement provided by nurses for patients' experiencing distressing voices. Although CMHNs believed that they met the needs of their patients, service users reported an absence of, and a need for, more exploratory conversations about voices. A comparable pattern was also found within the current programme of research with service users wanting more general conversation about their voice hearing experiences. Like Coffey and Hewitt (2008), it was evident that, for some clinicians, conversations about voice hearing experiences were limited by opinions of skill and job role. This was surprising as NICE (2016) guidance has stated that EIP care coordinators (also referred as Lead Practitioners) should be skilled to support service users across a range of psychological needs. However, it is important to acknowledge that interviews with clinicians took place prior to the publication of these guidelines.

7.4   The Clinical Implications of the Findings

This section will outline how the novel findings are relevant to clinical applications.

7.4.1   The Model of the Stages of Voice Hearing

The model presented in this research programme expands upon, and offers novel insights, that could enhance the wider body of voice hearing literature. Although the model is preliminary and cannot be generalised to patients outside of this research, it highlights the role of beliefs within the recovery pathway of distressing voices. The model illustrates the importance of understanding beliefs for voice hearing and management, while suggesting a way for clinicians to begin to disaggregate the effect of beliefs. The suggestion that the modification of beliefs was associated with acceptance and meaning-making, while a lack of modification appeared to maintain struggles, is consistent with CBT for voices, which maintain that voice-related distress results from

the appraisal rather than the voice per se (Byrne et al., 2006). Milligan et al. (2013) call for qualitative research examining how changes in appraisals support a shift from 'rejecting' to 'accepting' voices. Although the research did not identify the mechanisms underlying this change, it did infer that the modification of beliefs concerning voice origin (external or internal), omnipotence and omniscience seemed to be linked to the acceptance of voices. Additionally, in line with the empirical literature (Birchwood & Chadwick, 1997; Chadwick & Birchwood, 1994), beliefs regarding origin, omnipotence and omniscience also appeared to mediate affective and behavioural responses to voices. Consequently, the model highlights the benefit of clinical services identifying and working with unhelpful beliefs near to the disclosure of voices.

The 'common pathway' demonstrated that help from services, family and/or friends occurred once participants reached a point termed 'watershed'. Prior to this, the duration of hearing voices could span years. This suggests that increased educational work around the symptoms of mental health (e.g. voice hearing) may assist people troubled by distressing voices to disclose earlier. The design and implementation of mental health educational programs could be supported by consumer-driven groups such as Hearing Voice Networks (HVN) and take place within schools and youth groups. This may help people to recognise the symptoms of psychosis, encourage self-enquiry into one's mental health and reduce stigmatisation. It would also support people to make an informed choice regarding help-seeking.

The model outlined three new possible pathways – two illustrating recovery and one non-recovery. These pathways may offer the initial stages of a framework to help unpack and appreciate differences in voice hearers' journeys past the point of disclosure. The 'model of the stages of voice hearing' provides the groundwork for a testable model delineating separate recovery (and non-recovery) pathways. Such a model could support clinical services in how they respond to people who exhibit differences in their appraisals of, and trajectories, with voices. For example, to try to prevent the negative cycle presented in the 'Voices continue but beliefs do not change' pathway, service users who have difficulties attaining understanding into their experiences may need more support within this area than those exhibiting a tendency toward the 'Voices continue but beliefs change' pathway.

7.4.2 Conversations about Hearing Voices

The evidence from the research programme indicated that people benefit from talking about voices. Whilst different types of conversation at different levels of

intensity may be beneficial, findings suggested that having such conversations was not always easy for either service users or clinicians. One of the barriers to disclosure, and having conversations about voices, was stigma. Due to stigma, people are often unwilling to talk about their voice-hearing experiences (Vilhauer, 2017). This can result in feelings of isolation and affect beliefs about self, others and voices (Ruddle et al., 2011). To support disclosure, and reduce fear of stigmatised responses, people entering EIP services may benefit from consultation with peer support workers and HVNs.

There is a need for EIP services to offer service users the chance to discuss voices outside of formal therapy. However, as demonstrated in the current dissertation, as well as the broader literature (Coffey & Hewitt, 2008), not all clinicians are confident to talk about voices. Hearing voices is the most common type of hallucination reported in psychosis (National Alliance of Mental Illness; NAMI, 2011). It would therefore be appropriate that all EIP clinicians (not just who are qualified to deliver high-intensity therapies, e.g. psychologists), receive specific training to engage with voice hearing. Training could be in line with arguments favouring symptom-specific interventions rather than disorder-specific approaches (Lincoln & Peters, 2018).

EIP services could offer a three-tiered approach to working with distressing voices: a) starting conversations and supporting disclosure of voicers b) continuing conversations about voices through the delivery of low intensity CBTp based therapies, such as coping strategy enhancement (CSE; Tarrier et al., 1990) and/or Guided self-help cognitive Intervention for VoicEs (GIVE; Hazell, Hayward, Cavanagh, Jones, & Strauss, 2018) and c) high-intensity psychological CBTp therapy.

The first stage, starting conversations and disclosure of voices, might be supported by a semi-structured interview for voice hearing. The PANNS (Kay, Opler, & Fiszbein, 1987) provided a framework for both service users and clinicians to start a conversation about voices. The introduction, and standardisation, of specific interview guides for voice hearing (e.g. Auditory Hallucinations Interview Guide (Trygstad et al., 2014) may enable both clinicians and service users to find a mutual language to begin to talk and explore voice hearing experiences. Instead of just focusing on the delivery of treatment, offering a space for informal conversations would encourage the caring features of the clinician-service user relationship (Laugharne, Priebe, McCabe, Garland, & Clifford, 2012). Laugharne et al. (2012) found that listening time is not only valued by service users but can also build clinician-service user trust (Laugharne et al., 2012).

The implementation of stage two would require all EIP clinicians to be trained to deliver low intensity therapies such as CSE for managing voices (Hayward, Edgecumbe, Jones, Berry, & Strauss, 2018). Clinicians wishing to work more deeply with voice-related distress could be offered additional training to provide low-intensity, non-formulation driven therapies, such as GIVE (Hazell et al., 2018) which target mechanism that maintain distress (e.g. negative beliefs about self, beliefs about voice omnipotence, self-esteem). Stage three, high intensity CBTp therapy, could then be offered to service users requiring further therapy.

The first two tiers of the approach, delivered prior to high-intensity therapy, would support disclosure of voices, continue conversations about voices after disclosure and provide evidenced-based low-intensity therapy. Having different types and levels of conversations may meet the needs, and readiness, of a patient's ability to explore their experiences. In addition, it would also support clinicians to tailor conversations, and focus of therapy, to align with a person's recovery style (McGlashan, Levy, & Carpenter, 1975), a factor which has been found to play a role in service engagement and treatment (Startup, Wilding, & Startup, 2006; Tait, Birchwood, & Trower, 2003). Recovery style, sealing-over or integration, may be viewed as part of a continuum within psychosis. Sealing-over is associated with a lack of curiosity, understanding of psychotic symptoms and an inflexible approach to illness. Alternatively, 'Integrators' are flexible, wish to explore symptoms and view them as part of the framework of their life (McGlashan, Levy & Carpenter, 1975). Although different recovery styles were evident within the current programme of research, a 'sealing-over' style was not always fixed. Struggles with voices appeared to influence style of recovery with some participants tending to exhibit a 'sealing-over' style during times of distress (wanting medication and not wishing to explore voices), and an 'Integrator' style when not distressed. It was during this time that reflection on experiences with voices occurred. Clinician-service user conversations would allow exploration of experiences when a person felt able/ready to manage such enquiry.

7.4.3 The Value of More Informed Conversations

The evidence from this dissertation implies that having more informal conversation could help the following:

7.4.3.1 *Allow clinicians to provide a space for user led enquiry into their own experiences, rather than therapy led.*

General conversations outside of formal therapy would offer service users a supportive space to explore their voice hearing experiences. The service user would have the opportunity to direct conversations at their own pace and through their own lens of inquiry.

7.4.3.2 *More normalising, less stigmatising, less intrusive.*

Informal conversations exploring voices may be more normalising, less stigmatising, and considered less intrusive than high-intensive therapy. Through a process of normalisation, they can help to re-frame the phenomenon as part of a continuum of human experience (Romme & Morris, 2013).

7.4.3.3 *Might be enough to reduce need for formal therapy.*

Conversations can support individuals to explore beliefs, test realities, reflect upon the experience, define and take ownership of their experiences (Intervoice congress, 2012; Kay, Kendall & Dark, 2017) without being the focus of formal therapeutic attention. In addition, having such a conversation may enable self-recovery and be enough to reduce voice-related distress. Such conversations may build positive therapeutic relationships which, Priebe and McCabe (2006) argue, may be curative. A further consequence of having which, would be to reduce the pressure on overstretched formal therapy services.

7.4.3.4 *Ease the transition into formal therapy.*

It has been proposed that readiness and motivation for therapy might improve the effectiveness of CBTp (Woods, Burke & Morrison, 2015). Woods et al. (2015) argue that attempts should be made to overcome difficulties with service users' willingness to engage in therapy. These conversations can lay the groundwork and help service users prepare for higher-intensity CBTp therapy.

7.5 Limitations and Research Implications

The limitations of each of the studies presented in this programme of research will be discussed. Recommendations to address them through future research will be suggested.

7.5.1 The Study Participants – EIP Service Users

7.5.1.1 *The duration of hearing voices.*

The main reason for recruitment from an EIP service was to explore voice hearing as near to onset as possible. However, a limitation of the study was that

amongst the participants, the duration of hearing voices ranged from less than 1 year to 21 years. Consequently, with regards to the early course of the experience, the timespan between, and during, the different stages of managing voice varied. The heterogeneous nature of the sample, with regards to the length of time since voices started, meant that some participants were describing more distant experiences than other participants. However, despite this variance, the time since voice onset was not found to affect the early course of voice hearing. All participants shared a 'common pathway' and described similar stages of this trajectory.

It may be helpful if future research examined the 'common pathway' with participants reporting similar lengths of time since voice onset. Alternatively, although the early stages of the course were comparable amongst current participants, it may be fruitful to further investigate this pathway with people reporting differences in the duration of hearing voices. For example, as described in Chapter One (section 1.7), the length of duration between voice onset and disclosure heightens the risk of voices becoming more complex, with hearers becoming progressively ingrained in their experiences (Yung et al., 2007) and increasing the possibility of delusional ideation and general psychopathology (De Loore et al., 2011).

7.5.1.2 *The problem with retrospective recall.*

At T1 data collection period, participants reflected upon their experiences with voices from voice onset to current interview. As mentioned (Chapter Four: section 4.3.2), in some cases, the length of time since voice onset may have spanned years for some. Service user's retrospective accounts may have been influenced by attenuated recall. Future longitudinal research examining peoples' experiences with voice hearing could employ methodologies such as experience sampling method (ESM; Larson, 1983). ESM invites participants to record emotional, behaviour and cognitive responses on multiple instances over a set period. Data may be recorded through a range of data collection tools (e.g. journals, electronic devices). Digital technologies could be used to support ESM methods to gain 'in-the-moment' experiences with voice hearing.

7.5.1.3 *Not screening for developmental disorders.*

One limitation of the research was that there was no screening procedure for developmental disorders. For example, adults with a diagnosis of Autism Spectrum Conditions (ASC) have been found to be three times more likely to have experienced unusual hallucinatory perceptions, such as hearing voices, than adults who do not have this diagnosis (Milne, Dickinson, & Smith, 2017). In addition, anomalous perceptual

experiences have been related with autistic traits within the general population (Horder, Wilson, Mendez &, Murphy, 2014). ASC is a neurological disorder, and while unusual perceptions may be associated with psychological factors (e.g. negative experiences such as bullying), they have also been linked to innate chemical differences in the brain (ibid). As the current research programme was exploring changes in understanding, and recovery, of hearing voices, it is uncertain if non-psychological factors may have influenced the three sub-group pathways (e.g. influences on why beliefs did not change for the 'Voices continue but beliefs do not change' group). Future research should screen out for developmental disorders.

7.5.1.4 *The lack of diversity within the sample.*

A limitation of the research programme was the lack of diversity with the sample. I did attempt to address this issue by recruiting from EIP services within two NHS Foundations EIP services: a metropolitan borough located in the North of England (Manchester) and coastal towns located in the South East of England (Brighton and Eastbourne).

Although participants ranged in terms of education and employment, the sample lacked diversity with respect to age, ethnicity and geography. However, with respect to age, the study was limited to recruiting EIP service users up to the age of 35. Prior to 1 April 2016, EIP services were only commissioned for service users aged 14-35 (NICE, 2016). Recruitment within this programme of research took place in 2014 and therefore age was restricted. Future research should investigate the usefulness of the model of voices over time in more diverse clinical populations.

7.5.1.5 *The lack of triangulation between service user and lead practitioner data.*

Service users within the current research spoke of their need to have conversations about their experiences with voices with their mental health team. Consequently, it may have been beneficial if interviews had been conducted with service user's Lead Practitioners (LP). Although EIP clinicians participated in the research programme, as they were recruited independent of service users, it was not possible to triangulate both sets of data. Comparing findings may have offered further insight into the importance of conversations about voices. Both service users and mental health clinicians have been found to hold differences of opinion with regards to the professional response to patients experiencing voices (Coffey & Hewitt, 2008). Findings from the current study suggested a need for further research investigating the

value of informal conversations about voices. There is a need for more research to understand how to standardise informal conversations about voices. Future research examining conversations should seek to triangulate service user data with their LP.

7.5.2 The Study Participants – EIP Clinicians

7.5.2.1 *The interview schedule did not focus on clinician-service user conversations about voices.*

The interviews conducted with clinicians focused on their experience of service users' journeys and management of voices over time. They were not directed towards understanding how clinicians supported voice hearing or, more specifically, how they engaged in conversations. Although the finding that not all clinicians engaged in conversations about voices is in line with the broader literature (Coffey & Hewitt, 2008; McCabe, Skelton, Heath, Burns, & Priebe, 2002), further research should focus upon the barriers and enablers for EIP clinicians supporting voice hearers, and their confidence to engage with these experiences. Furthermore, given that being listened to by clinicians can facilitate the therapeutic relationship (Laugharne et a., 2012), a factor which effects psychotherapy outcomes for psychosis (Goldsmith, Lewis, Dunn, & Bentall, 2015), research should explore how clinicians (e.g. Lead Practitioners) can support service users during, and after, the receipt of a course of psychological therapy.

7.5.3 The Generalisability of Results outside of EIP Services

7.5.3.1 EIP Service users.

At the time of recruitment, participants were engaged with EIP services. Consequently, findings cannot be generalised to people who hear voices who have not accessed mental health services or service users beyond a first episode of psychosis. Additionally, the sample was small, and findings are therefore limited to participants within the programme of research and cannot be extrapolated to a wider population. Future research should investigate the revised model of voice hearing over time with a larger sample size of divergent populations of voice hearers and look to triangulate qualitative and quantitative data.

7.5.3.2 EIP Clinicians.

The study was limited by the size of the sample (ten EIP clinicians). Furthermore, as clinicians were recruited from two EIP services findings cannot be inferred to EIP clinicians more generally, or to mental health clinicians outside of EIP services. In attempting to investigate similarities and differences within EIP services, future research should look to recruit clinicians from EIP services both nationally and

internationally. Additionally, it may also be helpful to examine these factors more broadly and compare EIP clinicians with clinicians from other mental health services.

7.5.4 The Quantitative Data

The programme of research was designed as a mixed methodology. It was planned that quantitative data would corroborate (or not) qualitative findings. Although a brief analysis was conducted with the quantitative data, it was not fully analysed and therefore was not presented in this dissertation. Due to the success in participant retention (see Figure 10), the results chapters focused on the qualitative data set, as this was larger and richer than the quantitative data. A limitation of the quantitative data set was the amount of missing data. This was on account of a) two participants not wishing to complete measures at all time points because of fatigue and b) voices ceasing for six participants. This meant that three of the measures (PSYRATS-AH, Haddock et al., 1999; BAVQ-R, Chadwick et al., 2000; and the VAY, Hayward et al., 2008) were redundant for participants whose voices stopped as measurements referred to voice hearing experiences over the preceding week. Consequently, there were full data sets for four out of twelve participants. This meant that findings would not have been meaningful. However, the small quantitative sample size was not unexpected. It was always considered that the quantitative data would be less informative than the longitudinal qualitative data.

Future research should scope to quantitatively test the revised model of voice hearing over time. In line with Peters (2014) call to investigate differences between patients and their response to different therapies, delivered at different stages; a quantitative testing of the model might further support an examination of the effect of the three-tiered therapeutic approach (as suggested in section 7.4.2) on the three sub-group pathways represented in the revised model.

7.6 The Quality Control of the Research Programme

The qualitative research presented in this dissertation was guided by Yardley's (2000) criteria for good quality research. These criteria ('sensitivity to context', 'commitment and rigour', 'transparency and coherence' and 'impact and importance'), as previously outlined in Chapter Two (section 2.5), will be discussed.

7.6.1 Sensitivity to context

I was aware of the existing research and sought to link participant quotes within the context of the broader literature and theory. For example, in Chapter Four, quotes pertaining to the decision to disclose voices - "That's when I had to sort of tell them

because I couldn't hold it in anymore" - were associated to theories of stigmatized conditions. In Chapter six, the quote "I felt they were really, really you know ever so powerful over me" was discussed within the literature of voice omnipotence.

Sensitivity to the socio-cultural setting was demonstrated in Chapter Four by participants' social experiences of mental health issues. The family reaction to a participant's disclosure of voices - "for God's sake here we go again" - was interpreted to mean that, within the context of the family, hearing voices was considered a 'norm'.

To ensure sensitivity to the participants' views on the interpretation of the analysis, at the end of Chapter Six, participants were invited to comment on the written findings from their transcripts.

7.6.2 Commitment and rigour

The process of conducting a longitudinal study ensured that I was fully engaged with each stage of the research. In Chapter six, each participant's interview facilitated the development of the next interview. This meant that I was totally immersed in the interview, data and analysis. During the interview, findings from previous interviews were discussed. As well as paying close attention to the interviewee's responses (verbal and physical), I took notes and ensured that areas of interest were explored. Transcripts were read several times. To ensure that meaning and nuance was captured, analyses were compared to the original data sources. Conducting a longitudinal study meant that the data was continually re-visited and explored. Analysis was performed at several levels. For example, with regards to the explorations of participant's journeys with voices over time (Chapter Four and Chapter Six), analysis occurred at a case-by-case level as well as across the body of data.

Over time, I became increasingly skilled during the interview process and encouraged participants to explore their experiences with the topic. For example, one participant in Chapter Six felt that part of the reason that their voices had stopped was due to discussing and exploring voices with me.

In addition, Chapter Five focused on EIP clinicians' professional experiences with working with clients who heard voices. This enabled triangulation of the data.

Yardley (2000) contends that a sustained engagement with the topic should be maintained. This, however, should not necessarily just be in the role of researcher but also may take the form of sufferer, carer, etc. Outside of my role as a doctoral student, I worked in a voice's clinic for Sussex Partnership NHS Foundation Trust as a Senior Clinic Assistant. This work afforded me the opportunity to engage with both service

users and non-service users (e.g. patient and public involvement members) who experience voices. Consequently, I was able to immerse myself within the topic at an academic level, as well as outside of academia as a researcher and therapist for an NHS Trust.

7.6.3 Transparency and coherence

The papers that were produced from the research clearly outlined the limitations of each study. For example, the paper presented in Chapter Four reported that participants were recruited from a small select sample and therefore findings could not be extrapolated to non-EIP service users. Also, it was recognised that the themes generated might have been subject to the personal preconceptions of the research team. The papers described the procedures and analysis of each study. The paper presented in Chapter Six, illustrated the various levels regarding the analytic process of developing a model of the stages of hearing voices. Coherence of research methods and philosophical position was demonstrated through studies the studies presented in Chapters Four and Six. For example, in the study in Chapter Four there is a rational between the qualitative approach (experiential thematic analysis), the method of in-depth face-to-face interview and the philosophical standpoint of critical realism. Transparency within this paper was demonstrated by the fact that the stages of analysis are available on request.

7.6.4 Impact and importance

There is a broad literature discussing hearing voices amongst clinical populations. The importance of treating psychosis early has been clearly outlined in the literature and forms the basis of the development of EIP services (McGorry, Killackey, & Yung, 2008). The study presented in Chapter Four focuses upon the barriers and enablers to disclosing voices and offers insight as to why voices may remain undisclosed for significant periods of time. The study presented in Chapter Six builds upon the seminal work of Romme and Escher (1989) as well as the subsequent models hearing voices of Milligan et al. (2013) and deJager (2016). The revised model examining the different stages of hearing voices describes three novel pathways regarding the trajectory of managing distressing voices. The work demonstrates the importance of beliefs about voices and the importance of discussing and exploring them early. The three research studies (presented in Chapters Four, Five and Six) outline the importance of discussing voices, a view that has been widely discussed within the literature and is also central to the Hearing Voices Movement.

7.7 Reflexive Account

The researcher plays an active role within the research process. Subsequently, due to our values, past events, interests, and points of view, the development of the research is moulded by these subjective experiences. Reflexive research is intrinsically the degree to which the researcher recognises and reflects on their role within the process (Braun and Clarke, 2013). As part of the qualitative process, researchers acknowledge that it is not possible to totally separate from 'one's own perspective' and enter the subjective state of another (Elliot, Fischer, & Rennie, 1999; Denzin & Lincoln, 2002). Berger (2015) contends the importance of examining one's own part in the creation of knowledge; awareness to our own biases, views and experiences, within the context of the research; and attempt equilibrium between the 'persona and the universal'.

There is a general consensus within the literature with regards to the meaning of 'reflexivity': Reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome (Berger, 2015; Bradbury-Jones, 2007; Guillemin & Gillam, 2004; Stronach et al., 2007). However, as Howitt (2010) maintains, within student projects, reflexivity is not always properly considered. Consequently, as part of the research process, I continually attempted to re-focus the lens back to myself. I realised that it was important to acknowledge, question and take responsibility for, my subjective influences upon the programme of research.

7.7.1 The decision to study the research topic

Why had I chosen to explore peoples' experiences with distressing voices? This was a question that remained active throughout the study, one that I continually returned to. Personal experiences of mental health issues with close others had, in-part, influenced my decision to research the subject of mental health. However, my curiosity in the subject of voice hearing arose through my professional work within an NHS research clinic. I am interested in peoples' experiences of living with voices and how, and if, voices become integrated into a person's life. In addition, I wanted to explore peoples' understanding and meaning making of these experiences. The opportunity to conduct a longitudinal piece of research and explore peoples' journeys with their voices was of particular interest. I believed that exploring voice hearing experiences from a longitudinal perspective may provide insights that a cross-sectional study was unable to

offer. I am aware that my interests may have exerted an influence on both interviews and analysis. I tried to reflect upon this and discussed the research process with my supervisors. Consequently, I managed my expectations and was able to provide a report that was as objective as possible.

7.7.2 The interview processes

As part of the interview process, I was not only aware of how I was perceived but, how I perceived the interviewee. My positioning as a researcher, which included personal characteristics such as gender, age, race, beliefs, experiences, theoretical positioning, emotional responses, political and ideological stances would have had bearing on the interview. The relationship between the interviewee and the interviewer can be shaped by such features (Berger, 2015) and should be taken into consideration. For example, as a middle-aged woman some participants may have been more comfortable sharing certain experience than others. Alternatively, I needed to draw attention and to self-reflect upon my response to the personal characteristics of the interviewee as well as my pre-conceived ideas regarding service user populations and clinicians. It was important to understand my expectations prior to, and during, the interview and how my internal processes might direct the dynamics. In addition, I was cognizant that my reactions were not always neutral, and how these may have been perceived as offering encouragement/discouragement to a particular response. As a longitudinal study, relationships with service users developed over time and I was mindful of the effect that this may have upon my expectation of the interviewee, and in turn, theirs of me.

To bring awareness to the interview, I kept a journal which afforded me the opportunities to reflect upon the interviews and refer to them at later stages of the research process.

7.7.3 The analysis

Kacen and Chaitin (2006) state that the researcher's background and views of the world influence their construction of the world; use of language; questions posed; how information is filtered, made sense of and conclusions drawn. Within the present programme of research, I monitored the effect of my professional role and its effect upon the lens by which I analysed, understood and drew inferences from the data. I was mindful of my experiences of working with people who heard distressing voices and the influence that this may bring to the analytical process. In order that my pre-conceptions of what I hoped to find did not influence codes and themes, I discussed findings with

participants. Although an inductive analysis of the data was performed, I was mindful of the fact that I still had knowledge of the literature and therefore, a true inductive process was not possible.

7.7.4 Final reflexions

The process of research necessitated a continual "self-exposure" and "moment to moment confrontation (Kacen & Chaitin, 2006. p214) which brought awareness to my life experiences, beliefs and standpoints and how they may seep into and shape the process of inquiry.

7.8 Conclusion

The findings presented in this dissertation help to develop clinical understanding of service users' experiences with hearing voices. The focus of the programme of research shifted from the timing of therapeutic intervention to the importance of service users receiving clinical support to have conversations about voices. The complexities to starting and continuing these conversations have been considered. First, the barriers and enablers to the disclosure of voices have been explored. Second, the suggestion that not all clinicians are comfortable or confident to talk about voices with service users was discussed. Third, a preliminary model of voice hearing over time, which lays the groundwork for future enquiry in a clinical context, was developed. The model illustrated how beliefs about voices appeared to act as a moderator to recovery. The three recovery sub-pathways of the model suggested that clinical conversations should focus on beliefs about voices. The author has described a three-tiered approach to having conversations at varying levels and intensities. This approach included the suggestion that all EIP clinicians are trained to deliver low intensity therapies for distressing voices. Importantly, the findings presented in this dissertation suggest that there are differences of opinion amongst EIP clinicians, as well as EIP service users, with regards to clinicians' engagement with voice hearing. It was proposed that EIP services ensure that service users are offered a space to have conversations about voices outside of formal psychological therapy. The longitudinal, qualitative method employed in the research programme addressed limitations of existing models of voice hearing which were either developed from cross-sectional data or not empirically supported. It is hoped that this dissertation has helped to contribute to the wider body of literature and further future clinical research examining the recovery pathways of distressing voices.

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Appendices

Appendix 1: REC Approval Letter for Programme of Research

NHS
Health Research Authority

NRES Committee London - Chelsea

HRA
Research Ethics Committee (REC) London Centre
Ground Floor
80 Skipton House
London Road
London, SE1 6LH

Telephone: 02033117294

03 April 2014 - Corrected

Ms Leanne Bogen-Johnston
Doctoral Student
University of Sussex
Doctoral School (Psychology)
Pevensey 1, room 2c3
Brighton, BN1 9RH

Dear Ms Bogen-Johnston

Study title:	**A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases effect engagement with services and therapy?**
REC reference:	**13/LO/1730**
IRAS project ID:	**124121**

Thank you for your letter, 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.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Danyal Enver, nrescommittee.london-chelsea@nhs.net.

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.

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of

the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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:

Document	Version	Date
Evidence of insurance or indemnity		12 July 2013
Interview Schedules/Topic Guides	1	03 October 2013
Interview Schedules/Topic Guides	1	03 October 2013
Investigator CV		23 October 2013
Letter from Sponsor		22 October 2013
Other: Team Information Sheet	1	03 October 2013
Other: Team referral letter	1	03 October 2013
Other: Summary CV for Supervisor		23 October 2013
Other: explanation of qualitative methodology		
Participant Consent Form	1	03 October 2013
Participant Information Sheet: clinician		
Participant Information Sheet: service user		
Protocol	1	03 October 2013
Questionnaire: People's Journeys with voice hearing over time		
Questionnaire: assessment measure booklet		
REC application		
Response to Request for Further Information		

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.

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

13/LO/1730	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

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

Yours sincerely

P.P.

Dr Shelley Dolan Chair

Enclosures: "After ethical review – guidance for
researchers" *[SL-AR2]*

Copy to: *Dr Richard deVisser*
Ms Tanya Telling, Sussex Partnership NHS Foundation Trust

Appendix 2: EIP Services (Sussex) Team Leaflet

University of Sussex

Sussex Partnership NHS
NHS Foundation Trust

TEAM INFORMATION SHEET

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Study Full Title

People's journeys with voice hearing over time: what are the different phases of managing voices?

Study Team

Chief Investigator: Leanne Bogen-Johnston

Study Team: Dr Mark Hayward, Dr Clara Strauss, Dr Richard deVisser,

Collaborators: Dr Simon McCarthy-Jones, Dr Katherine Berry, Dr Georgie Paulik, Yvonne Awenat

Background

Although the experience of hearing voices (auditory verbal hallucinations) occurs in both clinical and non-clinical populations, clinical groups tend to experience voices as more distressing. Treatments are developing to try and reduce this distress. Researchers are interested in the possible phases of the voice hearing experience and understanding which phase(s), if any, might be more effective for treatment.

What is the purpose of the study?

This study will explore people's journeys with voices, identifying different phases of managing their voices, and how these phases may impact on therapy. At the end of the study, the information will be used to design a clinical model of the phases of managing voices.

Study Summary

The Voices over Time study is part of a PhD study which is sponsored by the University of Sussex and is also in collaboration with Sussex Partnership NHS Foundation Trust. Its purpose is to examine people's voice hearing experience, and whether there are different phases of managing their voices, over a three year period.

Thirty services users recruited through various Early Interventions for Psychosis (EIP) services across the country will be interviewed regarding their voice hearing experiences at nine monthly intervals over three years. Clinical participants will also be asked to fill out questionnaires enquiring as to their beliefs about voices, feeling about their self, voice hearing experience and relating with voices. In addition, fifteen clinicians from EIP services will be asked to take part in a one off interview focusing on their experiences with service users journeys with voices.

Service User Expenses

Service use travel costs to and from the meetings will be reimbursed. Participants can either make their own way to the meeting or transport (taxis) will be arranged.

As way of our appreciation, on completion of each interview and questionnaire service users will receive a £15 voucher.

Recruitment

Psychiatrists, psychologists and care co-ordinators working in EIP services in a number of sites across the country will be asked to identify service users who meet the study inclusion criteria:

- 18+ years of age
- Has been experiencing distressing voices for the preceding three months
- Does not have an organic illness or a primary diagnosis of substance misuse.

How to Refer

For further information about how to refer a service user to the study please contact
Leanne Bogen-Johnston at :

School of Psychology

Pevensey 1 Building, Room 2C3

University of Sussex

Falmer, Brighton

BN1 9QH

Email: L.R.Bogen-Johnston@sussex.ac.uk

Telephone: 07957000881

Appendix 3: EIP Service User (Sussex) Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Service Users

Study Title

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Invitation

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve. Please read the following information carefully and discuss it with friends, relatives, care team and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Who is conducting the study?

"A study exploring people's experience of hearing voices over time" is being conducted as part of a PhD student study. The research is sponsored by the University of Sussex and is also in conjunction with Sussex Partnership NHS Foundation Trust.

What is the purpose of the study?

This study will explore people's journeys with voices over a three year period. It will aim to identify different phases people may encounter with their voices, how individuals manage their voices and, if there are different phases, which phases might be more effective for treatment.

Why have I been chosen?

We want to speak with you because we understand you have heard voices for at least three months and a member of your care team said you may be interested in the study.

In total, 45 people (30 people who hear voices, and 15 clinicians) will participate in the study across the country. Everyone will take part in interviews discussing their experiences of voice hearing. People who hear voices will also be asked to complete a questionnaire.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are free to withhold any personal information or to withdraw at any time, without giving a reason. This will not affect the care you receive. Neither will a decision not to participate. Members of the team can meet with you to discuss the study if you wish.

What would taking part involve?

First, you would meet with the researcher to discuss the study and complete a consent form. This would take about half an hour. The next part of the study would involve an interview and a questionnaire. This would take approximately an hour and a half and could take place after completing consent or at another time which is convenient for you.

What would I have to do for the questionnaire?

The researcher will support you to complete four questionnaires. The four tick box questionnaires will ask you:

1. How you relate to your voice

2. Your experiences of hearing voices

3. Your beliefs about voices

4. How you feel about yourself

The researcher can help you to complete these questionnaires by reading out the questions or you may prefer to complete them on your own

What would happen in the Interview?

The interview would involve you discussing your voice hearing experience with the researcher. During the interview you can choose not to discuss certain parts of your experiences or to withdraw at any time.

After your first interview and questionnaire you would be invited back after approximately **nine** months to take part in another interview and questionnaire. As the study is taking place over three years we would like to interview you and complete the questionnaires every **nine** months for a period of three years.

To help the researcher remember what was said the interview will be audio recorded.

Where would I have to go?

The meeting with the researcher would take place at a convenient location like the place where your care team work, or at your GP surgery.

What about my travel costs?

Travel costs to and from the meetings would be reimbursed. You can either make your own way to the meeting or we will arrange for a taxi.

To show our appreciation of your participation, on completion of each interview and questionnaire we would also like to offer you a voucher for £15.

What are the advantages and disadvantages of taking part?

By taking part in the study you will be helping us to learn about people's journeys with voices, whether there are different phases with voices, how voices are managed and, ultimately, when is the right time for therapy.

Your care team including your Care Co-ordinator would know that you were taking part in the study.

Talking about experiences of hearing voices can be helpful, though it can also sometimes feel difficult or distressing. You would be free to access help from your care team, should you wish, and to drop out of the study if you wished.

Confidentiality

Your care team including your Consultant Psychiatrist and Care Co-ordinator would know that you were taking part in the study.

The research team will not share what you tell them during the meetings with your care team. The exception to this would be if you said something that led a member of the research team to believe that the safety of yourself or someone else was at risk. Under these circumstances we will have to pass this information to your care co-ordinator.

All information that is written and recorded during the course of the interview and questionnaire would be kept strictly confidential and stored securely. Only members of the research team would have access to these records. This information would be coded and have your name and address removed so that you would not be recognised from it. The study complies with data protection laws.

It may be necessary that members of the research team access your medical notes. This will be to collect information on your medication.

<u>What will happen to my questionnaires and interviews?</u>

Questionnaires: all the study questionnaires will be entered onto a password protected computer. Participant's questionnaires will be analysed by the PhD student to see if there are changes across the three years in beliefs about voices, experience of voices, relating to voices and beliefs about the way people see themselves.

Interviews: the recorded interviews will be transcribed onto a password protected computer. Recordings will then be deleted from the recorders. The PhD student will analyse the interviews using Thematic Analysis. This form of analysis will help identify different themes that link people's experiences of hearing voices across time.

<u>What if I am not happy about the study?</u>

If you wish to make a complaint please contact either the Chief Investigator, Leanne Bogen-Johnston on 07957000881 or email:

L.R.Bogen-Johnston@sussex.ac.uk

Or

Dr Mark Hayward (Supervisor) on 01273 877240 or email:

mih21@sussex.ac.uk

Or

The Patient Advice &

Liaison Service (PALS) on 01323 446042 or email:

PALS@sussexpartnership.nhs.uk

<u>What will happen to the results of the study?</u>

Findings from the study will be used to inform clinicians and research about peoples journeys with voices and what is the best time to start therapy.

<u>Who has reviewed the study?</u>

The study has been reviewed and approved by the Research and Development Department within your local NHS Trust. It has also been reviewed by a NHS Research Ethics Committee.

<u>Next Steps</u>

If you are interested in taking part in the study please allow yourself at least 24 hours to consider your decision before contacting the research team or before asking for a member of the research team to contact you. This is to ensure that you have had time to consider your decision.

If you would like to take part in the study, or to find out further information please call Leanne Bogen-Johnston on 0795700081

Leanne Bogen-Johnston

Doctoral School

Room 2C3, Pevensey 1Building

University of Sussex

Falmer, Brighton

BN1 9QH

If no-one is available to answer your call, please leave a message and someone will call you back.

If you are harmed by taking part in this research study, there are no special compensation arrangements. If you are harmed by someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, you are asked to contact the academic supervisor (Dr Mark Hayward) of the study. If this is unsatisfactory, then you can contact the Registrar & Secretary of the University of Sussex at the following address:

Sussex House
University of Sussex
Falmer
Brighton
BN1 9RH

You may also wish to seek advice form the Patient Advice and Liaison Service (01323 446042 – pals@sussexpartnership.nhs.uk).

If you decide to participate in the study you will be given a copy of this information sheet and a signed consent form to keep.

Appendix 4: EIP Services Team (Sussex) Referral Letter

US University of Sussex

Sussex Partnership NHS
NHS Foundation Trust

Team Referral letter

Title of Project: A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Name of referring Team Member:_____Title:_____

Tel:_____Team:_____

Name of service user:_____

PIMS:_____ Service User tel:_____

Address of service User:

Please write yes or no in the boxes to the following questions regarding the individual you are referring to the study.

1. Has the individual been hearing voices for at least the past 3 months?

2. Is the individual over 18 years of age?

3. Does the individual have a primary diagnosis of substance misuse or an organic illness?

4. Are there any risks with visiting the individual at their home?

Signature of referring team member:_____

Date:_____

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy? *Team Referral Letter, 17th April 2014, Version 3*
REC Reference Number: 13/LO/1730

Once completed please would you return this form to:
Leanne Bogen-Johnston at the:
School of Psychology,
Pevensey 1 Building, Room 2C3
University of Sussex,
Falmer, Brighton, BN1 9QH
Email: L.R.Bogen-johnston@sussex.ac.uk; Mobile: 0795700081

Appendix 5: EIP Services User Consent Form

US
University of Sussex

Sussex Partnership **NHS**
NHS Foundation Trust

Participant Identification Number:

CONSENT FORM (Service User)

Title of Project: A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Researcher leading the study: Leanne Bogen-Johnston

Initial box

1. I confirm that I have read and understand the Participant Information Sheet dated 30th October 2014 (version 4) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withhold personal information or to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.

3. I understand that if I choose to withdraw that any questionnaires or recorded interview I have already completed will be kept by the research team

4. I give permission for my Care Co-ordinator to be informed of my participation in this study.

5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?
Participant consent form: Service User 30th October 2014, Version 4
REC Reference Number: 13/LO/1730

6.I understand that in the event that I disclose information which may indicate new risk to myself or others, the researcher will be obliged to follow Trust risk procedures that may require release of my personal data.

☐

7. I understand that all interviews will be audio recorded. I agree to being audio recorded. This will allow the researcher to remember what was discussed during the interview.

☐

8.I give permission for members of the Research Team to access my medical records for the purpose of this study.

☐

9.I agree to take part in the above study

☐

Name of Participant   Date   Signature

_____   _____

          _____

Name of Researcher   Date   Signature

_____   _____

          _____

Please tick this box if you would like to receive a copy of findings from the study ☐

If you would like a copy of findings please indicate if you would like these by post ☐ or by email ☐

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?
Participant consent form: Service User 30th October 2014, Version 4
REC Reference Number: 13/LO/1730

Appendix 6: Service User Assessment Booklet

Participant ID:

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Assessment Measures

Participant ID: ……

Researcher: …………………….

Today's Date: ……………..

This booklet contains a number of questions asking about yourself and your voice hearing experiences.

Participant ID:

Information About You

    1) What is your age? ....

    2) Please indicate your sex (tick the appropriate box).

Male   ☐   Female   ☐

    3) Please tick the box that best describes your current employment status.

Employed full-time (paid)	☐	Employed part-time (paid)	☐
Employed full-time (voluntary) (voluntary)	☐	Employed part-time (voluntary)	☐
Unemployed (on benefits)	☐	Unemployed (not on benefits)	☐
Student	☐	Retired	☐
Self-employed	☐	Home-maker	☐
Other	☐		

If you ticked **other**, please provide details

....

    4) What is your marital status?

Single	☐	Married/Civil Partnership	☐
Cohabiting	☐	Separated/divorced	☐
Widowed	☐	In a long-term relationship	☐

    5) What is your country of birth?
....

    6) What is your first language?
....

Participant ID:

7) Please tick the box that best describes your ethnic group.

White (British) ☐ White other ☐

Asian/Asian British ☐ Black/ African/ Caribbean/ Black British ☐

Chinese/ Chinese British ☐ Mixed ethnicity ☐

Other ☐ I would rather not disclose ☐

If you ticked **other**, please describe

…………………………………………………………………………………………

8) Please indicate which of the following best describes when you left education.

Left school before 16 ☐ Left school at 16 ☐

Left school at 17/18 course ☐ Completed/completing College ☐

Completed/completing University course ☐

9) Please provide details of the highest level of educational qualification you have?

…………………………………………………………………………………………

10) What age were you when you started hearing voice(s)?

…………………………………………………………………………………………

11) Are you aware of having ever received a mental health diagnosis/ diagnoses? If yes, please give details?

…………………………………………………………………………………………..………

…………………………………………………………………………………………..

…………………………………………………………………………………………

12) If applicable, when did you receive this diagnosis (Age)? If you have more than one diagnosis please specify when each one was received.

…………………………………………………………………………………………

…………………………………………………………………………………………

Participant ID:

13) What (if any) medication(s) for mental health are you currently taking? If possible, please give dosage(s)

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

14) Have you ever had any psychological therapy?

Yes ☐   No ☐

If you **have** received any psychological therapy, please provide details

(e.g. how long ago did you receive this therapy, how much therapy did

you receive, the type of therapy if known)

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

15) How often, and who do you see from your mental health team e.g. Psychiatrist, Care Coordinator, Psychologist?

…………………………………………………………………………………

…………………………………………………………………………………

Participant ID:

Psychotic Symptoms Rating Scale – Auditory Hallucinations
PSYRATS (1999)

Haddock et al.

PLEASE COMPLETE THESE QUESTIONS WITH A MEMBER OF THE STUDY TEAM

AUDITORY HALLUCINATIONS

1. Frequency
Probing questions
How often have you heard your voices over the last week? Thinking about the last week, what has it been like?" e.g. every day, all day long etc"

Scoring criteria:
0) Voices not present or present less than once a week (specify frequency if present)
1) Voices occur for at least once a week
2) Voices occur at least once a day
3) Voices occur at least once an hour
4) Voices occur continuously or almost continuously i.e., stop for only a few seconds or minutes

2. Duration
Probing questions
When you have heard your voices over the last week, how long have they lasted? Have they lasted for a few seconds, minutes, hours, all day long for example....?"

Scoring criteria:
0) Voices not present
1) Voices last for a few seconds, fleeting voices
2) Voices last for several minutes
3) Voices last for at least one hour
4) Voices last for hours at a time

Participant ID:

3. Location
Probing questions
When you have heard your voices over the last week, where did they sound like they were happening? Did they sound like they were inside your head and/or outside your head? Whereabouts do your voices sound like they are coming from?

Scoring criteria:
0) No voices present
1) Voices sound like they are inside head only
2) Voices outside the head, but close to ears or head. Voices inside the head may also be
   present.
3) Voices sound like they are inside or close to ears and outside head away from ears
4) Voices sound like they are from outside the head only

4. Loudness
Probing questions
How loud are your voices? Are they louder than my voice, about the same loudness, quieter or just a whisper?

