

Feelings, Circumstances, and Hallucinations:
A Novel Systematic Review, Theoretical, and Empirical Study

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Abstract

**Feelings, Circumstances, and Hallucinations: A Novel Systematic Review,
Theoretical, and Empirical Study by Katie Melvin**

There is limited available research on the lived experience of hallucinations; with most existing research focusing on unimodal auditory hallucinations. Two systematic literature reviews suggested future research should study hallucinations across multiple modalities, their co-occurring feelings, and the circumstances and personal histories they arise within. To develop a conceptual lens, methodological approach, and research design to study these novel areas, theories of feelings (Cromby, 2007, 2015; Langer, 1967) and feeling-traps (Cromby & Harper, 2009; Scheff, 2012) were drawn upon alongside embodiment research scholarship (Ellingson, 2017; Reavey, 2011). Sixteen service-users from an NHS early intervention in psychosis service experiencing hallucinations most days, took part in a four-stage research design for up to eight weeks. This generated prospective and retrospective data on hallucinations arising in any modality through semi-structured interviews and arts-based methods of completing a visual diary with micro body-maps (for one week), an arts-based task and a visual life-timeline. This generated the first known body-maps of the feelings experienced during hallucinations. Participants reported unimodal and multi-modal hallucination experiences, which were characterised by a variety of feelings (emotional, extra-emotional, of knowing, of reality, generalised or localised within the body) and were situated in participants' unique lived circumstances and ongoing personal histories. The analysis demonstrated numerous novel aspects of circumstances in Britain were relevant to the lived experience of hallucinations including: time, location, company, activities, spirituality, digital technology, adverse and positive childhood experiences, education, work and employment, material (in)security and welfare, homelessness, drugs and alcohol, inequality and discrimination, and formal and informal networks of care. Future research and interventions aiming to reduce distress, may appropriately seek to prioritise improving the lived circumstances which people are struggling to navigate. Future hallucination research may also benefit from the application of feeling theories and the current research protocol which effectively generated a comprehensive dataset.

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Table of Abbreviations

Table 0.03

Guide to Abbreviations Used Within the Thesis.

<u>Abbreviation</u>	<u>Full Term</u>
ABRM	Arts-based Research Methods
AH	Auditory Hallucinations
ASA	Adult Sexual Assault
AVH	Auditory Verbal Hallucinations
BH	Bodily Hallucination
CBT	Cognitive Behavioural Therapy
CH	Cenesthetic Hallucinations
CPA	Child Physical Abuse
CSA	Child Sexual Abuse
DSM-5	Diagnostic and Statistical Manual of Mental disorders 5 th Edition
EIP	Early Intervention in Psychosis
FEP	First Episode Psychosis
GH	Gustatory Hallucinations
HRA	Health Research Authority
MH	Musical Hallucinations
MMH	Multimodal Hallucinations
NHS	National Health Service
NVAH	Nonverbal Auditory Hallucinations
OH	Olfactory Hallucinations
POWs	Prisoners of War
QOL	Quality of Life
SR	Systematic Review
Te	Temporal Hallucinations
TH	Tactile Hallucinations
UK	United Kingdoms
UNHRC	United Nations Human Rights Council
VH	Visual Hallucinations

1. The Empirical Context of Research on Varieties of Experience and a Systematic Review of What Hallucinations Feel Like.

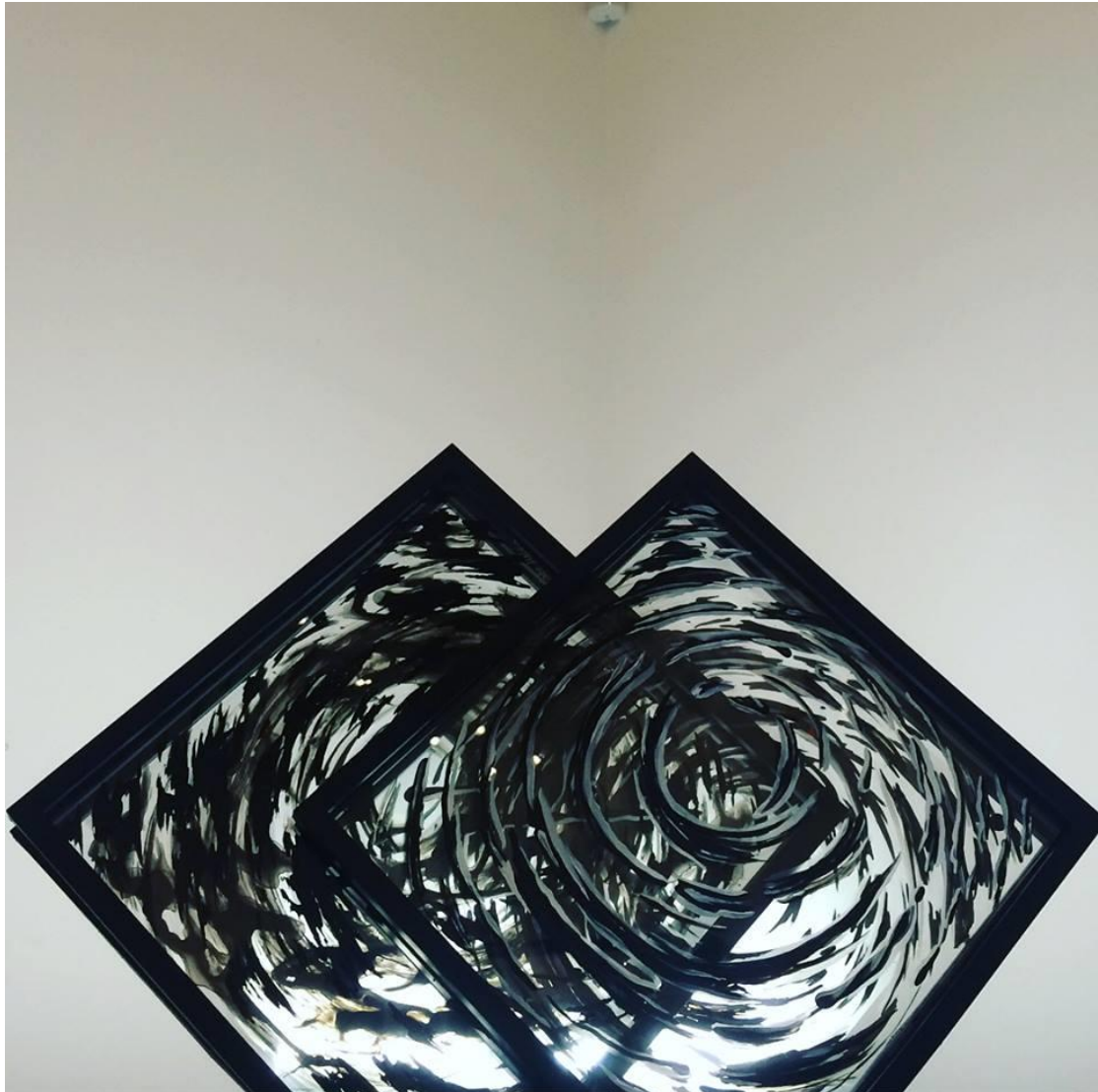


Figure 1. Still Photographic Image of an Installation from the Feeling-In-The-World Art Series during Gallery Exhibition at Attenborough Arts Centre in Leicester, 2018.

1.01 Of Hallucinations

There is variation between us all in how we perceive and understand the world. At times our understanding and perception of reality may differ markedly from the consensus of those around us. Sometimes we may have sensory experiences, seemingly without a corresponding immediate external source (Blom, 2015). At times, too, we may strongly believe things to be true, which those around us consider to be false. These kinds of experiences may be respectively described as hallucinations and delusions, and often collectively referred to using the medical term of psychosis (APA, 2013). This thesis describes a study of the situated feeling of hallucinations. Hallucination is a term used to describe sensory experiences such as seeing, hearing, touching, tasting, or smelling things, which are not shared by those around us (Correia, Moreira & Gonçalves, 2015). To begin to understand hallucinations we must place them within their context.

The etymology of terms relating to hallucination points to the cultural process of medicalisation of human experience in recent centuries. Historians mapping the development of descriptive psychopathology have written that prior to this time hallucinations were understood as:

Part of the common baggage of humanity. Various named, these experiences were in earlier times culturally integrated and semantically pregnant, i.e. their content was believed to carry a message for the individual or the world. That this feature of hallucinations has been lost is a consequence of their 'medicalization' during the eighteenth century. During this period, hallucinations were considered as independent 'diseases'; indeed, the view that they were 'symptoms', i.e. fragments of behaviour common to various diseases is a nineteenth century invention. (Berrios, 1996, p.35)

Use of the term hallucination within this thesis points to the earlier historical sense of meaning and is part of a process of reclaiming and reorienting the concept as embodied, meaningful and circumstantially situated. As Berrios (1996) implies, the term 'hallucination' often holds psychiatric and medical connotations. To avoid such associations, phrases referencing hallucinations'

sensory components may be used instead; such as ‘hearing voices’ or ‘seeing visions’. The ongoing growth of the Hearing Voices Movement may serve as a prime example of how such language can be used in organising knowledge and sharing practice (Corstens, Longden, McCarthy-Jones, Waddingham & Thomas, 2014).

This thesis demonstrates through systematic literature review however that such colloquial terms may often bear little resemblance to the lived experiences they aim to describe. As this thesis seeks to map the feeling of hallucinations, such framings had problematic potentials. During the process of the research it became apparent that turning to colloquial linguistic terms, may inadvertently draw attention to experiences best fitting their descriptions at the expense of others. This would serve to further reinforce biases within systems of knowledge; that for example hallucinations are unimodal, are most valid in particular sensory forms (i.e. as external heard voices), or that non-auditory or multimodal hallucinations are uncommon. To maintain a focus towards the breadth of perceptual experience, the most appropriate linguistic term seemed to be hallucinations, in its historical sense.

The complexities of the language surrounding hallucinations are not focused upon in the thesis, and further discussion is beyond its scope. However, throughout the process of developing this thesis, the available linguistic tools were struggled with. The language used to reference hallucinations throughout this thesis therefore shifts into many diffractive forms, using ‘hallucination’ as a central anchor. This shifting language represents the many different ways experiences described as hallucinations are spoken of, both by those who experience them and the research field. The struggles with language point to a broader issue which this thesis addressed with its theory, methodology, methods and analysis; that each moment of lived experience is embodied, visceral and characterised by feeling the process of numerous continuously emergent interrelationships. This is a very different kind of phenomenon than the written language used to describe it.

There is an inherent difficulty in communicating inter-relational and intra-relational ideas within written and spoken language; its serial form loses the very

kinds of relationships such language tries to share. Writing a thesis on phenomena which are inherently difficult to describe provided a challenge and an opportunity. With a focus on interrelationships and aims to generate a thicker insight into lived experience, visual and arts-based research methods (ABRM) were used to triangulate the data-generation. However, consistent with the scholar's traditional mode of communication, the thesis is predominantly presented in academic prose although arts-based methods of communication are drawn upon along the way.