Scoring criteria:
0) Voices not present
1) Quieter than own voice, whispers
2) About same loudness as own voice
3) Louder than own voice
4) Extremely loud, shouting

5. Beliefs regarding the origin of voices
Probing questions
What do you think has caused your voices?
Are the voices caused by factors related to you, or due to other people or factors? Are your voices caused by your mental health problems or illness?

How much do you believe that your voices are caused by (add interviewee's contribution) on a scale from 0-100 with 100 being that you are totally convinced, have no doubts and 0 being that it is completely untrue?

Scoring criteria:
0) Voices not present
1) Believes voices to be solely internally generated and related to self
2) Holds a less than 50% conviction that voices originate from external causes
3) Holds 50% or more conviction (but less than 100%) that voices originate from external
   causes

Participant ID:

6. Amount of negative content of voices
Probing questions
Do you think that your voices have said unpleasant things or negative things over the last week? How much of the time do the voices say these types of unpleasant or negative items?

Scoring criteria:
0) No unpleasant content
1) Occasional unpleasant content
2) Minority of voice content is unpleasant or negative (less than 50%)
3) Majority of voice content is unpleasant or negative (50% or more)
4) All of voice content is unpleasant or negative

7. Degree of negative content
Probing questions
Can you tell me a bit about what you have heard your voices saying over the last week? Can you give me some examples of the things you have heard this week?

Scoring criteria:
0) Not unpleasant or negative
1) Some degree of negative content, but not personal comments relating to self or family e.g.
    swear words or comments not directed to self, e.g. "the milkman's ugly"
2) Personal verbal abuse, comments on behaviour e.g. "shouldn't do that or say that"
3) Personal verbal abuse relating to self-concept e.g. "you're lazy, ugly, mad, perverted"
4) Personal threats to self-e.g. threats to harm self or family, extreme instructions or commands to harm self or others and personal verbal abuse as in (3)

8. Amount of distress
Probing questions
Have you found your voices to be distressing over the last week?
How much of the time have they caused you distress over the last week?

Scoring criteria:
0) Voices not distressing at all
1) Voices occasionally distressing, majority not distressing (<10%)
2) Minority of voices distressing (<50%)
3) Majority of voices distressing, minority not distressing ($\geq$ 50%)
4) Voices always distressing

Participant ID:

9. <u>Intensity of distress</u>
Probing questions
Over the last week when your voices have been distressing, how distressing has that been? Thinking about the worst distress you could feel, over the last week, how have your voices compared to that? For example, has it been slightly, moderately distressing etc?

<u>Scoring criteria:</u>
0) Voices not distressing at all
1) Voices slightly distressing
2) Voices are distressing to a moderate degree
3) Voices are very distressing, although interviewee could feel worse
4) Voices are extremely distressing, feel the worst he/she could possibly feel

10. <u>Disruption to life caused by voices</u>
Probing questions
How much disruption have the voices caused to your life over the last week? Can you tell me how the voices stopped you from working or doing any other daytime activity that you wanted to do?

How much have they interfered with your relationships with friends and/or family? How much have they prevented you from looking after yourself, e.g. bathing, changing clothes, etc?

<u>Scoring criteria:</u>
0) No disruption to life, able to maintain social and family relationships (if present)

1) Voices cause minimal amount of disruption to life e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.

2) Voices cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The interviewee is not in hospital although may live in supported accommodation or receive additional help with daily living skills.

3) Voices cause severe disruption to life so that hospitalisation is usually necessary. The interviewee is able to maintain some daily activities, self-care and relationships whilst in hospital. The interviewee may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.

4) Voices cause complete disruption of daily life requiring hospitalisation. The interviewee is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

Participant ID:

11. <u>Controllability of voices</u>
Probing questions
What control had you had over your voices over the last week?
How much control have you had over your voices when they happened over the last week? Can you get rid of, dismiss or bring on your voices?"

<u>Scoring criteria:</u>
0) Interviewee believes they can have control over the voices and can always bring on or dismiss them at will
1) Interviewee believes they can have some control over the voices on the majority of occasions
2) Interviewee believes they can have some control over their voices approximately half of the time
3) Interviewee believes they can have some control over their voices but only occasionally. The majority of the time the interviewee experiences voices which are uncontrollable
4) Interviewee has no control over when the voices occur and cannot dismiss or bring them on at all

Participant ID:

The Voice and You
VAY (2008)
Hayward, M., et al.

A PERSON'S ASSESSMENT OF THE RELATIONSHIP THEY HAVE WITH THEIR PREDOMINENT VOICE

PLEASE READ THIS BEFORE YOU START

The statements listed here are the sorts of feelings and attitudes which people sometimes have about or towards the voices they hear. Please read each statement carefully and indicate, by ticking the appropriate column, the extent to which you think it applies to you in relation to your predominant voice.

Try to be completely frank and honest about yourself. Avoid answering the way you would like to be or the way you would like others to think of you, rather than the way you really are.

Try as far as possible, to place your ticks in the "Nearly always true" and "Rarely true" columns. The two middle columns are really for if you cannot make up your mind.

Participant ID:

	Nearly always true	Quite often true	Sometimes true	Rarely true
1. My voice wants things done his/her way				
2. My voice helps me make up my mind				
3. I prefer to keep my voice at a safe distance				
4. My voice makes hurtful remarks to me				
5. My voice does not let me have time to myself				
6. I have a tendency to look up to my voice				
7. When my voice gets too close to me, it makes me feel uneasy				
8. My voice constantly reminds me of my failings				
9. My voice dislikes it when I exclude him/her by showing an interest in other people				
10. I allow my voice to take control of me				
11. I feel I have little to offer my voice				
12. It is easy for my voice to change my mind				
13. My voice does not give me credit for the good things I do				

Participant ID:

	Nearly always true	Quite often true	Sometimes true	Rarely true
14. My voice tries to accompany me when I go out				
15. I feel deserted when my voice is not around				
16. I try to hide my feelings from my voice				
17. My voice tries to get the better of me				
18. My voice dislikes spending time on his/her own				
19. My voice's judgment is better than mine				
20. I do not like to get too involved with my voice				
21. My voice makes me feel useless				
22. I need to have my voice around me a great deal				
23. I don't like my voice to know what I am thinking				
24. I have difficulty letting go of my voice				
25. My voice tries to make me out to be stupid				
26. My voice finds it hard to allow me to have time away from him/her				
27. I have a great need to talk to my voice				
28. I don't wish to spend much time listening to my voice				

Participant ID:

The revised Beliefs About Voices Questionnaire
BAVQ-R (2000)

Chadwick, P., Lees, S., & Birchwood, M.

There are many people who hear voices. It would help us to find out how you are
feeling about your voices by completing this questionnaire. Please read each statement and tick the box which best describes the way you have been feeling in the *past week*.

		Disagree	Unsure	Slightly Agree	Strongly Agree
1	My voice is punishing me for something I have done				
2	My voice wants to help me				
3	My voice is very powerful				
4	My voice is persecuting me for no good reason				
5	My voice wants to protect me				
6	My voice seems to know everything about me				
7	My voice is evil				
8	My voice is helping to keep me sane				
9	My voice makes me do things I really don't want to do				
10	My voice wants to harm me				
11	My voice is helping me to develop my special powers or abilities				
12	I cannot control my voices				
13	My voice wants me to do bad things				
14	My voice is helping me to achieve my goal in life				
15	My voice will harm or kill me if I disobey or resist it				
16	My voice is trying to corrupt or destroy me				

Participant ID:

		Disagree	Unsure	Slightly Agree	Strongly Agree
17	I am grateful for my voice				
18	My voice rules my life				
19	My voice reassures me				
20	My voice frightens me				
21	My voice makes me happy				
22	My voice makes me feel down				
23	My voice makes me feel angry				
24	My voice makes me feel calm				
25	My voice makes me feel anxious				
26	My voice makes me feel confident				
27	I tell it to leave me alone				
28	I try and take my mind off it				
29	I try and stop it				
30	I do things to prevent it talking				
31	I am reluctant to obey it				
32	I listen to it because I want to				
33	I willingly follow what my voice tells me to do				
34	I have done things to start to get in contact with my voice				
35	I seek the advice of my voice				

Participant ID:

The Brief Core Schema Scales: beliefs about self and others

BCSS (2006)

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Fowler, D., Freeman, D., Smith, B., Kuipers, E., Bebbington, P., Bashforth, H., Coker, S., Hodgekins, J., Gracie, A., Dunn, G., & Garety, P.

This questionnaire lists beliefs that people can hold about themselves and other people. Please indicate whether you hold each belief (NO or YES). If you hold the belief then please indicate how strongly you hold it by circling a number (1-4). Try to judge the beliefs on how you have generally, over time, viewed yourself and others. Do not spend too long on each belief. There are no right or wrong answers and the first response to each belief is often the most accurate.

			Believe it slightly	Believe it moderately	Believe it very much	Believe it totally
MYSELF						
I am unloved	NO	YES➤	1	2	3	4
I am worthless	NO	YES➤	1	2	3	4
I am weak	NO	YES➤	1	2	3	4
I am vulnerable	NO	YES➤	1	2	3	4
I am bad	NO	YES➤	1	2	3	4
I am a failure	NO	YES➤	1	2	3	4
I am respected	NO	YES➤	1	2	3	4
I am valuable	NO	YES➤	1	2	3	4
I am talented	NO	YES➤	1	2	3	4
I am successful	NO	YES➤	1	2	3	4
I am good	NO	YES➤	1	2	3	4
I am interesting	NO	YES➤	1	2	3	4
OTHER PEOPLE						
Other people are hostile	NO	YES➤	1	2	3	4
Other people are harsh	NO	YES➤	1	2	3	4
Other people are unforgiving	NO	YES➤	1	2	3	4
Other people are bad	NO	YES➤	1	2	3	4
Other people are devious	NO	YES➤	1	2	3	4
Other people are nasty	NO	YES➤	1	2	3	4
Other people are fair	NO	YES➤	1	2	3	4
Other people are trustworthy	NO	YES➤	1	2	3	4
Other people are accepting	NO	YES➤	1	2	3	4
Other people are supportive	NO	YES➤	1	2	3	4
Other people are truthful	NO	YES➤	1	2	3	4

Participant ID:

THIS IS THE END OF THE QUESTIONNAIRES.

Thank you for completing this booklet

Appendix 7: T1 Semi-Structured Interview Schedule

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Topic Guide (Service User): Time 1

Introduction

The focus of this interview will be on your experience of hearing voices. Everything you tell me will only be used for this research project, and will not be shared with anyone outside the research team unless you disclose information which may indicate new risk to yourself or others. You have already consented to the interview with the consent form. Do you have any questions before we begin?

Background Information

- **Ask demographics (relax participant)**
  Prompts: age, marital status, educational level, work, children

- **Opening Questions**
  Broad questions around voices i.e. Can you tell me a little bit about your voices?
  Prompts: How many voices, sex, identities, how long been hearing them, experience every day, certain times of day?

Key Areas

   Experience of Voices
   Prompts: First voice hearing experience, circumstances, what did you make of it

- **Changes in voice hearing experience over time**
  Prompts: changes in voice, why have they changed, feelings

- **Seeking help**
  Prompts: friends, family, services; circumstances around asking for help

- **Therapy**
  Prompts: experience of therapy

- **Impact of Voices (over time)**
  Prompts: impact personally – change as person (outlook, goals, behaviour); changes social, career circumstances

- **Relationship with voices**
  Prompts: make sense of them, meaning, relationship with voices similar to other relationships

- **Managing voices (over time)**
  Prompts: strategies, differences over time, different strategies according to circumstances

Closing Interview

- **Voices and future**
  Prompts: beliefs about voices and future, feelings about voices and future

Experience of voices and helping others
  Prompts: advice to others who hear voices

Outro Questions
- Do they have questions
- Add anything to what has been said
- Anything that thought would be discussed but wasn't
- Any topics discussed that surprised about

Note to self: Don't turn off recorder until participant has left room

Appendix 8: T2 Semi-Structured Interview Schedule (Participant 12)

T2 Interview Schedule (General Framework) Part 12

Voices:

When we last spoke you said that (re-cap on key points)

Voices moderate.
Being positive managed them
Voices people you met but also had old lady an alien
You were unemployed

Yes	No
Prompts:	*Prompts:*
• *Have voices changed since we last met i.e. what they are saying? Why do you think this has changed?* ***Being negative***	• *When did they go? Did they go suddenly or gradually?*
• *Experience same number of voices?* ***Voices from lots of people and tv—any other places?***	• *Did they all go or just some?* ***i.e. the experience of having voices from lots of people and objects like tv***
• *Same voices?* ***Still old lady an alien***	
• *Experience them as much/more/less?*	**Voice Hearer**
	Emotional response:
• *Same pattern of experience i.e. same time or same type of circumstances?* ***All the time***	*Prompts:*
	• *How do you feel about not having voices?* ***Said wanted them to go.***
Voice Hearer	
Emotional response:	• *Thinking back, what do you feel about them now?*
Prompts:	
• *How do you feel that voices are still around since we spoke 9 months ago?* ***Said wanted them to go***	• *How did they make you feel?*
	• *What was it like when they went?*
• *How do you feel about them?*	
	• *Do you miss them?*
• *How do they make you feel?*	
• *What's it like when they are not around?*	Behavioural response
	Prompts
• *Do you think that you'd miss them if they went?*	• Did you used to do things (i.e. coping managing) because of voices? Has that changed? ***Being positive***
Behavioural response	
Prompts	• Are there things you are able to do now that you couldn't because of voices? **Concentrate, conversations, relationships**
• *How do you cope/manage with voices?* ***Used being positive—voices can't come to you (said last interview) Explain***	
• ***So if feeling negative i.e. depressed is this a way for voices to come to you***	
• *Have ways of coping changed since we last met?*	
• *Are there things you don't do because of voices? Has this changed since we last met?*	

Appendix 9: Graphs of Participant's Quantitative Measures

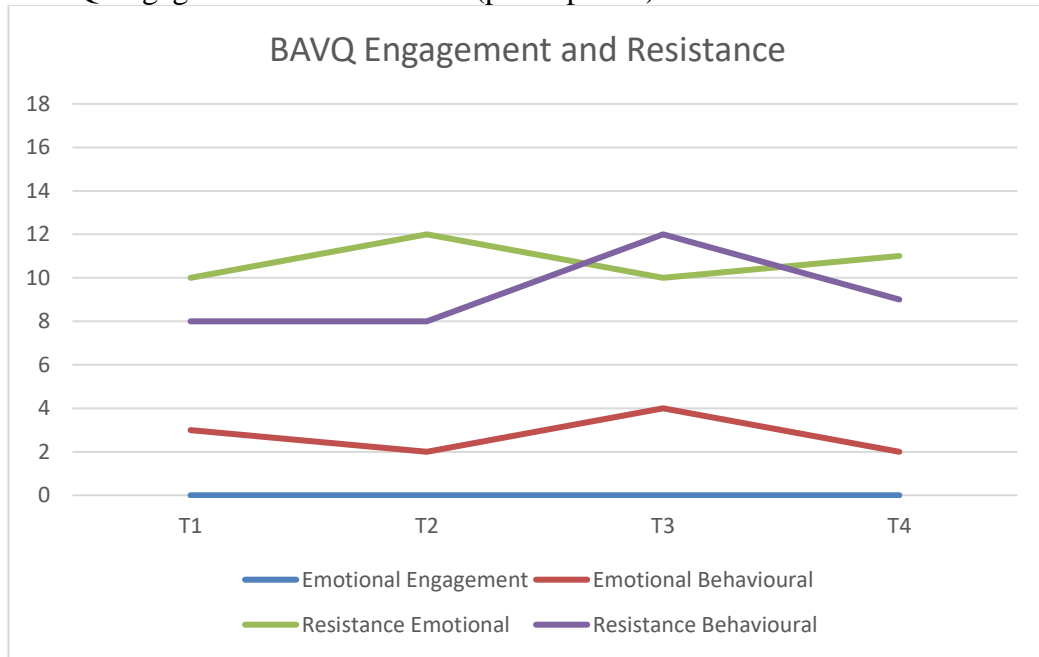**Participant 1**
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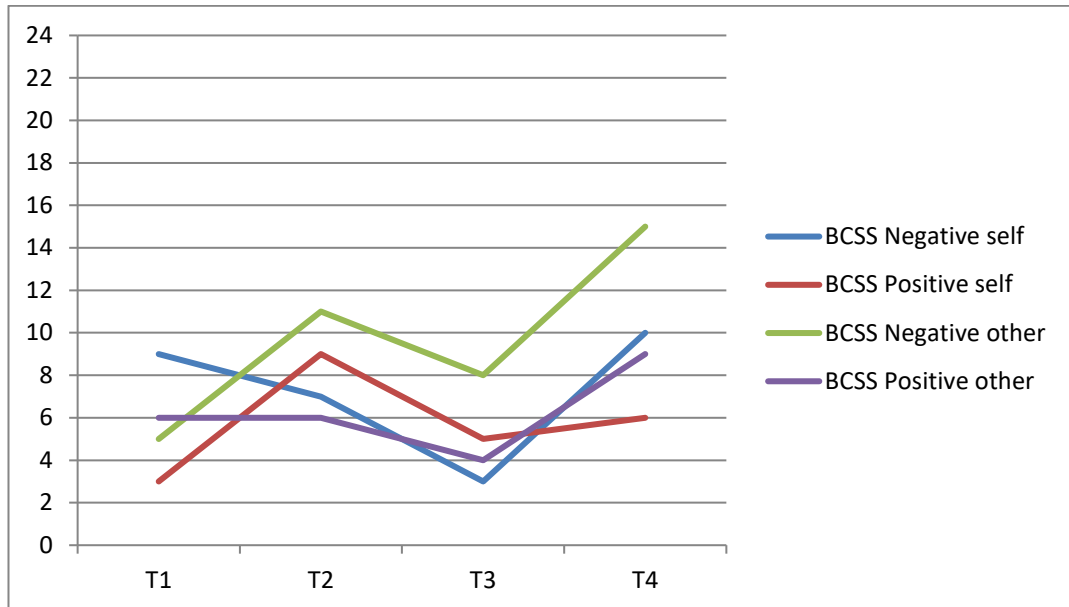
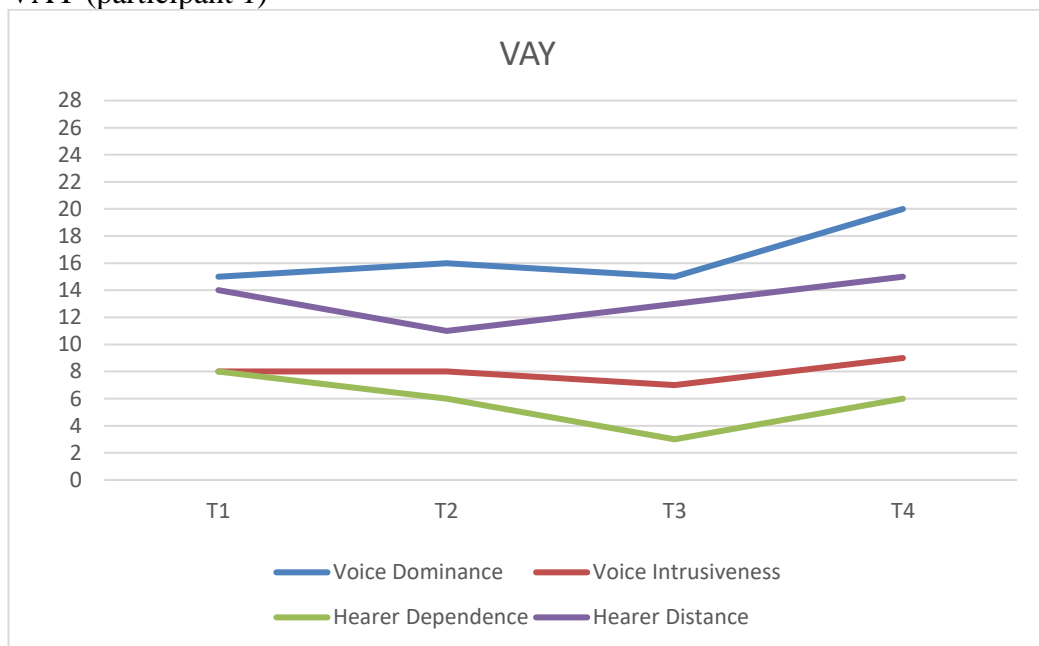Psyrats Total Scores
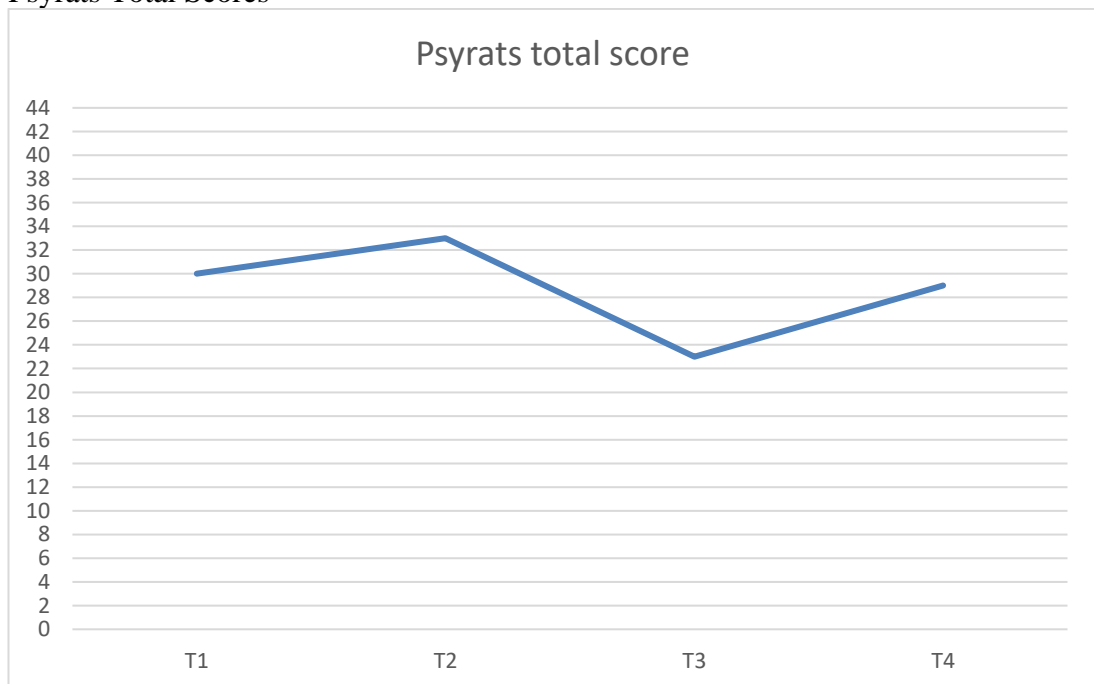
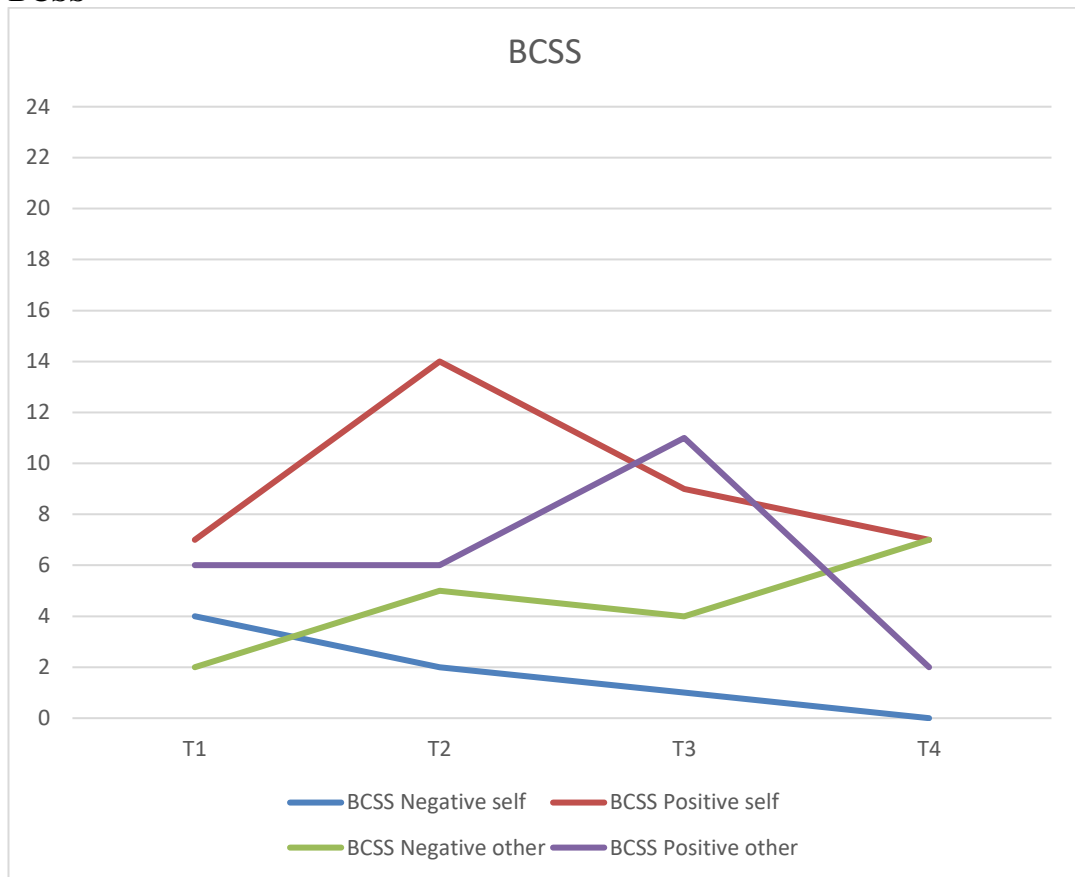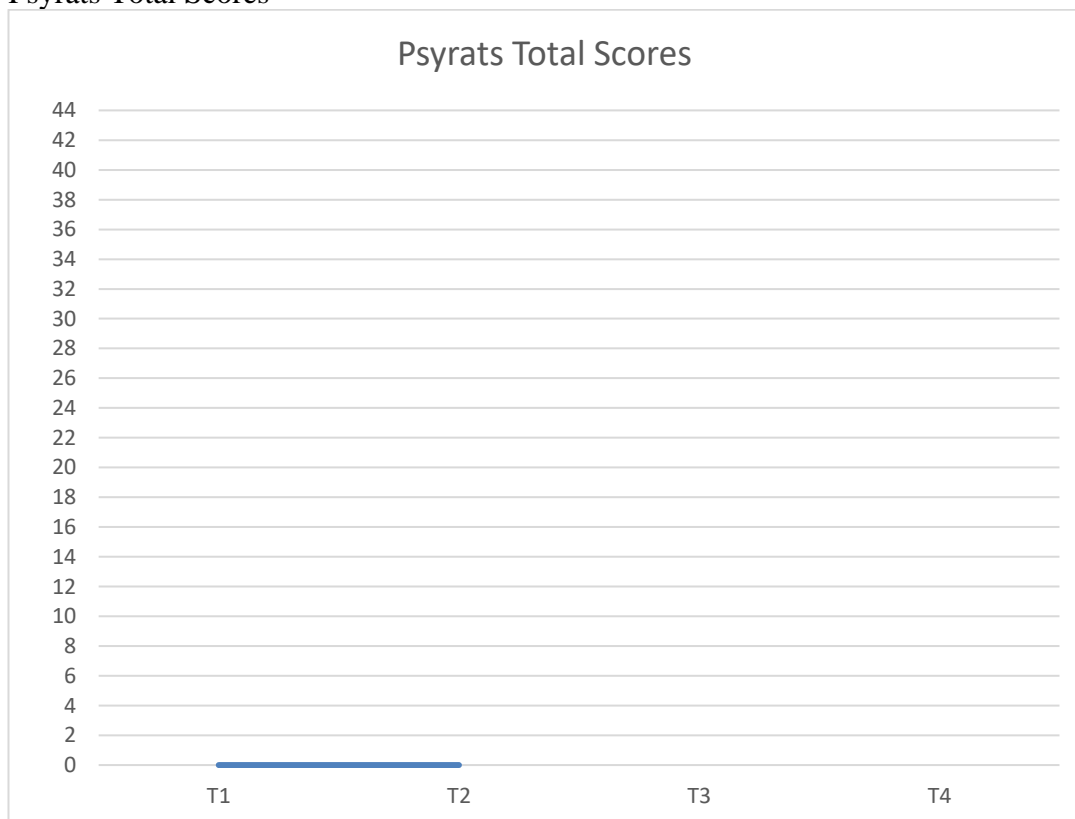Psyrats sub-scales (participant 1)
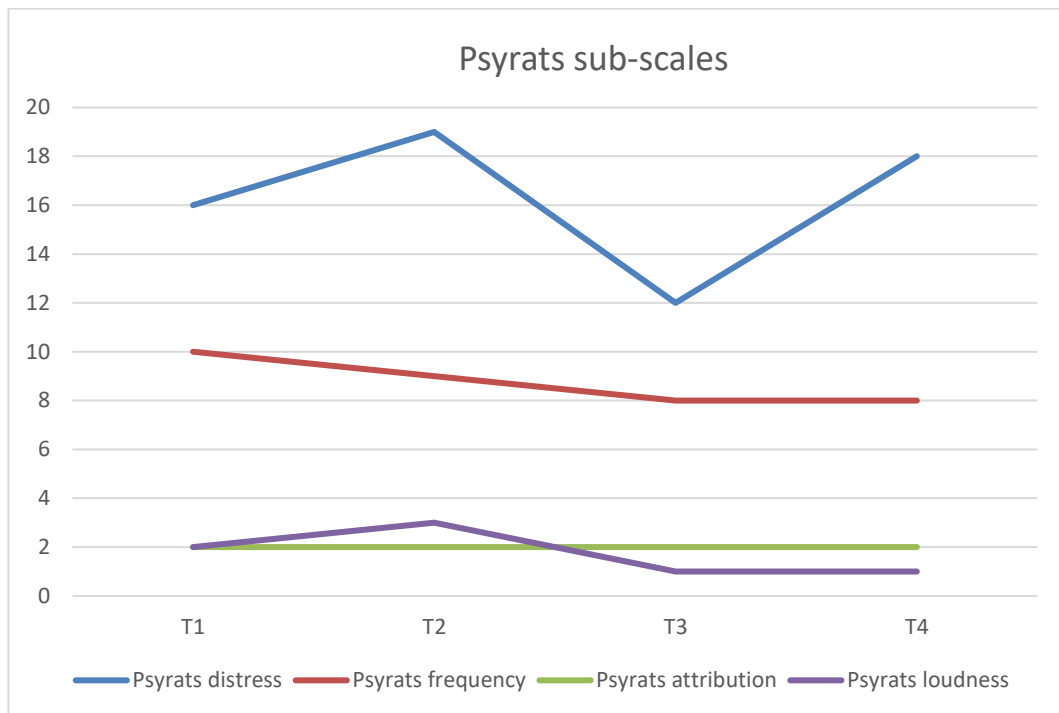
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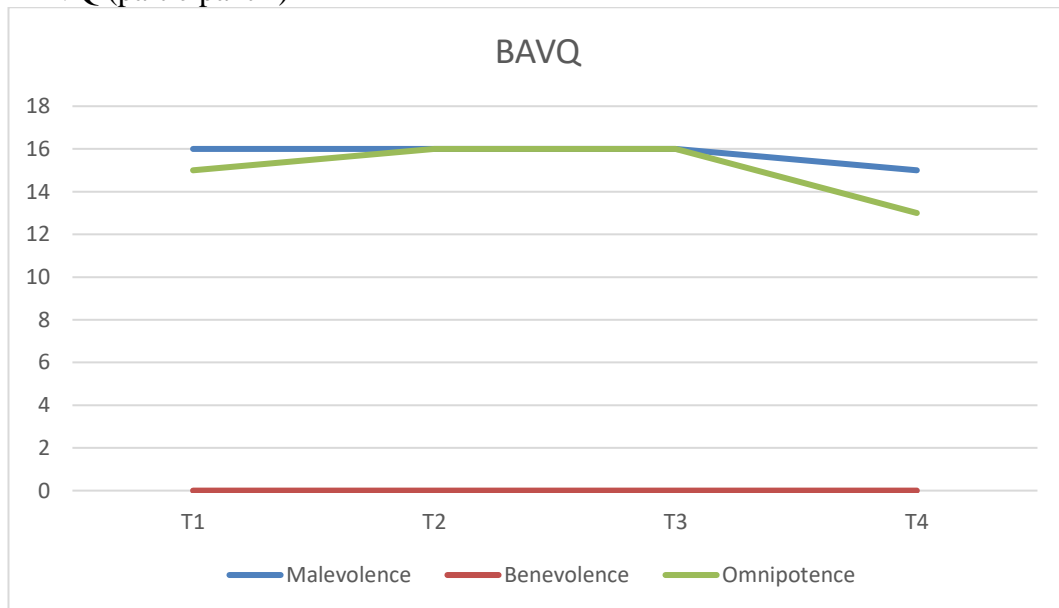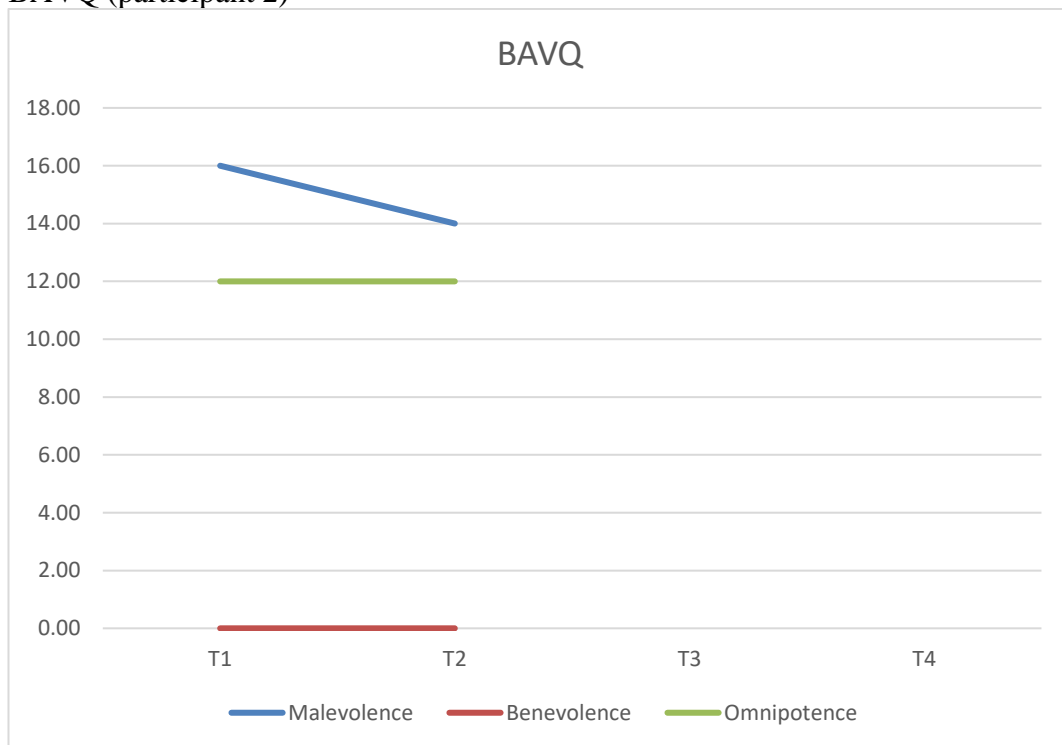
BAVQ Engagement and Resistance (participant 1)

VAY (participant 1)

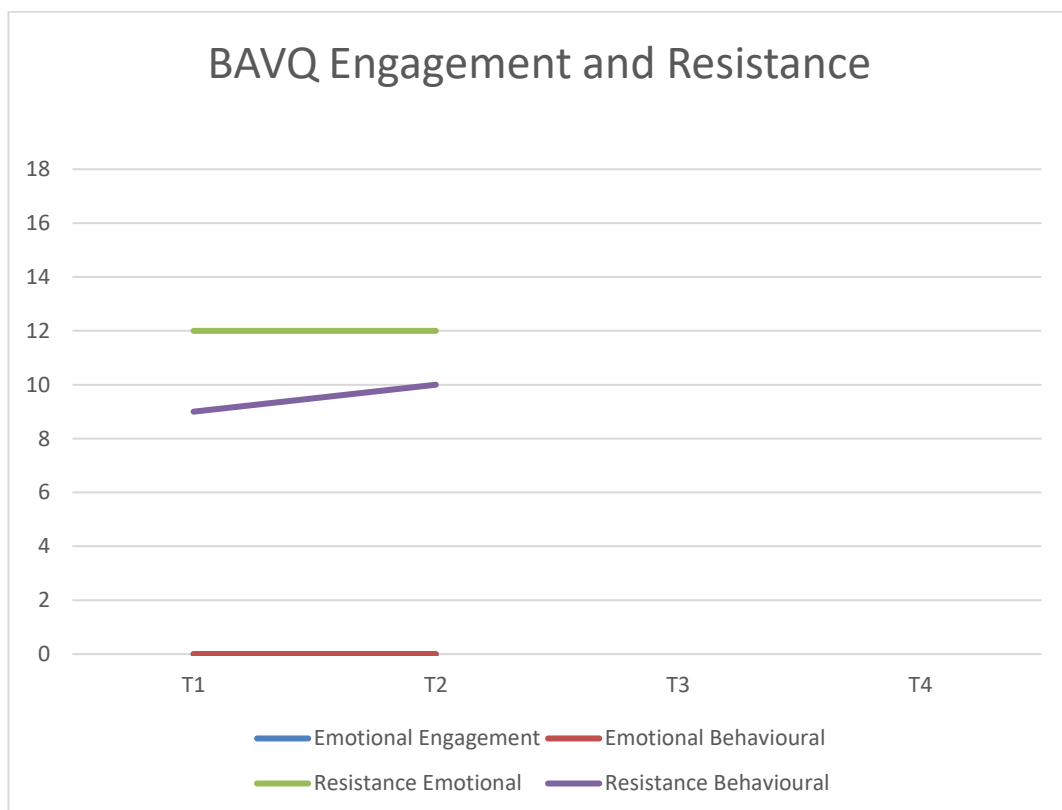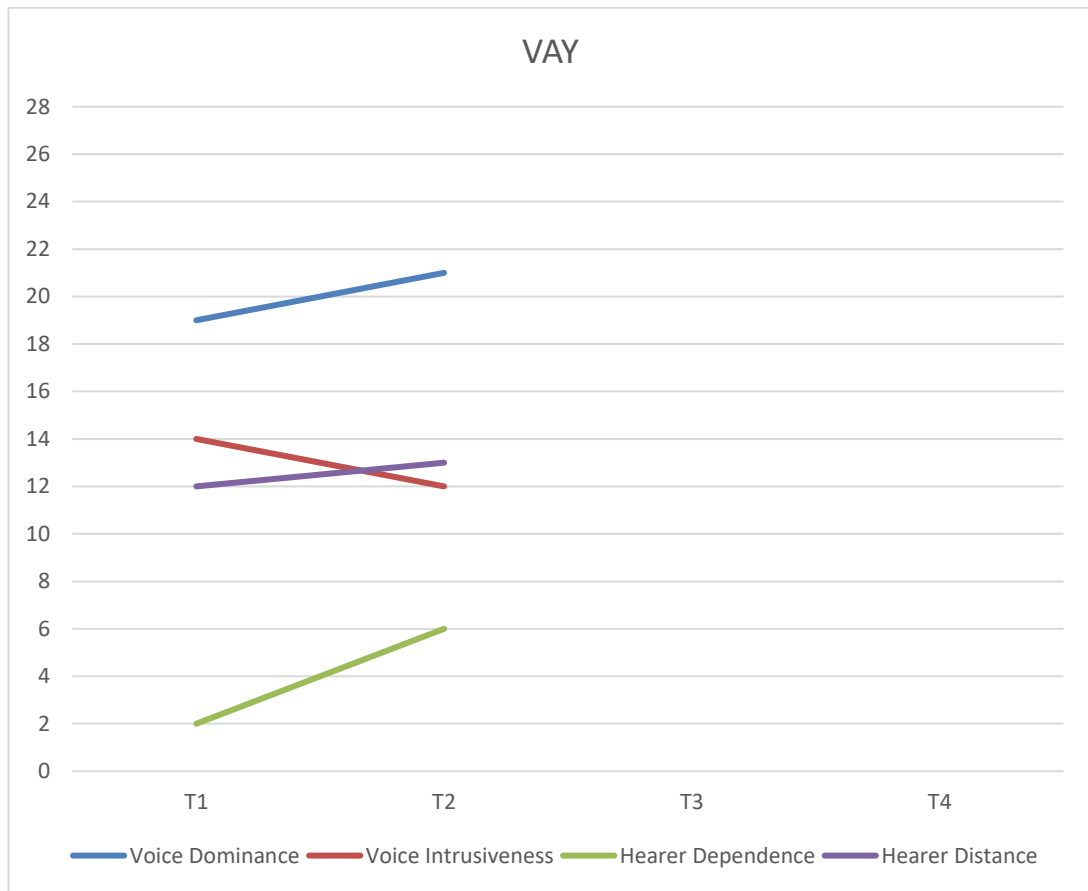**Participant 2**
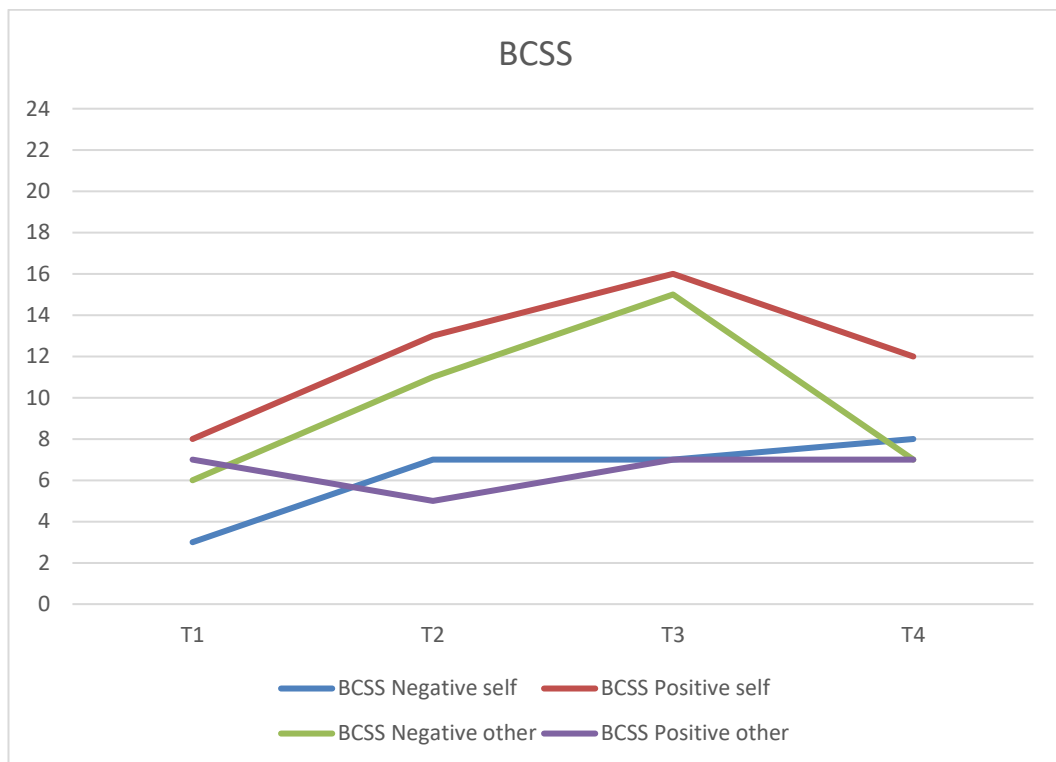
BCSS

Psyrats Total Scores

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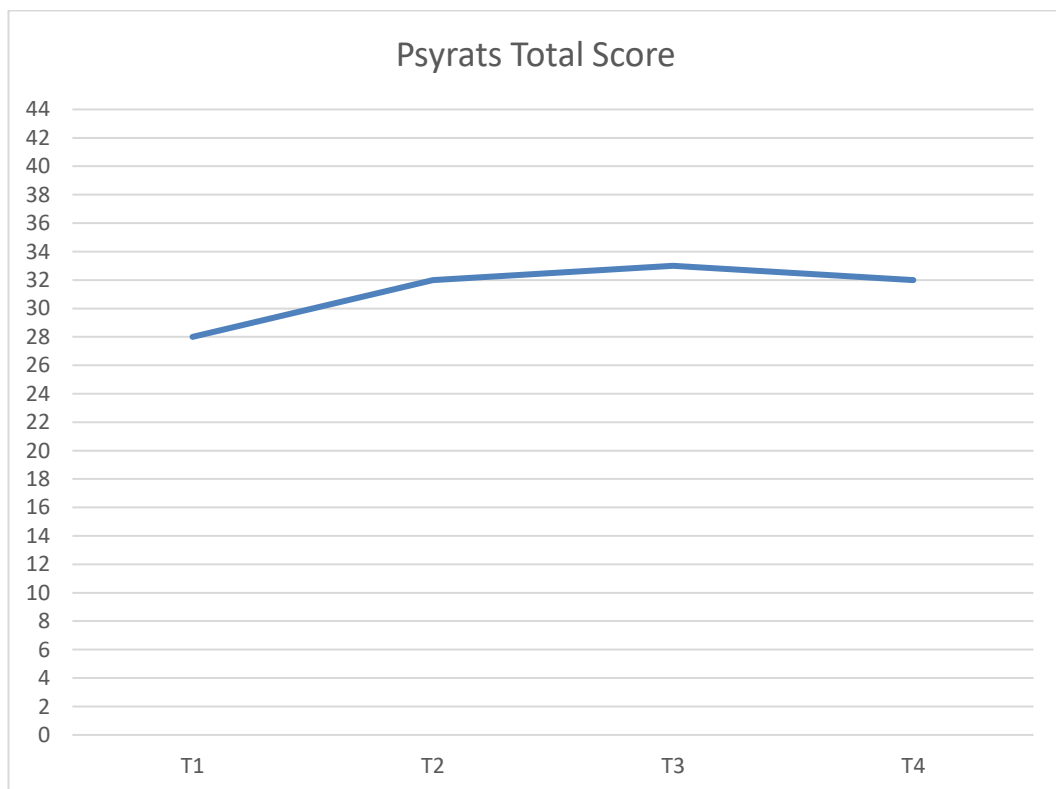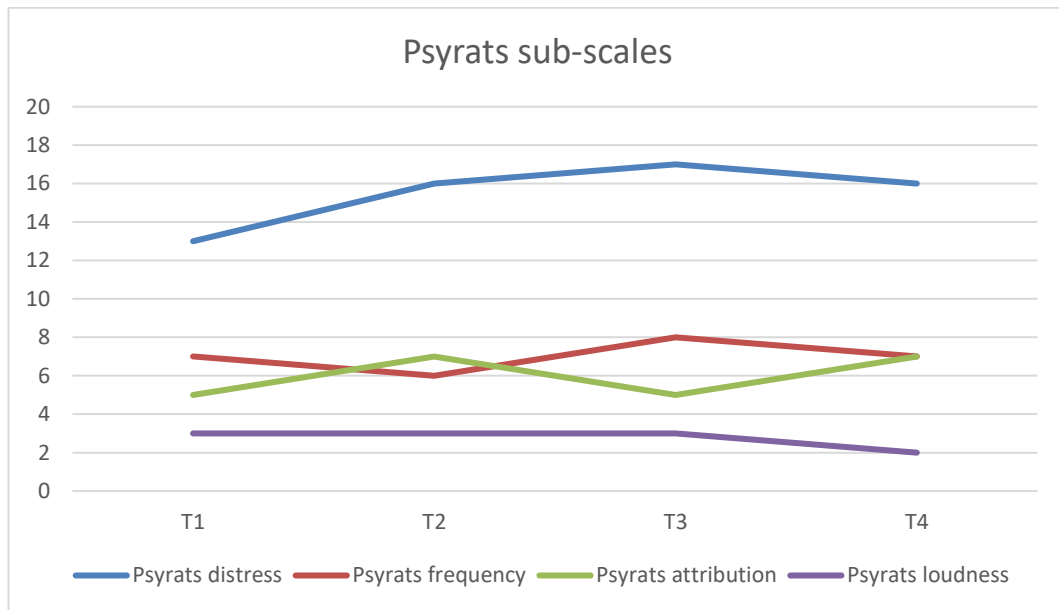

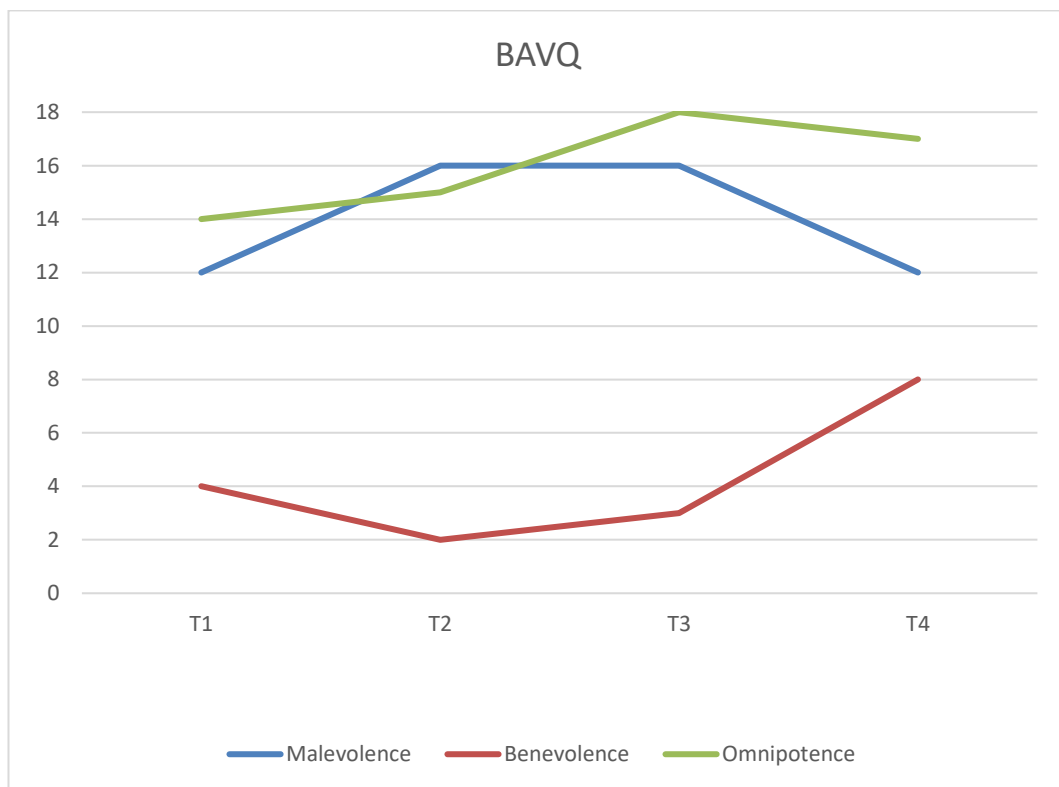BAVQ (participant 2)

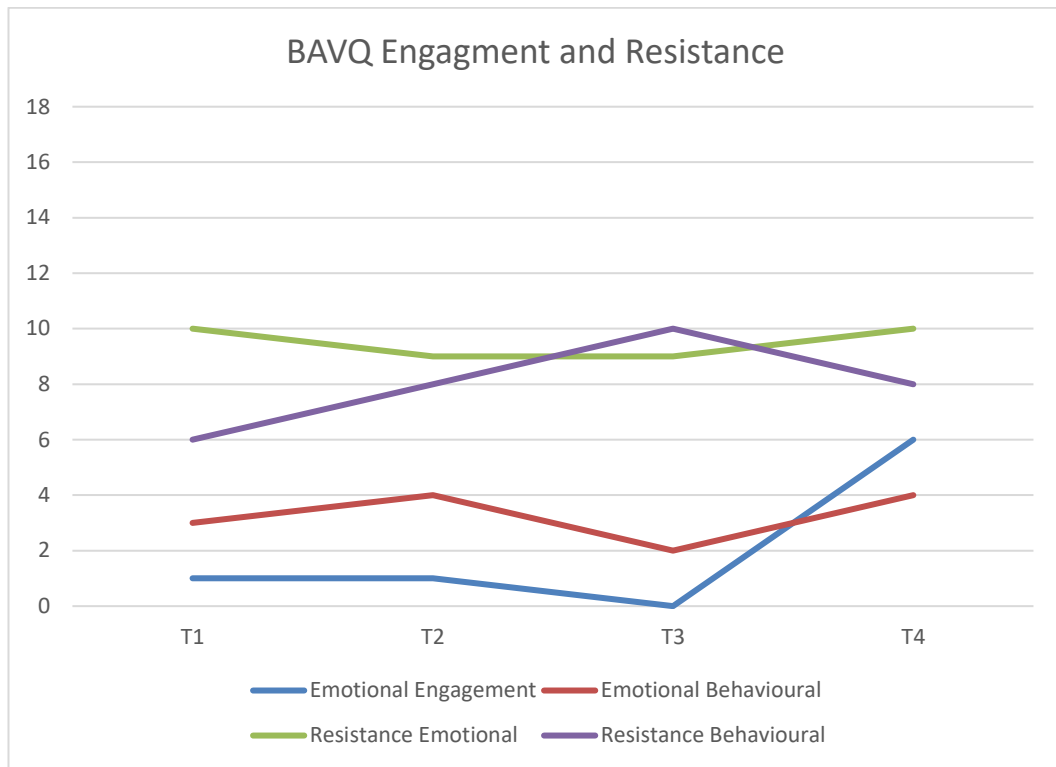VAY (participant 2)

BCSS (participant 3)

Psyrats (participant 3)
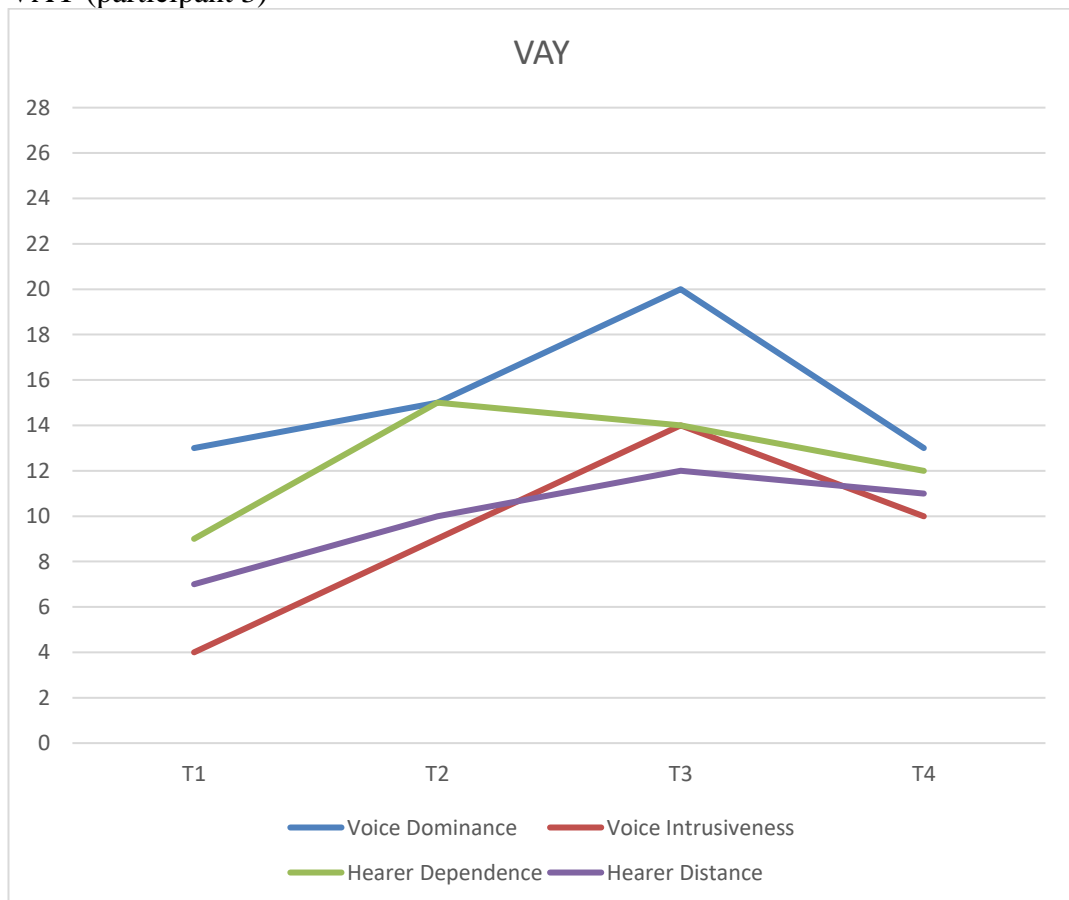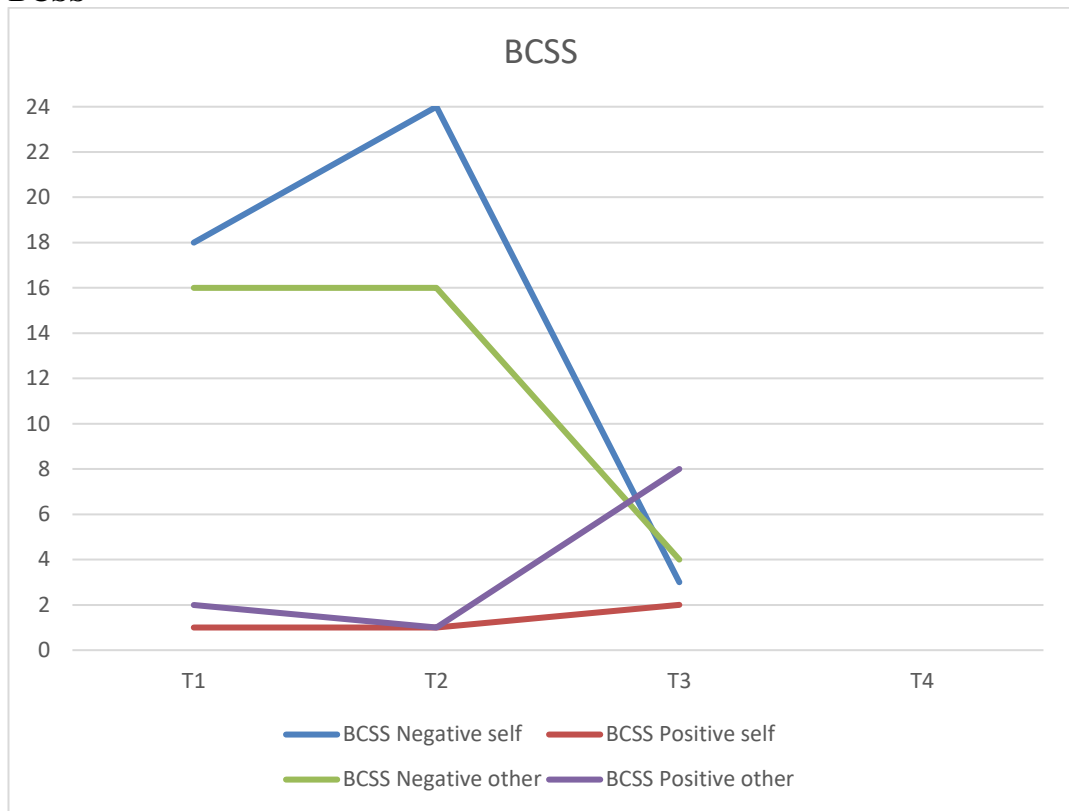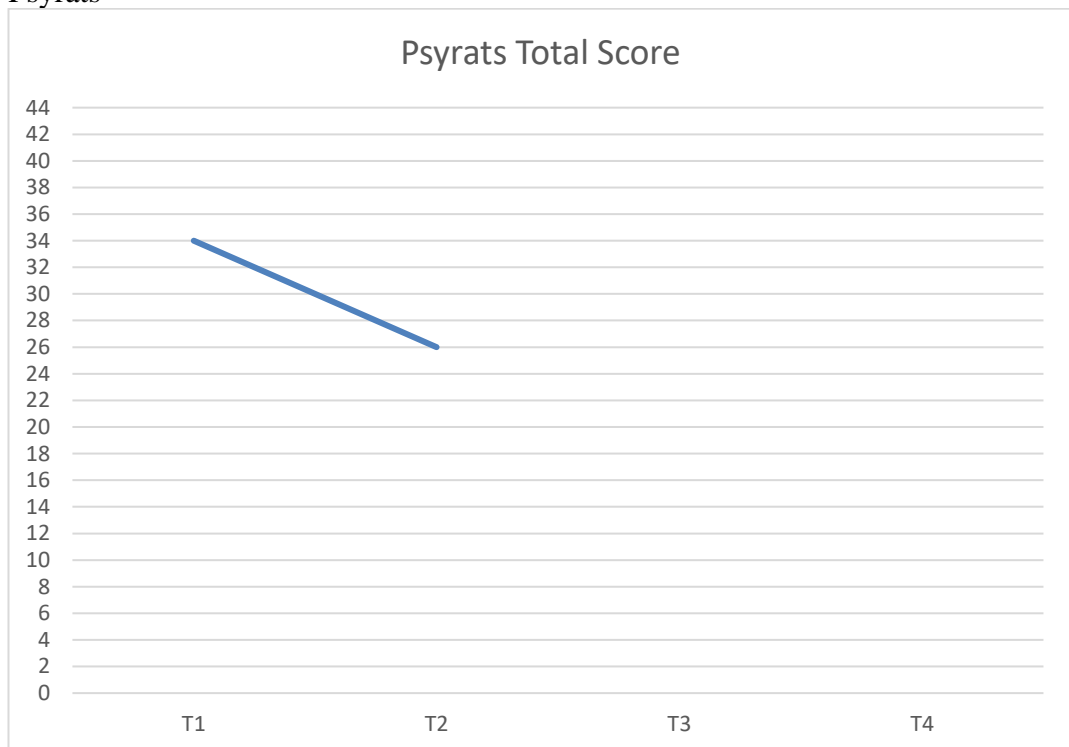
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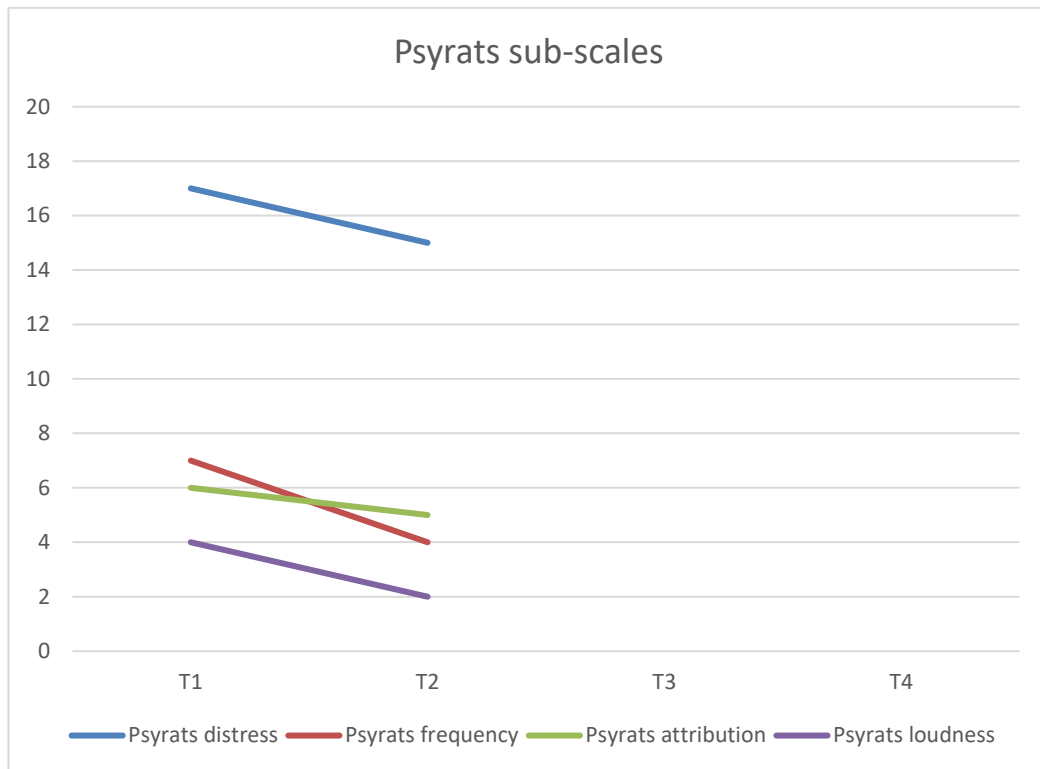BAVQ (participant 3)

Participant 3

BAVQ (participant 3)

VAY (participant 3)
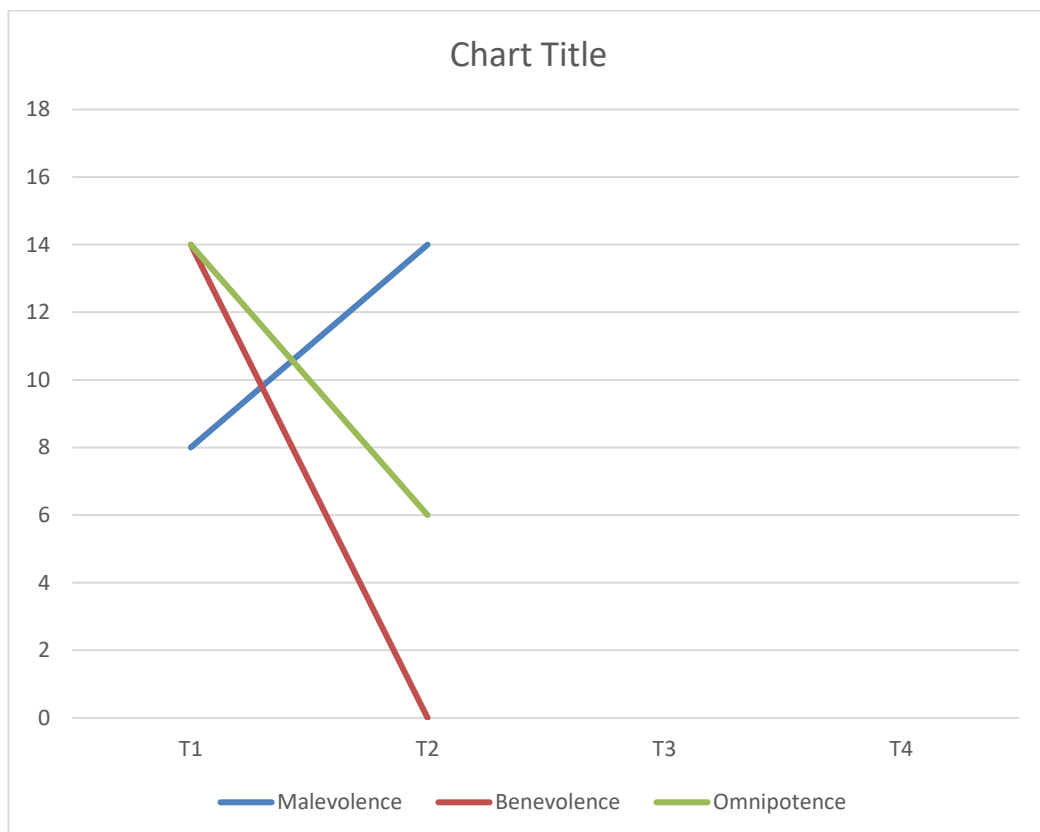
Participant 6

BCSS

Psyrats

Psyrats sub-scales (participant 6)

BAVQ (participant 6)

BAVQ Engagement and Resistance (participant 6)

Participant 9

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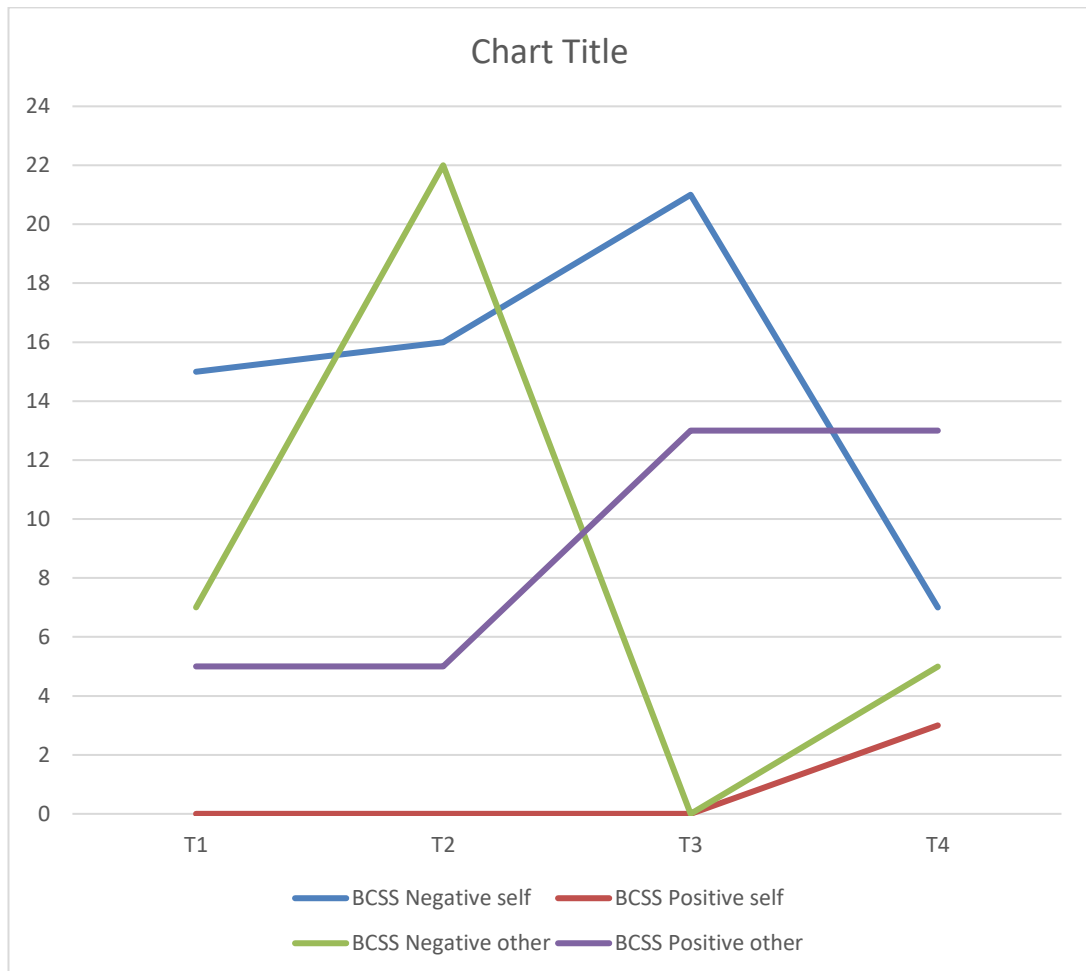
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Psyrats sub-scales

BAVQ (participant 9)

BAVQ

BAVQ (participant 9)

BAVQ Engagement and Resistance
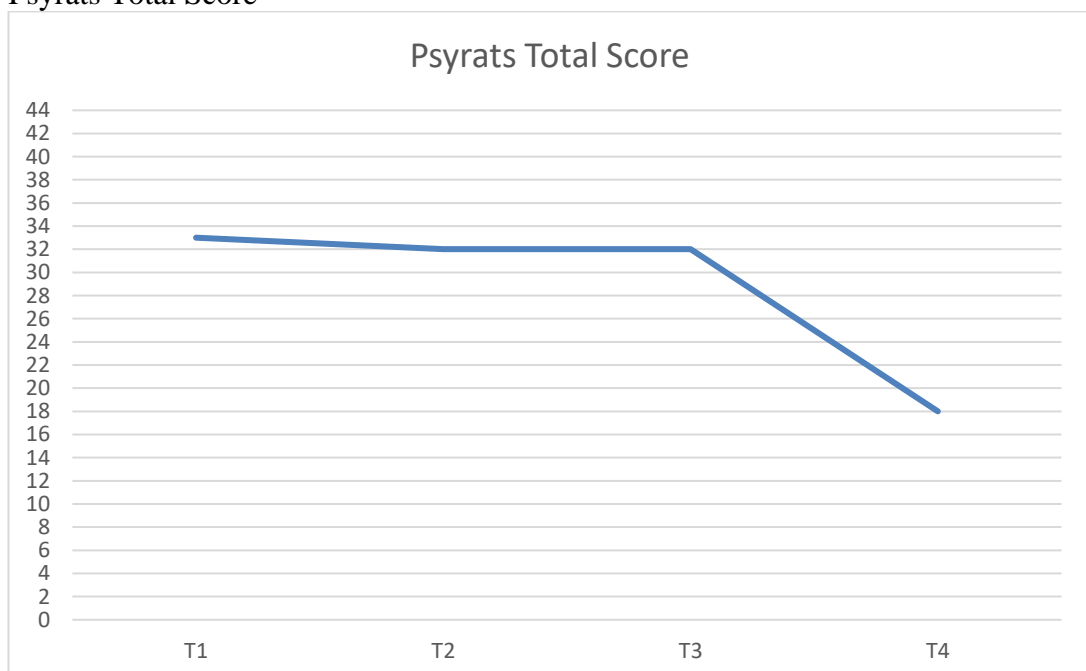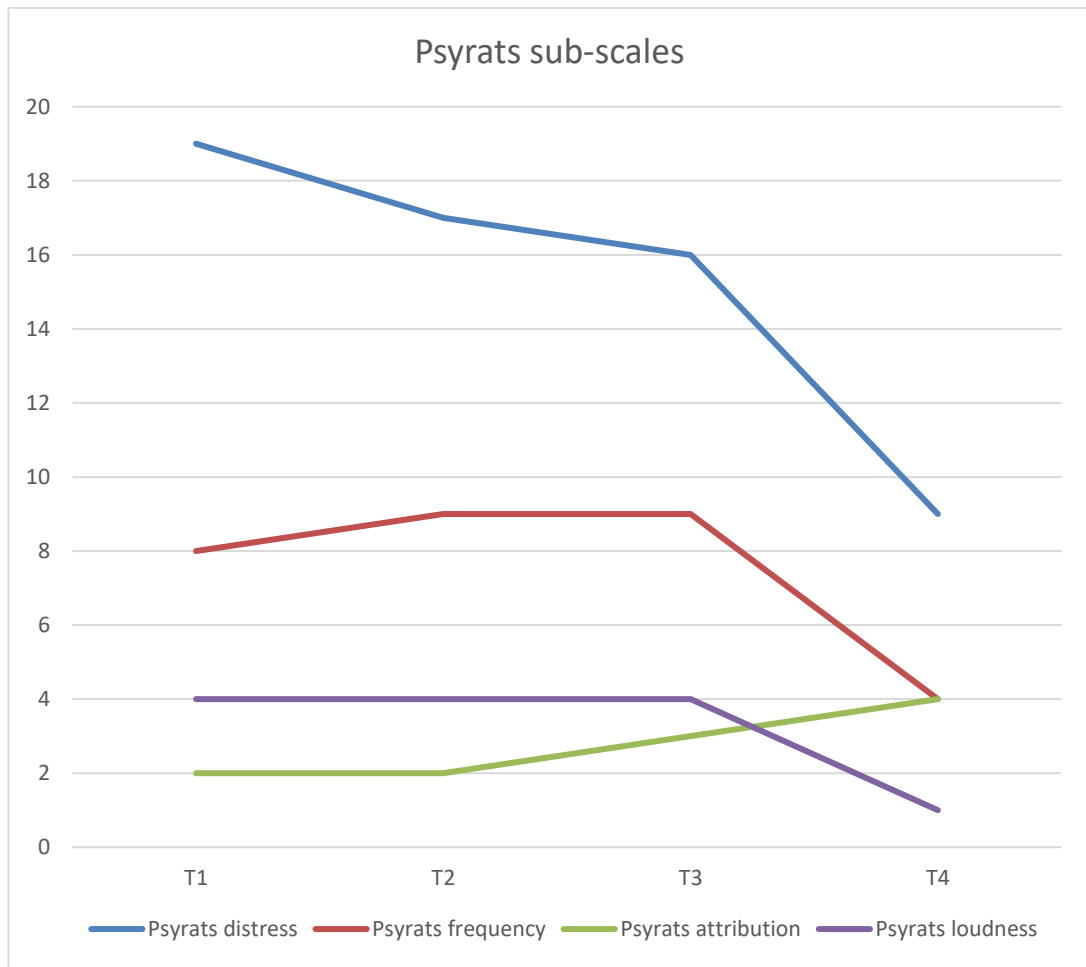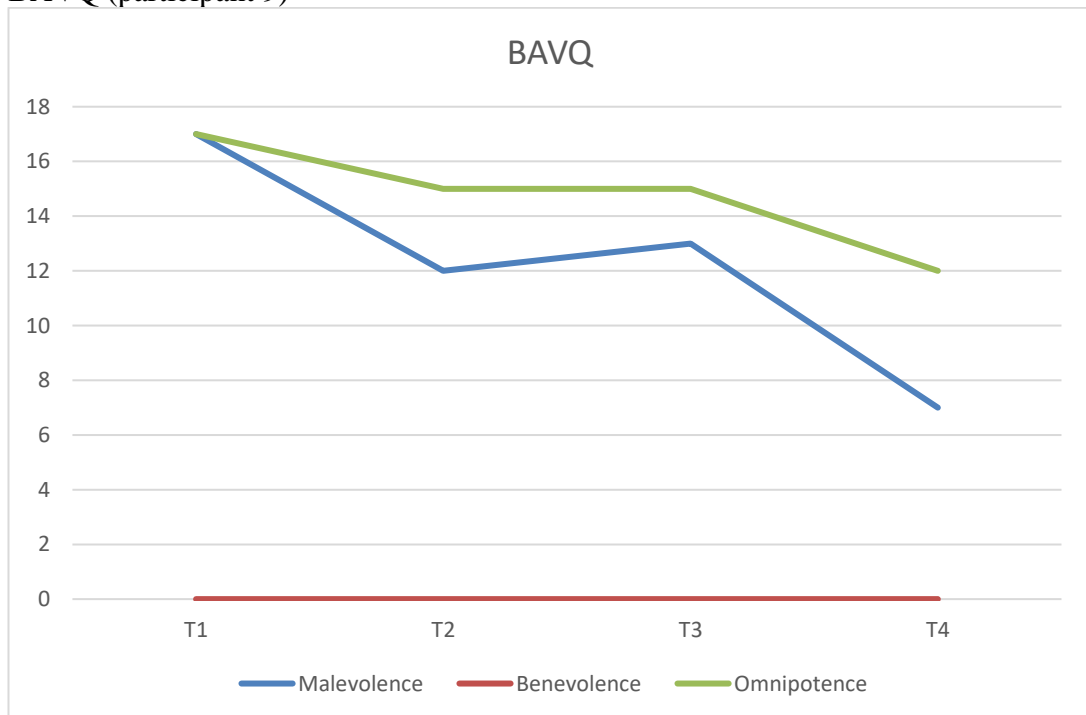
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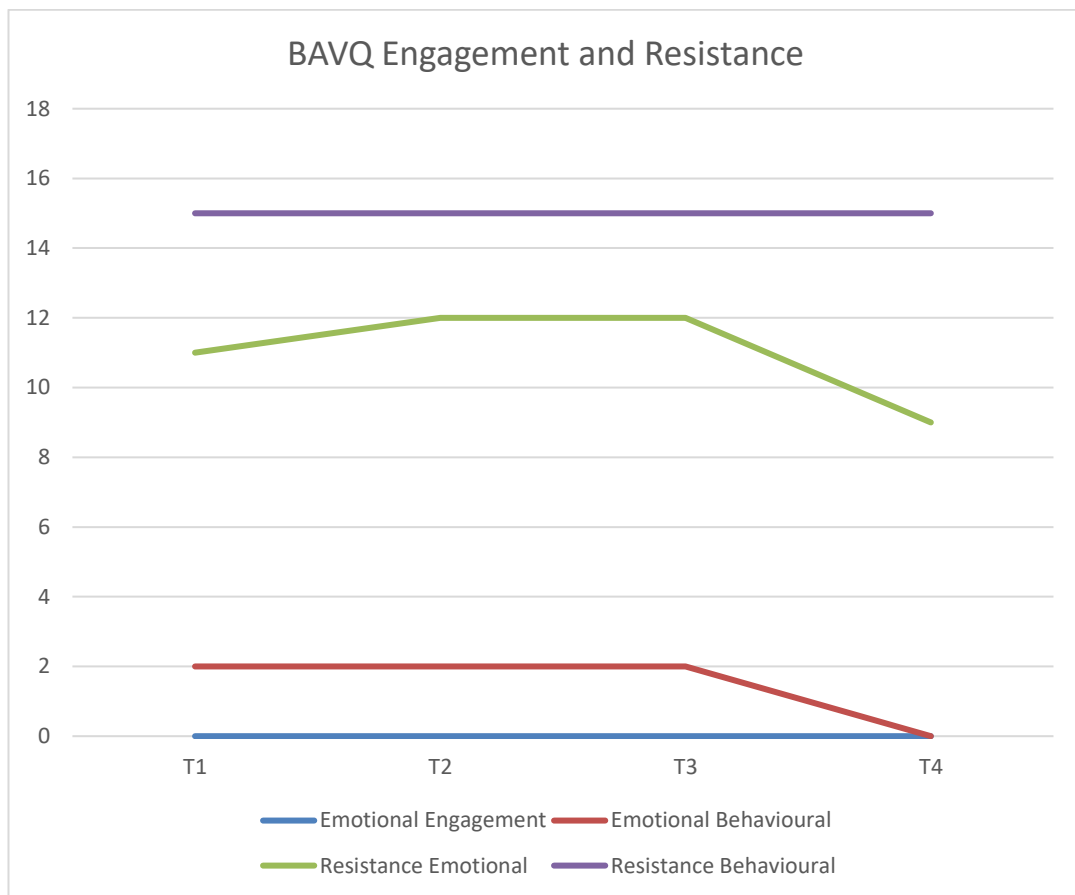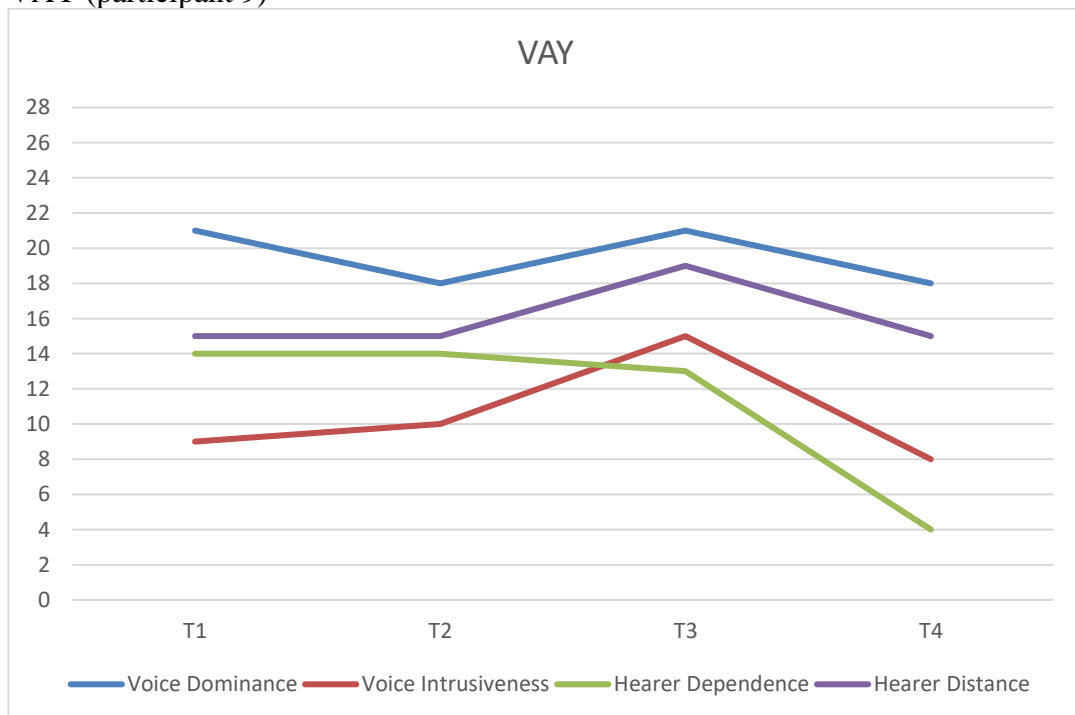
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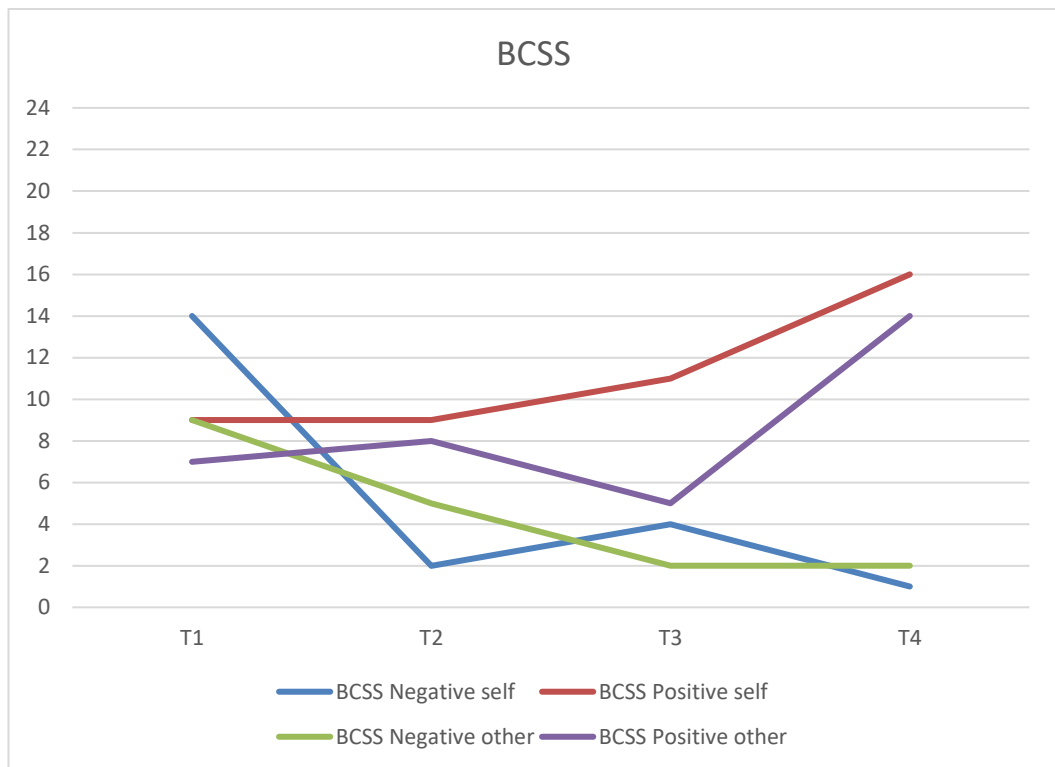
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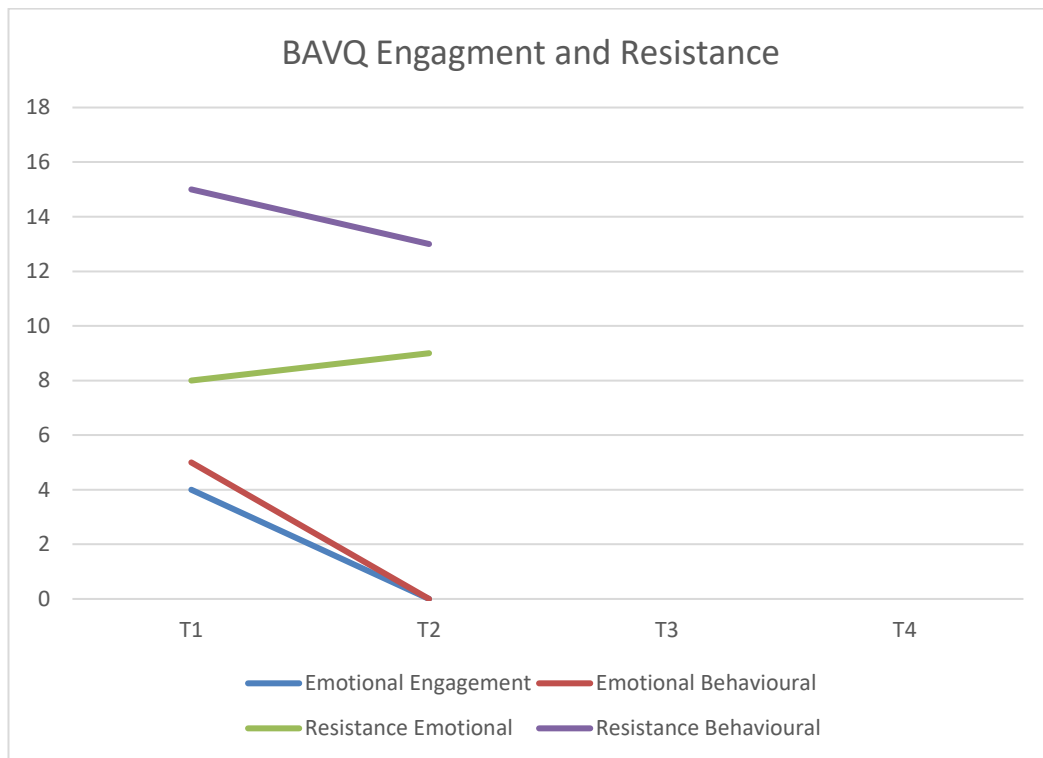