1.01.1. Thesis Overview.

This thesis holds a multi-modal map; a map which pulled together knowledge of hallucinations as they have been studied in research and as they are lived. This map was generated from a journey of studying the feelings and circumstances of hallucinations through many interrelated yet diffractive aspects of the field. The journey was composed of three parts and 10 chapters.

Part one (Chapters 1-3) considers the empirical context of the thesis with systematic reviews of the feeling and circumstances of hallucinations. Part Two (Chapters 4-5) was mapping theories of feelings, including their interrelationship with circumstances and distress formation. After outlining the research questions, methodologies were considered to generate knowledge from situated feelings. The thesis explored scholarship of Langer (1967), Cromby (2007, 2015), Scheff (1990, 2012), and ABRM, alongside a process of self-practice and self-reflection. Part Three (Chapters 6-10) documents empirical study of hallucinations with an early intervention in psychosis (EIP) service-user sample. These chapters present the methods and outcomes of novel research which included semi-structured interviews and ABRM (a visual diary, micro-body-maps, arts-based task and life-timeline). The analysis and discussion are combined in three chapters on the: immediate feelings and circumstances of hallucinations; broader feelings and circumstances of hallucinations; and the extent to which feeling-trap theory was useful in understanding the data. The thesis' closes with a conclusion of what was learned from the journey and propositions of the implications of the research. The thesis continues by exploring the empirical context of hallucination research.

1.02 The Empirical Context of Hallucination Research

Chiming with descriptive psychopathology, across many disciplines, research studying hallucinations and experiences associated with distress are often structured through psychiatric diagnostic categories (Cromby, Harper & Reavey, 2013). When reviewing literature relevant to experiences such as hallucinations, researchers are left with little option other than to include many studies framed using psychiatric diagnoses. The prominence and dominance of diagnostic and pathological conceptualisations of distress form core features of the thesis' context. Opening with descriptions of diagnostic categories relevant to hallucinations, and research framed through a biomedical lens reflects the available literature. It does not serve as an endorsement of the psychiatric diagnostic categories discussed, or their utility for structuring research. This thesis uses diagnostic and biomedical concepts and language only as far as necessary, to utilise and refer to the existing evidential and institutional structures the thesis is situated within. The term distress is used to communicate many different difficulties without diagnostic inference. This chapter introduces the psychiatric diagnoses hallucinations are associated with before critically discussing dominant approaches to distress and outlining alternatives. Section 1.04 forms the beginning of the systematic reviews of hallucination research which continue into chapters two and three.

1.02.1 Of Psychosis.

When perceptions, understandings, and beliefs seem to diverge from those held by people around us, terms such as psychosis or psychotic episode may be used to describe a perceived loss of touch with consensual reality. Sometimes these experiences may be driven by a physiological cause such as substance use, neurological conditions, or infectious diseases (Keshavan & Kaneko, 2013). If support is sought from a medical doctor when a physiological cause is not identified, a diagnosis such as schizophrenia or schizo-affective disorder may be given (APA, 2013). Distress can be described as co-morbid and more than one psychiatric diagnosis may be given to describe experiences. With further interaction with services, new or additional diagnoses may be given, such that experiences are described in terms of a series of psychiatric diagnoses (Maj, 2005).

The National Institute for Health and Care Excellence (2011) estimates a 1.45% lifetime prevalence of schizophrenia and related diagnoses in the UK, with higher incidence rates among men, young adults, black and minority ethnic groups (BME) and people living in urban areas such as cities (Kirkbride, 2012). Research is studying the intricacies of how distress is stratified by demographic variables. There is much contention surrounding how best to understand and manage experiences described as schizophrenia and psychosis. There is however agreement that the experiences these terms describe are associated with a range of economic, social and personal costs.

Department of Health research estimated Wales and England's annual economic costs at £8.8 billion for experiences described as schizophrenia and £5 billion for experiences described as bipolar disorder or psychosis with depression (Kirkbride, 2012). The economic burden is associated with the costs of healthcare services, informal care and lost employment. There are further personal and social costs which include the primary and secondary experience of subjective distress, the disruption and breakdown of interpersonal relationships, loss of child custody, difficulties gaining and retaining employment, imprisonment, homelessness, being unable to live independently, and traumatic experiences of medical treatment (Shepherd et al., 2012; Thornicroft et al., 2004). Further research highlights that schizophrenia diagnosis is also associated with an estimated threefold higher overall mortality risk (Brown, Kim, Mitchell, & Inskip, 2010) and lost life of 14.6 and 9.8 years respectively for men and women (Chang et al., 2011). Mortality figures are elevated partially due to the much higher suicide risk (Saha, 2007), with particular risk close to when these experiences start (Palmer, Pankratz, & Bostwick, 2005). Such research highlights experiences of severe distress have a varied range of costs with impacts felt on multiple levels.

The early 21st century saw a focus upon Early intervention in Psychosis (EIP). With research demonstrating that EIP helps manage experiences and reduce costs, numerous EIP services were developed (Singh, 2010). In the UK, the past decade has seen substantial funding cuts to public services (Stuckler, Reeves, Loopstra, Karanikolos, & McKee, 2017). Statutory healthcare organisations struggling with limited resources has been associated with

worsened mental health and threat to EIP service provision (Cummins, 2018; Knapp, 2012; Mattheys, 2015; Mills, 2018). Some EIP services have been integrated into generic mental health services, whilst others face reduced budgets and increased caseloads (McDaid, Park, Lemmi, Adelaja & Knapp, 2016).

1.02.2 Of the Medicalisation of Health and Human Experience.

The biomedical model is the dominant approach in understanding and managing mental health within the west and global north (Mills & Fernando, 2014). Here, presumed abnormalities in bodily function are conceptualised as the primary factor catalysing and maintaining symptoms and illnesses. Diagnostic categories are constructed to classify supposedly homogenous presentations, to develop effective treatments and efficiently communicate clusters of experiences. Rectifying supposedly homogenous abnormalities is assumed to resolve illness; consequently, biological treatments such as medication are encouraged (Wade & Halligan, 2004). And yet, pharmacological treatments do not appear to rectify a biological abnormality in psychosis, and their description as ‘antipsychotic’ has been critiqued and questioned (Moncrieff, 2013).

Despite the dominance of biomedical approaches, research has not found a biomarker or gene robust enough to identify any major psychiatric disorder or predict pharmacological treatment responses for them (Charney et al., 2002; Deacon, 2013). Research has not mapped psychiatric taxonomy onto pathophysiology. Some researchers have suggested the contributions of biological mechanisms to distress must be so many, and so broad, any vulnerabilities are distributed across much of the population, and only actualised by living through certain (most likely noxious) circumstances (Bentall, 2003; Read, Bentall & Fosse, 2009).

Internationally, The United Nations Human Rights Council (UNHRC, 2017) observed empirical uncertainties regarding the biological contributions to distress are seldom acknowledged in practice and policy, nor communicated to people seeking support. Frontline healthcare services are characterised by diagnosis, pharmacological treatment, and biomedical gatekeepers to care. The

biomedical model's dominance (with associated diagnoses and pharmacological treatments) has been studied in cross-cultural research. The outcomes paradox denotes that contrary to most other aspects of health, some evidence suggests people meeting diagnostic thresholds for schizophrenia in lower-income countries are more likely to have a better outcome (and less likely to have a worse outcome) than people in higher-income countries (Kulhara, Shah & Grover, 2009; Padma, 2014). Kulhara et al. (2009) cite the potential impact of family structures, industrialisation, migration, social support, urbanisation and technological complexity. The outcomes paradox and associated evidence raises interesting considerations of how culture, concept, and social practice weave through research, evidence and clinical practice.

Here in the UK, pharmacological drugs form the primary treatment for people given a schizophrenia diagnosis. A recent audit of England and Wales estimated 97.5% of service-users given a schizophrenia diagnosis receive one or more 'antipsychotic' drugs (Cooper et al., 2014). The evidence base surrounding medications described as antipsychotic suggests their benefits are inconsistent; they may be helpful, unhelpful or even harmful (Moncrieff, Cohen & Mason, 2009). Researchers have highlighted that drug trials seldom consider participants' quality of life and functioning, such that those not taking antipsychotic medications may fare better in the long-term (Moncrieff, 2015; Whitaker, 2005). Furthermore, antipsychotic drugs are associated with increased mortality risk, tardive dyskinesia, weight gain, sexual dysfunction, diabetes, and emotional blunting (Rummel-Kluge et al., 2010; Moncrieff, 2015; Moncrieff et al., 2009; Murray-Thomas et al., 2013). Alongside rising concerns of unwanted consequences of antipsychotic drugs, researchers are calling for "an urgent need to ascertain whether the high mortality in schizophrenia is attributable to the disorder itself or the antipsychotic medication" (Joukamaa, 2006, p. 122).

Parallel to concerns about managing distress pharmaceutically, research has provided evidence to generate doubts regarding the validity, reliability and clinical utility of psychiatric diagnostic categories (Deacon, 2013). In the Diagnostic and Statistical Manual of Mental disorders (DSM-5) (APA, 2013), test-retest field trials reliability analysis reported intraclass kappas of 0.39 and 0.50 (pooled 0.46) for schizophrenia diagnosis, which were described as good by their

statistical norms (Regier et al., 2013). These statistical norms have relaxed over time, leading some to argue norms for “the DSM-5 field trial are unacceptably generous” (Vanheule et al., 2014, p. 313).

Further to diagnostic reliability concerns, due to the heterogeneity of experience within diagnoses, two people sharing a diagnosis (such as schizophrenia) may not experience any of the same ‘symptoms’ (Kinderman, Read, Moncrieff & Bentall, 2013). Concerns persist that diagnoses such as schizophrenia, do not seem to reliably describe or classify homogenous groups of experiences to guide clinical practice or research (Bentall, 2014; Tew, 2017). This may spur a ripple effect compromising prognosis predictions, treatments (and outcomes), and service provision. From a service-user perspective, a primary benefit of diagnosis should be access to accurate information regarding people’s experiences and how they cope (Rose & Thornicroft, 2010). Since evidence suggests diagnoses such as schizophrenia lack reliability and validity, these benefits are unlikely to be achieved. Where diagnoses are imprecise or inaccurate, and research seldom incorporates lived experience, one could argue schizophrenia diagnosis may offer little to researchers, practitioners, and service-users alike.

With mounting concerns surrounding psychiatric diagnosis, pharmaceutical industry influence has been questioned. During the most-recent DSM revision, panel members were required to disclose financial conflict of interests; 83% of psychotic disorder panel members disclosed pharmaceutical industry financial ties (Cosgrove & Krinsky, 2012). Concerns of ties between industry, research and clinical practice have grown on an international level. The UNHRC (2017) has argued human experiences are discursively transformed into symptoms, illnesses, and diagnoses, such that pharmaceutical treatment is inappropriately justified as a suitable and cost-effective management strategy. This has consequences on multiple levels, including health-care delivery and the wellbeing of people prescribed pharmaceutical drugs. In healthcare services for example, research suggests a comparative lack of clinical guidance and delivery of non-pharmaceutical treatments such as practical support or talking therapies, family interventions and trauma management (Cooper et al., 2014; Sara & Lappin, 2017).