Psyrats Total Score

Psyrats sub-scales (participant 12)

BAVQ (participant 12)

BAVQ (participant 12)

BAVQ Engagement and Resistance
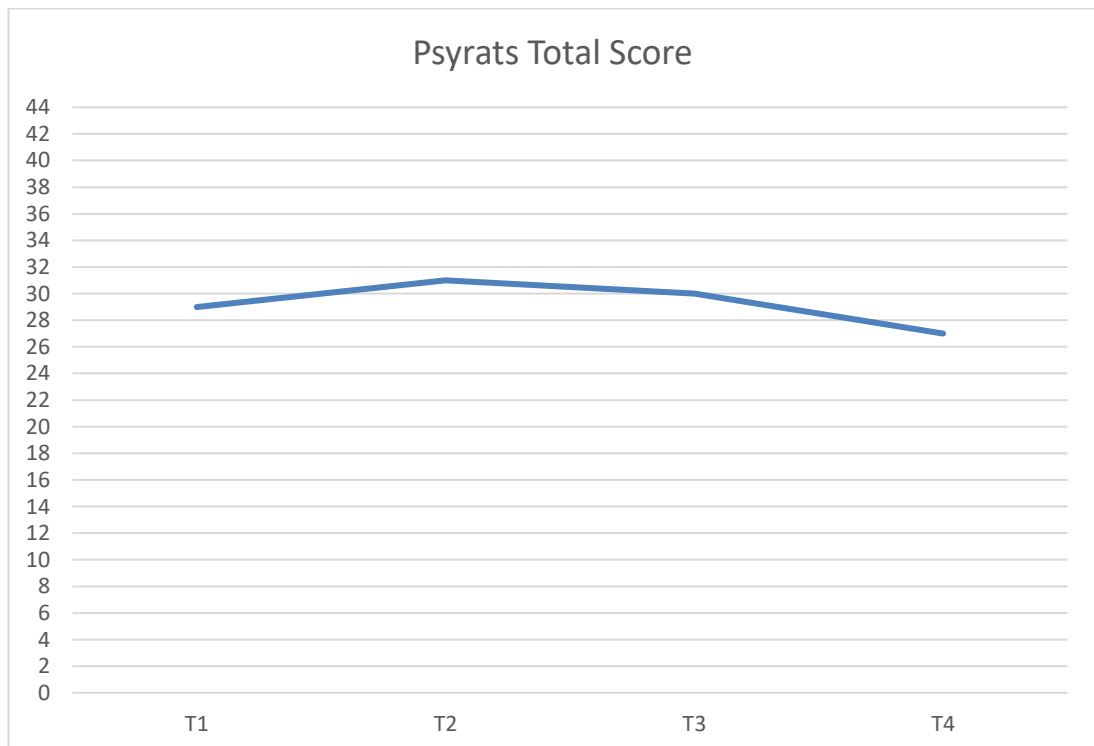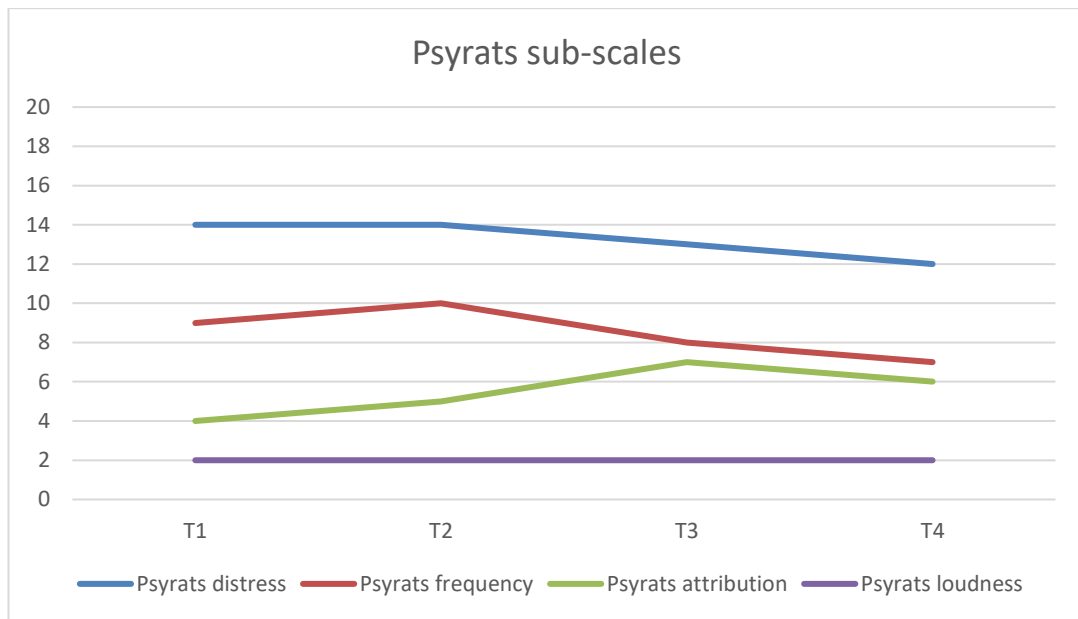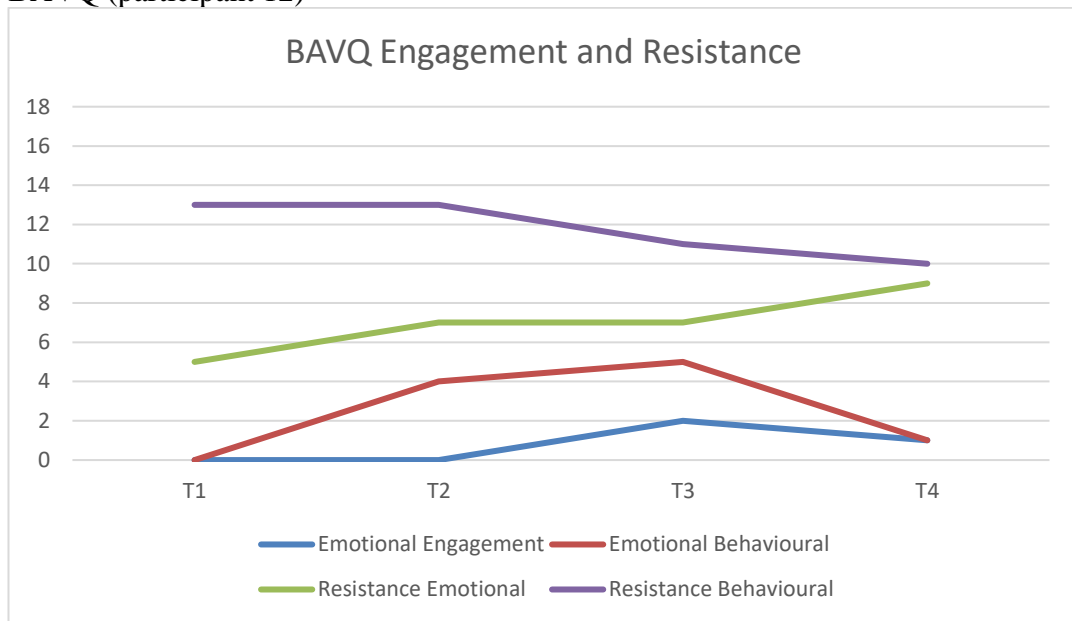
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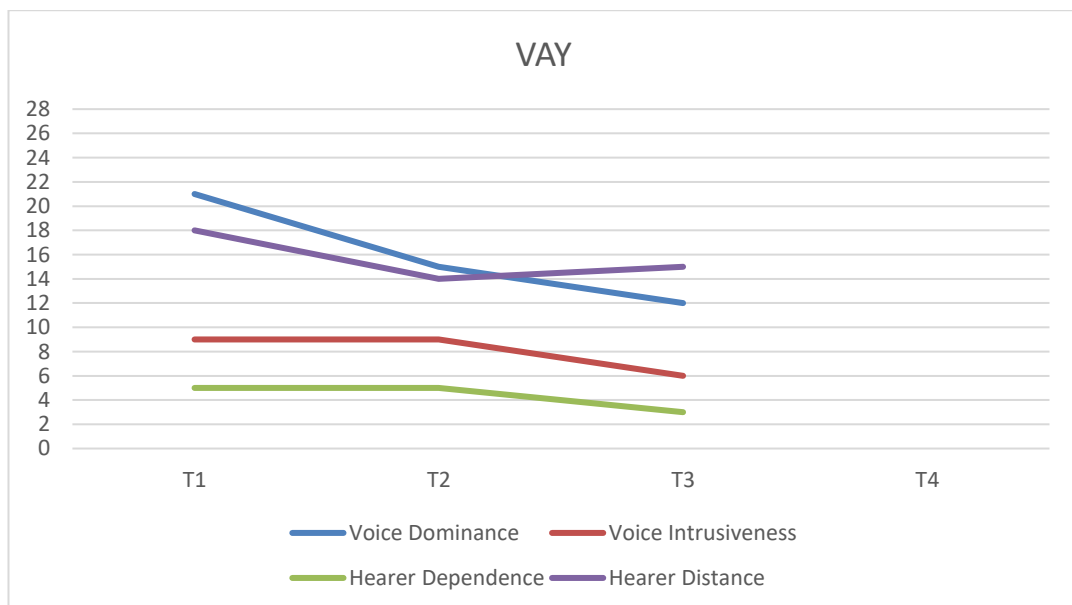
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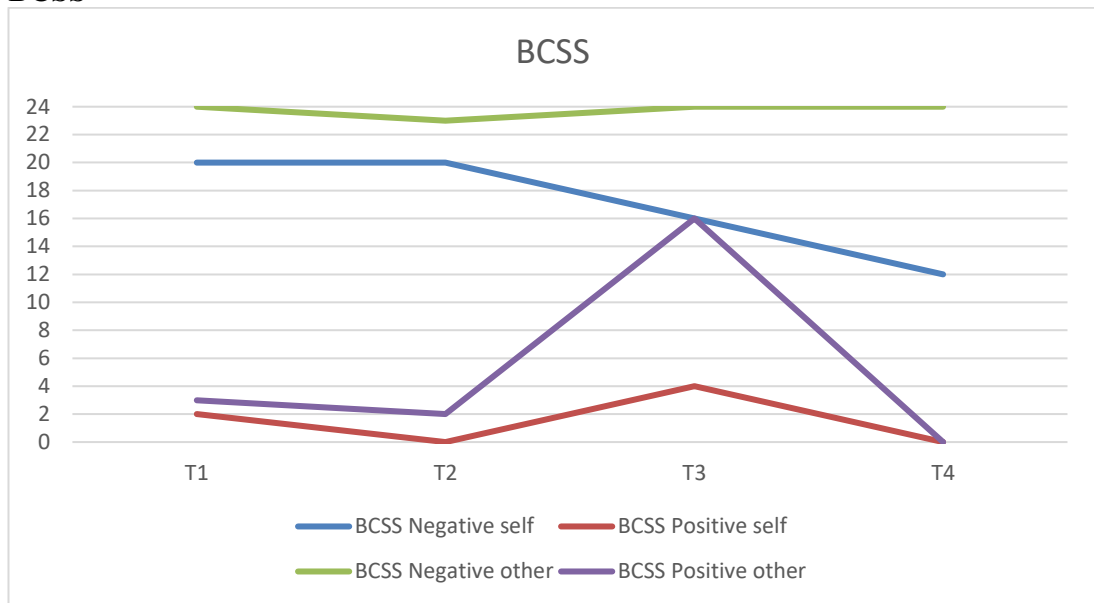
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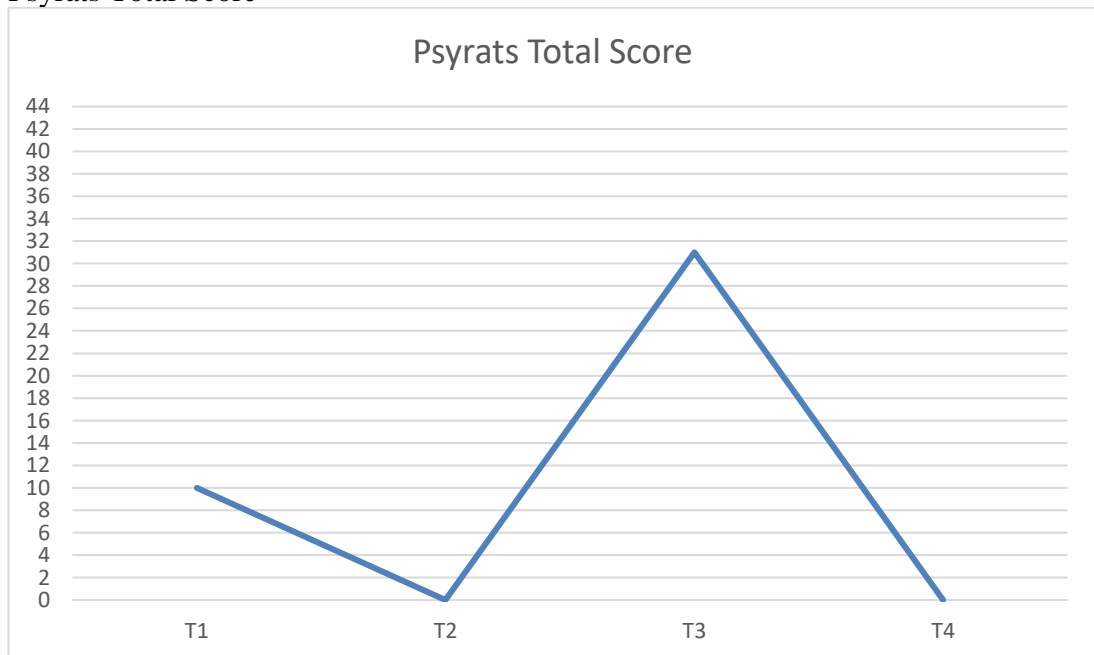
Voices stopped at T2 and T4

Psyrats sub-scales (participant 13)
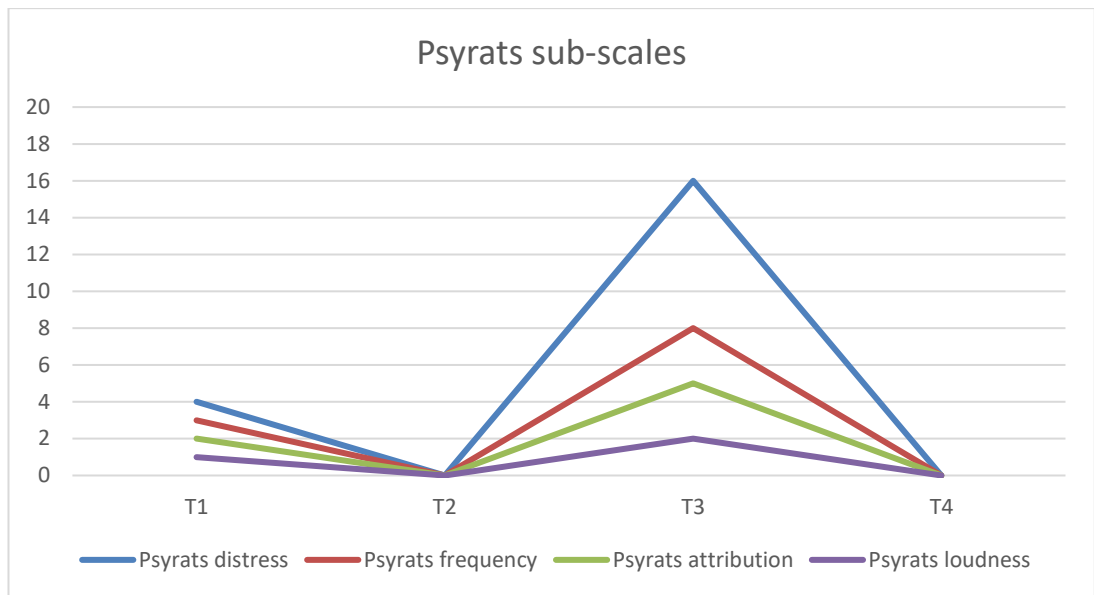
Psyrats sub-scales

Voices stopped at T2 and T4

BAVQ (participant 13)

BAVQ

Voices stopped at T2 and T4

BAVQ (participant 13)

BSVQ Engagement and Resistance
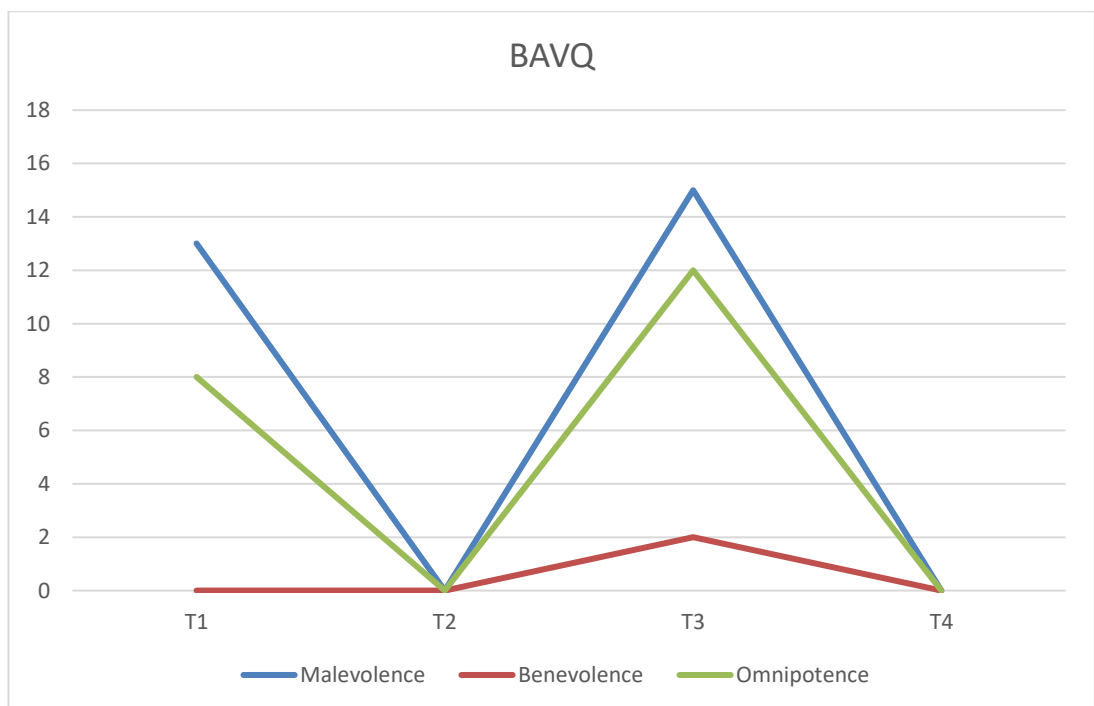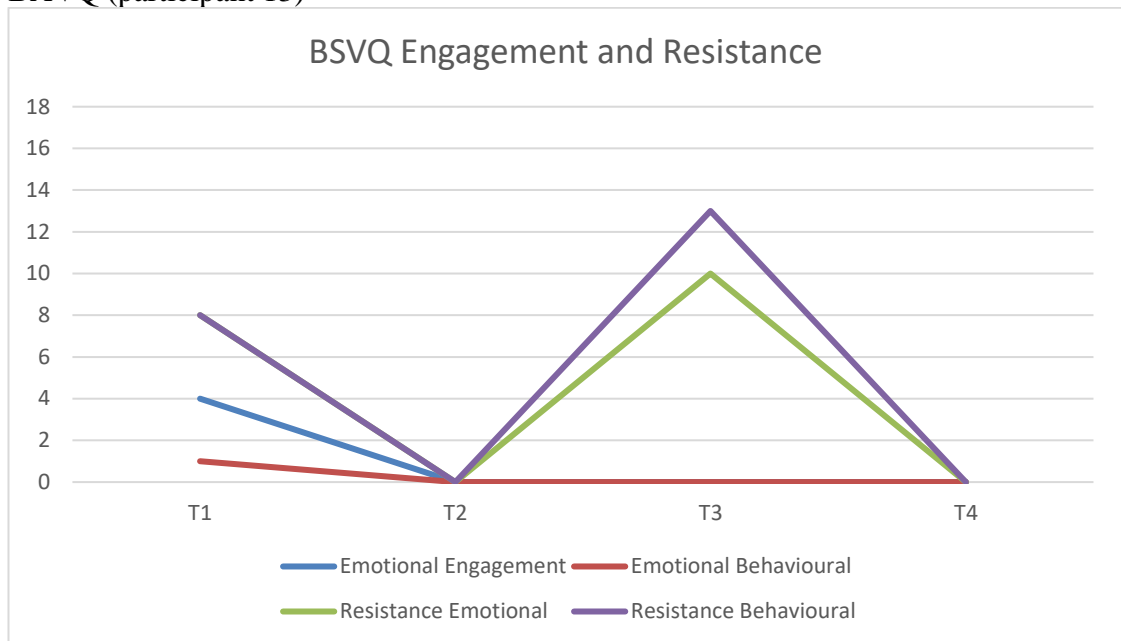
Voices stopped at T2 and T4

VAY (participant 13)

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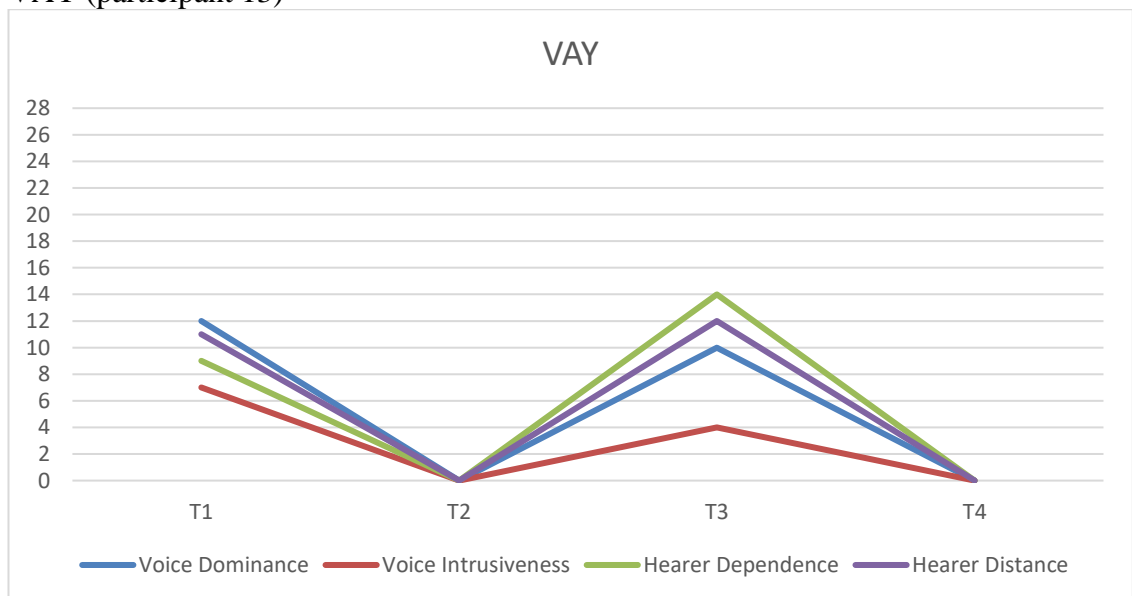
Voices stopped at T2 and T4

Participant 14

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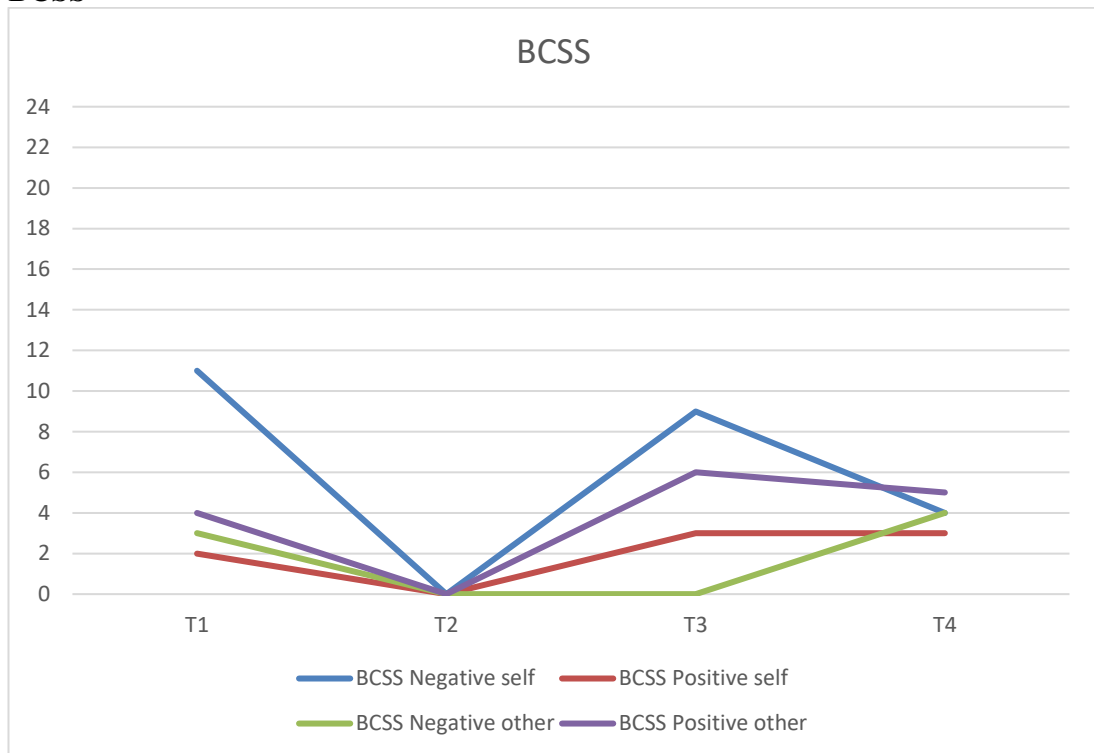
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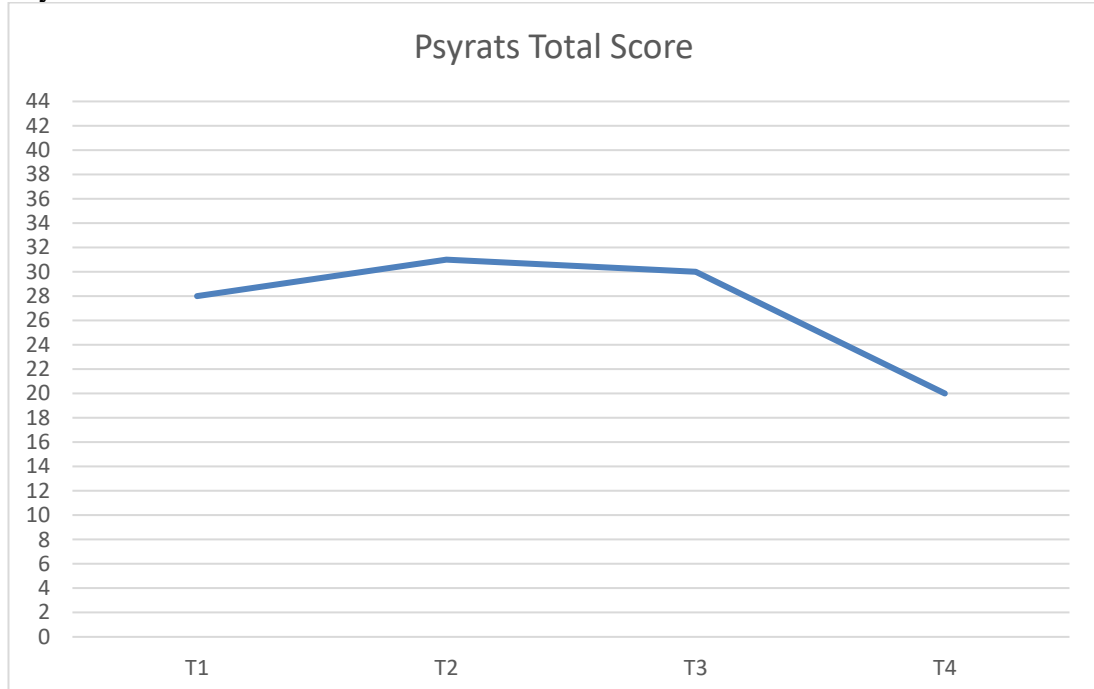
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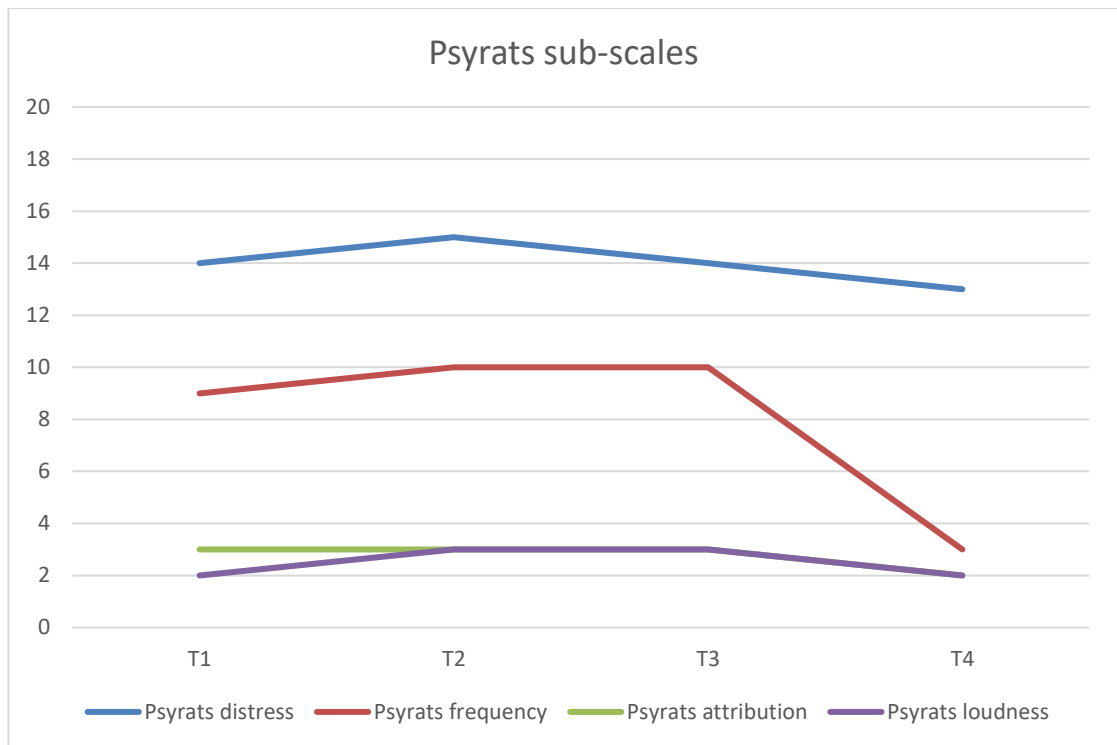
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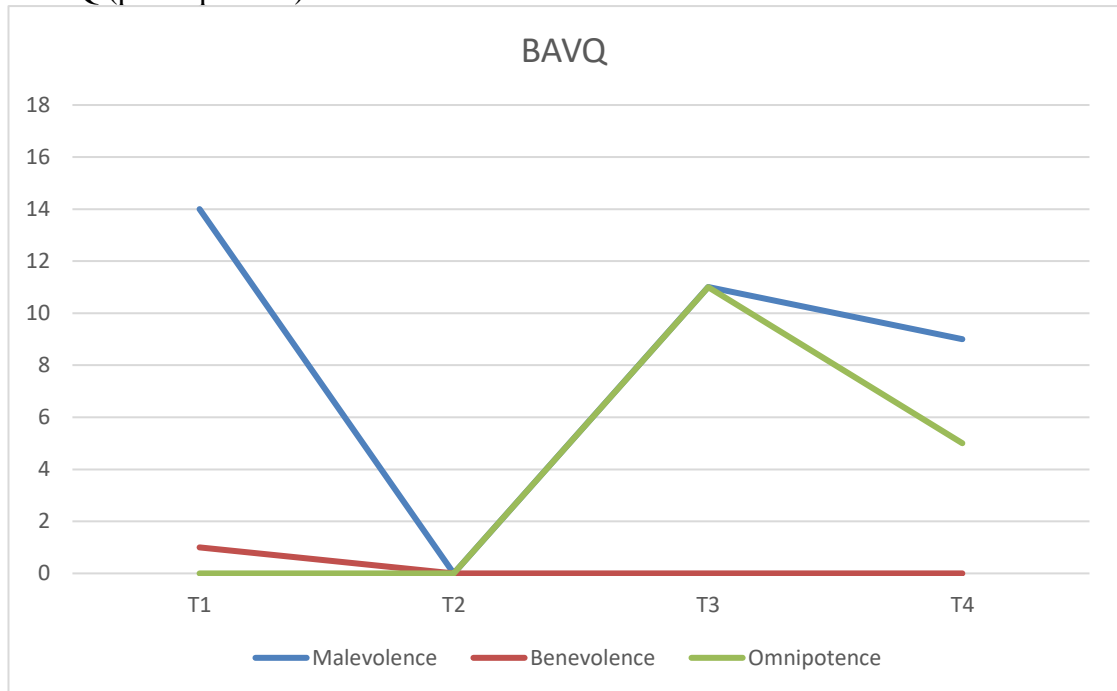
BAVQ

Missing data T2

BAVQ Engagement and Resistance (participant 14)
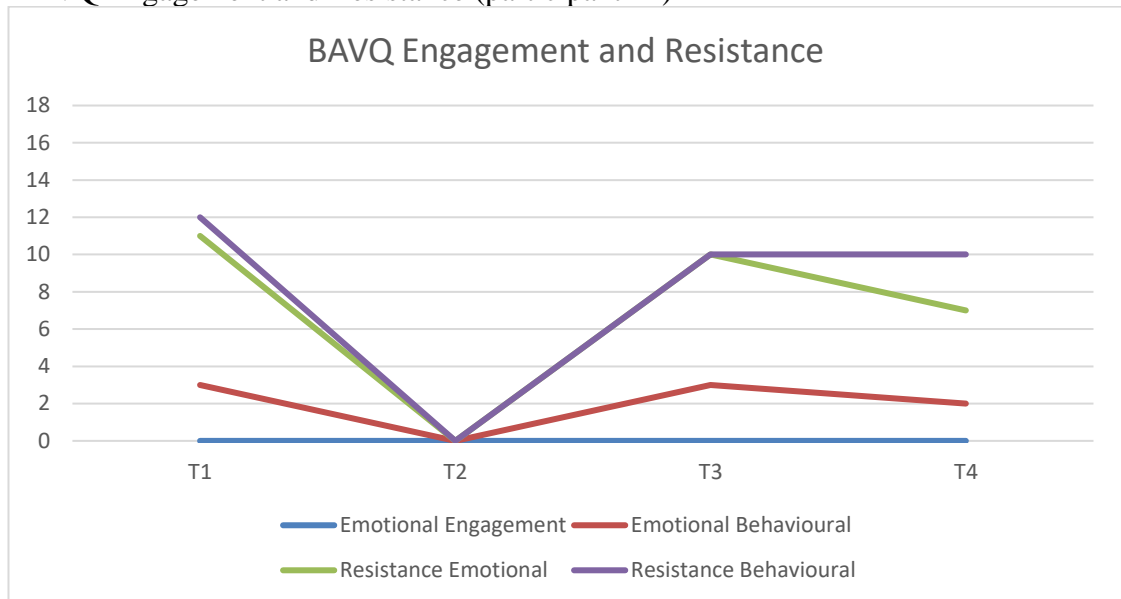
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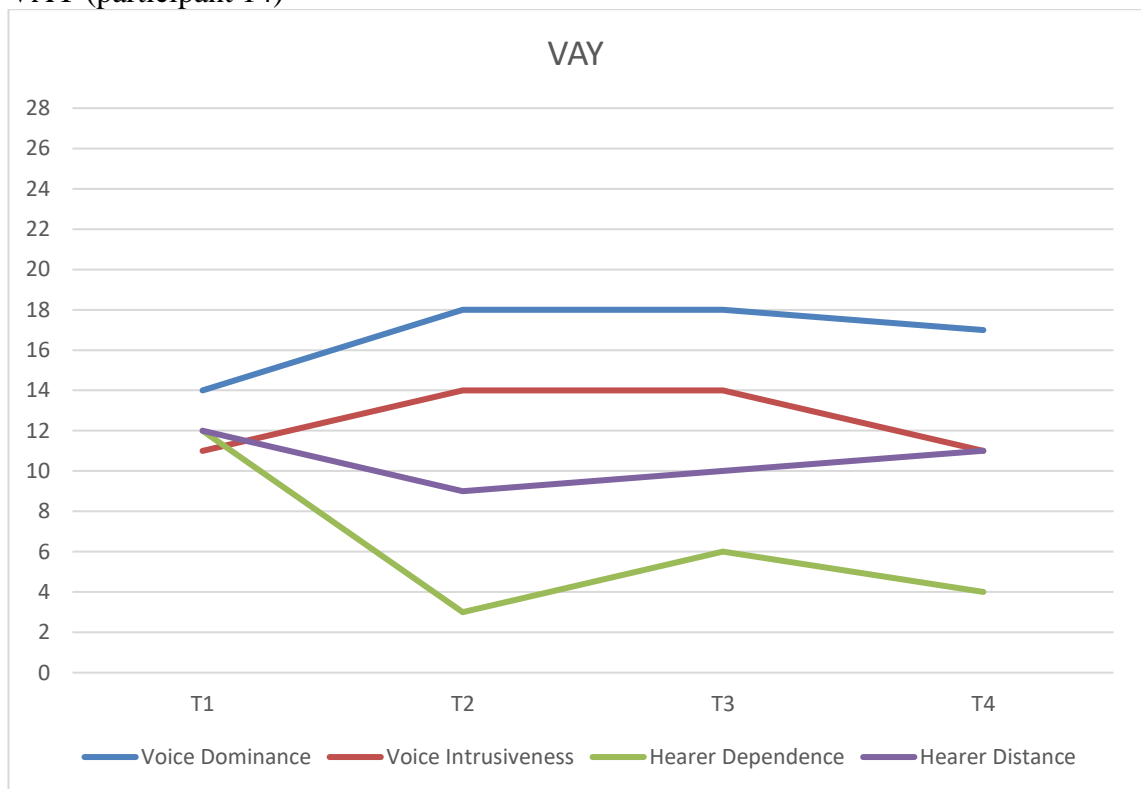
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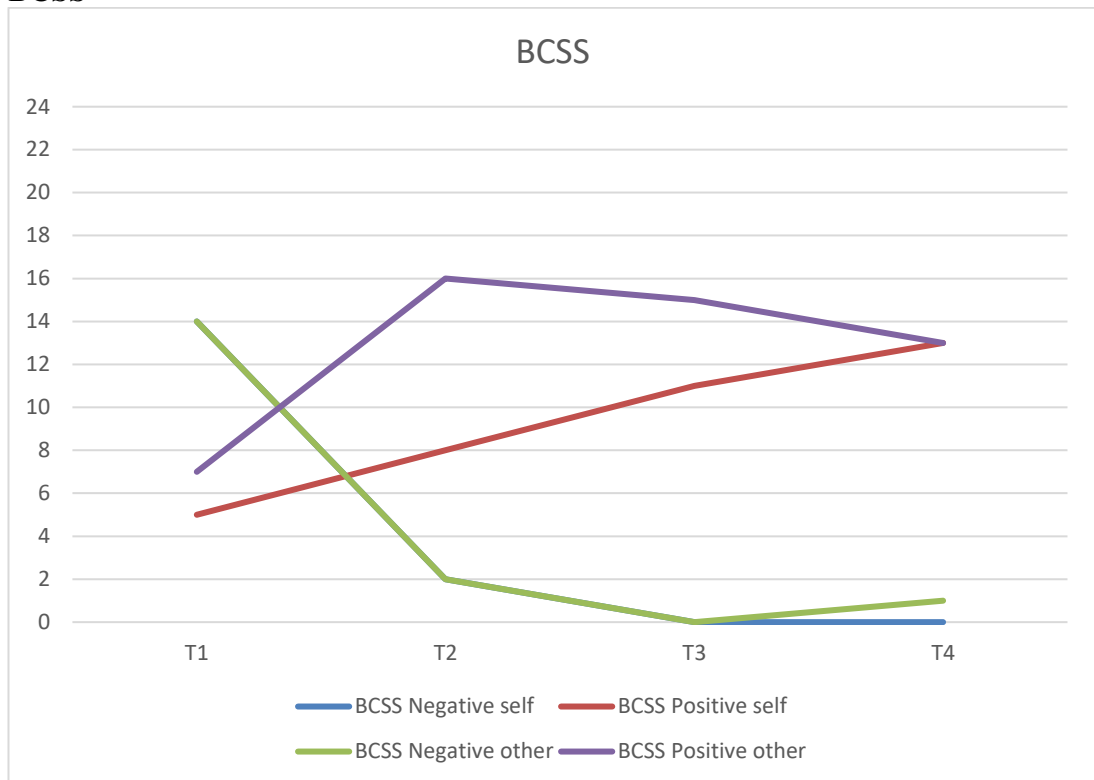
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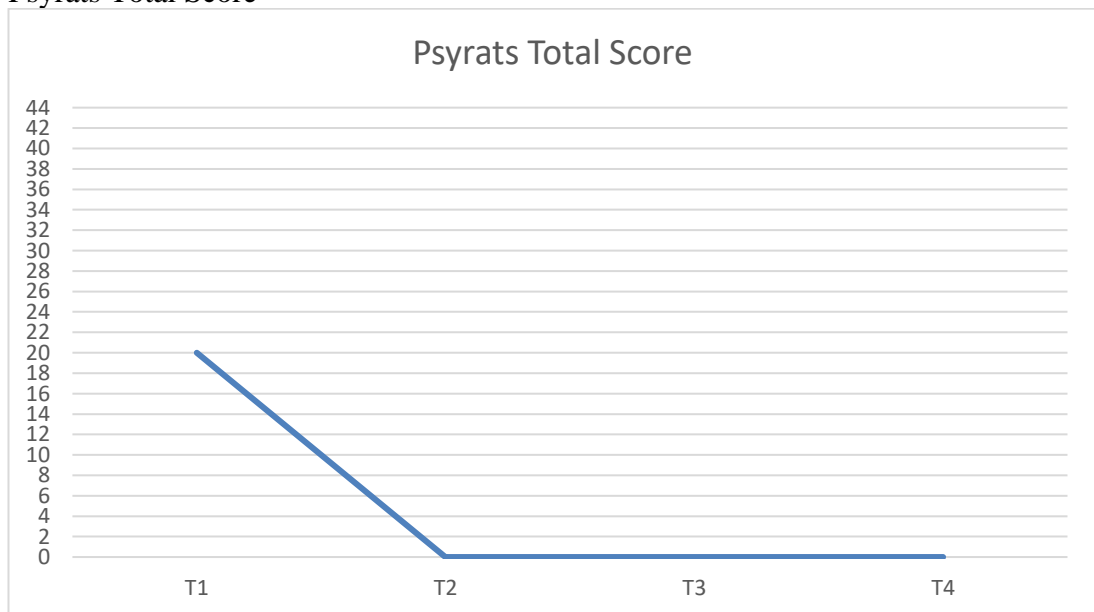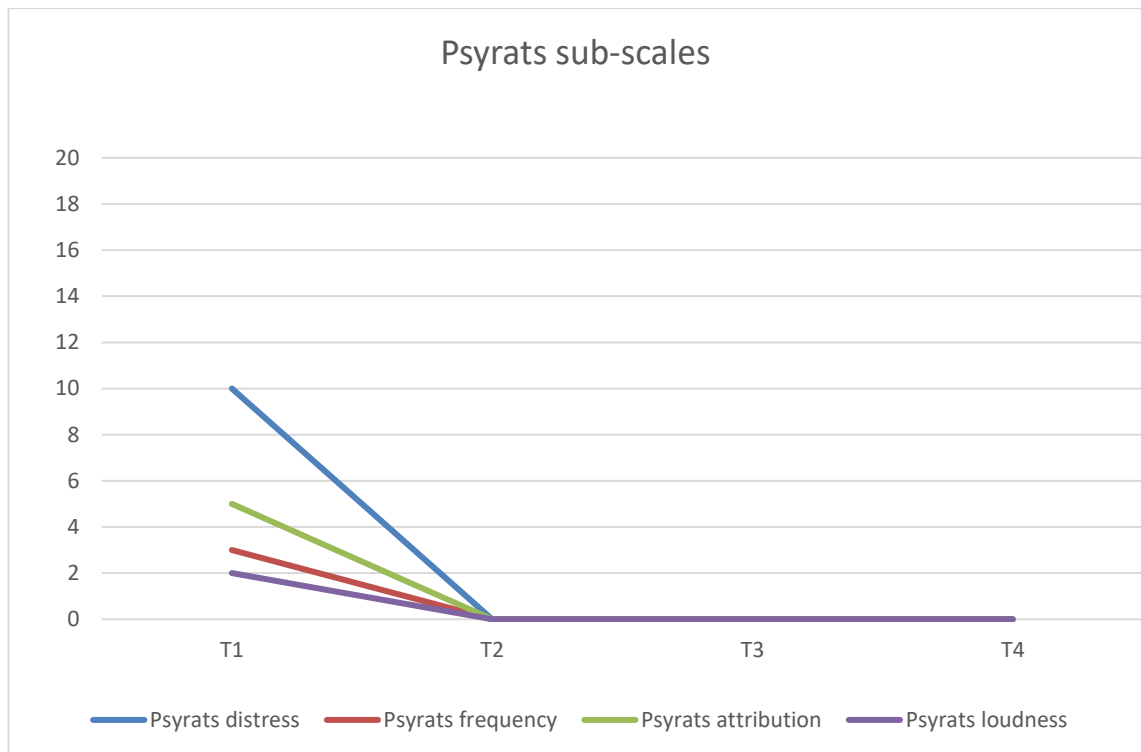
Voices stopped at T2

Psyrats sub-scales (participant 18)

Voices stopped at T2

BAVQ Psyrats sub-scales (participant 18)

Voices stopped at T2

BAVQ (participant 18)

BAVQ Engagment and Resistance
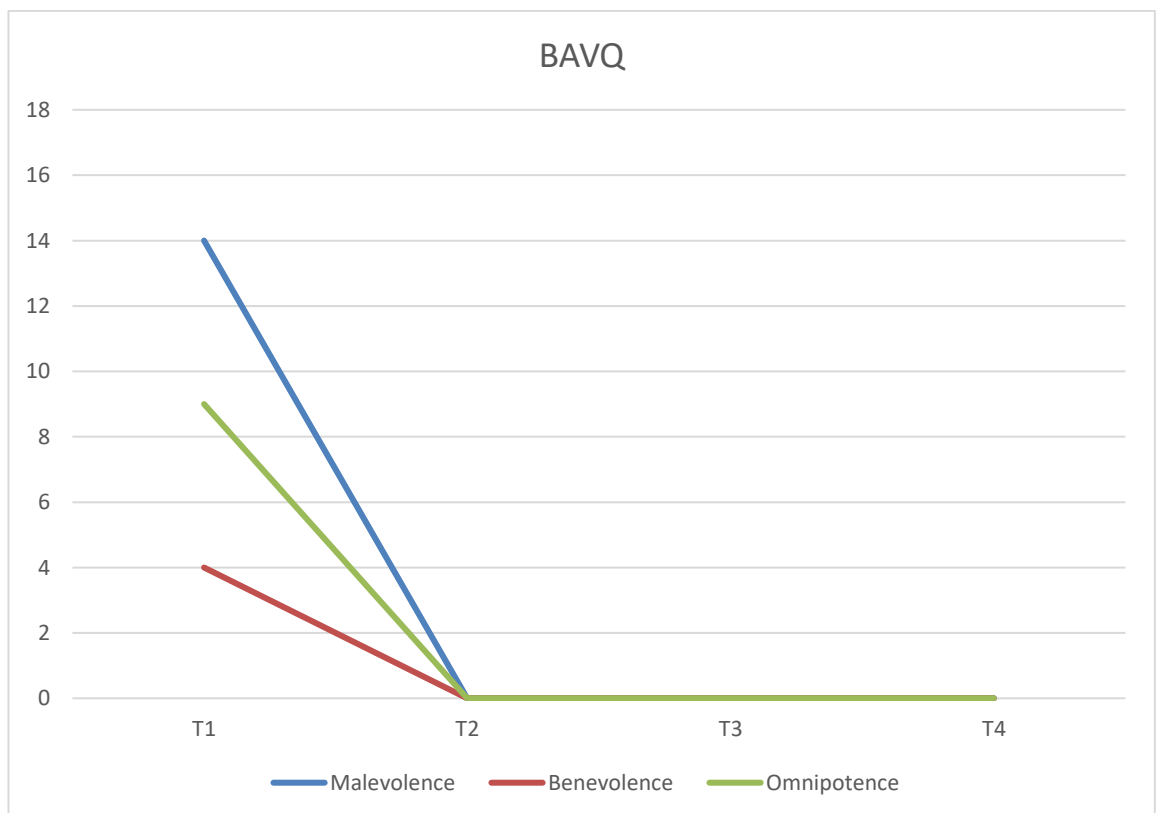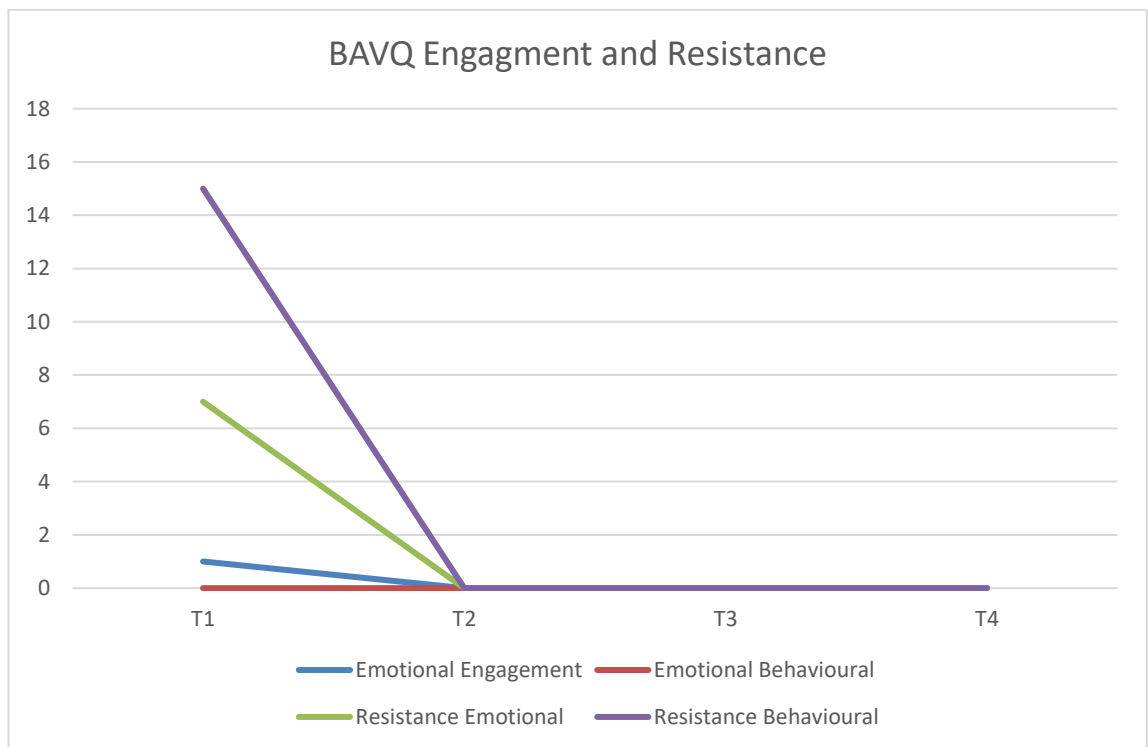
Voices stopped at T2

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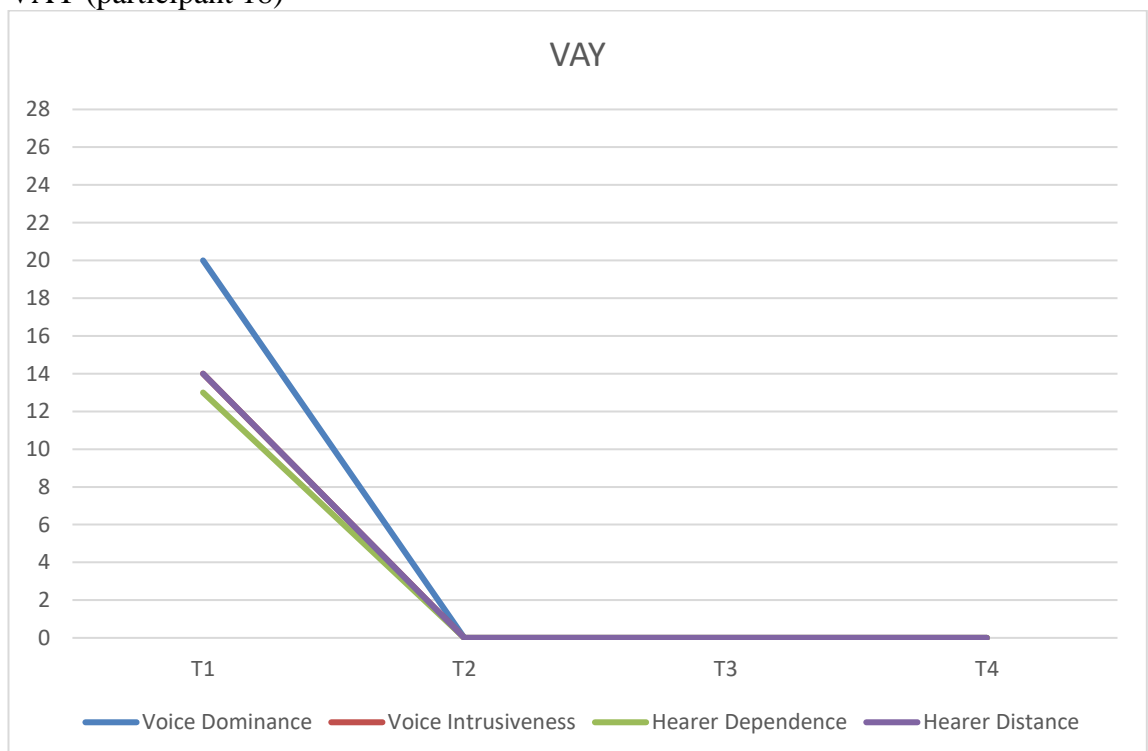
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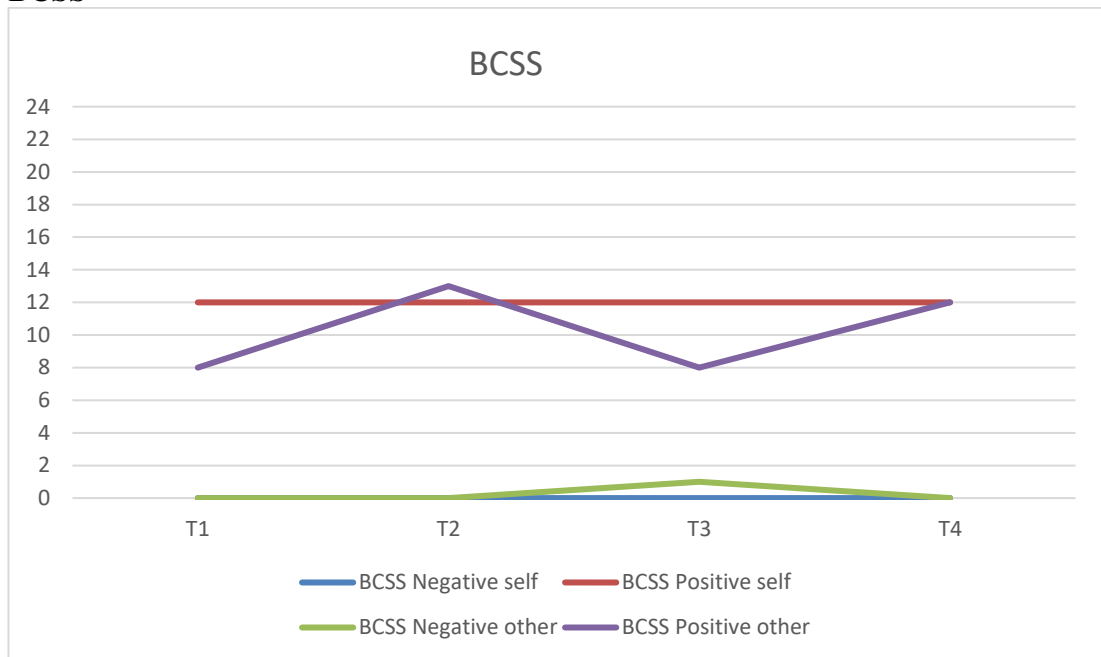
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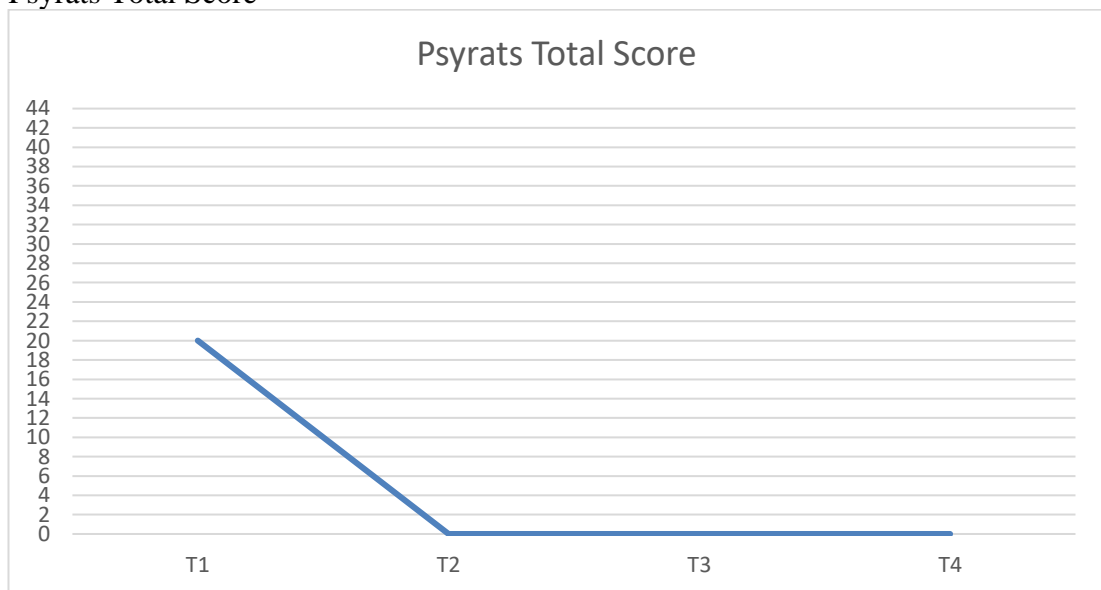
Voices stopped at T2

Psyrats sub-scales (participant 19)

Psyrats sub-scales

Voices stopped at T2

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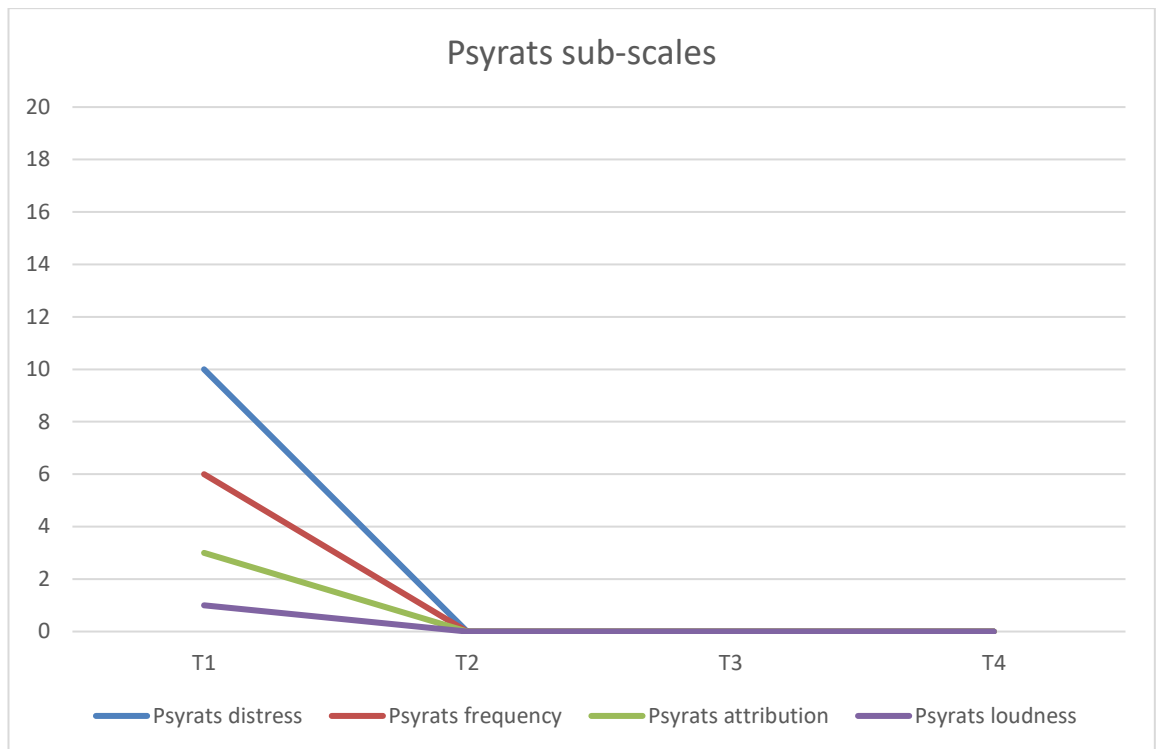
BAVQ

Voices stopped at T2

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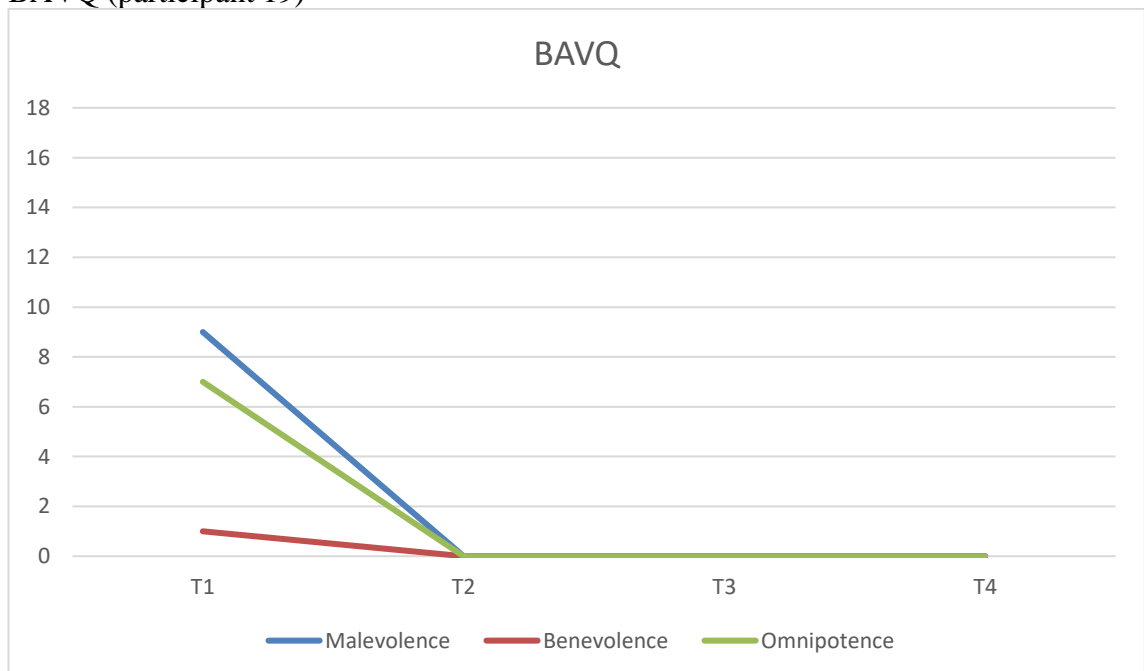
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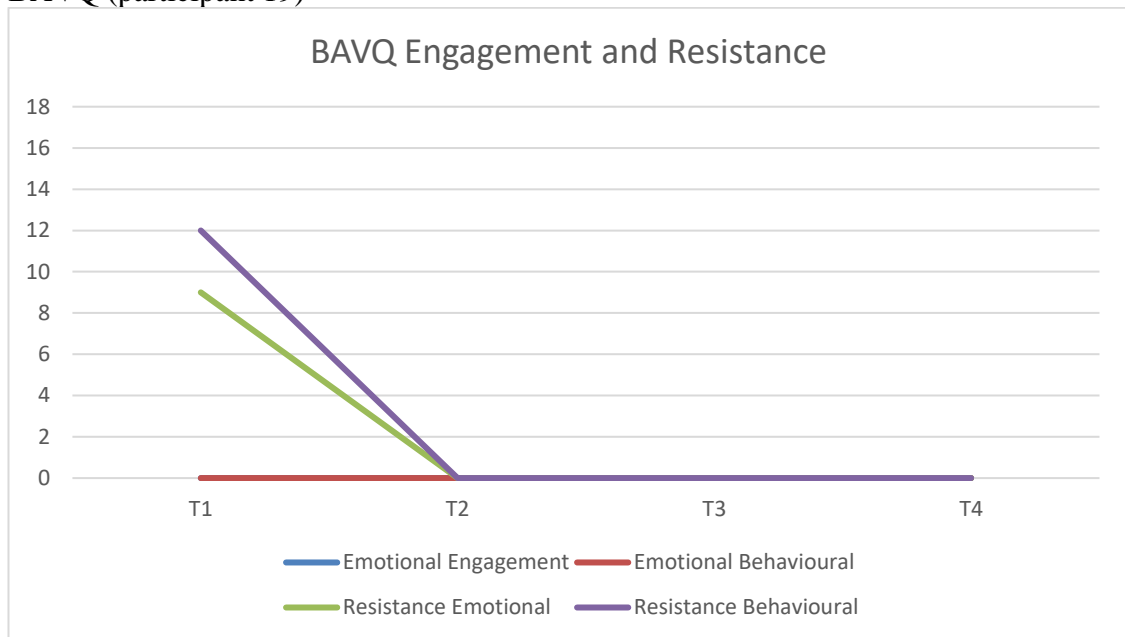
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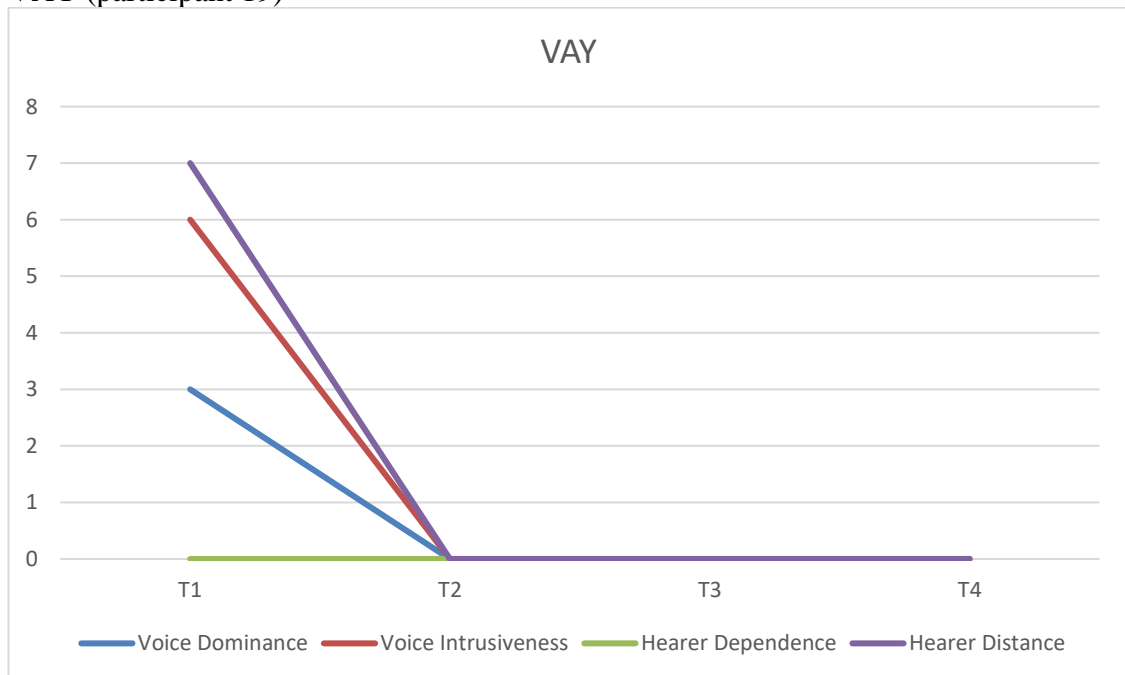
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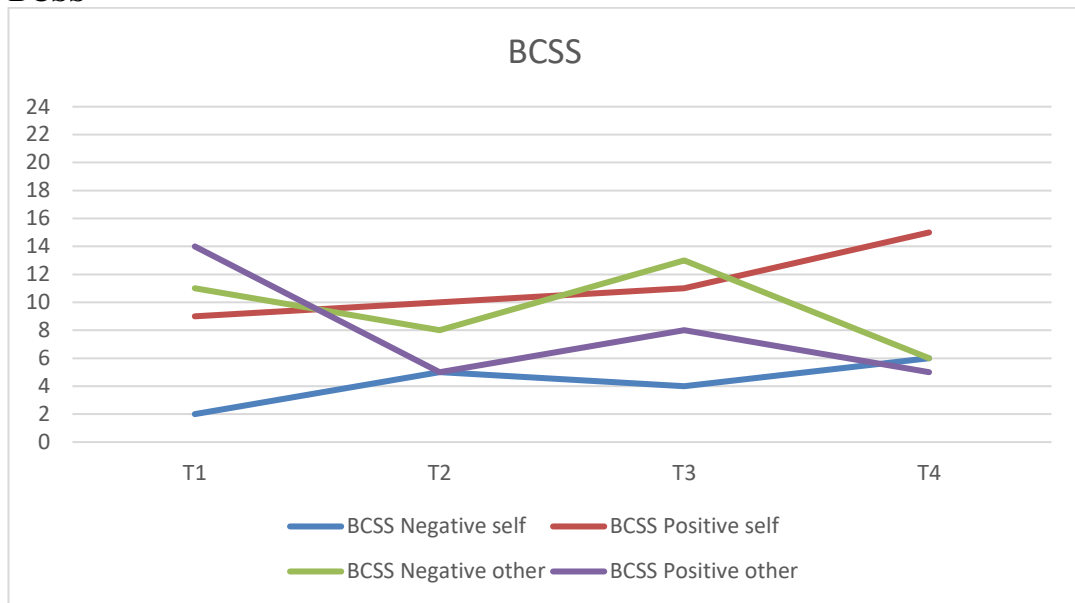
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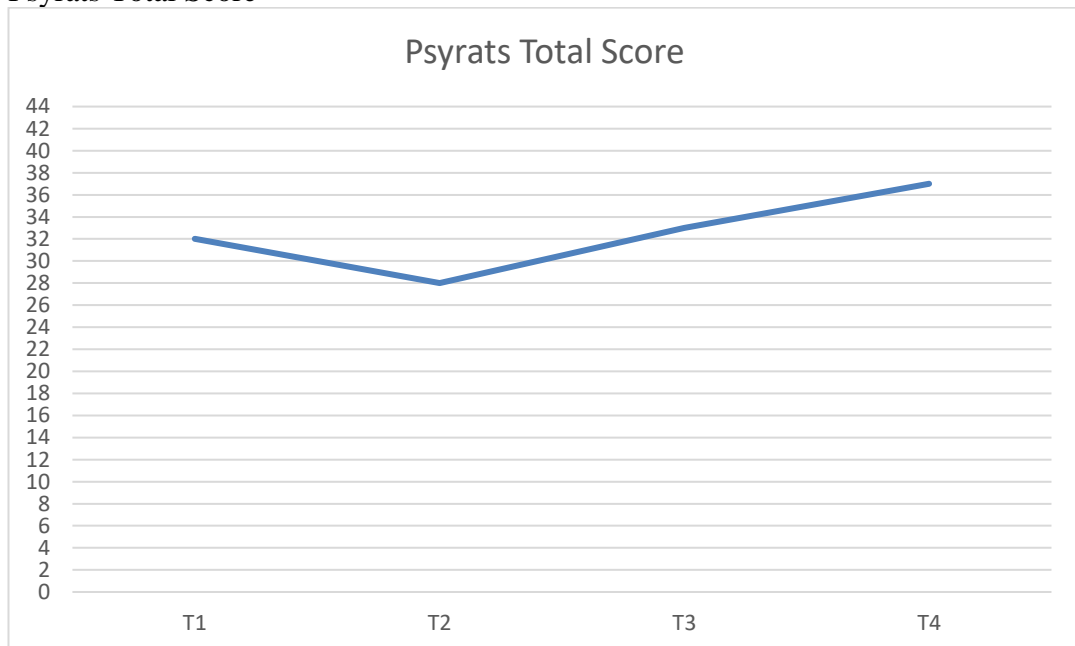
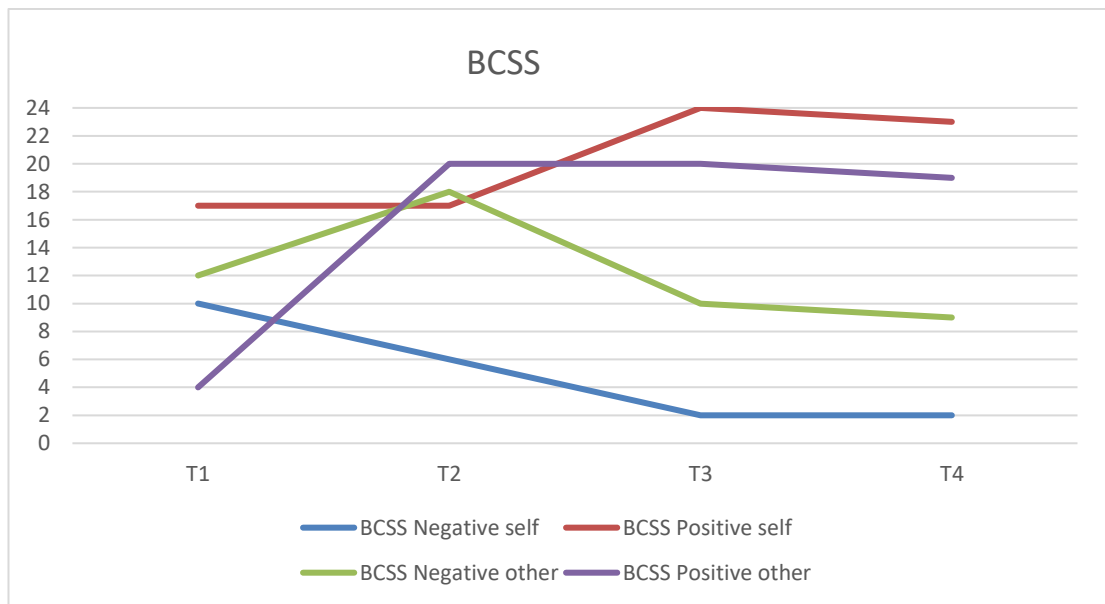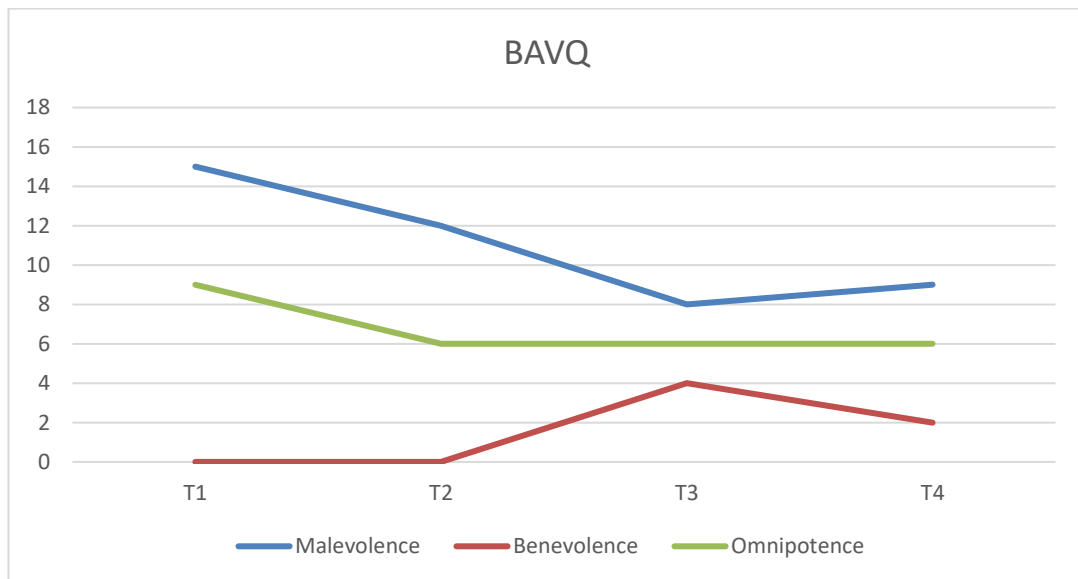Psyrats sub-scales (participant 20)
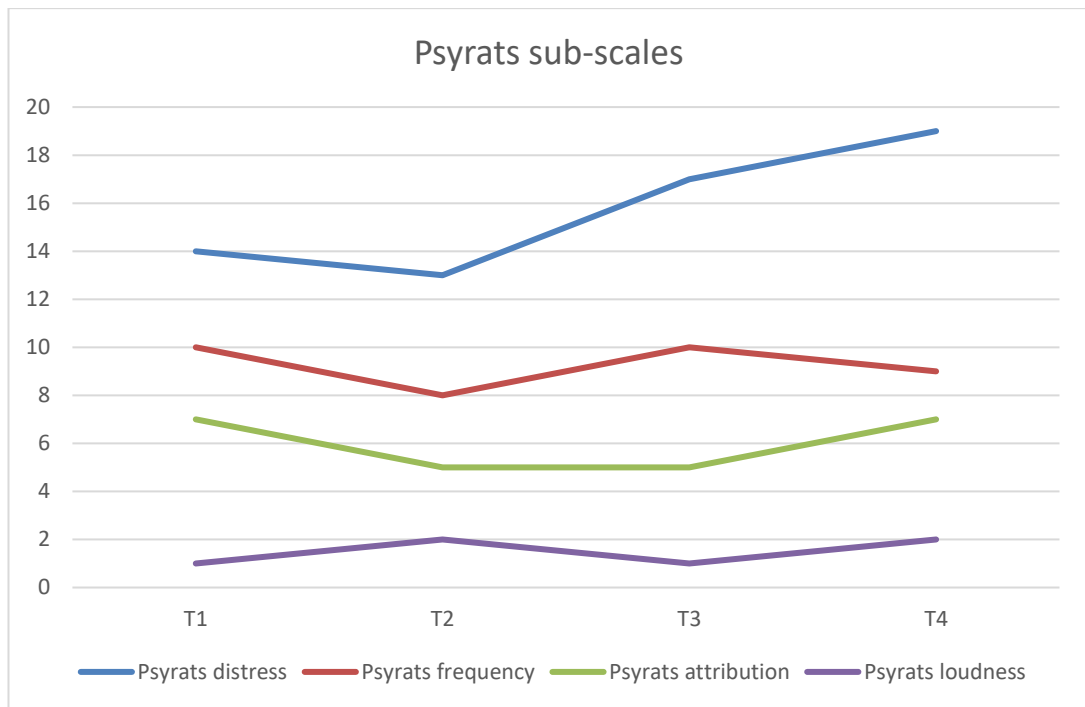
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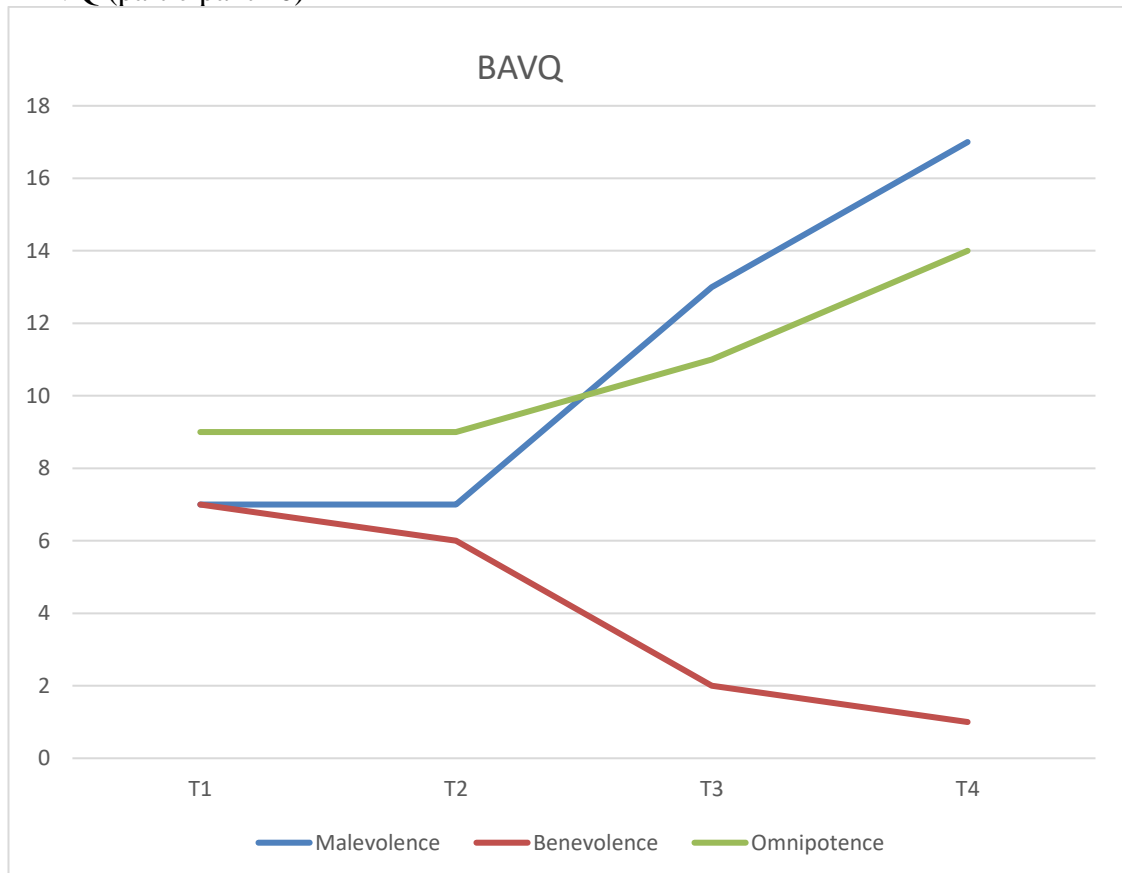
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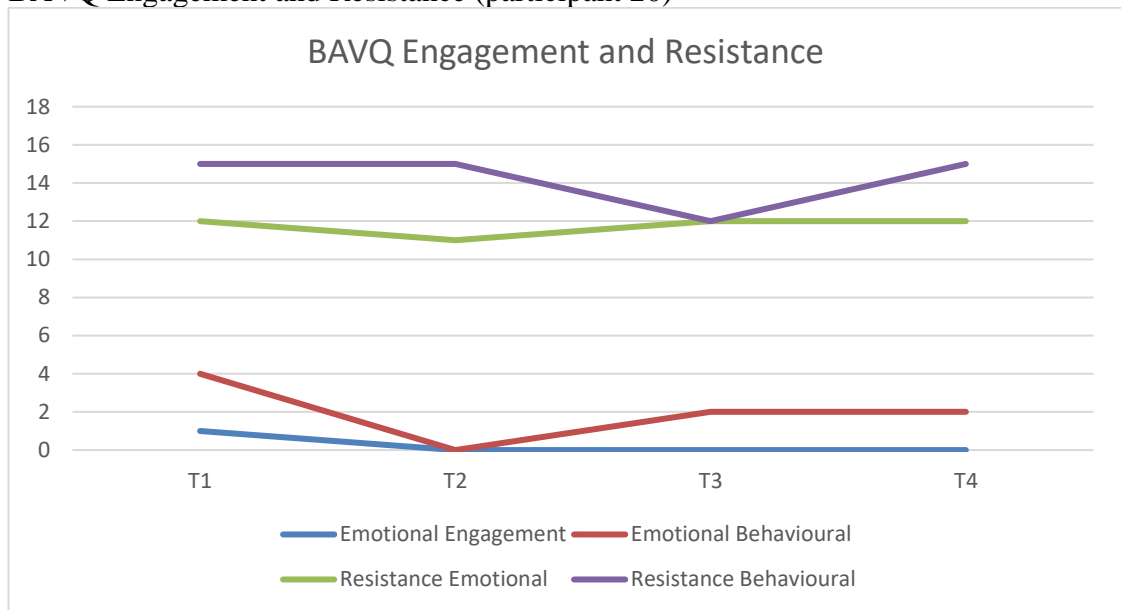
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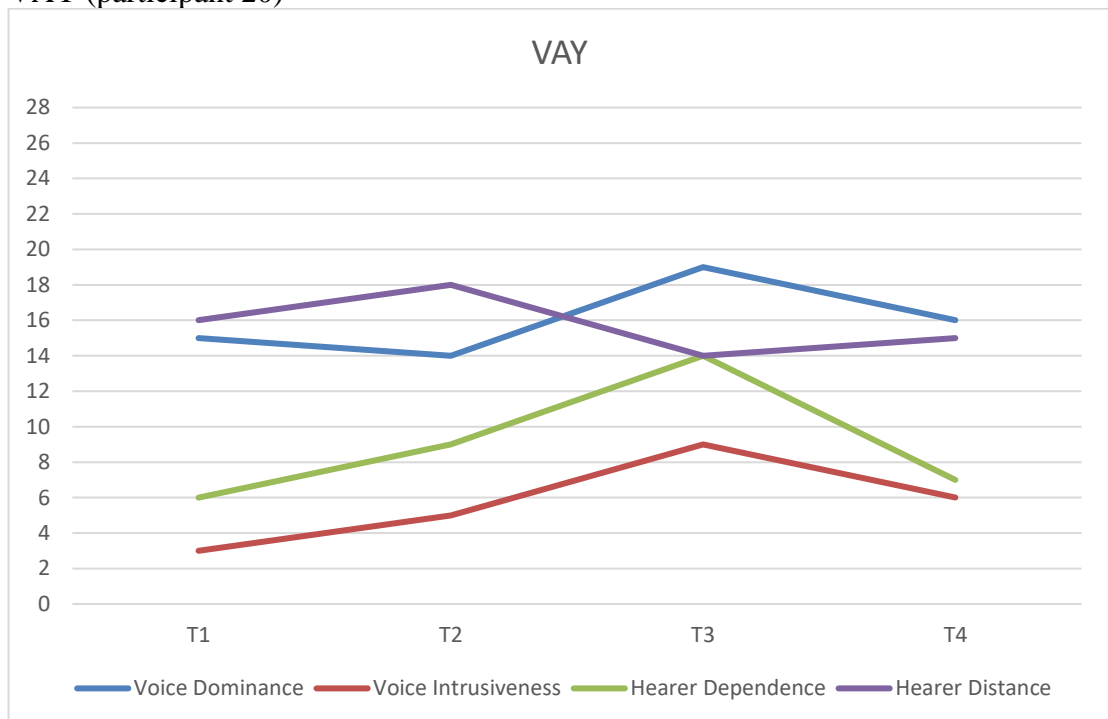
Appendix 10: Analysis of T1 Interviews - Barriers to the Disclosure of Voice Hearing (Chapter Four)