Despite concerns, diagnostic and pharmaceutical interventions still form the frontline of healthcare for distress including hallucinations and psychosis. The biomedical model's dominance in distress management sits in an economic, political and cultural landscape. Its individualised approach fits within the western culture of individualism and neoliberalism, and the broader diagnostic and medical approach to health management (Mills & Fernando, 2014). With this format of help-seeking and health-care delivery being familiar and culturally valued for wellbeing, it is understandable that diagnosis and drugs are sought and that some people report finding such approaches helpful. Rose and Thornicroft (2010) reported diagnosis may be sought and used in attempts to contain fearful and chaotic processes associated with distress. It is concerning, however, that the consequences of being given a psychiatric diagnosis have a "sparse if not non-existent" evidence base (Rose & Thornicroft, 2010, p.140), despite diagnosis being a primary pillar of mental healthcare. It seems important to consider literature at community and service-user levels, surrounding lived consequences of diagnostic and biomedical approaches to experiences described as psychosis.

1.02.3 Of Community and Service-user Perspectives.

Schizophrenia diagnosis has been historically associated with poor prognosis and deterioration (Frese, Knight & Saks, 2009). Consistently, research suggests being more aware of "having a psychiatric disorder" is associated with reduced wellbeing (Ohayon, Kravetz, Roe, David & Weiser, 2006 p. 265). Although some service-users report benefiting from diagnosis, other service-users report negative impacts of the medicalisation of distress whilst seeking help. Waddingham's (2017) writings describe how:

It feels crazy to talk about rumination and insomnia without speaking of the dreams I have about finding my friend dead in her flat. It's bizarre to talk about my low mood without the hole in my heart. It's madness to talk about my suicidal ideation without honestly exploring the pain that makes it so difficult to continue to live in this world. Yet, over time, I get used to it. It becomes the currency of care – the dance I have to engage in to get the help I need. In time, the idea of me being mentally ill becomes more

concrete as the context of my distress – the suicide of my friend – becomes relegated to a mere trigger of an underlying illness. Waddingham (2017)

Waddingham continues by describing how mental illness terminology facilitates distance to avoid consideration of the painful and complex circumstances eliciting distress. For some people, this distance may be helpful, however Waddingham argues that by de-contextualising distress “we are – unintentionally – causing harm”. Furthermore, Dillon (2010, p.82) argued biomedical and diagnostic approaches systematically obscure and invalidate the relationships between difficult life experiences, trauma, and distress, leaving some service-users feeling “re-abused” by systems of (supposed) care. Rather than considering, on a person-centred basis, the complex, circumstantially situated experience and ongoing history of a person arriving in clinic, diagnosis may function to override complexity, reducing lived experience to an instance of a category (Rose & Thornicroft, 2010).

By locating distress onset and maintenance within an individual, the biomedical model lends itself to dualisms of separate internal body and external environment (Wade and Halligan, 2004). This downplays how lived experience is formed through, and relationally situated in social and material circumstances within which we live, act and interact (Bracken et al., 2012). Experiences of distress may be lost within circular logic where for example Jamie is given a schizophrenia diagnosis due to hearing voices, and Jamie hears voices because they have schizophrenia. This may leave little opportunity to make sense of experiences outside of diagnostic terms. The context and feeling of experiences are omitted from paradigms of distress focused on diagnosis, pathology and pharmacology. This is reflected by the research publication landscape, where it's estimated sixteen individualised biologically focused research articles are published for each one study considering the circumstances of distress (Read, Bentall & Fosse, 2009).

Although research studying the circumstances of distress is less common, often of a smaller scale and lesser funded, the results are internationally recognised (UNHRC, 2017). Research has evidenced robust circumstantial risk

factors for experiences described as psychosis and schizophrenia including experiencing socioeconomic inequality, poverty and deprivation (Harrison, Gunnell, Glazebrook, Page & Kwiecinski, 2001; Read, 2010), an excess of stressful life events (Bebbington et al., 1993), urban living (Sundquist, Frank & Sundquist, 2004), being a first or second generation migrant (Cantor-Graae & Selten, 2005; Coid et al., 2008) and being a refugee (Parrett & Mason, 2009). Experiences of trauma and neglect in childhood have been robustly associated with psychosis, with large scale research suggesting a dose-response relationship (Read, van Os, Morrison, & Ross, 2005; Misiak et al., 2017). Psychosocial approaches emphasise 'psychosis' represents a human capacity which can emerge in response to difficult life events, and noxious environmental circumstances (Bentall, 2003).

These contributing factors do not function in isolation: they interact and catalyse one-another to form toxic grounds for health and development. An example described in cross-cultural research is an economic trap, where those with lower socioeconomic status have a higher schizophrenia diagnosis risk, whilst those with a schizophrenia diagnosis are less likely to gain and retain employment (Rathod et al., 2017). Here socio-economic disadvantage, distress and employment difficulties form a mutually reinforcing spiral of personal and social decline. Similarly, in the UK, many factors are likely to contribute to the higher incidence of schizophrenia diagnosis in BME populations (Kirkbride, 2012). The higher risks associated with ethnicity could be relationally nuanced through multiple intersecting risk factors such as discrimination, socio-economic disadvantage and being a first or second-generation migrant (Cooper et al., 2008).

Recent incidence and prevalence research in England has studied schizophrenia diagnosis variation across geographical areas. Patterns of schizophrenia diagnosis in some areas of Nottingham, for example, have remained relatively stable over a 40 year period (Kirkbride et al., 2012). The researchers suggested socio-material factors such as social disadvantage, discrimination and deprivation may be enduring realities in some areas. This is consistent with the research of geographers such as Dorling, wherein health inequalities have been evidenced as spatially sorted such that regions and

localities hold and gain residents with similar levels of health and illness (Dorling, Mitchell, Orford, Shaw, Tunstall, 2009). In London, research has illustrated environmental neighbourhood-level risk factors were present for experiences described as non-affective psychoses, even when age, ethnicity and sex were controlled for (Kirkbride et al., 2007). By looking beyond individualistic boundaries, researchers, practitioners and communities may move towards more comprehensive and effective approaches to distress.

Research studying circumstances could address the outcomes paradox. Improved mental health outcomes are proposed in relation to socio-cultural variations like better social support, social networking, fewer critical remarks, and stronger familial networks for care and support (Kulhara et al., 2009; Padma, 2014). Furthermore, despite less access to treatment, people in rural areas may have more opportunities for social inclusion and forms of employment to integrate, interact and recover. Cross-cultural research illustrates high-income country mental health systems are often fragmented, expensive, and primarily focused on outcomes which are not relevant to service-users (Rathod et al., 2017). Consequently, lack of exposure to these systems (and to potentially harmful psychiatric diagnoses and treatments) could also serve to improve outcomes (Kulhara et al., 2009; Padma, 2014).

1.02.4 Of Psychosocial Understandings of Varieties of Human Experience and the History of Psychosis and Emotion

Taking a psychosocial approach may help researchers to understand the nuances of how distress feels within lived circumstances; such that management interventions hold more relevance to daily life. This may facilitate innovations like Hearing Voices Groups developed through the Hearing Voices Movement (Corstens et al., 2014). Within dominant biomedical models, the content, context, and feeling of experiences such as hallucinations, may be proposed as separate, unrelated and subordinate to primary concerns of disturbances of bodily function (Bracken et al., 2012; Wade & Hilligan, 2004). Consistently, the experience and contribution of emotion and feeling within episodes described as psychosis, has been neglected in both empirical and theoretical research (Freeman & Garety, 2003). This bias exists without corresponding evidence to justify it. In

presentations described as psychosis, there is much to understand regarding the circumstances (including social and material environment features) and felt lived experiences (including emotion, feeling and embodiment). Despite having been neglected, they seem to represent core facets of the experiences researchers are aiming to understand and which practitioners are trying to manage. Studying the feeling and circumstances of distress form two priority areas for future research.

Despite this comparative neglect of emotionality in psychosis research, there is a history of interest within some theoretical models and service-user movements to be acknowledged. Within the Hearing Voices Movement, Romme, Honig, Noorthoorn and Escher's (1992) research documented variations in the reactions of voice hearers and their ability to cope. Voice hearers who reported being unable cope were much more likely to be psychiatric service users. Consistently, Garety, Kuipers, Fowler, Freeman, and Bebbington's (2001, p.189) cognitive model of psychosis proposed "a central role for emotion". Within their model, the onset and maintenance of psychosis is partially mediated by emotional changes arising from either trigger situations or, experiences conceptualised as anomalous. Such scholarship has substantiated psychological interventions such as Hearing Voices Groups and Cognitive Behavioural Therapy for Psychosis. These interventions provide greater potential space for the experience and acknowledgement of emotions, than pharmacological interventions arising from biomedical traditions. Livingstone, Harper and Gillanders (2009) research argued that perhaps the role of emotion had been wrongly historically neglected due to conceptual separations between disorders of psychoses and neuroses (with emotions traditionally being more relevant to the latter). Research in recent decades has challenged the implications this conceptual divide and provides a basis from which examination of more specific experiences may be studied.

This thesis is aligned with increasing bodies of research, studying more specific and homogenous experiences associated with distress regarding which there is comparably less research (Vanheule et al., 2013). Studying experiences such as hallucinations, rather than relatively heterogenous diagnostic categories, can generate more reliable, valid and clinically useful research outcomes. Woods

et al. (2014) argued focused research could inform advances in clinical practice through more nuanced and precise understandings of hallucination experiences; with potential developments in research identifying hallucination causes. Despite the sometimes profound, disrupting and distressing aspects of hallucinations little research has looked at these experiences specifically (Bentall, 2014).

1.03 Overview of Empirical Literature Review Chapters

With a research context infused with problems from biomedical and diagnostic research legacies, a focus upon the feeling and circumstances of hallucinations enables three means to navigate the challenges facing mental health research. A focus on a specific experience of distress overcomes the problems of diagnoses; a focus upon circumstances attunes to the growing evidence of social-material causes of distress; and a feeling focus appreciates the situated lived experience of people who experience distress first hand. As there is now a growing International Consortium of Hallucination Researchers studying these experiences in their own right, with an accompanying growing evidence base, they are a timely experience to study. Studying the feeling and circumstances of hallucinations can navigate the challenges infused in existing mental health research, whilst benefiting from a novel and growing evidence base.

Existing hallucination research was reviewed systematically. Two systematic literature review searches generated three analyses (as Table 1.01 summarises). An initial systematic literature search (SR1) provided research from which analyses SR1a and SR1b mapped the feeling of hallucinations. This literature held some mention of the circumstances of hallucinations, identifying this as another area which merited investigation. To build a more comprehensive understanding regarding this topic, a second systematic literature search was performed (SR2), with its processes and resulting analyses provided in chapter-3.

Table 1.01

Brief Overview of the Systematic Reviews Forming the Remaining Empirical Literature Review Chapters.