Higher Order Theme	Theme	Sub-theme	Code	
Should I Tell?	Others	Considering Others	I shouldn't disclose because of them	Don't want to worry gi...
				Worried what family w...
				Don't want to bring it u...
				Not disclosing due to b...
				Didn't tell as didn't wa...
				Not worrying others (P...
				We aren't telling my fa...
			I should disclose because of them	Family or Voice? (P18)
				Disclosed due to fear o...
				Got a family to conside...
				Duty to tell (P19)
		Assumptions about Others	Who could I talk to?	No one to tell but girlfr...
				No one to turn to (P14...
				Didn't feel I could talk...
				Never really speak like...
				Don't trust others
			Would they understand?	Sister wouldn't unders...
				Normal person wont u...
				Didn't tell family as to...
				They'd think I was bark...
				Not talking to friends ...
				They'd think I was mad...
				Others will think it stra...
				Didn't tell services as ...
				They'd think I was mad...
				Scared others would th...
				Attention seeking (P13...
				If told they might think...
				To wacky for anyone t...
				Family wouldn't believ...
			How would they respond?	World fell apart when ...
				They want to take voic...
				Fear of rejection (P14)
				It might get around (P1...

	Me	Hope/Opportunity		Telling at least one per...
				little bit of hope that r...
				Taking a risk and tellin...
				A chance to let others ...
				Family might accept VI...
		I feel too ashamed		Shame around disclosi...
				Too Embarrassed to di...
				Too scared and asham...
				Not something to brag...
				Too embarrassed to te...
		Autonomy	Autonomy (Self-reliance)	Not used to receiving h...
				Didn't tell as have own...
				I just kept it to myself ...
				Must help self as cant ...
				A man deals with own ...
			Autonomy (No choice about dis)	Disclosed through suic...
				Found out when mum ...
				Forced to disclose to w...
				Forced to disclose (P2(...
				Pressured to tell GP ab...
				Forced to get help (10)...
			Autonomy (Is there a problem?)	It was a constant frien...
				Voice was empowering...
				Good to have positive ...
				Didn't tell but it was lik...
				Voices not problem as ...
				Private world of voices...
				Voice as friends (P3)
				Voices not a problem t...
				Reassured by voice (P3...
				Didn't tell as not too b...
				Didn't tell as thought if...
				Voices was okay (P3)
				Might go away (P12)
				Denial of voices by ign...
				Not admitting there w...
				Admitting there was a ...
	Voices	Fear of Voice Repercussions		Fear of repercussions i...
				Threatened into silenc...
				Voice convinced me th...
				Voice told me to say I v...
				Too scared to tell anyo...

I Did Tell	Critical Point			Couldn't hold it in anyr...
				Enough of living that w...
				Getting help became p...
				Need to talk about exp...
				Got to do something a...
				Need to tell someone (
				Decided I'd had enoug...
				Can't do this anymore
				Told GP when felt like
				Broke down at doctors
				Had to tell as it was lif...
				Became too distressing
				Disclosed when voices
	Enquiry			AVHs norm in family (F...
				(P1)
Reflecting	What did I feel when I disclosed?			Had to come to terms
				exposed
				Felt better to tell (P11)
				Speaking to people hel...
				Relief to tell (P14) - rel...
				Telling meant not so al...
				Talking about it made
				People finally underst...
				Telling was wait off sh...
				What will voice do now
	Reflections on disclosing			Ruined my life by not t...
				If only I'd told (P18) - R...
				Wish I'd told someone
				Best to tell people as g...
				Now tell family what v...
				People should talk (P1...
				Friends are not obligat...
				Friend still spoke to me
				Couldn't rule me wher...
				Telling others negates
				Don't know how didn't

Appendix 11: Summary of Participants' courses of Voice Hearing over the Four Data Collection Periods

Participant 1
Experience: one male negative voice and whispering voices (still present at T4)

Time 1: onset to current interview – May 2014

Mental health issues first started at the age of eighteen (twenty-five at time of interview) when P1 experienced extreme anxiety whilst under pressure at college. Voices began to emerge a year later. At first, two voices whispered and called his name during the night. He wasn't concerned and ascribed it to part of the process of going to sleep. When P1 asked his mother and friends about voices they all said that they hadn't such experiences. He thought it was bizarre and unusual. At twenty, P1 had his first contact with Mental Health services where he disclosed voices. The Doctor said that hearing voices was common when going to sleep. P1's experience with Mental Health services had not been positive. He kept being given the wrong diagnosis and consequently, the wrong medication. P1 experienced whispering voices, which he attributed to his thoughts and a symptom of the bipolar diagnosis he had been given. However, as he couldn't control his thoughts, voices didn't feel like they were his thoughts.

A year after onset, voices became louder and eventually one male negative voice emerged. The male voice occurred during the day and was derogatory, issued suicidal commands and, what P1 described, paranoid comments. Whispering still occurred at night. He said that beliefs about voices developed. He now found voices scary. P1 believed that voices had got louder due to a decline in his mental health. He told his mother that voices had got louder. He divulged this information as he feared that everyone would think he'd "lost the plot." He became more socially isolated. Paranoid thoughts emerged at twenty-two.

At twenty, due to voice commands and racing thoughts, P1 set light to a car and was sent to hospital for the first time. He described the voices as 'peaking' during the evening. As voices peaked, so did his anxiety and he felt that he couldn't control his actions. Since the first admission, he has been in-and-out of hospital. At twenty-two he had a diagnosis of schizophrenia. A change in medication resulted in an improvement in his mental health.

Over the years he has had anxiety and depression as well as high mood swings.

T1 Current:

P1 felt that since onset, he'd become more aware of hearing voices. He still considered voices to be thoughts that he couldn't control. P1 felt that the voices were in his head but not part of him. When anxiety was low P1's voices were not too distressing, and he was able to manage daily activities. However, when voices were loud and issued suicidal commands P1 became scared, unable to cope and typically was admitted to hospital. His dog had died. P1 had recently been admitted to hospital as voices had become extremely loud and distressing. P1 was not aware of triggers which may have affected voices.

P1 listened to music as a way of managing voices. He also wore sunglasses as this "de-sensitised" his experience. He didn't like being alone, as voices were louder, and he tended to listen to them. Consequently, socialising was a way of managing

voices as this meant that he was not focused on them. At home, if voices became louder he went out.

P1 hoped that voices would become more manageable in the future but didn't believe that they would ever go. He wanted to be able to manage his voices so that he could return to work. Returning to work was an important goal for P1.

T2 interview – February 2015

P1's voices (whispering voices and the male voice) were still present. He had been admitted to hospital in June as voices had become louder, more intrusive and were issuing suicidal commands. He had nearly acted on their commands and had planned suicide. At the time he had felt anxious, depressed and unsafe. He had been scared that he might act on suicidal commands and had felt like he had no control. P1 described feeling like a zombie. He went to hospital, as he had been there many times and considered it a place of safety. According to P1, this had been one of the worst episodes with voices.

Since coming out of hospital voices had been "up and down" but currently they were more stable. Voices were always present and became progressively worse throughout the day and night. They were most intense before bed. P1 took medication to manage this. Voices were not as bad throughout the day as he tried to focus on other things such as music, swimming and socialising. According to P1, anxiety helped to manage voices. Anxiety protected him from behaving rashly and acting on voice commands. When voices were more distressing P1 was unable to use typical coping techniques. During these times voices would become more intense and distressing. P1 was aware of one trigger (dog dying) that had made voices worse. Although he believed that for the majority of time voices became louder for no apparent reason, P1 was aware of a pattern of when he was becoming unwell.

Currently, as he was not engaging or acting on their commands, P1 felt that he had slight power over voices. At present, they were quieter, and he was able to get on with life. When voices were quiet, P1 did not speak to them. He said that he didn't want to acknowledge them unlike when they were loud. Voices attacked his self-worth. However, when they were quiet he was able to reflect upon their content. During these times, he realised how voice content contradicted his current achievements. This was something that he was unable to accomplish when they were loud. P1 said that it seemed that everybody could hear his voices, that voices and thoughts were not private.

P1 believed that voices were due to an imbalance of chemicals in his brain. He didn't view himself as successful as he was unemployed. He attributed unemployment to voices.

T3 interview – November 2015

The past nine months had been positive and P1 was no longer under a mental health team. Voices (same voices) were still present but were quieter than when we had previously met. They had remained stable over the past nine months. He contributed this to a change in medication which had helped to dampen voices. He still had days when voice intensity increased. This worried him as, on these days, he thought that he was becoming unwell. Typically, voices "faded away" and he was able to manage everyday life. When voices were quiet he was able to have more control and not act on their commands. P1 was happy as he hadn't had a hospital emission. He usually had one at least every six months. He said that it felt weird being well. P1 believed that the improvement in mental health was due to moving into new accommodation (moved into

a flat) and feeling independent. P1 had been accepted for a job. He was socialising more and passed his motorbike test and now had a licence.

P1 believed that voices would always be present. However, as he had them for nine years, and they had been "terrible", as long as they were quieter he felt that he would be able to live with them. His hope was that voices would stay quiet and then he wouldn't be troubled by them. Voices were still loud at night, but this was managed with medication. For most of the time, P1 was able to ignore voices and "zone out." It was when voices became louder that he noticed them. He described these times as "weird." During the interview, P1 appeared more matter of fact about his experiences and felt that he had learnt to live with them. For the first time, P1 believed that he had the power. He had control over his life and not his voices. Voices were secondary and he made the decisions to do as he pleased. He said that this felt "brilliant."

Instead of a means to coping with voices, P1 now went to the gym, listened to music and socialised for pleasure.

T4 interview – August 2016

Voices had been a problem over the last couple of months. Although voice content was the same, they had become louder when P1 was physically unwell and had become depressed. Prior to this, P1 had lost his job. Voices became worse on this occasion and he had expected to become unwell. However, he had been able to manage his voices and avoid becoming mentally ill. He had gone to the doctor but rather than increasing medication had wanted to prove that he could manage voices alone. P1 had managed them by forcing himself to face his experiences. He believed that voices were due to his physical health and if he got well physically he would get well mentally. For the last two weeks they had quietened. Voices were loud in the morning until meds dampened them.

He had learnt that when he wasn't socialising he was becoming unwell and used this as a means to gauge his mental health. He still listened to music for pleasure but used headphones, gym and sunglasses as a means to cope with voices when they were distressing. He still sometimes "zoned out" with voices. He said that when they were loud and intrusive he tried to put them to the back of his head. He likened this to a brick wall of voices which he had to shout over. When he was well there was no wall and voices evaporated into his brain. They were still horrible, but he was able to ignore them.

He felt that he now had more control and, most of the time, was able to not act on voice commands. P1 believed that the reason why voices hadn't become worse when he lost his job was due to an increase in his control. He said that this felt "weird" as negative events typically caused his mood and voices to spiral out of control.

P1 did not believe that voices would ever stop. However, they could be managed to be quieter. When they were quiet he could partly dismiss them and continue with life. He felt that was all that he could hope for and had come to terms with this. However, it made him sad. He had accepted that they had become part of his life. Services had told him that he would always have relapses and he believed this. He still felt that it was "weird" to be well and not involved with services. He hadn't been admitted to hospital for over two years.

Participant 2

Voices over 3 years come and go.
Experience: one negative voice. Voice also becomes positive (voices fluctuated over years – T4 not present)

Time 1: onset to current interview – June 2014

Prior to the onset of voices, P2 was physically abused by her partner and raped. She first heard voices immediately after an argument with family members. At the time, she was stressed and feared that she was going to harm her baby. Voice onset was sudden. The voice told her that she was a bad mother. It lasted for a few seconds and she was surprised by it. P2's reaction was to leave the house. At the time, she felt that the cause of the voice was due to tiredness and that either her mind or her mother was playing games. She also believed that it might be what she, and her mother, termed her "inner child." P2 explained the "inner child" as the frightened, hurt child inside trying to get out. Voices did not occur for another six weeks. This was also after an argument and again, her reaction was to leave the house. She believed that her mind was playing tricks due to tiredness, hunger and a headache. Voices didn't return for another three to four months. When they did occur, it appeared to coincide with stress, tiredness or if P2 had a headache. They tended to last from a few seconds to ten minutes. As stress increased so did voices. Voices became more aggressive and were accompanied by visual hallucinations. Voices were worse when P2 was not occupied. P2 would react to these experiences by screaming, shouting and violent behaviour. Afterwards, she would leave the house and walk the streets. She felt dissociated and if her body had been taken over. P2 believed that she had no control over her experiences. Her partner did not know about voices or visions at the time.

At onset, P2's mother had found her walking the streets. She contacted P2's GP. P2 tried to speak to her mother about hearing voices. However, her mother had told her that she was being "silly", voices were normal, and everybody experienced them. P2 disclosed voices to GP at onset. Her GP diagnosed her with post-natal depression. She felt that nobody took her seriously. It was only after moving to a new GP three years previously that she felt her experiences were taken seriously.

P2 said that her EI care coordinator had not engaged with her experiences with voices. Her care coordinator only spoke about medication. Over time, her voices (and visions) became worse. After a change in medication, approximately six months prior to the current interview, voices and visions decreased. Voices now only occurred with visions. Her last experience with voices and visions had been three weeks ago.

T1 Current:

P2 couldn't make sense of voices. She felt that it started and that medication had slowed it down. Her experience was that voices were "there one minute and gone the next." She described it as "odd." She had just finished therapy with a Psychologist which she found helpful regarding her behavioural response to voices (constantly checking child). Working with the therapist, P2 had found her "happy place." P2's coping strategies with voices had changed from leaving the house to trying to do something constructive with her child. Previously, she had wanted to be alone. This now frightened her as she felt that she could not control voices by herself. Being with others was her way of managing voices. Although voices were frightening, P2 also referred to them a "silly" and that it was the result of her mind "playing tricks" on her. Recently, prior to the start of vices, she had started to smell burnt. Now when she heard

voices, she thought "here we go again." There had been a change in voice content from focusing on negative self-esteem to voices also issuing commands. P2 found this "weird." Voices told P2 that she was not a good mother. However, she felt that this was positive as it had made her realise that this was not true. According to P2, having received a diagnosis had helped her to manage voices.

She believed that voices wouldn't be present for much longer.

T2 interview – March 2015:

Voice frequency had decreased to once a month. Voice content had changed from always negative to mostly positive. This change had occurred six months previously. P2 perceived her voice as supportive. It reassured her when stressed. She did not want this voice to go as it enabled and rewarded her. She believed that the voice came once a month to make sure she was okay. Her voice also supported her to have a healthy lifestyle. She no longer puts herself in danger by going out late at night. P2 found that she was now able to go cycling and take her child out.

Eight months previously, due to an increase in stress, P2's voice had become more distressing. Recently, when P2 had again experienced stress, she had feared that her negative voice would increase (return to how it was previously). P2 said that when she felt happy she had more control over her voice. Her voice used to make her feel worthless but now she felt better about herself. P2's self-esteem had improved as she was more confident and felt more like a "normal person". She felt more in control and that she able to combat the negative voice. She also believed that she had control over it starting and stopping. When her voice was critical, she was able to tell it to go away. P2 used writing as a way of coping with her negative voice. She used to find this difficult as the voice interrupted her. However, she was now able to write. She still believed that her voice was her "inner child" but it was now "growing up". She considered her voice to be evil when it was negative. She believed that her negative voice was due to stress and the abuse she had previously endured. P2 hoped that voices would stay positive until they went.

T3 interview – December 2015:

All voices, including the positive voices, had nearly gone. The negative voice went first and then the positive voice. Positive voices went during an extremely stressful time when she also felt depressed. P2 believed that voices had gone because she had stopped worrying and becoming stressed. She believed that voices had been around because of the physical abuse, anxiety, stress and post-natal depression. She had felt lonely when the positive voice went. It had been an incentive and praised her. She questioned their reality as to whether they had actually been there or a part of her body that had gone wrong. P2 still felt that they were "silly" but also helpful. However, she no longer missed her positive voice and felt more in control. Her self-schema was still positive, and she felt good about herself. She had told a clinician from her Recovery Team that she was giving herself nine months to recover. She was no longer with services and which she was happy about. However, visions had started to return P2.

T4 interview – September 2016:

P2 said that voices had stopped. However, she spoke about a recent event whereby her partner had heard her talking to someone when nobody was present. She said that she had no recollection of this. Voices had started to return four months prior to the interview. She said that they weren't too bad, more like an annoying whisper in her ear. The content had been negative and similar to when they first started. She felt

that this was due to depression. She was angry that they had returned and feared that she might be going back to how she had been previously. When voices returned she decided that she didn't want medication and felt that it would take too long to get professional support. P2 didn't tell anyone about voices. She had the confidence to manage them herself. P2 said that she had been able to make voices go away by "bettering myself"- losing weight, having a part-time job, going out of house and walking all day. As voices were present when she was inside of the house she had spent all day outside. She said that being active enabled her to ignore voices. She had re-focused her attention away from voices through activities. As she lost weight voices became softer, further away and positive until they finally went. P2 was unsure whether voices might return in the future and was worried about this. She said that this was the reason why she went out so much and tried to keep occupied.

P2 felt that she was back to her "happy bubbly self again."

Participant 3

T1 onset to current interview-June 2014

P3 experienced five voices (three men and two women) although one of them was not currently present. Although her voices were unknown they had distinct identities. Two voices (one male and one female) were particularly aggressive. The first voice to appear, was kind and caring. Other voices started to appear a month later. A positive voice that reassured P3, had not be heard for a little while. She also experienced another positive voice. P3 found this voice funny and thought of her (the voice) as a teacher. There were two aggressive voices. One was particularly hostile. The other came at mealtimes and told her that the government was coming for her. These two voices also came during exams. She described them as evil.

Voice onset occurred during the summer of 2010 after she had finished school. Prior to voice onset, P3 had been studying for her GCSE's. Due to her nerves, she had studied at home. P3 was on her own when she heard her first voice. She was surprised and looked around the house to find out where it was coming from. She found the voice comforting and considered it to be a friend. The positive voices were her companions.

Initially, she heard the voice every few days. It started to increase in frequency until the other voices appeared. At first, voices would make comments. However, a year-to-two years later they became more aggressive. P3 did not tell anyone about these experiences as they would think she was "mad." She did not seek help as voices were not too distressing or that frequent. At first P3 was ambivalent towards them. During her A levels voices became more aggressive. They told P3 to harm herself. She acted upon these commands and was distressed. Voices interfered with concentration and she became more withdrawn. Her mother noticed that she was talking to voices and initiated help through the GP. At the time, as she had managed voices for a while, P3 did not believe that she needed help. However, upon reflection she realised that they were becoming more aggressive and that this had been the right decision. P3 said that, if her mother had not insisted, she would not have sought help from the GP

P3 refrained from shouting at voices but instead, tried to get on with them. At first, when positive voices comforted her, she would talk to them in her head. At this time, no one was aware that she heard voices. She began to talk out loud to them when voices became aggressive and increased in frequency. P3 told voices to stop and that, at this point, she didn't want them. Voices worried her, affected her academic performance and social life. They told her that she was a failure and she doubted herself.

T1 current

Aggressive voices were present at mealtimes while pleasant voices occurred randomly. Voices issued both negative and positive commands, told her what to do and reassured her. P3 said that negative voices gave aggressive commands, told her to self-harm and frightened her. She felt that positive voices were trying to help her. She liked her positive voices and wished that the negative voices would stop.

P3 said that she had been told that she should speak out loud to her voices. She did not feel comfortable to do this in front of others as it was too personal. However, she was happy to speak out loud to them when alone. She believed that voices would always be present.

P3 was about to start university.

T2 Interview-March 2015

P3's voices had not changed since the last interview. Voices were still present at the same time e.g. during the evening meal. Voice content and frequency had not changed either. Negative voices were undermining. P3 said that she felt scared and vulnerable when negative voices were present. She found the positive female voice comforting and reassuring. Negative voices were worse during exams. She would act on commands when she felt low in mood and vulnerable. P3 believed that negative voices wanted to make her life difficult. She was unsure why they were still present. Alternatively, she believed that the purpose of her positive voices was to mother, support and help her to increase in confidence. She said that the mothering voice was dead. P3 thought that the negative voices worked for the government. She believed that only she could hear the voices. Despite her family assuring her that voice content was not true (i.e. voices were not from the government), she tended to believe what her voices told her.

P3 was currently at university. She did not tell the other students about her experiences as she feared that they would think of her negatively. Although she did not consider herself to be "mad", she worried that others may think that she was.

P3 felt supported by her family, university and mental health team. However, her father believed that she was possessed by the Devil. Her mother had never encountered voice hearing before. She was ending with EI and moving to the Recovery Team. EI said that she'd never had in-depth conversation about voices.

Voices were still distracting and affected her life. P3 said that voices made her self-harm. She believed that she did not have control; they had the control and power. Ignoring voices did not help. However, her positive voice empowered and comforted her. She tried to cope by talking to her family, listening to music and ignoring voices. P3 would be pleased if all voices went but would miss the 'mother' figure. She was ambivalent to certain voices.

T3 interview-December 2015

Negative voices had become worse. P3 felt that they had taken over more. Voice content was still the same, but frequency had increased. In addition, her paranoia about voices had amplified. This change had been sudden. P3 attributed the deterioration to a reduction in medication. Voices had been better nine months previously. She found voices overpowering and she felt that they made her act on their commands. If she did not, she believed that there would be consequences. P3 did not feel safe and that they made her self-harm. When voice threats did not materialise, she felt relief. P3 wanted more control over voices. Although positive voices were also powerful, she felt that this

was good. She would try to distract herself by talking, going for walks or listening to music.

P3 was still unsure why she experienced voices. They told her that she was special, but she was unsure about whether this was true. She believed that voices wore cloaking devices and followed her inside and outside of the house. P3 was struggling to attend university. She had lost motivation. Because of voices, she was not going so frequently, not socialising and wanted to be alone. She felt that voices had affected her university grades. Voices still affected her confidence. She still did not disclose voices to university friends as they might think that she was "crazy." She did not believe this and said, "I'm normal really."

Her mother reassured her when voices were bad. P3 wanted positive voices to stay; they reassured her, and she was happy that they were powerful. Her mother told her that voices did not have power over her. She still felt supported by her family. P3 did not feel that the Recovery Team were different to the EI team. She found that that they could be supportive. She wished that she were still having CBT as this had helped her to challenge voices. She said that she was struggling without therapy. She had had CBT before her voices had recently declined.

T4 interview-September 2016

P3 had graduated from university and had a job interview. Voices were still threatening and saying that the government was tracking her. Currently, she had two negative voices, one voice that was "okay" and her "joking" voice. Voices had grown in power over time. P3 felt that if she did not act on their commands they would punish her. She last self-harmed one month previously. Being able to resist voices depended on her mood, as when in a low mood voices "took over" her. Voices became worse as mealtimes approached. However, she was trying to live her life, and this meant not letting voices rule her. She felt that voices always had the control and that she was powerless as they didn't listen to her. P3 said that voices overpowered her, and she had to listen to them. Depending on their power, she tried to re-focus her attention. Her mother still tried to reassure her that they did not have the power.

P3 coped by talking to family members if voices were bad. She would hide in the house if she felt particularly paranoid and tried to distract herself. Coping had not changed. To calm herself she would try to re-focus her attention.

P3 felt that she had to accept that voices were part of her life now. However, accepting voices also meant that she could now get on with her life and getting a job. Acceptance had occurred six months previously when she had realised that medication did not work. For P3, getting on with life meant not letting voices rule her. Her goal from when she had had therapy previously had changed from eliminating voices to accept them. CBT had helped with paranoia. She would like to be able to talk more in-depth about voices with her Recovery team but said that this was not possible. She would like therapy. She worried about voices even if they were not present. P3 said that they scared her, caused anxiety and were the cause of her low mood.

She was not sure if voices were due to a chemical imbalance or whether she had special powers to hear them. She felt that she was chosen to hear them. P3 said that she would miss voices if they went as they alerted her to the danger of the government. Her positive voice still comforted her, and she wanted this one to stay. She was annoyed the negative voice was still present. She would like voices to go but was also used to them. She believed that she would have performed better in her degree if she had not heard voices as they had distracted her. They also had stopped her from socialising.

On reflection, P3 felt that voices had increased in power over time. Content had become more negative and they had become progressively worse. She did not understand why this had occurred.

Participant 6

T1 onset to current interview-June 2014

Voices first occurred when P6 was eighteen (seven years ago). The first voice he experienced was of the God Imhotep. P6 had been trying to get in contact with this God by performing "rituals" (he was interested in the occult). He did not find the voice of Imhotep malevolent but interesting. However, at first, hearing the voice "freaked" him out. He came to consider the voice as beneficial but, as he found it distracting, it was not an experience that he wanted to occur constantly. His voice did occur on a daily basis. P6 only disclosed his voice to his girlfriend at the time who also agreed that it was positive. At the time, he did not have anyone else to disclose voices to. As this had been a positive experience, he made contact with other Gods.

P6 began experiencing "scary" voices. At first, during the interview, he thought this had first occurred at age twenty but later referred to it at age eighteen. Prior to this, P6 had sought to make contact with particular voices of his choosing. Unlike the occasions, this was the first time that voice onset had occurred without him seeking out the voice. The demonic voice occurred infrequently. P6 believed that this voice was the magic of somebody who had a grudge against him. When it first occurred, P6 had been paralysed with fear and lost consciousness. In addition, he also experienced a noise which sounded like static.

At the time, P6 was not working. He had a girlfriend and was living with his parents. P6 had difficulty with a relationship that ended. It was during this period that the "archetypal" male and female voices of the "God and Goddess" began. He did not seek these voices out but believed that they had come to help him.

P6 lost his friendships when he tried to discuss his voices. He had been asked to leave the band in which he was a member and consequently his friendship circle. He said that, "his world fell apart and he felt abandoned. He did not speak to his family either as he felt that they would not understand his experiences. He said that they believed that he had "gone nuts." P6's mother took him to the Doctor for depression. At first, P6 did not disclose his voices due to his previous experience of disclosure with his friends. He also did not consider voices a problem. On the fourth occasion, P6 disclosed voices to the Doctor. He felt like he was he was losing his mind and needed to discuss his experiences with someone. He was referred to EI.

P6 spoke of a childhood trauma of his father committing suicide.

T1 current

P6 currently experienced three main voices: voice of an alien, a Demon voice and voices of the God/Goddess. P6 believed that the purpose of his voices was to improve and help him. He believed that the Demon voice had taught him fear. It had also helped him to understand himself better. However, he knew that the Demon voice's "days were numbered." On some days, P6 was terrified and hated this voice, while on others, he felt that it was ridiculous and that no one else experienced this voice.

He felt that, while he had no control over the Demonic voice, when in a threatening situation he was able to channel the voice's energy through himself. He managed the Demon voice by playing his guitar or laughing at it. Alternatively, P6 believed that the God/Goddess voices were his constant friends. He considered the

Alien voices as loving and peaceful. P6 wished to keep the positive voices and manage to gain control over the Demon voice.

At present, P6 e felt low in mood. He said that this was due to his situation of living, home and his experiences that no one understood. He also felt that he was becoming more disinhibited and said that he was trying to "re-programme" himself.

T2 interview-April 2015

The God/Goddess voice and alien voices had stopped. The Demon and Fear, voices were still present, but frequency was less. P6 did not like silence as he could hear the Fear voice (a voice coming through the static noise). Consequently, he always played music or had the television on (even when asleep). He used to use alcohol to cope but said that he no longer did this. However, his voice was quieter, and he was now able to listen to music. P6 believed that the Fear voice was the manifestation of the evil inside of himself. It was destructive, oppressed and an angry self. Fear was an expression of his self-loathing. The Fear voice was his fear. He regretted that the Alien voice had gone and felt empty without his voices. He considered that he was poor at making decisions and that voices had supported him to do this. He felt that it was nihilistic having 'somebody' (voices) leave him and felt isolated without them. He did not feel as confident as when he had his positive voices. He did, however, feel safer as he knew that he could get the support from EI services if he "lost his mind" again.

P6 said that he was glad that he had come out of the other side of the experience. He reflected on the experience and described it as both terrifying and fun. He appreciated it. He felt that nothing could be as frightening as your "mind turning on you." He did not understand that if voices were part of him then why he could not do anything about them. They had felt alien.

P6 said that he had not told anybody about his voices, as he had feared that they might section him. He had also not wanted to believe that he might be having mental health issues. When he had first experienced voices he had been scared that he was losing his mind.

Interview 3-January 2016

P6's voices had stopped. He reflected on the experience and now believed that voices were his own thoughts. He felt that it was due to his inner negativity. When the Fear voice went, he felt that he was becoming a stronger person. He questioned as to why at the time he had believed that it could have harmed him. It never had and, as he reasoned, no one else had seen or heard it.

He attributed voices stopping to discussing their reality with his EI care coordinator. In addition, he also felt that having had the chance to explore voices with me during our interviews had given him an outlet to express his experiences. He had never been able to discuss them in such depth with anyone. P6 felt that he was only able to engage with services when he began to question his beliefs about voices. He said that he would have been receptive to therapy only after hearing voices for a couple of years. He acknowledged that therapy may have be better at the start of his experiences however, he would not have been ready to engage.

Currently he felt more positive and more balanced. He said that his mood was not at the mercy of his voices and he felt safer. However, he also felt lonely and unsupported without them. He described them as a comfort but was now alone. The experience had been both good and bad. On reflection, P6 would not mind if voices returned as it had been an interesting experience. He said that, to become stronger, he used to embody the Fear voice. P6 thought that it was better that the Fear voice had

gone as he was now able to socialise. He was able to manage tension without having the support of voices. Now that voices had stopped, P6 felt more autonomous and was becoming accustomed to having control. He was still not comfortable with silence as it was during these times that he used to hear negative voices. However, he still experienced a static sound which he described as inside his head.

P6 was at university and wanted to get a job as a music teacher.

Participant 9
T1 onset to current interview-August 2014
Experienced voices for four years.

P9 experienced a negative male voice plus a group of five voices. Prior to their onset, P9 had planned to go to university. She'd also been part of a large social circle. Voice onset occurred a couple of weeks before she was due to undergo an operation for her back. Because of her physical problems, P9 had not been able to leave her house. As a consequence of this, she lost many of her friends. Life became boring.

P9 was in bed when she first heard a "scary" male voice. She said that she had found it strange and was surprised by it. She attributed it to tiredness and the medication she was taking for her back. However, when she woke the next morning the voice was still present and very negative. At this point, her voice felt more real and seemed like a part of herself. The frequency of hearing the voice increased and she started to believe that it was a Demon or Monster that was internal. She also believed that she deserved the negative content. P9 was scared and began to listen to what her voice said. It made her feel lower in mood. A couple of weeks after voice onset, her voice had become unbearable and, at the voice's command, she began self-harming. Voices went when she self-harmed. She would self-harm when they became too much. P9 would write down what voices said and her response to them. She found this a release.

At first, she was too ashamed to disclose. She felt "crazy". Several months later, the experience became too much. P9 reached point where she was shouting and self-harming in front of her family. It was during this time that she disclosed. She said that that she'd felt beaten and that she had to tell someone. Her family were understanding. They told her that voices were not real, in her head and would go. She didn't believe them. However, the support from her family helped her self-esteem. She realised that she wasn't worthless and didn't deserve to hear the negative comments. On a number of occasions, when voices became too bad, she tried to suicide.

The group of voices came six months after the onset of the first voice. She had been arguing with her voice. She said that the voice had affected her confidence and that, after the constant negative constants, she had known that she wouldn't be able to go to university.

T1 current

P9 no longer believed that there was a Demon or Monster inside of her. Instead, she believed that it came from her head. Through working with her care coordinator, she no longer viewed voices as real. When voices were too much, P9 would still self-harm. However, self-harming had become less frequent. She viewed it as a sign of weakness and that voices had won. The male voice was the main voice. When voices became more distressing she experienced the "group of people." P9 coped with voices through music, painting, reading, watching horror movies, walking the dog or listening to them and waiting for them to go. Voices were louder when she was alone.

P9 had been experiencing voices for four years and now considered them as part of her. She said that there was a constant "buzz" in her head and that she never had a clear mind. She he had forgotten what a "normal" head felt like. P9 believed that the voices were generated by her mind.

When voices become distressing, P9 is able to speak to both her family and care coordinator. She finds this helpful. Sometimes at work, when voices are bad, she finds it hard to concentrate. However, she had also come to realise that voices were not as strong as she had previously thought. At times, when voices were particularly distressing, such as at work, she felt able to control them by not listening to what they said. She was now able to "push them away" more than before. This change had occurred through to talking about her experiences with her family and boyfriend. She would tell them the negative comments and they would challenge them. Even though she felt that voices were destroying her life, she also felt stronger. P9 said that voices had stopped her from being herself.

T2 Interview-May 2015

P9 said that voices were becoming louder, more powerful and were always present. She said that, a year ago, she had thought that voices would have stopped by now. It appeared that there was a power struggle between P9 and her voices. She felt that she was becoming weaker and that voices were more powerful than her. However, she also felt that most of the time she had control and was able to quieten them to a whisper if they became too loud. As they were part of her, she felt that she was controlling them. Although she would love voices to stop, if they did go, she would feel like she was missing a part of herself (like a limb). P9 believed that they wanted to take control of her mind, her emotions, what she felt and thought. Voices told her that she was useless and worthless. She felt that this was affecting her more than it used to. It felt like something in her head. Despite considering voices as part of her, she didn't believe that she deserved to hear them.

She had stopped self-harming as she had decided that "enough is a enough" and that voices lied. P9 felt that it was her life and not theirs. Voices had affected her life. They affected her sleep and socialising. She did not feel normal and they had affected her confidence. Voices had changed her, and she was not her normal self. She believed that they had ruined her life. She wanted to return to how she was before the onset of voices.

P9 no longer tried to communicate with voices through writing. Instead she wrote voice content on a piece of paper and then threw it into the rubbish. This made her feel as if she'd won, she was powerful and in charge. Talking to others was still helpful. Voices were most distressing during the night when they would wake her. On these occasions she would lie awake, waiting for them to stop.

T3 Interview-February 2016

Since the last meeting voices and voice content had not changed however, they had had become quieter. When P9 was less stressed voices were not present. She said that she felt stronger. She was able to cope better and could dispute the negative voice. P9 accepted that voices may always be present. She no longer self-harmed to appease them. The point of change came when P9 began to challenge negative comments about her self-worth. She now felt stronger than her voices, they didn't scare her as they were not real. Questioning the reality of voices gave her a new perspective. P9 felt like she was returning to her old self. One morning she had woken and felt positive about herself and had decided that she wanted to live her life. This had been another turning point.

P9 continued to write down and throw away voice comments. This helped to release anger. She was annoyed that voices were still present but also felt that they were part of her. She accepted that they were part of her life. Her family were also more accepting of her voices. A couple of months previously she had woken, and voices were not present. Her head had been clear, but she didn't like it. It was strange. She was pleased when voices returned. P9 liked having, what she termed, a "buzzing" in her head. This was not voices talking but a sound which she felt comfortable hearing. She didn't like it when it wasn't present.

When voices were distressing they still affected her mood but generally, her mood had improved, and she felt calmer. When they were negative she felt angry but when it was just a "buzzing" she felt more caring and her "normal" self.

P9 had been discharged from EI and referred to the Recovery services. However, she said that she was not ready to be discharged. She felt scared and deserted. P9 thought that it would have helped if she had been able to explore her experiences with voices in more depth with her EI Care Coordinator. She hadn't wanted to go to Recovery. P9 didn't want to have to tell her story again to someone else. She was currently receiving CBT privately and felt that it was helping with her confidence. She felt that the therapist listened and understood her.

T4 Interview-December 2016

Voice frequency and loudness had decreased to once a week. She still heard her voices when her mood was low, or she felt stressed. P9 was able to refute negative comments and push the voice away. She felt stronger than her voice. Acceptance of the voice had resulted in more control. P9 said that CBT had been the turning point where she had gained control. She no longer felt that the voice was in her head. P9 said that she had been emotional when she gained control and now felt like a different person. CBT had helped her to realise that voices were her thoughts. Voices were less frightening when she realised this. She now believed that voices were a manifestation of depression. P9 was however, scared that her voice would go into her sister's head. P9 said that EI's views on voices had frightened her. They hadn't understood her experiences which had left her feeling alone. She did accept however, that EI had been beneficial.

P9 feared that voices may increase in frequency again. She still lacked confidence to go to university. She was worried that being away from her family, and alone, may trigger voices. Fears of her illness returning also worried P9 and she did not like to think about the future. Although she was scared of voices increasing she also felt that, if they did, she would be able to cope.

Now that voices had quietened she felt that her family trusted her to be alone. She still felt that it was not normal when voices were quiet and missed the "buzzing" in her head. However, voices no longer prevented her from doing things. For example, P9 was now confident to go outside by herself. Having control over voices made her feel like a different person. Voices had changed her. However, she was sad as she reflected on the fact that she would never be the person she had been prior to the onset of voices. Her self-esteem had improved. Being someone who heard voices made her feel special and not "normal."

She likened the experience of hearing voices as being on a rollercoaster.

Participant 10
T1 onset to current interview-August 2014

Voice onset occurred while at university. P10 heard the voices of her housemates. At first she acted with curiosity. Voice frequency increased, she heard them on a daily basis and began to respond. As voices developed, she experienced more of them. They became negative, abusive and issued commands. P10 believed that voices were triggered by either a negative event with her housemate or substance misuse. However, when voices began she was also experiencing anxiety. She heard voices of other people and believed that she was being stalked and spied upon. Voices were narrating her life. She became delusional and that she had infestations of insects P10 said that she tried to explain her experiences to others but, at the time, was lost in her "subjective reality."