<u>Systematic Literature Search No.</u>	<u>Systematic Review No.</u>	<u>Code</u>	<u>Chapter</u>	<u>Systematic Review Question</u>
1	1	SR1	1-2	What do Hallucinations Feel Like?
1	1a	SR1a	1	What do Unimodal and Multimodal Olfactory, Visual and Tactile Hallucinations Feel like?
1	1b	SR1b	2	What do Unimodal and Multimodal Auditory Hallucinations Feel Like?
2	2	SR2	3	What are the Circumstances of Hallucinations?

1.04 Systematic Literature Review Search Protocol

Biondi-Zoccai, Lotrionte, Ladoni and Modena (2011) described systematic reviews are characterised by a focus on a clinical problem, and a process of reviewing literature where the steps are clearly stated to facilitate potential replication. Hallucination research is composed of a mix of methodological designs and approaches. To maximise the available pool of knowledge for review, a mixed methods integrated design was used, whereby studies are selected for inclusion by their capacity to address the target research question (Sandelowski, Viols & Barroso, 2006).

The systematic review process was composed of 7 complementary steps summarised in Appendix A1. The steps included systematic literature searching using EndNote software. Endnote data from the literature search yields was exported to a literature database where it was organised. The exclusion criteria summarised in Table 1.02 were applied through brief and full screenings of the articles. Remaining articles were reviewed for quality, using the quality review protocol and framework (Appendix A2). The quality review framework was developed by drawing upon Caldwell, Henshaw and Taylor's (2011) standards for reporting and critiquing health research. Such standards includes clarity and suitability of research features such as the article aims, design, methods,

analyses and outcomes. Caldwell et al.'s (2011) standards fit hallucination research well, as they are built to consider both qualitative and quantitative methodologies. PRISMA standards were also drawn upon to recognise the role of bias; including conflicts of interest and funding (Liberati et al., 2009).

Table 1.02
Systematic Review Exclusion Criteria.

<u>Exclusion Number</u>	<u>Exclusion Criteria Described</u>
1	Research of hallucinations due to a physical health condition or identified physiological cause (e.g. Parkinson's disease, sensory impairment or brain lesion).
2	Induced hallucinations (e.g. acute effects of a substance, medication or an experiment).
3	Intervention research.
4	Research which did not collect data.
5	Studies which are not within the remit of the review. Studies must be investigating one of the following:
5a	SR1: What do hallucinations feel like?
5b	SR2: What are the circumstances of hallucinations?
6	Conference abstracts.
7	Unable to access the material to assess suitability.
8	Not in English language.
9	Duplicate or equivalent research.
10	Hallucination type not specified.

Consistent with an integrated systematic review design, research was synthesised by choosing the most appropriate way to combine data to explore the review question (Sandelowski et al., 2006). All the reviews were considering the quality of experience and so the data was meta-synthesised into qualitative discussions. NVivo and Microsoft-Word software were used. Consistent with the review literature, the proportion of participants reporting experiences are described where such information was available. The wealth of information available for SR1 regarding AVH, resulted in SR1 being split into its 2 sub-questions of SR1a and SR1b. This is described further in section 1.09.

1.05 Systematic Literature Search: What do Hallucinations feel like?

Figure 1.01 documents the publication rate increased steadily increasing before a rapid and sustained increase since 2000. The outputs of the SR1 search were recorded and documented in Appendix A3 and A4. The searches retrieved a total yield of 163 articles. Figure 1.02 illustrates the final publication-rate maintained the same overall trend. As summarised in Table 1.03, 146 articles were removed due to meeting the exclusion criteria. 17 remaining articles were reviewed for quality and methodological rigour.

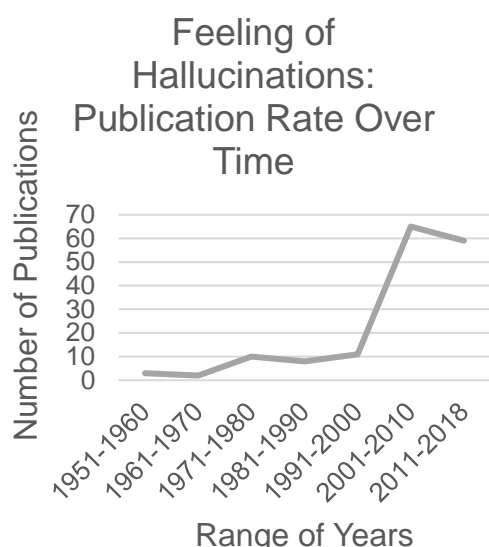


Figure 1.01 *The Publication Rate Over Time of Hallucination Articles Retrieved in SR1 Stage 1 Search*

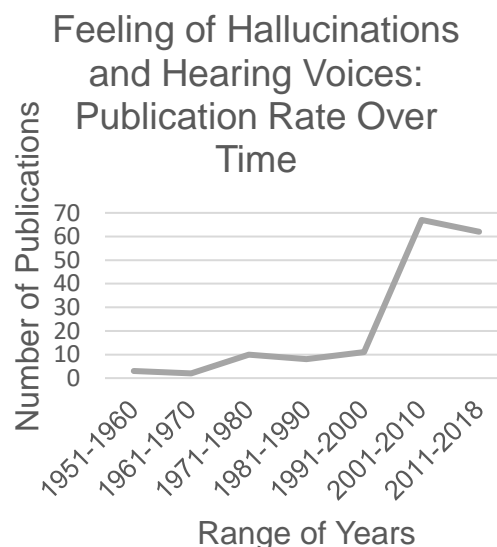


Figure 1.02 *The Publication Rate Over Time of Articles Retrieved in SR1 Stage 1 and 2 Literature Search.*

Table 1.03

Numbers of Papers Excluded by Exclusion Criteria.

<u>Reason For Exclusion</u>	<u>Number of Articles Removed</u>		
	<u>Brief Screening</u>	<u>Full Screening</u>	<u>Total (%)</u>
Health Condition	30	0	30 (21%)
Induced Hallucination	10	0	10 (7%)
Intervention Study	2	0	2 (1%)
Did Not Collect Data	33	1	34 (23%)
Not Within Review Remit	26	0	26 (18%)
Conference Abstract	21	5	26 (18%)
Unable to Access	2	2	4 (3%)
Not Written in English	4	0	4 (3%)
Duplicate or Equivalent Research	0	8	8 (5%)
Type of Hallucination Not Specified	0	2	2 (1%)
Total	128	18	146 (100%)

1.06 Systematic Literature Search 1: Quality Review Process Outcomes

SR1's quality review scoring matrix is held in Appendix A5; including scores of the final rankings and removed papers. The following features of the literature appeared to generate problems:

- Use of multiple concurrent standardised measures to study different aspects of hallucinations;
- Generating data at a single time-point;
- Reporting qualitative information primarily as statistical outcomes;
- Few studies explored hallucinations as occurring within a broader body;
- The circumstances of hallucinations were placed beyond the research remit (to be further explored in chapter-3).

The prominence of these features seemingly suspended the experience of hallucinations in a timeless, space-less, de-contextualised, immaterial, body-less void. Looking at statistical outputs of standardised measures may provide a contrived sense of phenomenology, with minimal insight into the texture of what it may feel like to experience and navigate within a world with hallucinations. Similarly, reporting the outcomes of qualitative data primarily as statistical outputs, may also pull apart the rich textures of the interrelated multifaceted felt aspects of experiences. The quality and methodological screening aimed to identify articles most able to comment on what hallucinations feel like. Most final articles were qualitative in method and phenomenological in approach.

1.07 Comparing Review Literature with Existing Prevalence Research

The review literature was most overtly organised via primary sensory modalities; research predominantly focused upon unimodal hallucinations (especially AH). This is consistent with reports empirical research has historically focused on AVH; that other hallucination types are typically overlooked as they were thought to be very uncommon. Such assumptions have not been supported by contemporary clinical research (Clark, Waters, Vatskalis & Jablensky, 2017; Waters et al., 2014). Waters et al.'s (2014) research drawn from 29 studies with 5873 participants given a schizophrenia diagnosis, reported that although AH seem more prevalent than VH, both are common at 59% and 27% respectively (Waters et al., 2014). Clark et al.'s (2017) clinical research of 1772 people (1303

described as first-episode psychosis [FEP], 469 chronic schizophrenia) reported 11-15% prevalence of OH and 12-17% prevalence of TH and/or gustatory hallucinations (GHs). Such research illustrates studying unimodal hallucinations of many kinds is appropriate given their prevalence in clinical populations.

Research published in the past five years has also suggested studying hallucinations involving multiple modalities is relevant. Clark et al. (2017) reported VH almost always occurs alongside hallucinations in other modalities (typically AH or OH). Their FEP participants reporting VH were 12 times more likely to experience hallucinations of multiple types than those without VH. Contemporary prevalence research concluded MMH were the most common perceptual experience among people given a schizophrenia diagnosis (Lim, Hoek, Deen and Blom, 2016), research therefore needs to look both within and across sensory modalities.

1.08 Brief Literature Overview from Systematic Review 1: What do Hallucinations Feel Like?

Table 1.04 summarises the research regarding only those participants who reported hallucinations. Figure 1.03 illustrates most research was in the global north and high-income countries, especially the UK; most online participants were also in the global north. Sample sizes ranged from 1 to 299 participants, aged between 16 and 80. Samples were biased towards being of white ethnicity, with more diverse samples being recommended in future (Upthegrove et al., 2016; Woods et al., 2015). The review outcomes therefore mostly (though not exclusively) reflect this bias.

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Table 1.04
Summarising the basic research information of SR1.

<u>First Author (Year)</u> <u>Author Location</u> <u>[Research</u> <u>Location if</u> <u>Different]</u>	<u>N=</u>	<u>Clinical</u> <u>Only?</u> <u>Mean</u> <u>Age</u> <u>(Range)</u>	<u>Mode</u>	<u>Method</u>
Stevenson (2011) Australia	N= 51	Yes 42 (23-63)	OH	1 Structured Interview
Gauntlett-Gilbert (2003) United Kingdom	N= 20	Yes 41 (29-53)	VH	1 Structured Interview
Suryani (2013) Indonesia	N= 13	Yes (19-56)	AVH	2 Semi-Structured Interviews
Upthegrove (2016) United Kingdom	N= 25	Yes 26 (27-37)	AVH	Diary, Photo- Elicitation, 1 Semi-Structured Interview
Lowe (1973) Canada	N= 60	Yes (18-80)	Unimodal & MMH	1 (Or More) Structured or Semi- Structured Interviews
Jones (2016) USA [Ghana, India, USA]	N= 80	Yes 40	AVH	1 Semi-Structured Interview
Moseley (2018) United Kingdom [Online]	N= 44	No 38	MH	Online Survey
McCarthy-Jones (2014) Australia	N= 199	Yes 33 (15-63)	AVH	1 Semi-Structured Interview
Nayani (1996) United Kingdom	N= 100	Yes 38	AVH	1 Semi-Structured Interview
Woods (2015) United Kingdom [Online]	N= 153	No (16-84)	AVH	Online Survey
Daalman (2011) The Netherlands	N= 229	No 39 (18-65)	AVH	1 Structured Interview (Standardised Measures)
Smith (2006) United Kingdom	N= 57	Yes 39 (19-65)	AH	1 Structured Interview (Standardised Measures)
Heveling (2004) Germany	N=1	Yes 68	TH	Case Study



Figure 1.03 Geo-graph Illustrating the Concentration of Hallucination Research in the Global North.

1.09 Splitting Systematic Review 1 In 2

Consistent with the SR1 literature, the review analysis was organised in terms of sensory modalities. After quality review, the literature database held numerous high-quality articles on the phenomenology of AH and AVH, with very few articles studying other modal kinds. To form a sound empirical understanding for further study and pay due attention to these comparative levels of available research, SR1 was split into 2 sub-questions:

- SR1a: What do Unimodal and Multimodal Olfactory, Visual and Tactile Hallucinations Feel like?
- SR1b: What Unimodal and Multimodal Auditory Hallucinations Feel Like?

The review analysis was conducted through in-depth article coding using NVivo. SR1a analysis had 1 or 2 articles for each hallucination type. SR1b could draw upon multiple sources commenting on similar aspects of phenomenology; providing an opportunity for more thorough comparative exploration. SR1b's AH analysis forms chapter-2. The current chapter presents the remaining articles of non-AH.

1.10 Systematic Review 1a. What do Unimodal and Multimodal Olfactory, Visual and Tactile Hallucinations Feel like? Outcomes from a Systematic Review Analysis

SR1a presents the available literature on what olfactory, visual and tactile hallucinations feel like, before the chapter closes with a brief summary analysis and considers areas from which further research should build.

1.11 Olfactory Hallucinations (OH)

Stevenson, Langdon and McGuire (2011) focus on OH was a unique contribution to SR1. Their Australia-based cross-sectional study, used a structured telephone interview with 51 participants (given diagnosis of schizoaffective disorder [n=14] and schizophrenia [n=37]). Figure 1.04 summarises the varied 139 OH smells documented; despite the variety, participants reported repeatedly experiencing a small group of OHs. Stevenson et al. (2011) also explored the interrelationship between OH and other senses. Participants experiencing OH more frequently, also reported more severe tactile

and auditory (particularly nonverbal) hallucinations. This indicates the relevance of multimodality to some participants experiences.

Most OH's were experienced monthly or less (59%), although they were weekly or more for 38%. OH valence varied, with negative OH's being most common, although participants most-often experienced a mix of OH's. Stevenson et al.'s (2011) participants were asked to report their most bothersome OH's. These were characterised by full or partial insight (78.9% of OH), negative valence (78.9%), vivid (84.2%), intense (68.4%), lasting a short time (between a few seconds or minutes) and mostly of an animal-like or burnt smell. The analysis of these most bothersome OH's, point to how varying feelings may combine to characterise the texture and salience of OH experiences.

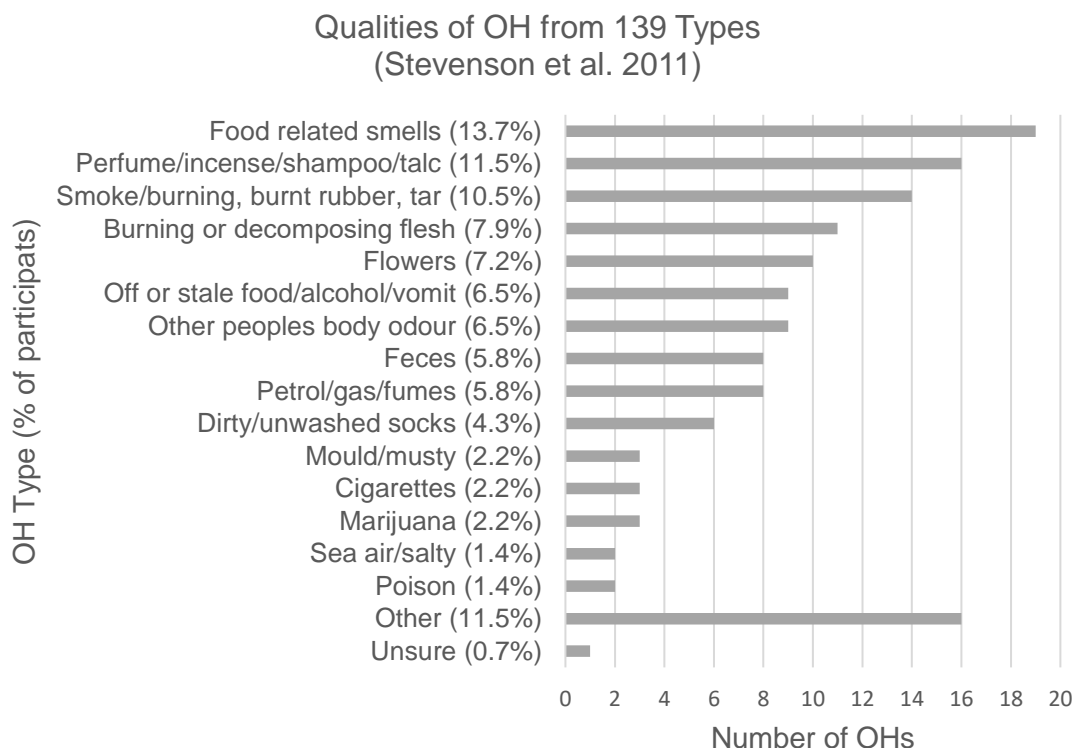


Figure 1.04 *Graph summarising the relative prevalence of descriptions of smells provided by Stevenson et al.'s (2011) participants.*

Participants reported actions to stop OH including relocating, smoking and looking for its source; the latter was reported less by those described as holding partial or full insight. This interrelationship between OH's and actions taken to manage them, highlight OH experiences arise in ongoing circumstances. Although the circumstances of hallucinations were not Stevenson et al.'s (2011) focus, they reported the most bothersome OH's typically occurred when at home.

Furthermore, they were described by 34.2% of participants as related to their past. This indicates a potential interrelationship between present OH and one's personal history.

Figure 1.05 summarises what experiencing OH may feel like: likely identifiable, real, emotional and potentially multi-modal. Stevenson et al. (2011) reported OH were not homogenous; although clusters of characteristics were shared, OH content, valence, feeling of reality, and multimodality varied. This review continues by exploring research regarding visual hallucinations.

OH Feel Identifiable		
• Smell Types (Animal-like, Body Odour, Burning [Rubber], Flowers, Food, Fumes, Gas, Marijuana, Mould, Petrol, Poison, Smoke, Tar)		
OH Feel Real		
• Vivid	Memory	• Insight
• Time (Frequency, Repetitiveness)		• Source
OH Feel Emotional		
• Varying Valence		• Negative Valence
OH Feel Multimodal		
• Tactile		• Auditory (Nonverbal)

Figure 1.05 Summary of the feeling of olfactory hallucinations.

1.12 Visual Hallucinations (VH)

Guantlett-Gilbert and Kuipers (2003) UK-based research was the first systematic study of VH phenomenology in a psychiatric sample; it was also the only review article focused on solely VH. Their research involved a structured interview focused upon the most emotionally impactful vision. The characteristics of VH included a feeling of identifiable quantity although no more than 3 were reported, and 60% of the sample saw only 1 type of VH. These visions had characterful properties which were typically humanoid (70% of sample); 64% of which were whole figures (individuals or groups) and 36% were faces or skulls. Other visions included animals (10%), objects (10%) and unformed visual phenomena such as electricity (10%). Humanoid visions were relationally

experienced as powerful both real and mythical) by 64% of the sample, or as strangers (29%) or acquaintances (7%).

Their study of unimodal VH also documented MMH prevalence. Simultaneous MMH regards hallucinations involving multiple modalities in parallel (e.g. seeing and hearing), whereas serial MMH regards the experience of hallucinations involving different modalities at different time-points (e.g. seeing then hearing). Simultaneous MMH, were reported as VH with voices by 20%, and VH with TH for 5%. Serial MMH were reported by a much larger proportion; as VH with AVH by 70%, VH with OH by 15% and VH with TH by 10%. Another SR1 article by Lowe (1973) similarly reported the prominence of VH with AH MMH among their participants described as paranoid.

The research suggests VH often feel identifiable, characterful and relational, and may be experienced in the felt context of other modalities. Gauntlett-Gilbert and Kuipers (2003) research shed further light on the feeling of VH, in terms of their visual perceptual qualities and feeling of reality. Visions were mostly experienced spatially in one's visual field within the midline or both hemifields (for 75% of sample) and mostly held a feeling of size constancy (70%) but were out of reach to touch (80%). Qualities of visual form included opaque with edges (80%) and seeming monochrome (55%). VH held dimensional qualities with 40% being 3D and 60% were bound to a surface. These perceptual qualities indicate how VH feel can feel similar or different to other every-day percepts.

In the moment, VH were described as feeling "definitely present", although certainty reduced with hindsight; the feeling of presence was consistent but less than half felt VH were concretely real. This provides an interesting distinction between feelings of presence and feelings of realness. Similarly, within Lowe's (1973) research, among participants experiencing VH with AH, in retrospect these experiences were reported to feel less real. Such research provides interesting implications for the interrelationship between feeling of realness and the flow of time. Interestingly, in Lowe's (1973) research, among those mostly reporting MMH of VH with AH, notable changes in one's sense of time were also reported. This suggests interrelationship between VH and one's feeling of time.

Looking to the felt source or origin of VH, 80% of Gauntlett-Gilbert and Kuipers (2003) participants felt VH were from an external source and 95% felt they consisted of something unseen before for; VH felt supernatural for 55% of participants. The combination of perceptual qualities alongside a presence, provides a complex feeling of un/reality to VH. VH were also described in terms of time; of frequency, duration, and one's sense of time. Frequency ranged from constant (for 15% of their sample), to occurring between 1-3 times (40%), with a duration of lasting typically seconds or minutes (65%). For some, VH arose during episodes (less than a fortnight), whereas for others VH were long-lasting, either in bouts or constantly (up to 12.5-years). 35% of participants saw visions for more than 1 year and for 90% they did not change with time. Suggesting an overall feeling of consistency regarding VH, akin to the aforementioned OH research where experiences tended to be of repeated clusters.

Gauntlett-Gilbert and Kuipers (2003) considered the relationship between VH and feelings. First VH experiences were reported as precipitated by feelings of stress for 85% of the sample, tiredness (60%) and loneliness (50%), as well felt circumstances of relationship difficulties (50%). For current VH, affective states were identified triggers for 45% of their sample; intentions or thoughts were not reported as precipitative of VH by any participants. At the beginning of a VH, they were felt to be surprising and unanticipated by 90% of the sample. Feelings during VH are summarised in Table 1.05. The feeling of being overwhelmed was reported most; although fearful and miserable feelings were common and positive feelings were reported by some participants.

Table 1.05

Summary of Gauntlett-Gilbert and Kuiper's (2003) Research on the Emotional Feeling of Visual Hallucinations.