P10 disclosed her experiences to her housemates who told her that they weren't real. She didn't want to believe them. If her experiences weren't real, she would have to admit that she may have mental health issues. Her housemates and girlfriend took her to hospital when she became agitated. For a year, P10 denied that she was hearing voices. She argued that her experiences were due to her housemates spying on her. It was through her care team and speaking with friends who had psychosis that she began to recognise that she heard voices. She realised that she wasn't the only person with psychosis, and, in fact, this realisation wasn't too bad. P10 said that, at the time, she had been trying to prove that voices were real, but her friends also described similar experiences. She wondered why she had previously questioned their reality. Realising that other people also heard voices was a relief and she felt "normal" when she was with them. P10 reflected on her journey to date and felt that she had passed through different stages with voices: denial, anger, acceptance, realisation and, the final stage, action planning. She kept a journal about her experiences and wrote about these stages. However, while reading her notes she became sceptical about her beliefs. P10 began to accept the diagnosis of psychosis.

T1 current

P10 believed that voice content would always be negative. She would never make friends with her voices nor would she let them control her. P10 believed that voices were due to low self-esteem. As a way of coping, she rationalised what voices said. She felt that because she had experienced voices for so long she had forgotten how intense they could be. Currently, she experienced voices of people who were known to her or alternatively, strangers she passed in the street. She no longer heard the voices of her housemates. Previously, voices had been inaudible. Now, they were whispers. In addition, content had changed from narration to making fun of her. Due to the voices, she avoided public places. They would occur randomly but increased when she was anxious. P10's ways of managing voices had changed. Previously, she had reacted by violent outbursts. This had been a way of feeling in control. Instead, she now ignored them. As an alternative to self-harming, P10 had taken up hobbies such as knitting, jewellery making and reading. She kept herself busy so as not to ruminate as this was when voices tended to occur.

P10 still questioned whether voices were real. However, as she believed that she would never have closure on their reality, she felt that it was pointless to try and find it. P10 did not have a relationship with her voices. She felt dislocated from them and did not consider it to be part of her. She did not want to "glorify" her voice as it would tell her that she was a failure.

Currently, P10 struggled to socialise with people who didn't experience psychosis. She didn't feel "normal" when in their company. It felt different to being with people who had psychosis. Being with "normal" people was different, whereby she

experienced a "them and us mentality." She only felt comfortable and safe with people who experienced mental health issues.

She now felt safer knowing that her experiences were not real, that they were voices, and that people couldn't read her thoughts. P10 believed that voices would eventually stop. However, if they returned, which may arise to stopping medication, they would be stronger. She currently felt stable and that she had entered the 'action-plan' stage of her journey.

P10 felt supported by the EI service and her Care Coordinator. She had CBT.

T2 Interview-May 2015

Four months previously, voices had gradually dissipated. Instead, P10 experienced intrusive thoughts. She preferred experiencing intrusive thoughts to hearing voices. P10 believed that voices had gone due to a change in circumstances and a change in beliefs. CBT had also helped with voices stopping. When voices had been present, P10 had self-harmed as this gave her control. She had felt powerless against voices and they had taken control of her life. There had been a shift in power when voices faded. Her self-esteem had improved. Since voice had gone, P10 felt happier. Voices used to make her angry and suicidal. She had also reduced her medication.

P10 felt that voices had shaped her, made her stronger and had changed her core beliefs. Voices had changed her. She knew that she would never return to the person she had been prior to their onset. As voices had faded, she that she had returned. Reflecting on the experience, P10 said that it had been positive as it had made her grow-up. Having had the experience, she was now aware of her triggers and did not want to lose control again. She worried that voices may return but felt that it was unlikely that she would relapse. P10 had started to go out as previously she wouldn't leave the house. She was searching for employment and thinking of going back to university. She wanted to work in the field of mental health. She still felt most comfortable with friends who experienced mental health issues.

Reflecting on her experience, P10 believed that awakening to the experience of voices helped to move her on. The cycles, or phases of voices hearing, were now complete.

T3 Interview-February 2016

Voices were still not present. P10 felt that the experience had helped her to grow as a person. Mental Health issues had changed her course in life and had afforded different opportunities. She wanted to work in Mental Health. However, people with Mental Health issues now irritated her.

She believed that voices had been a reflection of her inner self. She felt more confident since voices had gone. It had been hard to build her confidence after it had been shattered by her mental health problems. However, having a job had helped with her confidence and self-esteem. P10 felt that psychosis leads to self-doubt and the belief that one will never get control back. She said that she felt like a shell of the person she used to be.

P10 felt that mental health professionals had not explored her experiences with voices in depth. She believed that therapy should be near to onset. In her opinion, CBT could get you to a plateau, but it was the responsibility of the individual to continue the work required

T4 Interview

Voices were still not present. P10 reflected on her experience and felt that hearing voices had been like a rollercoaster. The hearer goes through stages of self-doubt when they realise that voices are not part of the self. She felt that after recovery, psychotic blips were important as they helped to build a person's foundations. It was also essential to remember psychosis but not to re-live it. She wanted to make the most of her experience. P10 felt in control. She was now socialising more and did not feel isolated. P10 said that she gained confidence when she re-focused her attention away from her internal world towards the external world.

P10 worried about voices returning. If they did, she now believed that she would know that they were self-generated. She felt that if the appropriate 'safety mechanisms' were in place, then she wouldn't relapse. She only thought about her voice hearing experiences when stressed. Her reaction to voices returning depended upon how they would manifest. Understanding psychosis from a scientific perspective had helped her to overcome it. Changing her attitude had also helped voices to stop. P10 believed that gaining employment had been pivotal to her recovery. According to P10, change had occurred when she modified her ways of engaging with voices and had moved away from focusing on the internal to the external world. Medication had also helped. Acceptance of psychosis had allowed her to move on.

P10 felt that, due to voices, she had lost part of herself. However, although it had been a terrible experience, it had also shaped her. Coming through voices had helped her to grow. Voices had "hammered" her down but then "built" her back up. Hearing voices had left an imprint. P10 believed that mental illness shatters confidence but it was up to the individual to choose how to manage it. Her advice for voice hearers was to focus on something that they did have control over.

Participant 12
T1 onset to current interview-September 2014

Voice onset occurred at seventeen, just after GCSEs. He did not remember voice onset but here were four of them. At the time, P12 was bullied at school. He was depressed. He hoped that voices would go away. When P12 woke, voices were not present. However, as the day progressed, voices would return. He did not tell anyone about his experiences as he didn't want to "put the burden" on others. In addition, he didn't trust others to help him. He wanted to help himself. P12 didn't tell his parents as he hoped voices would stop. He said that he wanted to feel confident. He managed to control voices by staying positive. He would challenge voices to perform tasks. When they failed, and he realised that he was able to do the task that they couldn't, P12 felt positive about himself.

Over the years he would "relapse." During university he experienced a "ghost" of a voice from everyone he came into contact with. He did not complete university as he was unable to concentrate.

P12 didn't disclose to anyone until he was twenty-eight (three to four years ago) when he became suicidal. At the time, he had felt that he would be unable to live if he didn't disclose voices. He told his GP that he was experiencing voices and he was referred to EI services.

T1 current

P12 experienced four voices: a woman who thought she owned him and told him what to do, an alien, and two other people who he described as ignorant. He said that they were all negative and "bad people." Voices were also experienced through the TV. P12 believed that voices were part of a plan to make him ill. They were the cause of his

illness, cognitive problems and the fact that he was socially awkward. He felt that voices were controlled by someone else. Voices occurred continuously and were distracting and disruptive. He believed that the best way to manage them was not to care and remain positive. P12 coped with voices by pretending he was part of an anti-voice campaign. He was Batman and this was how he would stop voices. When voices did stop, he didn't understand why they returned.

Although P12's family were aware that he heard voices, they never spoke about them. He never discussed his experiences with his parents. He said that he didn't want them to worry. He believed that they would eventually stop as, according to P12, more people liked him, and voices wouldn't be able to contend with that.

P12 felt that voices had had a serious effect on his life. When asked about his outlook on life, he said that he didn't have one. He just stayed alive and hoped for the best.

T2 Interview – June 2015

It was difficult to understand how P12 made sense of his voices. His speech was less coherent, and his train of thought was difficult to comprehend. Voices were still present.

Depression had improved and he felt that he was more able to interact with others. As a result of this change, voices were being forced to change to being positive however, they were reluctant to do this. P12 felt that even though voices no longer needed to be negative, they always were. The voice of the 'old lady' was constant. Recently, she had tried to be his carer. She had told everyone that she was taking care of P12 and basically she was his mother. He said, "no way!" She had failed. He also experienced the 'Alien' voice. He described this voice as menacing and controlled what the public said. In addition, P12 heard a ringing. When this occurred, he would hear "sorry." This was an apology for the negative decisions other people had made which had affected him. This tended to occur weekly. The 'ghost' voices of others were also present. Voices were constant. P12 felt low that voices had not stopped. He said that he felt pessimistic.

If circumstances became negative, P12 would try to make changes. For example, if the content of TV programme was negative, then he would stop watching, go to his room and play a video game. He turned away from negativity. This would sometimes help with voices.

During the interview, P12 disclosed that he had been admitted to hospital in 2013 when he had tried to suicide. He hated being in hospital and had become extremely depressed. He had felt that he was in isolation.

He believed that voices had given him depression. Depression was part of their 'arsenal.' Voices attacked by making a person depressed. Giving him depression was their way of attacking him. Occasionally, when voices stopped (during the night when he woke to go to the bathroom), he hoped that they would not return. It was at these times when he felt happy, he said that nothing was happening. He described it as "my time…my freedom." When voices are present, he didn't feel free. He felt threatened. P12 said that voices were complete strangers and that they didn't act in the correct manner. He felt that action should be taken against them and that they were evil.

P12 said that he, due to his voices, he was forced to rely on others to help him. He was unable to work and had to depend on his parents to allow him to live with them. He was unable to perform practical, everyday activities such as shopping alone. He didn't have friendships. He said that voices controlled his mind, they affected his concentration and made him unable to speak to others. They stopped him going to the

gym as they had caused him to have a groin injury. When he looked in the mirror, he saw a different reflection to himself. He saw someone who was ugly. Although, he couldn't explain why he heard voices, P12 was looking forward to them going. He believed that they originated from negativity – racism, slavery and feuds between people. He likened the experience of hearing voices as being trapped in a Dungeon such as the London Dungeon. He believed that someone was controlling the voices.

He still coped with voices by being "positive." He understood that voices were part of his depression. At times, he argued back to voices. This had been taught to his as part of Relating Therapy. He had hoped that by practicing RT some of his voices would stop. However, this hadn't happened. However, when he did argue back, his voices did become silent. This felt good.

P12 had left EI and was now with Recovery services. He was still waiting for a care coordinator. He still didn't speak about voices with his family. His family had previously attended meetings with his doctors. However, he didn't speak about his experiences with them as thought that it might change their relationship. His mother never spoke about his voices.

He was thinking about returning to college. He had liked being with EI services as he had met other people with similar experiences. His care coordinator had taken him to meetings with other service users and he'd had the chance to have a conversation with them. He no longer had this opportunity.

T3 Interview-March 2016

It was hard to understand P12's train of thought.

Voices were still present but a little less frequent. P12 said he experienced the same "arguing" voices of the older woman, a menacing man and a young man (he hadn't mentioned a young man previously but said that he'd always experienced this voice). The menacing voice made people do bad things to P12. It appeared that although voices had been better they had affected his self-esteem and confidence. Voices could make him feel low and helpless. He believed that voices were connected to his negativity. He tried to stop his negativity, but it seemed that he had been unable to do this. Voices were worse when he was feeling negative. However, as P12 was feeling happier voices had been more positive (didn't treat him as "nothing"). Sometimes voices stopped when he woke in the middle of the night. He felt happier as he was more active i.e. gardening, exercise. He believed his change in mood was due to anti-depressants. He felt that voices were less troubling because he was helping himself with his mental health issues by remaining positive. Voices were pushed to the background but remained there waiting and grumbling. P12 was starting to be able to engage in conversation with others. However, he still felt that voices were the cause of his difficulties with having a conversation. He made sense of this in terms of voices taking up his thoughts and that he did not have any further capacity left for a conversation. Voices were no longer coming out of the TV. However, they were present when he was lonely and bored. He still did not speak about voices to his family. At times he believed that they were part of the voices.

P12 felt that his depression had been due to his voices. However, as his mood had improved his voices had lost their control in making him feel low. He wasn't sure why voices wanted to harm him but felt that this may be due to them coming from "a bad place." He wanted voices to permanently stop. He believed that they withheld the truth and tried to make him think that there was nothing to live for. P12 felt that he had the control and power. He felt supported and this was helping with confidence. However, he worried about his self-esteem.

He was with the Recovery Team and saw his psychiatrist every three months. P12 had been offered a job as a Carer.

T4 Interview-December 2016

Voices were still present. P12 related voices to real people and thought they were "bad people." Sometimes he thought that they were his parents. He believed he heard voices as he'd evolved as a person.

Currently, voices were not as forceful and demanding. He said that they had allowed him to become more confident. P12 felt that he had more control over them as they were less interfering. He felt their control was bad and his control was good. Control was equal. Although he was able to tell voices not to come, they were still present even when he decided not to listen to them. He felt anxious that voices may return to how they were previously.

P12 still tried to be a good person so that voices weren't able to be negative about him. Voices were negative and distressing when he felt that he had done wrong. When voices were distressing, P12 felt that he was able to manage them. He said that this was due to his job. He was happy as voices were not telling him that he should be suicidal.

He was still working, and socialising had improved. His self-esteem had improved, and he was able to hold a conversation. He felt positive as he was getting on with life. P12 was less lonely as he was active. When he was anxious, he felt like his old self (negative) and was happy when anxiety went away. Voices could make him anxious. He felt that if voices went his life would go back to normal. Normal meant being "sane" inside and having experiences that were real (no voices). When voices were too frequent he doubted his sanity. He believed that voices had taken away his intelligence and social abilities. He was no longer in services.

Participant 13

T1 onset to current interview-October 2014

P13 experienced one voice which sounded like his own but deeper and quieter. Although voice onset had occurred in the previous January, he didn't remember first hearing them. His voice had occurred occasionally. In July, his voice experience had improved. P13 said that he experienced impulses in his head and then his voice would issue commands. For example, his voice would repeatedly command him to jump down a flight of stairs. This would build up until he had to act upon the command. His voice appeared to be associated with his emotions such as anger, boredom and anxiety. His voice had told him to attack his work manager, but he felt disgusted and distressed by this and resisted the urge.

He believed that his voice had been triggered by severe depression. P13 had become suicidal. When it first started, he disclosed to his mental health team. He did not, and still hadn't, disclosed to his family. He said that he cared too much about what they thought, and they might think he was attention seeking. He did not tell friends as he feared that he might lose them.

T1 current

P13 believed that his voice was definitely part of himself. He was not sure where it came from. He believed the voice he experienced now was different to the one he experienced during his severe depression. During that time, his voice had told him to kill himself and that he was worthless. That voice was "dark". The present voice told

him to act on impulses and he considered these commands to be "petty." P13 felt that the voice had changed because his depression had lessened. P13 said that his medication had helped with depression. He was in a new relationship and believed that this also had a positive effect on depression and voices. P13 felt "freer" now that voices had improved. His girlfriend had distracted him, and he no longer felt as worthless. When he first met his girlfriend, his voice had told him to murder her family. He was disgusted. His emotional response to this command was his way of controlling his actions. He did not want to be "that guy on the newspaper who's like killed family, kids, the dogs a stuff."

He did not feel that his voice had power. It niggled at him and felt like a pest. P13 felt that he had control over which commands he would act on. He weighed them up as to the effect on himself and others. When his voice was distressing, he would try to ignore it. He also convinced himself that it was just a voice and should not affect his life. As his voice helped with boredom, he felt that he did have a type of relationship with it. Despite wanting his voice to go, he also thought that he would feel alone if this happened. His voice made life more interesting.

P13 said that he would never forget his voices. Some of them had been bad. He believed that as long as he did not act on the violent commands then they wouldn't have a severe impact on his life. P13 was happy that that his voice was not too distressing or having too much of an effect on his life. He believed that voices would always be present, but this made him feel that he wouldn't be alone.

T2 Interview-August 2015

The voice had stopped. P13 said that they "just went." He believed that the voice stopping was due to a combination of re-focusing on other things, medication, sleep and positive mood. He had also changed jobs and felt less scrutinized. He did not feel so angry and life was better.

Now that he no longer heard the voice, P13 felt safer. However, it was not as exciting, his voice had relieved boredom. P13 felt more as ease with himself. He wasn't sure how he felt as someone who had heard voices but felt liberated at not having to act on their commands. He described voice hearing as like Stockholm syndrome. Because the voice was part of him, he said that he'd had a connection to them. P13 had disengaged from EI services as he believed that he was more capable of helping himself than they were. Services made him focus on his problems which he hadn't found helpful. He believed that therapy didn't help everyone.

P13 was left questioning reality, whether the voices that he heard in the world were real or not. He said that he felt "normal."

T3 Interview-May 2016

P13's voice had returned. He hadn't noticed its return but had begun to feel nihilistic. He had been stressed, bored and angry. The voice reacted to his mood. His lack of emotion was worrying him, and he felt ambivalent towards himself. His voice issued commands and he said that he had no control over hearing it. He managed voice hearing by believing nothing mattered. He said that he didn't care that the voice was back. It couldn't hurt him if he didn't care about himself. He read and watched films to cope. However, he was distressed by voice content and said that he wasn't enjoying having the voice as it was more depressing. He reflected on the 'good times' with his old voice. However, that had now ended.

P13 had lost hope of getting better and felt that it was too late for therapy as he was too "tangled up." He didn't want to waste the therapist's time. He felt that his life

didn't mean a lot to anyone, least of all services. Helping him was "just a job" for them and they didn't really care. He thought that his voice might go away again. He still questioned whether sounds were real or not.

T4 Interview-February 2017

T13's no longer heard his voice. He was not sure if it would return. When the voice had returned he found it more demeaning and negative. He had heard his voice when his mood was low. Focusing on things other than hearing his voice had helped to manage it. Forgetting and not caring about it had also helped. He disclosed that he used to use alcohol to manage his voice hearing experience. He appeared ambivalent to his voice stopped and felt that it was one less thing to worry about. However, he felt threatened that it might return and chose not to think about it in case this was a trigger. He avoided therapy as this might make the voice a reality. For this reason, he had failed to attend a GP appointment. Talking about hearing a voice made it real.

He felt that his journey with voices had been up-and-down. When his voice had been present, it had been consuming and the only thing he had thought about. However, at the same time, he hadn't cared about his voice or anything else. His voice had become more depressing and "dark". He assumed that it was due to his negativity and experienced it because he was "fragile." P13 viewed himself as "less" than others. He never spoke about hearing voices as he didn't want to be viewed as "less" and "weird". He tried to fit in and be "normal." Hearing voices made him feel different.

Participant 14
T1 onset to current interview-October 2014

Prior to voice onset, P14 suffered a bereavement. Her close friend had died. She felt guilty over his death. P14 was also bullied at school. Voice onset occurred on the anniversary of the death of her friend. She felt that the voice had been waiting to enter. It was negative and blamed her for the death. At first, she was "freaked" out and frightened by the voice. P14 thought it was her dead friend who had returned to punish her. Voice content focused on her self-worth and suicidal ideation. She believed that he (the voice) had full control: mental and physical. Her voice made her self-harm. She felt that the voice was able to change her words. P14 believed that it controlled her through fear. She felt dissociated from her body when she self-harmed and could not find a way back in.

For three months, P14 he did not tell anybody about her experiences. However, she finally reached a point where she could no longer cope with the experience and became suicidal. She felt that she could not manage it alone and hoped that she could get help. P14 told her mother who took her to the GP. During the visit, her voice tried to prevent her from disclosing to the doctor. It screamed and told her not to say anything. P14 said that she had been relieved to be given the opportunity to discuss her experiences and gain support. During this period, P14 self-harmed.

T1 current

P14 believed that the voice had grown from negative past events. Her experience felt as if she was sharing her head with the voice. P14 visualised the voice as a disembodied head with eyes and a mouth. When she was alone, her voice would have a conversation with her. She did not respond and felt as if it was one-sided. Her voice was loudest when she was alone. Eventually she was forced listen to it. Her voice would make her feel low. Currently, P14 felt that she had returned to, and inhabited, her body.

She felt supported by her family, friend and partner. They all helped her to manage her experiences with the voice. P14 also felt supported by EI services. Her care coordinator encouraged her to keep a journal. Through her journal, she was able to communicate voice content with others. She managed her voice through music, going outside and talking with close others. However, the voice still affected activities. It took time to concentrate. P14 felt that she had gained confidence and there were some days where she was able to fight against the voice and feel in control. During these times, she was able to tell her voice when it was, and wasn't, convenient to talk. However, this incurred a punishment whereby the voice would be more distressing, and make her suffer, the next day.

P14 was looking forward to her voice stopping. She had decided that it would go. This had become her main focus. She felt that once her voice had gone she would be able to continue with life and plan for a future.

T2 Interview-July 2015

P14 was still experiencing the same male voice. It was noisy when other people were around but worse when she was alone. Recently, she had been unable to go to work due to physical illness. Her voice had been more distressing during this period. It intensified negative self-beliefs. P14 still wrote or texted voice commentary as she felt too scared to verbalise it. She said that she fought for control. On good days, she was able to gain control but on bad days the voice took control. P14 felt that her voice was attached to her like a "bad shadow." It was a constant companion that looked through her eyes. She felt monitored and that he had possession of her.

She was having therapy to manage and make sense of voices. Services helped with voices practically. P14 believed that her voice was present due to her grief. It had been created from her avoidance of negative experiences and she was being punished. P14 was more open to talk about voices with others. She didn't want to be "trapped in the dark with voice." She no longer self-harmed, she knew this would upset her family and was now able to manage voice commands. She felt that therapy helped to manage voices.

P14 accepted that her voice would always be with her and she would have to find a way to live with it. She could not imagine a life without it. She hoped that it would become positive and hated the daily uncertainty of whether or not it would be distressing.

T3 Interview-April 2016

The voice was still present and negative. It focused on her low confidence and fears. It was worse when she was physically ill or anxious. However, P14 considered her voice to be a diminishing shadow. She felt that she was demolishing her voice by working through her past pain. She was taking her voice apart. P14 was able to challenge negative voice comments about herself. She was able to take time away from her voice by other activities such as watching a film or playing a game. However, during the last week her voice had been particularly distressing, and she did not feel safe alone. P14 experienced days where her voice was "too much" and she would do anything to stop it. On those days, she would speak to her mother. Although she would feel a need to self-harm, P14 managed to avoid it.

Working was a way to empower herself over her voice. Her family, fiancée and friend supported her with her experiences. EI services also enabled her to continue with life. P14 wanted her voice to stop but also believed that she might miss it. Hearing the voice meant that she was never alone. She felt that it would be weird if it went as it

would be quiet. However, if her voice did not entirely go, she feared the reprisal and the effect this would have. P14 wanted to set a goal of distancing herself from her voice. She wished she'd had therapy at onset before she had become too imprisoned by it. P14 felt like she was serving a sentence.

Interview 4-January 2017
 Despite the voice still being present, its frequency had diminished. Now when she was with other people, it no longer commented. She said that this was because she didn't listen to it. P14 had accepted that she would have to live with her voice as this was her punishment. However, accepting her voice had also made her stronger.
 Relating Therapy had taught her to argue back to her voice in a respectful way. This had helped her to cope. P14 believed that acknowledging the voice lessened its power. She felt that she had control. This was a result of therapy. Therapy had helped her to respond assertively and manage her voice. For her, recovery meant gaining control. P14 reflected on therapy and felt that it was only effective when one was ready. To be ready, meant acceptance of the voice. Recovery for P14 was having control. She now visualised her voice as a faceless head. If she gave it the chance it would re-build its body.
 P14 was no longer affected by her voice. Hearing a voice was like a little hurdle. She said that she was making progress. P14 knew that hearing voices could de-stabilise her and she needed a means to ground herself. Consequently, she coped with voices through support from others and writing. She was pregnant; this had been a wish that, previously, she did not believe could happen. P14 was now able to socialise. She was able to live her life rather than waiting for her voice to go. She accepted herself.
 On reflection, P14 felt that there had been times when she was able to manage and cope with voices. She believed that, although everyone was capable of getting through the experience of hearing voices, it was not something that could be quickly cured. P14 felt "There's not enough words to say what it's like."

<u>Participant 18</u>
T1 to current-November 2014
 P18 experienced one male voice which was unknown to him. Voice onset occurred during childhood. P18 first heard his voice after another child had hit him with a piece of wood which had a nail. He had lost control and hit the other child. He was confused by his voice and didn't understand it.
 During childhood, P18 had found his voice empowering. However, he was also distressed by its violent commands. Despite being negative, it was also a constant friend. He didn't tell anyone about it as he didn't think it was normal. This continued into adulthood. He had coped with the experience by using alcohol, self-harming and hiding himself away from others. P18 didn't have many friends and he relied upon his voice for companionship. Although it was horrible, it was also his best friend. P18 believed that his voice had power over him.
 Voice disclosure came when P18 attempted suicide. He had considered suicide to be his only release from his voice. This was eighteen years after voice onset. Previously, he had visited the GP about his mood. However, his voice had convinced him not to disclose. P18 had been in a quandary as to whether he wanted his voice to go or stay. It had been present for so long that he had feared he would be lost without it. He had been scared of losing it, he had considered it part of himself. If his voice had stopped, he would grieve and felt as if he had lost a brother.

T1 Current

Voice frequency had decreased. He no longer had the constant voice. Over the last few weeks his voice had occurred once due to stress. P18 said that he felt "daft for letting it back in." He believed that he had the control to tell his voice to go. P18 was upset that he had heard his voice. He felt weak when his voice had returned. He had tried to focus on other matters. His voice eventually went but the experience had left him tired. As his family and work knew about his voice he believed that he had the strength to manage it.

Disclosure meant that his voice no longer ruled. He regretted not disclosing sooner as he felt that this had ruined his life and prevented possible achievements. Previously, P18 had been separated from his family. At the time of the interview, he had returned home. He felt that returning to his family, to a normality, had helped to overcome his voice. He was pleased and said that his head felt clearer. He could think and his head no longer felt "numb." He considered overcoming his voice an achievement. P18 still had low self-esteem and issues with confidence but was hoping that CBT would help. He didn't feel totally well but believed that he would get better by taking a step at a time.

T2 Interview-August 2015

P18 no longer experienced his voice. It had stopped eight months previously. He was currently experiencing depression and stress. Due to CBT, he believed he would come through this period. He likened his moods to a rollercoaster. P18 believed that it was a combination of CBT and medication that had helped with voices stopping. His therapist had encouraged him to socialise. At this point, his voice had still been present, but he was able to keep it "at bay." He was able to cope with it and "brush it off." This made him realise that it wasn't real and that he could control it. He reflected how CBT had made him think differently. Therapy had come at the right time. He had wanted to change, and therapy gave him the tools. Keeping focused (through swimming and football) helped with P18's mood which had helped to stop voices. He believed that being busy had supported him to manage hearing voices.

P18 had felt sad and low in mood when his voice stopped. It had been a bereavement. His voice had been supportive. However, he came to realise that his experiences with voices had been real and just his mind playing tricks. He questioned as to how a voice could suddenly appear. P18 felt better that his voice was no longer present and that he was no longer felt controlled by it. He didn't want to feel like that again. P18 said that he had taken back control over his life. The voice had been bad, and he had felt trapped. He now felt free. He had power over his mind again. He believed that his voice had also been linked to the stress in his marriage (he was separated).

P18 said that hearing voices had ruined his life and regretted not getting help sooner. He considered that talking about voices was the only way to overcome them. He'd now learnt to talk about it.

T3 Interview-June 2016

Voices were still not present. P18 reflected on his experience with hearing voices. He felt that therapy had helped his voice to stop. Therapy had changed behaviours. However, it had not been directed at hearing voices. He also, had never spoken in-depth about his experiences with the voice with his care team. Sleeping and exercise had helped with managing his voice. At first, he had missed his voice but overtime this had become less. His voice had been his confidant. He still sometimes missed it, when he was alone, but he was pleased that it wasn't there as it had made him

feel low. P18 said that his voice stopping had been life changing. He was less stressed, could think more clearly, happier and felt like a different person. He was no longer "bogged down" by the voice.

P18 said that, although hearing voices was not a normal experience, at the time, his voice had become part of his norm. It had made him feel special. However, it now seemed strange that he had experienced it. If voices returned he knew that he would be able to cope with them.

T4 Interview-March 2017

P18 was no longer with services. The voice was still not present. However, at times, when he felt stressed, he feared his voice would return. Recently, he had become stressed whilst thinking that his illness may return. So that he did not become unwell again, P18 ensured that he was busy. He felt that having heard voices had made him stronger. He believed that, if his voice returned, he would be able to cope with it. In addition, the skills that he had acquired through CBT would also support him. If he did start to experience hearing voices, he was confident that he would be able to stop it. He would, however, seek help through mental health services.

P18 said that, whilst hearing voices, he would have like to have spoken to someone about the experience. Services had been very good, but he would have liked to have had sessions focusing on voices. His care coordinator would enquire as to how he was feeling but never focused on voices. If he experienced voices again he would like to explore them with services. P18 believed that services should have an option to explore and discuss voice hearing.

He felt that it had been strange that something, a voice, had been present but was now no longer there. P18 believed that to understand voice hearing, a person needed to have had the experience. Hearing voices had been like being on a rollercoaster: both emotionally and trying to manage them. It had been physically and mentally draining. He was now "off the rollercoaster." Hearing voices had been both good and bad. It had given him confidence but had also taken confidence away. It had made him feel untouchable, powerful and unique. He was now gaining confidence without the voice. P18 said that he had always known that there had been something wrong with his head. He no longer felt bereaved that his voice had gone and was happy. Since his voice had stopped he was able to socialise, learn to drive and interact with others.

Participant 19
T1 to current-November 2014

P19 experienced a crowd of voices. Voice onset had occurred recently. When it occurred, P19 remembered it as a regular day. At first, his ears became muffled. As they cleared, he heard voices. They sound like voice on a radio. He contributed it to stress. P19 waited for an hour to see if it would stop. The experience continued and he realised that something was wrong. He said that he was not stressed but found the experience distressing. He told his family the same day and sought professional help.

P19 had resented his father. He had troubles expressing his problems and had been to CAMHS when he was younger.

T1 Current

For P19, hearing voices was like standing in the middle of a crowd. However, voice hearing had quietened since onset. P19 said that this was due to medication. He now had periods when he didn't hear voices. He had found voices distracting and had

been unable to concentrate. During this period, P19 had found it difficult to communicate with others and wasn't able to function. He was now able to form his words and could hear over them.

At first, when voices started, he believed that he was not going to be able to live his life. He thought that he would be sectioned. He no longer believed this. His partner was pregnant, and he said that he now had something to plan for.

P19 attributed voices to the "darker part of himself." When voices were present, he would "zone out." He wasn't sure if this was because he was trying to listen to voices, to make sense of voices, or just trying to ignore voice. Afterwards, he felt distressed. When voices first began, P19 tried to make contact with them. He wanted to understand what they were saying (experience was muffled) but as they didn't speak to him he stopped trying. At times, voices were distressing. However, as he became accustomed to the experience he no longer found it as distressing. P19 felt that having to cope with such an experience had made him stronger. At present, he was able function on a daily basis. He said that he did not have a choice as he had a family to consider.

When voices first began, P19 felt a power struggle between them and him. They wanted him to do things which he was determined not to do. He felt that he was fighting his own mind. P19 told himself that he was in control of himself. Currently, he felt that he had control and power. He would not let voices win. He said that he controlled his experiences through concentration. Feeling more in control meant that he felt better about himself. However, he still felt that something was wrong with him. He felt that he was defected. P19's self-esteem was improving.

T2 Interview-September 2015

Voices were no longer present. Since our last meeting, voices had become gradually quieter until they had stopped. He felt relieved when they had started to go. Although P19 no longer heard voices, he'd had a couple of minor experiences. He had seen a shadow and heard a whisper. He attributed this to stress. These experiences had not intensified and resulted in voices. P19 said it had just been a sound. However, when the experiences first occurred, he had thought "here we go again." He immediately sought help and contacted his care coordinator. His dosage of medication had recently been reduced. He said that he had been feeling suicidal. P19 was not surprised that this had happened as he had known that stress could initiate such experiences. He felt better but was still low in mood and found it hard to concentrate. P19 was still experiencing whispers a couple of times a day but this had reduced in frequency. He was not distressed by this sound. It had not surprised him like when he first heard voices.

P19 reflected on hearing voices and felt that it had been a strange experience. He said that nothing could prepare a person for such an experience. His felt that his mind had turned on him and he'd had to fight it. Because of having heard voices, P19 believed that he now had greater understanding of his mind. In order to recover, he'd had to fight himself. Fighting his own mind had been terrifying. It was a fear that he had to control otherwise it would have consumed him. To control voices, he'd had to concentrate hard and lose focus on everything else. This meant creating problems that he would have to concentrate on to solve. This was the way he had managed control over voices. Voices had not stopped him from doing things. If they had stopped him, then they would have won. Although voices effected his concentration, interactions with other and going out, P19 denied that they had affected his life. He needed to maintain control.

Voices held no meaning for him. He did not know why he had experienced them. He believed that they were the hateful part of himself. P19 never wanted to make sense of voices and explore them with others. He wanted to keep his thoughts about it private. He might not have liked the answer if he had explored them.

If voice hearing returned P19 said that he would seek help and get medication.

T3 Interview-June 2016

Voices were not present. P19 had changed anti-depressants which he attributed to voices stopping. He first noticed that they were not present when he was going to bed and realised that he hadn't heard (or seen) anything that day. His experiences did not return. Although P19 attributed voices to stress, he wasn't sure as to what had caused the stress. He realised that he ruminated on matters. P19 concluded that voice hearing was a symptom of mental health. He also thought that it may be due to depression. He had changed jobs to manage stress.

P19 felt that he would like to explore voice hearing experience but was unsure how to instigate this. He was now open to therapy and curious about his experiences with voices. However, he was also scared that exploring voices might "open a can of worms." His family did not want to talk about voices. His mother feared that re-visiting the experience may cause it to return. P19 did not believe that therapeutic intervention should occur while a person was hearing voices. He did not think that this was the correct time.

He feared that voices would return but tried not to dwell on this thought. P19 gave a percentage of ninety percent when asked about whether he believed that voices were self-generated. However, according to P19, there were unknown mysteries (such as the occult) that could have also caused voices.

When he spoke about hearing voices with others, he joked about the experience. He used to manage voices by "zoning out" and "deep thinking." He no longer did this. Playing video games had been a means to coping but now he played them for pleasure. On reflection, due to how voices had affected his life, he realised that he did not have power at the time. He felt that he now had control over his thoughts.

T4 Interview-February 2017

P19 was about to be discharged from services. Voices had not returned. Despite recently feeling hopeless, voices had not returned. P19 believed that voices had been due to stress and his mood. He still felt that there was a small chance that voices may have originated from an external source, but he didn't want to think about it.

P19 was hesitant about receiving therapy. He feared that it might trigger voices. He avoided dwelling on his voice hearing experiences in case they returned. However, he wondered what would happen if did start to hear voices again. He said that he was always in fear of being back on the "rollercoaster".

When his mood had become low, P19s care team did not ask about voices. They had never asked if he was worried about voices returning. To try and make sense of his experiences, P19 researched about voices through the internet. He found the subject intriguing and wanted to understand it. Learning about other people's voice hearing experiences helped him to make sense without having to focus on his own. Through voices, P19 had learnt that he was in control and was able to ignore worries. He felt that he had control over his thinking and was able to follow a thought process. Now that voices were no longer present, P19 had an understanding of control.

His journey with voices had been like a rollercoaster. After voice onset, there was a period of assent. Voices got worse as the rollercoaster progressed. As the journey

continued, it was necessary to change his lifestyle. P19 felt that if one didn't believe that voices would get better then there would be a continual descent. If he had lost belief in recovery then he would have lost belief in himself. It was necessary to keep hope. The final steps of recovery were when one realised that the experience wasn't that bad.

Since voices had gone, P19's cognitive and affective responses had improved. He felt that voices had changed him as a person. Having hear voices had made him feel unique, odd and different. It had made him stronger and resilient. His confidence and sense of self-worth had improved. He could not remember a time before voices.

Participant 20
T1 to current-December 2014

Voices first occurred when P20 was in bed two years previously. It had been frightening and she felt as if she was losing her mind with the loudness of the voices. However, she did not remember when voices first occurred as she had been experiencing them for a while. During this period, P20 had thought that she had been kidnapped and had a brain operation. She thought that they (a political conspiracy) wanted her to be a spy and were communicating through her body. P20 was devastated and frightened by the experience. Over the next few weeks she experienced panic attacks and called an ambulance. Her daughter didn't want to live with her and went to live with her grandmother.

When she became ill she pleaded with her father for help. She hadn't seen him for several years. She wasn't sure the exact point when disclosed about voices. She thinks she told the ambulance crew but wasn't sure. She had felt dissociated from her body. P20 didn't disclose for about six months as she wasn't used to receiving help. In addition, she didn't think that she would be believed. Her mother contacted the GP as she had become suicidal from hearing voices. She was referred to EI. She disclosed voices but had believed that EI was part of the conspiracy.

Voices went away through medication. P20 was relieved when they went as she felt that she didn't have to be trapped in her head with voices.

T1 Current

P20 hadn't experienced voices over the past year until recently (two weeks ago) when they returned. She wasn't sure why they had come back but on reflection thought that it may be due to her not taking her medication. She had stopped taking meds as she believed her therapist when they said that that it might have been an episode that she was now over. She believed she was cured. When they returned she found it upsetting as she felt that it might be there for the rest of her life.

Voices were whispers and constantly present. The female voice made fun of her (parody of own voice) while the male voice bargained with her to do things (sexual acts). They also instructed her (e.g. how speak). She found it distressing. P20 believed she was being videoed. She believed voices were political and wanted to change her. However, as voices hadn't hurt her, she had started to trust them. She believed that, as they hadn't come and hurt her, she could live a happy life.

The fact that voices were present meant that they were powerful. They didn't sound powerful but the fact that someone had managed to place them inside her body meant that they were. P20 felt in control of herself but as she couldn't get the voices to leave meant that they had control. However, she felt that control was more equal than when they first appeared. She now considered them to be acquaintances. P20 accepted that they may always be part of her life and she had to get along with them. She wanted voices to stop but felt that the more time they shared together the less likely they would

go. P20 felt that she had built up a relationship with voices. However, she felt that there was no trust on either side. She believed that they were trying to help to improve her. However, as she was constantly holding an internal conversation with voices, they were also preventing her from having a 'normal' life.

P20 cried when voices said negative comments about her self-worth. She argued and told them that nobody was perfect. Despite this, she often agreed with their comments. P20 believed that she was starting to gain confidence. CBT was helping with this. She also felt that her gain in confidence was due to that the fact that she was becoming accustomed to them. Voices have made her feel weak and helpless. Previously, she had believed that she was capable of doing anything. P20 felt that there was a possibility that voices would go away. Although this would be amazing, it would also be upsetting as it would mean that they didn't want to be with her anymore. P20 said that, as voices were trapped inside her head, they knew every facet of her personality.

P20 coped with voices by focusing on other things. She would sing in her head and try to talk to others. Currently, she was managing to not have internal conversations with her voices. Although hearing voices had prevented her from continuing with university, P20 was currently employed.

T2 Interview-September 2015

P20 still experienced voices. They had not changed. She felt that she had no privacy as they were always watching. It was like being in a video, which she had not given permission for others to see. She found the experience surreal but had finally come to terms with hearing voices. However, P20 was angry that voices had invaded her body. The experience of hearing voices meant that she felt less engaged with them. She was less curious about their reaction to her. She no longer tried to analyse voices but focused on trying to live her life. P20 felt that they (voices and herself) had become used to each other. She believed that they shared experiences.

If voices went, P20 said that she wouldn't miss them. However, she would feel lonely and that she wasn't good enough. She would also be forced to socialise. P20 felt that, hearing voices forced one to either sank or swim (voice knew every embarrassing thought in her head). Voice content could be boring i.e. talking about politics.

Voices made her question her personal achievements. She felt objectified but also felt that her self-esteem was improving. P20 believed that voices had power but was determined to live her life. P20 also believed that if she lost focus voices would take over. She felt that she was building up an immunity to the emotional effect of voices. She did not feel as weak. It was time to challenge voices and now tried to oppose their negativity. She viewed them as bullies.

P20 felt that there was a positive side to voices. They had helped her to know herself better, become more sociable and stronger. She believed that they were also trying to help her become a better person. P20 didn't feel that she had anybody to talk to about voices. She would like to talk about voices. However, she felt that CBT had helped her to not engage with them as much. She managed voices through holding a continual internal conversation.

P20 was in a better place to return to university. She was also socializing with work colleagues.

T3 Interview-June 2016

Voices had become more distressing. The effect of voice hearing had become worse over time and P20 was finding them exhausting and stressful. She believed that, as she was too tired to maintain a positive attitude, this had allowed voices to become worse. Voices affected her relationships. She found that she was constantly in an internal dialogue with them. Although music and singing helped with negative engagement, her coping strategies were no longer adequate.

At times, P20 felt a slight power and control. However, she was aware that voices existed inside her head and this made her feel vulnerable. She was too vulnerable to be in control. She did not feel that she had control over her emotions. P20 told voices every embarrassing point of her day as this gave her "immunity" to their comments. She felt hopeless as nothing worked. P20 felt depressed as voices had the power to ruin her life. Voices were so negative that she felt that there was no room to be friends with them. They psychoanalysed her weaknesses. However, she felt that voices now viewed her more as a person than as an object. She believed that they would never go.

P20 saw the benefit of therapy but felt that, when she had received it, she hadn't been ready. According to her, therapy was good to "pull you out of your head." She felt more control when she wasn't trapped in her head.

According to P20, voices were due to an implant in her head.

T4 Interview-April 2017

P20 still experienced a male voice (main voice) and a woman. She heard voices through other people. Voices were constant. Voices were negative, controlling and manipulative. She felt that voices had control over her body and had the power to murder her. P20 felt that she had no control. She was shocked that her mental health had declined and was now similar to her first episode.

She believed that she knew her mission and that voices wanted her to adopt a different persona. They wanted her to pretend to others that she didn't hear them. P20 was attending hearing voices groups. She coped with voices through swimming and alcohol. She tried to be mindful and not argue with voices. However, arguing back helped with her sense of self. She coped by being physically active.

EI had come to an end when she was feeling at her lowest. P20's voices had got worse as she didn't have regular contact with services. She was upset as she felt that her Mental Health team never spoke about voices with her. They dealt with practical issues, but she felt angry that she had not been allowed to talk or explore voices with services. She had been involved in a voices clinic but had stopped therapy as she had found it too distressing. She was now ready for therapy.