<u>Feeling</u>	<u>Feeling Defined As 1</u> <u>(or More) of the Following:</u>	<u>% of</u> <u>Sample</u>
Overwhelmed	Helpless, Intruded Upon More Out of Control, Overwhelmed	95%
Fear	Anxious, Frightened, Terrified	80%
Misery	Depressed, Sad, Hopeless	60%
Positive	Reassured, Happy, Inspired	45%

Further to VH's emotional feeling, they were also accompanied by feelings of how VH related to broader lived experience. For 90% of participants, VH felt important and 60% felt VH implied a needed action, with 35% feeling negative consequences would occur if action was not taken. These feelings were reported as impacting on beliefs (60%) by eliciting changes in belief certainty or introducing new beliefs. VH were described as most important evidence for beliefs by 66% of their sample. Furthermore, for 55% of their sample, VH were evidence for beliefs described as delusional.

The research also pointed to some of the ongoing and interactive circumstances of people experiencing VH. Actions in response to VH were varied, including being inquisitive of VH (20%), acting to stay safe such as moving away, returning home, or reassurance seeking (50%), taking precautions to prevent recurrence (40%), trying not to think about it (60%) and feeling frozen or there was nothing one could do (25%). Figure 1.06 summarises the feeling of VH; including feelings before, during and after their occurrence, with varying impacts on one's beliefs and behaviour. VH were also characterised by identifiable, characterful properties, a feeling of reality, relationality and the potential for multi-modality.

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VH Feel Identifiable		
• Identifiable Quantity (1-3)	• Humanoid (Faces, Groups, Single Figures, Skulls)	
• Animals (Dog, Monkey)	• Inanimate (Gravestone, Objects, Noose, Unformed)	
VH Feel Relational		
• Powerful (Mythical, Real)	• Known/Unknown (Acquaintance, Stranger)	• Precipitated (Relationship Problems)
VH Feel Real		
• Location (Beyond Touch, Both Hemifields, Midline, Size Constancy)		• Dimensions (3D, Surface Bound)
• Form (Edges, Opaque)	• Movement (Moving, Static)	• Source (External, Novel)
• Present (Concrete, Supernatural, Unsure)	• Time (Changed Sense, Duration, Frequency, Stable)	
VH, Feelings and Time		
• Feelings During VH (Fearful, Important, Miserable, Overwhelmed, Prompt to Action, Positive, Surprised)		
• Precipitative Feelings (Acute Distress, Loneliness, Stress, Tiredness)	• Feelings After VH (Belief-Changing, Frozen, Inquisitive, Safety Seeking, Precautious, Un/certain)	
VH Feel Multimodal		
• Simultaneous (Tactile, Voices)	• Serial (Olfactory, Tactile, Voices)	

Figure 1.06 Summary of the feeling of visual hallucinations.

1.13 Tactile Hallucinations (TH)

Akin to OH and VH, just 1 article focused on TH. Heveling, Emrich and Dietrick (2004, p.387) reported a case history of a 68 year-old German woman “with a 25-year history of chronic schizophrenia”. The case report focused on visitations from a shadow man, who visited a few times a week at night when she was alone. The shadow man would step towards her bed and she could touch him. She described being soothed by him; being given a feeling of safety and she wished for his continued presence. Heveling et al. (2004) did not report on the other senses during the experience which was described as TH, and a

delusion of another person. However, within the aforementioned VH literature and the AVH literature that follows, hallucinations were often described as characterised by a feeling of presence, entity, and another living consciousness. The ascription of this being a hallucination and a delusion may not be necessary, if these feelings are regarded as parts of hallucinatory phenomena.

There was limited available research on TH. Despite this, the evidence points to interesting textures of feelings; including TH's identifiable qualities alongside emotional and real feelings (as Figure 1.07 summarises). The interrelationship between the feeling and circumstances of TH are also pointed to, in that TH happened at night, at home, when she was alone in bed.

TH Feel Identifiable			
• Identifiable Quantity (1)	• Stable over time	• Humanoid	• Gendered
TH Feel Real			
• Movement	• Presence	• Touchable	
TH Feel Emotional and Relational			
• Safe	• Soothed	• Wishing for Presence	

Figure 1.07 Summary of the feeling of tactile hallucinations.

1.14 What do Unimodal and Multimodal Olfactory, Visual and Tactile Hallucinations Feel Like?

The research on OH, VH and TH pointed to many interesting ways hallucinations feel (summarised in Figure 1.08). Hallucinations across modalities could be understood in relation to numerous shared properties including feelings of: identifiability, relationality, reality, emotionality and multimodality. Each of these broader properties were composed of varying dimensions. Wherein for example the feeling of reality related to felt dimensions such as: spatial location, source, presence, objective realness, insight, and temporality (duration, repetitiveness, frequency and stability or change over time). These many properties and dimensions may facilitate a range in complexity; as simpler hallucinations may involve less dimensions, and complex hallucinations may involve more felt dimensions and properties. The quality of each property's dimensions and the extent to which they applied, seemed to vary both within and

across modalities of hallucinations. In this way, although OH, VH and TH held shared qualities, they also appeared heterogeneous, as they had the potential to vary in seemingly infinite ways (in terms of the quality and extent of numerous felt properties and dimensions). Despite the potential for endless varieties of felt qualities and complexities of hallucinations, each property and dimension provides a shared avenue for understanding. For example, hallucination experiences across modalities could be compared in terms of their emotional feeling.

OH, VH & TH Feel Identifiable		
• Sensory Content	• Identifiable Quantity	• Characterful
• Related to Animate Beings	• Related to Inanimate Objects	
OH, VH & TH Feel Relational		
• Relationally Precipitated	• Relational Experience	
OH, VH & TH Feel Real		
• Presence	• Movement	• Vivid
• Form	• Source	• Location
• Insight (Objectively Real or Not)	• Temporality (Change, Duration, Frequency, Repetitiveness, Stability)	
OH, VH & TH Feel Emotional		
• Before	• During	• After
• Varying Emotions	• Mostly Negative Emotions	
• Some Positive & Comforting Emotions		• Mostly Impactful Emotions
OH, VH & TH Multimodal		
• OH + TH	• OH + Nonverbal AH	
• VH + AVH	• VH + OH	• VH + TH

Figure 1.08 Summary of the feeling of olfactory, visual and tactile hallucinations.

The empirical context of hallucination research discussed that within psychosis research the contribution of feelings and emotions were rarely considered (Freeman and Garety, 2003). SR1a has illustrated OH, VH and TH

experiences were characterised by the contribution and quality of many feelings and emotions. In attempts to understand experiences of hallucinations or care for people experiencing them, feelings and emotions should be attended to. Within the review literature, the contribution of bodily, somatic or embodied feelings were not attended to, although they were considered in terms of tiredness, or feeling frozen in relation to VH. Such feelings may warrant further exploration in particular. Furthermore, the research pointed to some varying emotions related to hallucinations, although the felt texture of these emotions was not explored; nor were their corresponding bodily feelings. Further research should therefore explore both the emotions and bodily feelings associated with hallucinations.

Section 1.07 reported OH, VH and TH were common but understudied experiences among psychiatric service-users (Clark et al., 2017; Waters et al., 2014). Fitting with this, although few studies explored these experiences, all the participants in SR1a were drawn from clinical samples. Existing research has also demonstrated the relevance of MMH (Clark et al., 2017; Lim et al., 2016), which has also been further illustrated within this review. This provides a further empirical basis for research to study hallucinations as unimodal and multimodal experiences. Continuing the exploration of what hallucinations feel like, the next chapter reports an AH systematic review analysis.

2. What do Unimodal and Multimodal Auditory Hallucinations Feel Like? Outcomes from a Systematic Review Analysis.



Figure 2. Still Photographic Image of a Painting from the Feeling-In-The-World Art Series during Gallery Exhibition at Attenborough Arts Centre in Leicester, 2018.

2.01 Brief Chapter Overview

Consistent with the context of hallucination research, mental-health research is mostly structured through problematic diagnoses such as schizophrenia. The dominance of individualised and biomedical approaches have neglected the feelings and circumstances of distress. To navigate these challenges, systematic literature reviews aimed to investigate the feeling and circumstances of hallucinations. This chapter presents part b Systematic Review 1 (SR1b) which maps the feeling of auditory hallucinations (AH) (including musical hallucinations [MH] and auditory verbal hallucinations [AVH]). Table 2.01 summarises SR1b's literature which consistent to chapter 1, demonstrates a bias towards the global north and high-income countries.

Table 2.01

Summarising the basic research information of studies explored in SR1b only.

<u>First Author (Year)</u> <u>Author Location</u> <u>[Research</u> <u>Location if</u> <u>Different]</u>	<u>N=</u>	<u>Clinical</u> <u>Only?</u> <u>Mean</u> <u>Age</u> <u>(Range)</u>	<u>Mode</u>	<u>Method</u>
Suryani (2013) Indonesia	N= 13	Yes (19-56)	AVH	2 Semi-Structured Interviews
Upthegrove (2016) United Kingdom	N= 25	Yes, 26 (27-37)	AVH	Diary, Photo-Elicitation, 1 Semi-Structured Interview
Jones (2016) USA [Ghana, India, USA]	N= 80	Yes 40	AVH	1 Semi-Structured Interview
Moseley (2018) United Kingdom [Online]	N= 44	No 38	MH	Online Survey
McCarthy-Jones (2014) Australia	N= 199	Yes 33 (15-63)	AVH	1 Semi-Structured Interview
Nayani (1996) United Kingdom	N= 100	Yes 38	AVH	1 Semi-Structured Interview
Woods (2015) United Kingdom [Online]	N= 153	No (16-84)	AVH	Online Survey
Daalman (2011) The Netherlands	N= 229	No, 39 (18-65)	AVH	1 Structured Interview (Standardised Measures)
Smith (2006) United Kingdom	N= 57	Yes, 39 (19-65)	AH	1 Structured Interview (Standardised Measures)

This chapter explores many AH qualities (including identifiable, characterful, relational, real, emotional and embodied feelings) before exploring the feeling of multimodal hallucinations (MMH) and synthesising the literature into a concept map of what hallucinations feel like. This chapter concludes by pointing to the areas which warrant further study. SR1b begins by exploring nonverbal AH hallucinations (NVAH) before reviewing the feeling of AVH.

2.02 Auditory Hallucinations (AH)

This section explores AH including NVAH and MH. Although voices were the most researched hallucination type, McCarthy-Jones et al. (2014) reported for 33% of their sample, their first AH experience was nonverbal. Overall, 42-62% of participants reported experiencing nonverbal AH (McCarthy-Jones et al., 2014; Nayani and David, 1996). Nonverbal AHs were described as musical (46% of participants), ringing (43%), animal sounds (29%), clicks (27%), humming (24%) and water (10%), and 56% reported other nonverbal sounds (McCarthy-Jones et al., 2014). Consistently, Nayani and David (1996) participants reported hearing whispers (10%), cries (2%) and clicks and bangs (16%). Further verbal-like sounds were reported by Jones and Luhrmann's (2016) participants, 17.4% reported quasi-nonverbal voices, which held no decipherable words and were interpreted as garbled speech. These outcomes indicate AH hold identifiable qualities.

NVAH were also reported in association with varying emotions. McCarthy-Jones et al.'s (2014) participants reported levels of worry due to NVAH; varying from being less (53%), equally (18%) or more worrying (25%) than AVH. In Lowe's (1973) research, among their participants described as paranoid, they typically experienced a single longstanding AH, which most-often elicited feelings of anger. AH in general were reported as associated with depression and low self-esteem (Smith, 2006). These findings point to the emotional feeling of AH; to be explored further in AVH.

Overall, despite NVAH being reported as common, and most hallucination research studying AH, NVAH were seldom explored. Figure 2.01 summarises SR1b's NVAH and AH (non-specified type) literature and illustrates AH were reported as holding identifiable qualities and difficult emotions (experienced to

varying extents). These properties mirror those generated in SR1a’s analyses of OH, VH and TH; although feelings of reality, relationality and multimodality were not focused upon in NVAH research. Consistent with SR1a, the bodily feelings and circumstances of NVAH received little attention, and moreover these experiences did not appear to be studied in-depth. This chapter on the feeling of AH, continues by exploring the feeling of MH before mapping the feeling of AVH and hallucinations overall.

AH Feel Identifiable			
<ul style="list-style-type: none">• Nonverbal (Animal, Bangs, Footsteps, Clicks, Music, Ringing, Water)	<ul style="list-style-type: none">• Verbal	<ul style="list-style-type: none">• Quasi-Verbal (Cries, Garbled Speech, Humming, Murmuring Crowd)	
AH Feel Emotional			
<ul style="list-style-type: none">• Anger	<ul style="list-style-type: none">• Depression	<ul style="list-style-type: none">• Low Self-Esteem	<ul style="list-style-type: none">• Worry

Figure 2.01 Summary of the feeling of auditory hallucinations.

2.02.1 Musical Hallucinations (MH)

MH are an AH subtype, which involve the "perception of music when none is playing" (Moseley, Alderson-Day, Kumar & Fernyhough, 2018, p. 83). Moseley et al. (2018) studied MH using an online mixed methods survey. MH were also considered by two other SR1 studies. MH were the most common form of nonverbal AH, reported by 46% of McCarthy-Jones et al.’s (2014) participants.

Further attention to MH was paid in Nayani and David’s (1996) research which used semi-structured interviews to explore AH experiences among 100 London-based mental health service-users. 36% of their sample reported MH. MH content was most-often described as choral music; with pop songs and fragmented orchestral music also being reported. Moseley et al. (2018) studied some of the emotional feelings during MH. Interestingly, the researchers reported negative feeling states (such as depression or anxiety) were no more likely to arise from MH than any other type of inner music. Consistent with this, those experiencing MH were no more likely to have been given a psychiatric diagnosis, than participants experiencing other kinds of inner music.

Moseley et al. (2018) reported the feeling and phenomenology of MH was multifaceted and differentially indexed from other inner music (e.g. earworms) in terms of frequency, repetitiveness, familiarity, controllability, felt location, sense of source, and how one feels in one’s body (in terms of movement or humming). MH were reported as less frequent and less repetitive. MH music also differed; it was less likely to have lyrics, it was less easy to hum along to (at the time or hum afterwards) and participants reported moving their body less to MH. MH felt less familiar and were more likely to be mistaken for arising from an external stimulus and felt less controllable (compared to mental imagery where one generates music in their mind). Moseley et al. (2018, p.92) reported the combination of MH feeling more unfamiliar and externally located, may enhance the “feeling of alienness typically associated with hallucinations”.

Figure 2.02 summarises MH as having identifiable qualities, feelings of reality and a lack of synchronicity with bodily feelings. Notably, compared to other kinds of hallucinations considered thus far (OH, VH, TH, AH) MH were characterised by a relative lack of emotional dimensions. Akin to the reports of OH and NVAH, MH were also characterised by lacking relational dimensions. Having mapped the feeling of MH, this review now explores AVH.

MH Feel Identifiable		
• Genre (Choral, Orchestral, Pop)	• Un/Familiar (Less Familiar, One’s Own)	• Completeness (Fragmented, Songs)
MH Feel Real		
• Controllability (Less Controllable)	• Source (More External)	• Time (Less Frequent, Less Repetitive)
MH Feel Embodied		
• Movement (Less Inclined to Move)	• Humming (Difficult to Hum)	

Figure 2.02 Summary of the feeling of musical hallucinations.

2.03 Auditory Verbal Hallucinations (AVH)

AVH were the most common form of AH or hallucination of any type discussed within the SR1 literature. AVH have been defined as “hearing a voice with a compelling sense of reality in the absence of an appropriate external

stimulus” (McCarthy-Jones et al., 2014, p. 225). Despite focusing on AVH, some articles reported outcomes in terms of AH. As such, this section’s analyses may refer to AH as appropriate. With there being more studies on AVH’s phenomenology, their felt properties and dimensions were studied in more depth. Literature on AVH’s feeling had explored many properties including their: characterful content, relational and entity-like qualities, the felt reality within space, time, and one’s conscious experience. The somatic, emotional and multimodal properties of AVH were also explored and the literature points to some of the ways in which felt aspects of AVH interrelate. This section of the review continues by exploring each of these felt aspects in turn, to provide an overview of what AVH feel like.

2.03.1 Characterful AVH.

Experiences of voices were most often described in personified or characterful terms where voices held identifiable and often distinct characteristics with one participant describing: “I hear distinct voices. Each voice has their own personality...My voices range in age and maturity. Many of them have identified themselves and given themselves names” (Woods et al., 2015, p. 325). Most voice hearers (66-81%) described hearing multiple, distinct, identifiable voices (Nayani and David, 1996; Woods et al., 2015). Hearing a single voice, was reported by just 7% of Woods et al.’s (2015) sample. Participants reported hearing three to four voices on average, with a broad range from one to forty voices heard (McCarthy-Jones et al., 2014; Nayani & David, 1996). For some voice hearers the total number of voices was constant (48% of participants), whereas for others it varied.

The reported characteristics of voices varied in many ways including age, accent, language and gender. Voices were mostly felt to be adults, with 71% of McCarthy-Jones (2014) sample hearing adult voices compared to 2% who heard children’s voices and 26% who heard a mix of both. Regarding gender, the literature reported voices’ characteristics in terms of male and female binaries. Although participants were most likely to hear both male and female voices, male voices were much more common than female voices (McCarthy-Jones et al., 2014; Nayani & David, 1996). Through combining age and gender data on voices,

Nayani and David (1996) argued they were most-often experienced as middle-aged males, followed by young-adult males and young-adult females. Interestingly, although more than 75% of Nayani and David's (1996) sample reported middle-aged sounding voices, participants under 30 were significantly more likely to report younger voices (children, teens, young adults). This indicates an interrelationship between voice hearers' characteristics and their voices' qualities.

Looking towards the language of voices, this was not described in many articles. Perhaps lack of exploration of spoken language was due to voices speaking in languages known to the hearer, although this was not reported. Upthegrove et al. (2016) did report several participants experiencing voices speaking different languages. Whether these were known languages to the hearer was not explored.

Regarding the accent of voices, Nayani and David (1996) studied this in depth. 71% of their participants reported voice's accents were different from one's own. The class of voice accents were more likely to be middle or upper-class voices, than working class (11%, 30% and 17% of participants respectively), with the researchers suggesting higher class characteristics may represent voices as authoritative constructions. The region of voice's accents often differed from the participant's own but reflected their cultural heritage; for example accents from different countries were akin to accents of one's family. The role of accents in voice hearing varies within the literature, as although they were widely reported in Nayani and David's (1996) paper, 9% of McCarthy-Jones et al.'s (2014) sample reported their AVH often had accents, and the vast majority (74%) reported their voices never had accents.

Although level of investigation into the linguistic qualities of voices varied, many studies explored the extent to which voices were familiar. The identity of voices were often of known existing individuals, or of spiritual or supernatural beings (Daalman, 2011; McCarthy-Jones et al., 2014; Nayani & David, 1996; Upthegrove et al., 2016; Woods et al., 2015). The voice held the identity of a known person in 16.5-46% of participants (Daalman et al., 2011; McCarthy-Jones et al., 2014; Nayani & David, 1996; Woods et al., 2015). Upthegrove et al.

(2016) reported the communication from known AVH voices (such as family members) was intimate and personal. As well as being of known people, the voices were identified as spiritual or supernatural among 15-24% of participants in the research (Daalman et al., 2011; Nayani & David, 1996; Woods et al., 2015). It is also notable however that in some studies for 31% of samples, their voices identities were unknown (Daalman et al., 2011; McCarthy-Jones et al., 2014), suggesting variation in familiarity is common.

Though the characterful and often personified qualities of voices were common across the literature, for 14% of Woods et al.'s (2015) sample, their voices were not identified as having characterful properties at all. With the results of phenomenological research being primarily reported in quantitative terms, there may be a tendency in the literature and subsequent systematic reviews towards the majority trends in experiences. The nuances of deviations may therefore be left outside of the scope of explored research.

To summarise, although the majority of participants experienced voices as characterful entities, this was not the case for all reported experiences and there was variation within and between SR1b's articles. Nayani and David (1996) proposed AVH may be modelled on real voices as they were often of known people. This was supported by McCarthy-Jones et al.'s (2014) more recent research, where 70% of participants described AVH were similar to people they had spoken to and 56% of participants feeling their voice's message was linked to influential people in their life. McCarthy-Jones et al. (2014) proposed examining the lives of voice hearers may be informative. The broader research on AVH's characteristics illustrate how voice hearing experiences are nuanced in terms of one's own circumstances (age, cultural heritage, class). Further studying the lived circumstances and histories of people experiencing AVH, may support in understanding and making sense of these experiences.

As summarised in Figure 2.03, the felt characteristics of voices included a feeling of quantity -of how many voices one experienced- and of numerous characterful qualities, experienced to varying extents. These distinct, identifiable, characterful qualities included a feeling of age, gender, language, accent, and a feeling of un/familiarity. Further to the often characterful feeling of voices, they

were reported throughout the literature as holding relational and interactive qualities.

AVH Feel Characterful		
• Age	• Gendered	• Un/Familiar
• Language (Same or Different)	• Accent (Class and Region)	• Identifiable Quantity (Total)

Figure 2.03 Summary of the characterful feelings of auditory verbal hallucinations.

2.03.2 Relational AVH.

Further to AVH’s often characterful feeling, they were often described in relational, communicative and conversational terms. AVH experiences varied in terms of their conversational style, tone and content. The relationships people experienced with their voices varied across the review, as did the perceived power of voices. Throughout the research, AVH were typically described as conversational experiences, where voices separately addressed the hearer (McCarthy-Jones et al., 2014) and took turns (Upthegrove et al., 2016). Reports of voices speaking only single words or brief phrases were rare (Woods et al., 2015).

In addition to conversational voices, simultaneously speaking voices were described by 39-57% of participants; such as hearing collections of voices, classroom groups, choruses, mumbling crowds and gangs (McCarthy-Jones et al., 2014; Nayani & David, 1996; Woods et al., 2015). The majority (75%) of people who heard voices which conversed with one another, also heard voices which addressed the voice hearer directly. The form of address was typically reported as first or third person, and stable over time (McCarthy-Jones et al., 2014).