Voices had prevented her from working and having a relationship. P20 felt that voices had made hardened her as a person. She had to become stronger otherwise she would have committed suicide. They tired her and she felt tortured by them. Voices had changed her as a person. She worried about her future and that voices would not stop.

Appendix 12: Participant Feedback on Summary of Their Data

Participant Feedback on Summary Data

Participant 1
P1 felt that the summary was true to his life history. There wasn't anything that he felt needed changing

Participant 2
P2 had been diagnosed with epilepsy and didn't remember reading the paper in detail. However, if she said that if she had disagreed with anything she would have written it down. She felt that she hadn't disagreed with anything.

Participant 3
P3 said that the summary was a true representation of her voice hearing journey. She didn't want to change anything.

Participant 9
P9 agreed that the summary was a true representation of her experience. She did not want to change anything.

Participant 14
P14 said that she didn't want to change anything. She had felt emotional when she had read the summary as it had made her realise how far she had come in her journey with voices.

Participant 19
P19 said that he didn't want to change anything. He was extremely happy that he had received the summary. After reading it, P19 realised how strong he had been throughout his journey with voices. The experience of reading the summary had been like reading somebody else's story. P19 rarely thought about voices anymore but was grateful to have had had the chance to reflect upon it.

Appendix 13: Stages of the Development of the Integrated Model of Voice Hearing

<u>**Explanation of Combined Model**</u>

Colour coding
> Red: Romme & Escher et al., (1989)
> Blue: Milligan et al., (2012)
> Purple: deJager et al., (2016)
> Green: 2 or more authors

1. **Antecedent Phase (Romme & Escher, Milligan et al., deJager et al.,)**
   > Negative life events before prior to voice onset

2. **Voice Onset (Romme & Escher, Milligan et al., deJager et al.,)**
   > When voices begin – incorporates startle phase (Romme & Escher)

3. **Rejection phase (Milligan et al.,)**
   > Rejection as voices as self/voices will go away – may incorporate startle phase and partly replicates Romme & Escher's suggestion that voices are rejected as part of the self.

4. **Change**
   > This phase includes Milligan's phase of 'Crisis Induced Change' and deJager's processes leading to change. Milligan talks of a crisis point that leads to positive (Contact with services or/and Disclosure to others) or negative change (Voices become more negative – feeds back to 'Rejection' phase). deJager's pathway to change appears to have a temporal element of 'initial strategies ineffective' leading to 'overwhelmed/loss of control' to 'despair/exhaustion.'

5. **Divergent Typologies (deJager et al.,)**
   > DeJager discusses two types of recovery style: 'Turning towards voices' or 'Turning away from voices'. Both typologies have 'Common Processes'. 'Turning away from voices' incorporates 'Effective Medication'. 'Hearing Voices Network' contributes to the characteristics of 'Turning towards voices' - Transformation/growth, voice-specific skill and integration of voices. 'Hearing Voices Network' also contributes to 'Making sense of voice-hearing' and 'Contact with Mental Health Services'. All three processes: 'making sense of voice-hearing', 'contact with Mental Health Services' and 'Hearing Voices Network' contribute to 'Common Processes'.
   > Turning towards voices supports Romme & Escher's 'Organisational' and 'Stabilisation' phases.

6. **Managing Voices (Milligan et al., and Romme & Escher)**
   > Managing voices includes Romme & Escher's 'Organisational' phase and Milligan et al.'s' 'Discovery, Adjustment and Coping' phase that incorporates: 'Self', 'Others' and 'Services'.

7. **New Understandings (Milligan et al.,)**

8. Stabilisation (Romme & Escher)

Antecedent phase
(Negative life events)

Voice Onset

Startle

Rejection Phase
Not me
Go Away

Crisis Event

Initial strategies ineffective
Overwhelmed/loss of control
Despair/Exhaustion

Change

Colour Coding of Authors

Romme & Escher (1989)

Milligan et al., (2012)

deJager et al., (2016)

Multiple authors

Contact with Services

Disclosure to Close Others

Voices become more negative

Divergent Typologies

Turning Towards Voices

Turning Away from Voices

Transformation/growth
Voice-specific skill & integration

Effective
Medication

Hearing Voices Network

Contact with Mental
Health Services

Making sense of voice
hearing

Common Processes
General mental health skills
Meaningful activity
Connecting with others
Changed response to voices
Positive sense of self

Self

Others

Services

New beginnings

**Discovery, Adjustment
Coping**

Organisational

New Understandings

Stabilisation

Romme & Escher (1989); Milligan et al.; (2012) and deJager et al., (2016) suggested voice hearing pathways

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┌─────────────────────────┐
│     Antecedent phase    │
│   (Negative life events)│
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             │
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┌─────────────────────────┐
│       Voice Onset       │
└─────────────────────────┘
             │
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┌─────────────────────────┐
│          Chaos          │
│ (Startle, confusion,    │
│  desperation            │
└─────────────────────────┘
             │
             ▼
┌─────────────────────────────────────┐
│        Crisis Induced Change        │
│ (There's got to be another way:     │
│  divergent typologies)              │
└─────────────────────────────────────┘
             │
             ▼
┌─────────────────────────────────────┐
│          New Beginnings             │
│ Organisation (Enquiry and Learning) │
└─────────────────────────────────────┘
             │
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┌─────────────────────────┐
│   New Understandings of │
│          Voices         │
└─────────────────────────┘
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┌─────────────────────────┐
│      Stabilisation      │
└─────────────────────────┘
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<u>Combined Model Streamlined</u>

Antecedent – voice onset – Ahhhhh! (Startle, confusion, desperation) – Crisis induced change (there's got to be another way) – organisation (new beginnings) - stabilisation

Romme & Escher (1989); Milligan et al.; (2012) and deJager et al., (2016) suggested voice hearing pathways

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┌─────────────────────────┐
│     Antecedent phase     │
│   (Negative life events) │
└─────────────────────────┘
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│       Voice Onset        │
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│            Chaos             │
│ (Startle, confusion, desperation│
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┌──────────────────────────────────────┐
│        Crisis Induced Change         │
│ (There's got to be another way:      │
│         divergent typologies)        │
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┌─────────────────────────┐
│       Organisation       │
│     (New beginnings)     │
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│      Stabilisation       │
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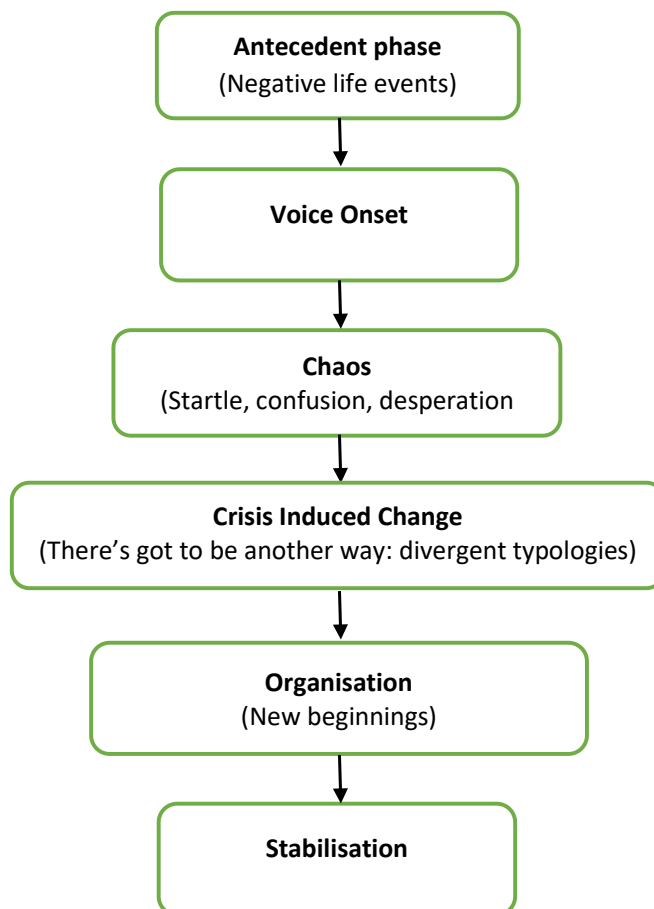
Appendix 14: Participants' Analyses of Journey with Voices Compared to Model

<u>Combined Model Streamlined</u>

Mark Hayward streamlined model: Antecedent — voice onset — Ahhhhh! (Startle, confusion, desperation) — Crisis induced change (there's got to be another way) — organisation (new beginnings) – stabilisation

Romme & Escher (1989); Milligan et al.; (2012) and deJager et al., (2016) suggested voice hearing pathways
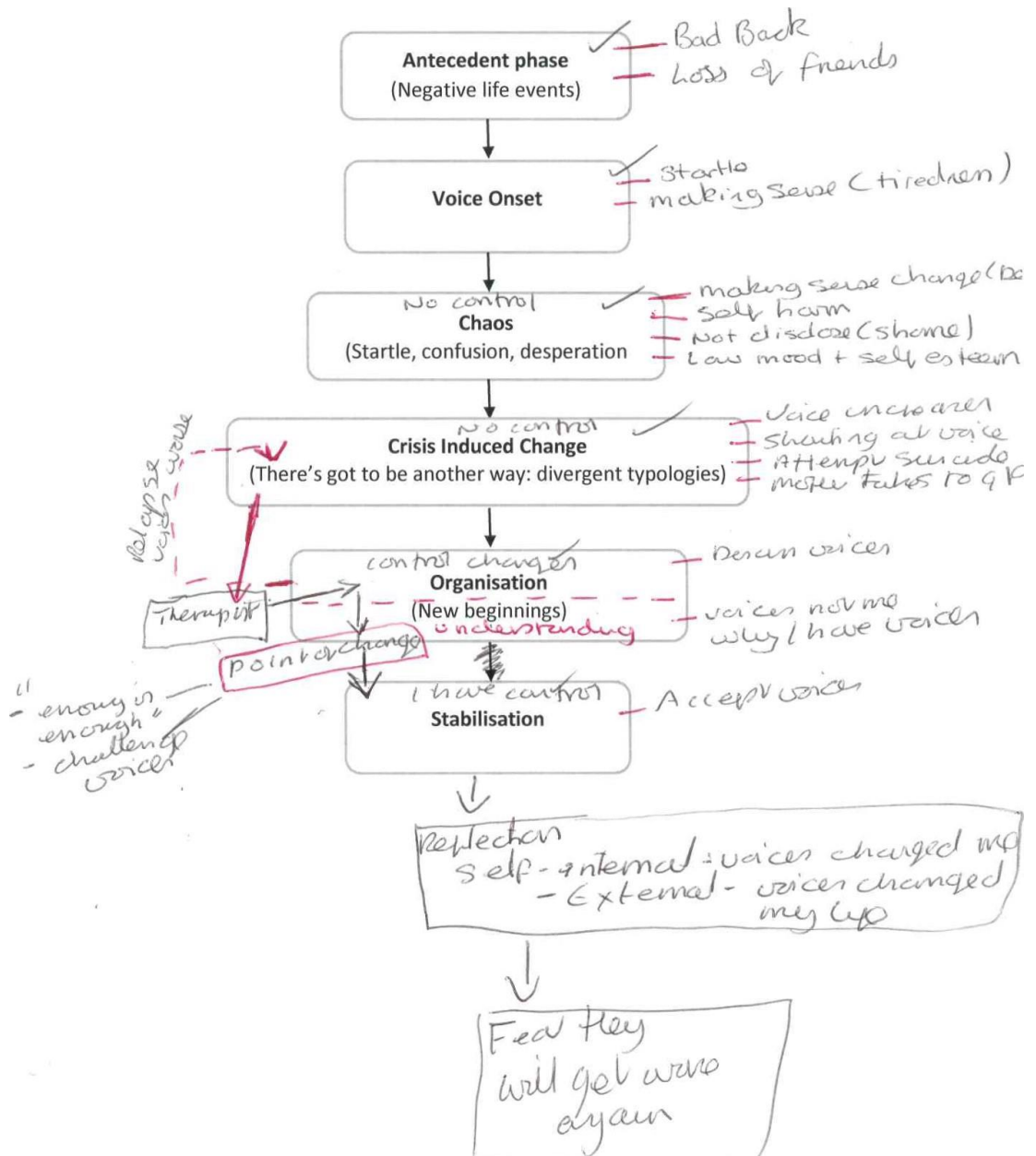
Appendix 15: Participants' Analyses of Data – Development of Themes

Group 1	**Antecedent Phase**
Part 1	**Neg Event:** Anxiety
Part 9	**Neg Event:** Back op, loss friends
Part 14	**Neg Event**: Bereavement, bullied

	Voice onset
Part 1	Tried to make sense, Belief falling asleep **TIRED (NORMALISING)**
Part 9	Startle, tried to make sense, Belief tired - **TIRED (NORMALISING)**
Part 14	Startle, no disclosure, Belief someone haunting her/neg part of self **(EXTERNAL)**

	Chaos
Part 1	Confusion, reject voice, no startle, **PARANOIA** (people hear thoughts), voices increase
Part 9	Belief (Demon), self-harm, no disclosure (shame), no control **PARANOIA**
Part 14	Control mind/body, self-harm, dissociate from self, no disclosure **PARANOIA**

	Crisis Event
Part 1	Voice worse, arson, paranoia (hear thoughts)
Part 9	No control, voice increase, suicide, disclosure
Part 14	Can't cope, suicidal, Disclose family/GP

	Change Through Help
Part 1	Meds, Therapy (not helpful), coping, self, Voice won't go but won't accept them, Beliefs (my thoughts)
Part 9	Meds, Talk to others, Coping, control changes, Belief (voice me - not demon)
Part 14	Therapy (EMDR), start to manage voice commands, Belief (due to avoidance and grief), accept voice, talk to family

	Trigger
Part 1	Dog dies, Physical illness
Part 9	No
Part 14	Physical illness

	Voices more Negative
Part 1	Voices gain control/ negative
Part 9	Voices get more powerful
Part 14	Voices get more powerful/distressing

	Chaos
Part 1	Relapse - voices increase, negative mood
Part 9	No
Part 14	No

	Crisis Event
Part 1	Suicide
Part 9	No
Part 14	No

Change Through Help

Part 1	Start to gain control, Job, voices quiet = get on with life **BUT 2nd Relapse -** voices get worse when physically ill BUT TAKES CONTROL AND GETS BETTER BY SELF
Part 9	Stop self-harming, voices lie, enough is enough, gaining control, coping, taking back life
Part 14	Talk to family, coping, Therapy (Relating)

New Understanding

Part 1	Accept voices part of life, I have control (Meds)
Part 9	Therapy - change, voices will stay, challenge voices, my life, accept voices
Part 14	Accept voices stay, taking control, challenge voice, get on with life, voice doesn't affect her

Stabilisation

Part 1	I have control, managing voices, living life with voices, socialise
Part 9	Ways of managing voices, control, socialise
Part 14	

Reflection

Part 1	Voices changed me, accept voices will deteriorate
Part 9	
Part 14	

Voices Relapse

Part 1	**Accept relapses with voices**
Part 9	
Part 14	**New Understanding**: **Accept voices stay**, taking control, **challenge voice, get on with life, voice doesn't affect her**

Group 2	Antecedent Phase
Part 3	**Neg Event:** Exam Pressure, nerves
Part 20	**Neg Event:** Father left when young; mother critical - indication problems with previous partner
Part 12	**Neg Event:** bullied, depression

	Voice onset
Part 3	(positive voice): startle, **Looking for voice**, **(NORMALISING)** relationship, private conversation, no disclosure
Part 20	Startle, fear, not me, try to understand, no disclosure **Belief Kidnapped (EXTERNAL)**
Part 12	No disclosure, Beliefs external beings (don't change) **can't remember what made of it.**

	Chaos
Part 3	Negative voice = Fear, self-harm, distress, loss control **PARANOIA**
Part 20	Voice powerful, not me, Belief conspiracy stops here), voice gets worse, control body **PARANOIA**
Part 12	Voice relapse over years, voices will go, no disclosure **PARANOIA**

	Crisis Event
Part 3	Mother notices unusual behaviour - voices distressing, talk out loud
Part 20	Suicidal, dissociated from body, **voice control**
Part 12	Suicidal, Disclosure to GP

	Change Through Help
Part 3	Meds, therapy, accepting voices, Beliefs don't change, get on with life, no control, voices not me, job
Part 20	Meds
Part 12	Meds, Ways of coping, Beliefs don't change, voices have power (sometimes I have control), get job, socialise

	Chaos
Part 3	N/A
Part 20	Beliefs fixed, voices powerful, believe trying to kill her
Part 12	N/A

	Change through help
Part 3	N/A
Part 20	Meds, therapy (stopped therapy as not ready) Social -Hearing voices group, Self - ways of coping - still no control, no change in belief
Part 12	N/A

Group 3	Antecedent
Part 6	**Neg Event:** Child trauma, Loss of friends with negative voice
Part 10	**Neg Event:** housemate, anxiety
Part 18	**Neg Event:** hit by child as child
Part 19	**Neg Event:** problem with father
Part 13	**Neg Event:** Severe Depression
Part 2	**Neg Event:** Rape/abuse

	Voice onset
Part 6	(positive voice): Actively sought contact with voices/ Negative voice occurs (startle, fear) **demon (EXTERNAL)**
Part 10	Curious, Belief housemates, negative voices increase **HOUSEMATES (NORMALISING)**
Part 18	(childhood), startle, voice had power, empowered him, friend, no disclosure **Confusing not sure what it was**
Part 19	Startle **Confusing not sure what it was,** very upset
Part 13	Suicidal period but **doesn't remember voice onset**
Part 2	Loss control, Disclosure negative, Belief tired - **TIRED (NORMALISING)**

	Chaos
Part 6	Negative voice= Fear, startle, fear, depression, no control, Beliefs demonic **PARANOIA**
Part 10	Voice increases, anger, voice has power, denial have problem **PARANOIA**
Part 18	(Adult) voice power, voice too much, suicidal, no disclosure
Part 19	Distressing, confusion
Part 13	Distressed at voice commands
Part 2	Belief (emotional explanation), no control, angry, dissociate

	Crisis Event
Part 6	No control, fear losing mind, disclosure GP
Part 10	Voices increase, Disclose, taken to hospital
Part 18	Attempt suicide, Disclosure
Part 19	Confusion, Disclosure
Part 13	Disclosure to GP, voice distressing
Part 2	Voice worse, disclose to others, others notice behaviour, angry

	Change Through Help
Part 6	Coping, trying to make sense, talking to others (queried voices) point of CHANGE - change in belief (voice starts to go)
Part 10	Change in manage voices, voice not me, Therapy, point of CHANGE (change in belief), change engaging, Job)
Part 18	I have control, others supportive, Therapy, Beliefs change, Voices due to stress
Part 19	Meds, ways of coping, no to therapy, Power struggle,
Part 13	Meds, Voices are me, no to therapy don't want to explore, don't want to talk about them - control, voices are me
Part 2	Disclosure positive, Therapy, coping, meds. Others, Gaining control Belief

Voices Stop

Part 6	Voices stop
Part 10	Voices stop
Part 18	Voices stop
Part 19	Voices stop
Part 13	Voices stop
Part 2	Voices stop

Voices return

Part 6	No
Part 10	No
Part 18	No
Part 19	Yes
Part 13	Yes
Part 2	Yes

Voice through to Voice stop

Part 6	N/A
Part 10	N/A
Part 18	N/A
Part 19	Voice onset - voice stop
Part 13	Voice through to Voice stop
Part 2	Voice through to Voice stop

Reflection

Part 6	Reflect on experience - why and how went, fear voices return
Part 10	Reflection - social media and writes about experiences, voices changed me
Part 18	Reflection - Fear voices return, I can cope if they do, what was it about
Part 19	Reflection - voice changed me, want to understand them, voice internal, maybe want therapy, fear voice return
Part 13	Reflection - fear voice return
Part 2	Reflection - it was mind, fear voice return

Appendix 16: EIP Clinician Participant Information Sheet

US
University of Sussex

Sussex Partnership **NHS**
NHS Foundation Trust

PARTICIPANT INFORMATION SHEET

Clinician

Study Title

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Invitation

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve. Please read the following information carefully and discuss it with your line manager and work colleagues. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part. Members of the research team can meet with you to discuss the study if you wish.

Who is conducting the study?

"A study exploring people's experience of hearing voices over time" is being conducted as part of a PhD student study. The research is sponsored by the University of Sussex and is also in conjunction with Sussex Partnership NHS Foundation Trust.

What is the purpose of the study?

This study will explore people's journeys with voices over a three year period. It will aim to identify different phases people may encounter with their voices, how

individuals manage their voices and, if there are different phases, which phases might be more effective for treatment.

<u>Why have I been chosen?</u>

We want to speak with you because we understand you provide care for people who hear voices.

In total, approximately 45 people (30 people who hear voices and 15 clinicians) will participate in the study across the country. Everyone will take part in interviews discussing their experiences of voice hearing.

<u>Do I have to take part?</u>

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you decide to take part you are free to withhold any personal information or to withdraw at any time, without giving a reason.

<u>What would taking part involve</u>?

First, you would meet with the researcher to discuss the study and complete a consent form. This would take about 30-40mins. The next part of the study would involve an interview. This would take approximately an hour and could take place after completing consent or at another time which is convenient for you.

What would happen in the Interview?

The interview would involve you discussing your experiences of people who hear voices with the researcher. During the interview you can choose not to discuss certain parts of your experiences or to withdraw at any time.

Although the study takes place over a three year period, clinicians will be interviewed on only one occasion. Therefore your time in the study would be approximately one and a half hours.

To help the researcher remember what was said the interview will be audio recorded.

Where would I have to go?

The meeting with the researcher would take place at a convenient location like where you work.

What about my travel costs?

Any travel costs incurred to and from the meeting would be reimbursed.

What are the advantages and disadvantages of taking part?

By taking part in the study you will be helping us to learn about people's journeys with voices, whether there are different phases with voices, how voices are managed and, ultimately, when is the right time for therapy.

We appreciate that clinicians are very busy and therefore it may be difficult to take the time for the interview. Talking about voices can be distressing and you may recall a difficult experience with someone you have provided care for.

Confidentiality

The research team will not share what you tell them during the meeting with anyone outside the study. The exception to this would be if you said something that led a member of the research team to believe that the safety of yourself or someone else was at risk. Under these circumstances we will have to pass this information to the appropriate healthcare provider.

All information that is written and recorded during the course of the interview would be kept strictly confidential and stored securely. Only members of the research team would have access to these records. This information would be coded and have your name and address removed so that you would not be recognised from it. The study complies with data protection laws.

What will happen to my interview?

Interviews: the recorded interviews will be transcribed onto a password protected computer. Recordings will then be deleted from the recorders. The PhD student will analyse the interview using Thematic Analysis. This form of analysis will help identify different themes that link patients' experiences of hearing voices across time.

What if I am not happy about the study?

If you wish to make a complaint please contact either the Chief Investigator, Leanne Bogen-Johnston on 0795700081 or email:

L.R.Bogen-Johnston@sussex.ac.uk,

Or

Dr Mark Hayward (Supervisor) on 01273 877240 or email: mih21@sussex.ac.uk

Or

The Patient Advice & Liaison Service (PALS) on 01323 446042 or email: PALS@sussexpartnership.nhs.uk

What will happen to the results of the study?

Findings from the study will be used to inform clinicians and research about people's journeys with voices and what is the best time to start therapy.

Who has reviewed the study?

The study has been reviewed and approved by the Research and Development Department within your local NHS Trust. It has also been reviewed by a NHS Research Ethics Committee and the University of Sussex Ethics Committee.

Next Steps

If you are interested in taking part in the study please allow yourself at least 24 hours to consider your decision before contacting the research team or before asking for a member of the research team to contact you. This is to ensure that you have had time to consider your decision.

If you would like to take part in the study, or to find out further information please call Leanne Bogen-Johnston on 0795700081

If no-one is available to answer your call, please leave a message and someone will call you back.

Leanne Bogen-Johnston
Doctoral School
Room 2C3
Pevensey1 Building
University of Sussex
Falmer
Brighton
BN1 9QH

If you are harmed by taking part in this research study, there are no special compensation arrangements. If you are harmed by someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, you are asked to contact the academic supervisor (Dr Mark Hayward) of the study. If this is unsatisfactory, then you can contact the Registrar & Secretary of the University of Sussex at the following address:

Sussex House
University of Sussex
Falmer
Brighton
BN1 9RH

You may also wish to seek advice form the Patient Advice and Liaison Service (01323 446042 – pals@sussexpartnership.nhs.uk).

If you decide to participate in the study you will be given a copy of this information sheet and a signed consent form to keep.

Appendix 17: EIP Clinician Consent Form

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Participant Identification Number:

CONSENT FORM (Clinicians)

Title of Project: A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Researcher leading the study: Leanne Bogen-Johnston

Initial box

1 I confirm that I have read and understand the Participant Information Sheet dated April 17th 2014 (version 3) for the above study and have had the opportunity to ask questions.

2 I understand that my participation is voluntary and that I am free to withhold personal information or to withdraw at any time during the interview, without giving any reason, and without my legal rights being affected.

3 I understand that if I choose to withdraw that the recorded interview will be kept by the research team.

4 I understand that in the event that I disclose information which may indicate new risk to myself or others, the researcher will be obliged to follow Trust risk procedures that may require release of my personal data.

5 I understand that all interviews will be audio recorded. I agree to be audio recorded. This will allow the researcher to remember what was discussed during the interview.

6 I agree to take part in the above study

Name of Participant   Date   Signature

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_____   _____

_____

Name of Researcher   Date   Signature

_____   _____

_____

Please tick this box if you would like to receive a copy of findings from the study ☐
If you would like a copy of findings please indicate if you would like these by post ☐ or by email ☐

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Appendix 18: EIP Clinician Topic Guide

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

Topic Guide (Clinician): Time 1

Introduction

The focus of this interview will be on your experience of patients who hear voices. Everything you tell me will only be used for this research project, and will not be shared with anyone outside the research team unless you disclose information which may indicate new risk to yourself or others. You have already consented to the interview with the consent form. Do you have any questions before we begin?

Background Information

- **Ask work related demographics**
  Prompts: job title, years in position, time with EIP, time with particular team, years working with voice hearers

- **Opening Questions**
  Broad questions around patient's voices
  Prompts: In your experience: how long patients been hearing voices for, number of voices, identify between voices, are voices known, is there one dominant voice? How distressed are people in response to distressing voices? If voices are comforting what are views about that? How work with voices i.e. voices are a problem or only when distressing

Key Areas

- **How have they worked with people who experience voices?**
- **General experience of working with people who experience voices**
- **What has struck them about people who experience voices**
- **What happens over time:**
  - **with voices**
  - **people's experiences of voices**
  - **How people manage voices**

Other Areas

- **First voice hearing experience – positive and distressing voices**
  Prompts: events in individual's life, reactions of individual, meaning, affect individual

- **Development of (distressing) voices over time**

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Prompts: notice changes at key stages of life regarding voices i.e. age, work, leaving home, relationships; good/bad circumstances (type)

- **Changes in (distressing) voice experience**
  Prompts: change in voices, voice content, why change
  Occurred; think of anyone else whose experience different

- **Reactions to changes in (distressing) voice experience**
  Prompts: meaning to individual, affect individual, reactions change over time?

- **Seeking help for distressing voices (not psychosis)**
  Prompts: time before disclosure, who talk to, why then, point of disclosure

- **Help from others**
  Prompts: help from family, friends, groups, services; types of relationships with these people; types of help; cultural views towards voices

- **Help seeking and time**
  Prompts: when is best time for help, seek help when ready, different type of help at different times

- **Psychological therapies (PT) for distressing voices (not psychosis)**
  Prompts: when is PT offered, when think right-time, factors influence best time for PT, type of therapy for voices, what feel a good outcome of PT (voices stop or people cope better),

- ***Experiences of therapy for distressing voices***
  Prompts: people's understanding of therapy, whose idea for PT, expectations, good/bad things, experiences

- **Impact of hearing voices over time**
  Prompts: impact on lives, changes over time i.e. behaviour, outlook, relationships, socially

- **Relationships with the voices**
  Prompts: changes with understanding and relate to their voices over time

- **Managing voices over time**
  Prompts: ways of managing, strategies, changes in strategies over time

Closing Interview

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- **Voices and the future**
  Prompts: will always hear voices, outlook for future around voices,

Outro Questions
- Do they have questions
- Add anything to what has been said
- Anything that thought would be discussed but wasn't
- Any topics discussed that surprised about

Note to self: Don't turn off recorder until participant has left room

Appendix 19: Protocol for Research Programme

US University of Sussex

Sussex Partnership NHS Foundation Trust

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?

RESEARCH PROTOCOL

Academic Supervisors   Dr Mark Hayward [a,]

Dr Richard De Visser [b]

Dr Clara Strauss [a,b]

Doctoral Student   Leanne Bogen-Johnston [a,b]

Collaborators   Dr Simon McCarthy Jones[c]

Dr Georgie Paulik[d]

Dr Kathryn Berry[e]

Yvonne Awenat[e]

[a] Sussex Partnership NHS Foundation Trust

[b] University of Sussex

[c] Macquarie University, Australia

[d] Rockingham Kwinana Early Episode Psychosis Program, Rockingham, Australia

[e] University of Manchester

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Contents

A study exploring people's experience of hearing voices over time: what are the different phases of managing voices and how might these phases affect engagement with services and therapy?*: Clinician April17th 2014, Version 3*

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1. Study Summary

Aim: the study aims to examine people's journeys with hearing voices, identifying different phases of managing voice hearing, and how these phases might impact on therapy.

Design: a longitudinal study will use mixed methods. Qualitative data will be collected from service users at nine monthly intervals over a **27 month** period (**four** time points). Service users will also complete quantitative measures at each time point. **After data collection has ended, participants will have the opportunity to meet with the doctoral student in order to offer feedback regarding the findings from their data set.** Qualitative data will be collected from clinicians at a single interview.

Expected outcomes: outcomes will include a theoretical model of the phases of managing voice hearing.

Anticipated benefits: a theoretical model of the phases of voice hearing will assist clinicians to understand and support the management of distressing voices. It is also hoped that the model will facilitate identification of the optimum point at which a service user will engage with and benefit from psychological therapies.

2. Introduction

The experience of hearing voices in the absence of an appropriate external stimuli (Laroi et al., 2012), may take place in both non-clinical and clinical populations. Research suggests that due to the prevalence in non-clinical populations hearing voices may not always be associated with psychiatric illness (Choong, Hunter, & Woodruff, 2007). However, studies have shown that the experience of voice hearing tends to differ between populations with clinical groups often deeming voices as more negative and distressing than non-clinical groups (Honig, Romme, Ensink, Escher, Pennings, & deVries,1998). Negative beliefs about voices are associated with negative emotional and behavioural responses (Csipke & Kinderman, 2006). Consequently, the importance of

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understanding the voice hearing experience, rather than just focusing on their presence, has given rise to a body of research exploring different aspects of the perceived voice and its associated distress. Although this research has been essential for the progress of theoretical models of voice hearing, as well as the development of therapeutic interventions, in general, studies tend to be cross-sectional rather than longitudinal (Milligan, McCarthy-Jones, Winthrop & Dudley, 2012). Findings from cross-sectional studies are based upon measures taken at a specific point in time and therefore, unlike longitudinal studies which focus upon measures taken over a prolonged period, conclusions are limited.

A twelve-month longitudinal study conducted by Hartigan, McCarthy-Jones & Hayward (in press) explored how the voice hearing experience, in particular beliefs about voice intent and the relationship with voices, changes over time in a clinical sample. Although the study did not reveal a significant change in styles of interrelating between voice and hearer, findings did suggest that voice-hearing related distress may be linked to how the hearer engages with the voice. Likewise, there was not a significant change in beliefs about voice intent (power and malevolence) over the twelve-month period but there was a trend towards beliefs about voice benevolence decreasing. However, there is still a paucity of research focusing on the experience of voices over an extended temporal period. In a recent study, Milligan et al. (2012) address the question as to what is it like to live with voices over time: what are the main changes, events and stages that the voice hearer may encounter? The researchers draw on the clinical work of Romme & Escher (1989) who advocate a model whereby individuals who have learnt to manage voices appear to encounter three phases of voice hearing: the startling phase, the phase of organization (coping), and the stabilization phase. However, Romme & Escher fail to provide empirical evidence to support their three phase model of voice hearing. Instead, the model appears to be developed from the anecdotal evidence acquired from attendees at a voice hearing congress. In addition, as Romme & Escher state, people understand and manage their experiences in many ways and that the phases suggested are three 'possible' phases which have been used as a means to categorise the author's clinical experience. In a qualitative study examining

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voices over time, Milligan et al., expand upon Romme & Escher's proposed three phase model of voices. The authors interviewed six adults with psychosis who experienced voices and found five themes associated with the trajectory of voice hearing: negative trigger (causative); rejection phase; crisis-induced change (disclosure of voices to others); new understandings (taking a new stance regarding voices); and discovering, adjusting and coping. The authors only find partial evidence of Rome & Escher's three phase theory. They propose that the 'startling' phase may in fact be embedded within the 'rejection' phase and the 'organisation' phase may be replaced by the 'discovering, adjustment and coping' phase.

It appears that there is no conclusive empirically supported theoretical model as to the phase's individuals may encounter when managing the experience of hearing voices. One reason may be due to the fact that research has tended to be based upon people's retrospective accounts of the voice hearing journey. Milligan et al., (2012) suggest a need for a longitudinal study examining the experience of voice hearing and recommend that future research build upon themes identified in their research with Early Intervention populations. Through a longitudinal study with a cohort of voice-hearers from Early Intervention for Psychosis (EIP) services, the proposed study will use a mixed-methods design to explore current accounts of changes in the voice-hearing experience over time. It is believed that a longitudinal study will identify current influences that retrospective studies may fail to reveal. The study will also consider the work of Hartington et al., (in press) and explore potential links between different phases of managing the experience of hearing voices, beliefs about voices and relationships with voices. It is hoped that findings may offer potential insight into how certain stages of voice-hearing may affect therapy. For example, work conducted by The 'Voices over Time' research team (McCarthy-Jones, Hayward, Paulik, Berry & Awenat) a body of researchers with an interest in people who hear voices, intimates that voice-hearers are unlikely to respond to therapeutic interventions when voices first begin (voice onset). Instead, help-seeking behaviour occurs when individuals enter the phase suggested by Milligan et al., (2012) of 'crisis-induced change', a phase whereby voice-hearers may seek help from others such as family, friends or services like EIP. This help-seeking

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behaviour is supported by the findings from a meta-synthesis of psychosis, which highlights a main theme of "Identifying a need for, and seeking, help" (McCarthy-Jones, Marriott, Knowles, Rowse & Thompson, 2012). Consequently, a need for a longitudinal study following voice-hearers entering EIP services has been identified by the 'Voices over Time' researchers. The proposed study will be supported by members of 'Voices over Time'. The aim of the research will be to examine people's journeys with voices, identifying different phases of managing voices, and how they might impact on therapy.

3. Proposed Methodology

3.1 Study Design

The study will use a mixed methods approach. It has been designed as a longitudinal study with qualitative and quantitative data collection taking place at nine monthly intervals over a **27-month** period. Qualitative and quantitative data will be analysed after each nine monthly collection period. Findings from the analysis of qualitative data at each time point will be used to inform the interview schedule at subsequent time points.

3.2 Participants

The study will seek to recruit service users and clinicians. Service users will be recruited from Early Intervention for Psychosis (EIP) services across the country. Inclusion criteria for service users will require that they are currently hearing voices and will have done so (at least intermittently) over the past three months. Inclusion will also require that all participants are 18 years of age or over. Service users will be excluded on the grounds of organic illness or a primary diagnosis of substance misuse. Clinicians will be recruited through EIP services across the country. Due to ethical reasons, the interviews with clinicians will not focus on service user's participating in the study but instead explore their general experience of service users who hear voices.

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The study will run for five years and aim to recruit a separate sample of 45 participants (30 service users and 15 clinicians). Allowing for an annual attrition rate of approximately 33%, 10 service users will remain in the study at the final time point.

3.3 Measures

Quantitative data will only be collected from service users. Psychometric measures will include the following:

Voice and You (VAY) – the VAY is a 28-item measure of interrelating between the hearer and their predominant voice (Hayward et al, 2008). Relating is measured across four scales; two concerning the hearer's perception of the relating of the voice – voice dominance and voice intrusiveness; and two concerning the relating of the hearer - hearer distance and hearer dependence. Each item is measured on a four point scale (03) generating the following range of scores for each scale: Voice Dominance 021; Voice Intrusiveness 015; Hearer Distance 021; and Hearer Dependence 027. The VAY has good internal consistency (α > .80 for all scales) and acceptable test- retest reliability (r > .7 for all scales).

Psychotic Symptoms Rating Scale (PSYRATS: Auditory hallucinations scale AHRS) the AHRS is an 11 item rating scale designed to measure the severity of different dimensions of the voice hearing experience (Haddock et al, 1999). Items include frequency, duration, loudness, intensity of distress and controllability. Each item is measured by the rater on a 5 point scale ranging from 04. The items relating to intensity of distress and controllability on the AHRS are the most often cited in the voice hearing literature and will be reported in this paper.

Beliefs about Voices Questionnaire Revised (BAVQR; Chadwick et al., 2000) the BAVQR is a 35-item self-report measure regarding people's beliefs, emotions and behaviour around auditory hallucinations. The questionnaire comprises of five subscales: beliefs about the voice's malevolence (six items), benevolence (six items), omnipotence (six items), emotional resistance (four items), emotional engagement (four

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items), behavioural resistance (five items) and behavioural engagement (five items) with the voice. Items are rated on a four-point Likert scale ranging from disagree (0) to agree strongly (3). The measure demonstrates satisfactory psychometric properties.

Brief Core Schema Scales (BCSS; Fowler et al., 2006) the BCSS is a self-report assessment of schemata centring on self and others in psychosis. It has 24 items measuring four
dimensions of beliefs about the self and others: negative self (six items, e.g. "I am worthless"), positive self (six items, e.g. "I am valuable"), negative other (six items, e.g. "other people are nasty"), positive other (six items, e.g. "other people are supportive"). Items are assessed on a five point rating scale (04). The BCSS has good psychometric properties.

3.4 Procedure

Participation within the study will involve the following stages:

1. EIP mental health teams from across the country will be invited to identify and refer service users who meet the study criteria. Care coordinators will be asked to discuss the study with the individual who will also be provided with a participant information sheet (PIS) explaining involvement within the study. The referring team member will complete a referral form confirming that the potential participant meets the inclusion criteria and is willing to discuss the research project with the doctoral student.

2. Service users who are interested in the study will be invited to meet with the doctoral student. On meeting, the study will be discussed with the aid of the PIS. Potential participants will have a chance to ask questions. If the service user wishes to participate in the study, and the doctoral student is satisfied that they meet study criteria and have capacity to consent, then informed consent shall be taken. The doctoral student will either conduct the interview and measures* after consent has been given or, if the service user prefers, arrange to conduct the interview and measures at a later date.

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3. Interviews will be guided by a semi-structured schedule. The interview will be audio recorded (participant's permission will be obtained) and notes may be taken. At the end of the interview and assessment measures, participants will be given a £15 voucher of their choice as a recompense for their time. Travel reimbursement will also be offered.

4. If a participant discloses information whereby they or someone else is at serious risk

of harm, confidentiality will be breached as stated in the consent form. The doctoral student will inform the participant that action will be taken, and a member of their mental health team or an appropriate service will be informed.

5. The doctoral student will contact service user's mental health teams at subsequent data collection points. Team members will be asked about the well-being of their client. Participants will be contacted if the team feel that the participant is able to continue with the study. Service users will be contacted at nine monthly intervals to undertake interviews.

6. **Each participant will be invited to meet with the doctoral student to discuss the findings from their data set. The doctoral student will contact participants' mental health teams regarding their client's well-being. If a participant is no longer with a mental health team then the appropriate care provider will be contacted i.e. GP. Participants will be contacted if the care provider feels that their client is able to continue with the study.**

7. Clinicians from EIP services across the country will be asked to participate in a single semi-structured interview.

*Measures will only be conducted with service users and not clinicians.

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3.5 Planned Data Analysis

Quantitative Data Analysis

Quantitative data will be analysed using single case statistics (Jacobson & Truax, 1991) to identify reliable and clinically significant change on each self-report measure of each participant.

Qualitative Data Analysis

Qualitative analysis will guided by inductive Thematic Analysis. An inductive approach was deemed appropriate as identified themes are strongly linked to the data and support the development of data-driven theory. Thematic Analysis allows the research question to extend beyond the individual experience and theories may be applied to populations outside the research study participant group.

3.6 Ethical considerations

Participant distress

It is anticipated that the process of exploring voice hearing experiences may be distressing for some service users. The likelihood of distress occurring will be minimised by seeking to recruit only those individuals considered by the referring clinicians to be sufficiently psychologically robust to participate in the study.

All of the service users that will be approached for participation within the study will be in receipt of on-going clinical care from EIP (NHS) services. At each nine monthly data collection point a member of the participant's care team will be contacted. Team members will be asked as to the wellbeing of the participant. Participants will be contacted if the team feel that he/she is able to continue with the study. Should an individual present with any difficulties of clinical significance during any stage of the study permission to pass concerns on to their care coordinator will be sought. If a participant discloses information that suggests he/she might harm him/herself or others, the researcher will be obliged to pass on this information. The limits of confidentiality in this respect will be made explicit prior to commencement of participation. These guidelines will apply to individuals who consent to and complete the study, individuals

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who consent to and subsequently withdraw from the process and individuals who do not give consent (and consequently do not participate). Participants will be free to withhold information or withdraw from the study at any time without giving reason.

Managing risk to the doctoral student

In terms of meeting with potential participants, the doctoral student will discuss any concerns about risk to others with the referring EIP team member before accepting a referral. If risks to others are deemed high this would be an exclusion criteria for the study and the person would not be offered the opportunity to participate. Potential risks to the doctoral student would be managed within Sussex Partnership procedures, such as working in accordance with the Trust

Lone Working Policy. The decision to offer the option of interviews in participant homes was made in order to include participants who may be reluctant to attend their mental health team base. Based on the research team's experience, this strategy allows us to engage otherwise hard to reach service users who may not participate in the study. Where the student meets participants in their homes they will follow the Trust Lone Working Policy.

Consent Process

The doctoral student will be responsible for obtaining informed consent from participants. The doctoral student has experience of working with adults with longstanding mental health problems and clinically-relevant research experience. The doctoral student has received training in obtaining informed consent from Dr Mark Hayward (Director of Research, Sussex Partnership NHS Foundation Trust), who will supervise obtaining consent and other aspects of the doctoral research study along with Dr Clara Strauss.

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4. Publication and Dissemination Strategy

The final theoretical model of voice hearing will be written-up for submission to a peer reviewed journal.

Papers for presentation will be targeted at appropriate local and national mental health research conferences and seminars.

Findings will be disseminated to study participants and service user groups. A summary of findings will be written up for participants and service users. Finding will be presented at Community Mental Health Teams, service user workshops and conferences.

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