The content of AVH varied in many ways, including experiences of comments, criticism, abuse, commands, and guidance. Commenting voices during daily activities were described as frequent, with a participant of Woods et al. (2015, p. 325) describing: “they comment on what I’m doing and whether I’m doing a good job or what I could be doing better”. Alongside commenting voices, critical or accusatory voices were also common; with Upthegrove et al. (2016)

describing a common belief from participants that their voices were punishing them. 'Simple terms of abuse' were the most common content type reported by 60% of Nayani and David's (1996, p. 182) sample. This abusive content was typically gendered, with insults of promiscuity used towards women and of homosexuality towards men. Similar to the characterful properties of AVH, this gendering of content suggests an interrelationship between AVH's form and the circumstances they arise in. Upthegrove et al. (2016) described a range of abusive content, including mockery, ridiculing, name calling (e.g. idiot) and threats; which ranged from unspecific to violent and graphic. Threats were described as a means of voices asserting control and emphasised by an aggressive vocal tone. In comparison, mocking for example was described as associated with sarcastic laughter (Upthegrove et al., 2016).

McCarthy-Jones et al.'s (2014) sample reported commanding voices as happening sometimes (32% of participants) or often (35%). Suryani et al. (2013) reported difficult outcomes when unable to resist commands, as one participant reported "I just did whatever the voices instructed me to do...I had eaten my stool and drank my urine." (p. 315). Larger scale research has however highlighted 76% of participants felt they were able to resist commands (McCarthy-Jones et al., 2014). The relevance and frequency of negative command hallucinations may be overstated in the literature and media, as these are culturally stereotyped and stigmatised in light of famous criminal cases such as the Son of Sam. Large scale meta-analytic research has proposed crimes such as stranger homicide in psychosis are rare (Nielssen et al., 2011). Consistently, Woods et al. (2015) reported only 5% of their sample experienced predominantly negative commands of any kind, and voices which were abusive and violent towards the hearer were much more common.

Though command AVH were discussed across the research, 25% of McCarthy-Jones's (2014) sample reported never experiencing them. Furthermore, Upthegrove et al. (2016, p.91) proposed the power implied by the term 'command' should not be assumed, and experiences reported in their research were more akin to demands. They also described occasional reports of guiding voices which offered broad or specific support including: defence, help and practical guidance (i.e. positive commands/demands). One participant

described being told “to avoid certain roads or... maybe get out a bit earlier or do certain things for my own good” (Upthegrove et al., 2016, p. 91). Potentially, reports of commands in the literature may be inflated. Terms such as demands and guidance may be more suited to many experiences.

Though the conversational form and content of voices varied, they were often described as relational experiences. 64% of McCarthy-Jones et al.’s (2014) sample described having a relationship with their voices; with these relationships almost-equally-split between being stable or changing over time. AVH’s relational form varied across the research; from a difficult controlling and inescapable authority regarding which one is passive, to experiences over which there is some room for control. A bitter intimacy was described by Nayani and David (1996, p.186), as their research described a relationship with the voices, came at the cost of one’s privacy; one participant described this experience as “an open mental wound”.

Upthegrove et al. (2016, p.90) reported similarly difficult experiences, where AVH were described as imposed relational experiences, where one’s “ears are made to hear it”. Their AVH analysis was characterised by a feeling of a level of authority and control from the voice, broader than simply command content. Voices were described as using abusive and complex interactions to gain power and authority over the voice hearer. Control was described as being able to influence hearer’s emotions, to mislead them into action and use their known information for manipulation. Description of the hearer’s lack of control, were discussed in terms of the voices’ constancy, inescapability, compelling feeling, authority and disruptive interference.

Contrary to Upthegrove et al. (2016), in Woods et al. (2015) just 22% of participants felt fully passive and unable to influence their voices; 35% could indirectly influence their voices through for example medication or changing environment, and 45% could directly influence their voices by engaging with them or exploring their meaning. This builds on Nayani and David’s (1996) research where 51% of participants could control their voices in some way, with 38% being able to start them and 21% sometimes being able to stop them. They reported responding to voices (for example through conversing with them), had

a significant effect on distress, with voice responders more-often described as being of low distress. As well as people interacting with their voices, some chose to ignore them with varying consequences. Ignoring would stop the voices for some (Suryani et al., 2013) and for others this would transform the sonic quality of voices, from being thought-like to audible (Jones and Luhrmann, 2016).

Perhaps the variation in capacities to influence voices reflects not only the heterogeneous feeling and form of the experiences, but also the varying methods and samples of the research. Upthegrove et al. (2016) conducted in depth qualitative research with a small sample of EIP service-users, whereas Woods et al. (2015) and Nayani and David (1996) conducted large scale surveys. Although Nayani and David (1996) had a service-user sample, Woods et al.'s (2015) was an online mixed sample. Despite the variation between these studies, they all indicate understanding and harnessing the relational qualities of voices, may be important in managing the wellbeing of voice hearers. The value of such processes may be reflected in the rise of the Hearing Voices Network and Hearing Voices Groups. Figure 2.04 summarises the relational qualities of voices as discussed in this section. SR1b has thus far demonstrated AVH are often identifiable, characterful, and relational experiences. This review continues to develop a picture what AVH feel like, by exploring their feeling of reality.

AVH Feel Relational		
• Identifiable Quantity (Talking at Once)	• Relationship	• Relational (Ignore, Influence, Interact, Power)
• Content (Abusive, Brief, Commands, Commenting, Conversing, Criticism, Demands, Guiding, Personal)		

Figure 2.04 Summary of the relational feelings of auditory verbal hallucinations.

2.03.3 Reality of AVH.

Further to AVH's often identifiable, characterful and relational experiences, they were also described as holding dimensions of reality. AVH most notably were described as holding a feeling of a real existent living entity (Nayani & David, 1996; Upthegrove et al., 2016). AVH's feeling of reality was characterised by interrelated features including: a feeling of presence, and of

being situated in time, material and bodily space, and one's conscious experience. This section of the chapter considers each of these.

2.03.3.1 Feeling of Presence and Entity, Situated within Conscious Experience.

A prominent theme in Upthegrove et al.'s (2016) research was a feeling of entity which the voice belonged to. AVH were described as veridical speech perceptions which felt real. A feeling of reality such that distinguishing between perceptions which did and did not fit with consensual reality became difficult. Participants reported surprise that others could not hear their voices, and AVH were akin to overhearing or having 'real' conversations. Upthegrove et al. (2016, p.92) reported "hallucinations thus resemble true perceptions and have all the vividness of real experience". This chapter soon demonstrates many experiences of AVH or 'voices' do not fit with these descriptions. Although they may still hold properties of reality with dimensions of presence and entity, AVH are often not experienced in forms akin to veridical speech or so-called true perceptions.

Exploring the feeling of reality of AVH further, 85% of McCarthy-Jones et al.'s (2014) participants reported a "very-real" level of reality. Notably however, 11% of McCarthy-Jones et al.'s (2014) sample reported experiences were dream-like or somewhat real. This suggests the feeling of reality of voices varies between voice hearers. Interestingly, only a weak correlation was reported by Nayani and David (1996) between the reality of hallucinations and level of insight. They therefore concluded the feeling of reality may be independent from the extent to which one accepts "that he suffers from a disease that causes it [AH]" (p.187-88); implying insight derives from more than the hallucination's feeling of reality and may interrelate with acceptance of a disease model of distress. Insight and feelings of reality were discussed as somewhat static experiences, perhaps due to generating data at single time-points by Nayani and David (1996) and McCarthy-Jones et al. (2014). It may be interesting to study voice hearers' understandings of what voices are and how voices feel of over time, to shed light on a more nuanced understanding of hallucinations' feeling of reality.

The feeling of AVH's reality, was often accompanied with a sense of authority and power, a "pull", with participants describing "It's the main part of my life...I am pretty powerless to stop it because of how strong it is" (Upthegrove et al., 2016, p. 93). With the voices feeling strong and oneself feeling weak, many participants described feeling powerless; some felt their voices were in control of their lives and thoughts. Suryani et al. (2013) reported some participants felt so under their voices' control they no longer felt human, as parts of their humanity felt lost.

Interestingly, Upthegrove et al. (2016) reported an association between voices' power and their unpredictability. This harks back to the overall feeling of a relational and authoritative entity, with power to control. Upthegrove et al. (2016) described AVH were experienced as physically imposing and forceful upon hearers, with a more than auditory overall experience. In keeping with this, 23% of Jones and Luhrmann's (2016) sample reported voices which held a felt physical presence for example, physically feeling voices within one's ears, even when they were not speaking. This points to some of the multimodality of AVH, which this chapter later explores. Chapter-3 returns to presence with regards to bereavement hallucinations.

Regarding the feeling of reality of hearing voices, there was a sense that AVH permeate through conscious experience, with reports of voices being compelling and difficult to ignore, with voices becoming the focus of one's attention and awareness (Upthegrove et al., 2016). In relation to one's own thoughts, half of McCarthy-Jones et al.'s (2014) sample reported the content of voices may have reflected one's own past thoughts. For 46% of Nayani and David's (1996) participants, AH voices had replaced their own inner voice of conscience, with some relying on voices for guidance. There was an overall sense voices became intimately embedded within conscious experience.

The felt reality of AVH seemed to involve the experience of another distinct conscious entity(ies), which was felt and sensed within one's own consciousness. A dominant theme within Jones and Luhrmann's (2016) research, was the convergence of voices, thought passivity phenomena (e.g. thought insertion) and attenuated ego boundaries (difficulty distinguishing

between oneself and others). This is consistent with propositions that experiences such as AVH and thought insertion could be considered on a spectrum (Humpston & Broome, 2016). Within Jones and Luhrmann's (2016) sample, 60% reported reduced ego boundaries, 71% reported thought access and 55% reported thought control. They described a core experience of disrupted subjective boundaries between private thoughts and oral speech, as well as mental exteriority and interiority. This was reported as a more common and homogenous experience than any sensory AH pattern within their cross-cultural sample; suggesting disruptions of self may be most characteristic of AH (Jones and Luhrmann, 2016). This outcome was distinct within the review. Overall, the literature described AVH as feeling enmeshed within yet separate from one's own consciousness. AVH were mostly reported as not one's own voices or thoughts (though they may reflect or guide them).

Exploring research on the felt source of voices may support in teasing apart how hallucinations feel within, yet somewhat distinct from, one's consciousness. Voices were ascribed external explanations for 72% of Nayani and David's (1996) sample; of evil or good forces (51%), plots or conspiracies (16%), or ghosts, spirits or aliens (5%). In Daalman et al.'s (2011) comparison voice hearers described as healthy, compared to those accessing psychiatric services, 'Healthy' participants were described as significantly more likely to hold predominantly external explanations for voices. Figure 2.05 illustrates further differences between the two groups, in terms of the felt characteristics of the AVH's external sources.

Regarding the source of voices in relation to one's own consciousness, some voices were described as akin to memory. From McCarthy-Jones et al.'s (2014) sample, 31% and 12% described voices were similar or identical to memory replays respectively. This was described as reflecting the 'gist' recall of memory. It also harks back to the earlier described characterful properties of many AVH, which often resemble known, familiar people and social interactions.

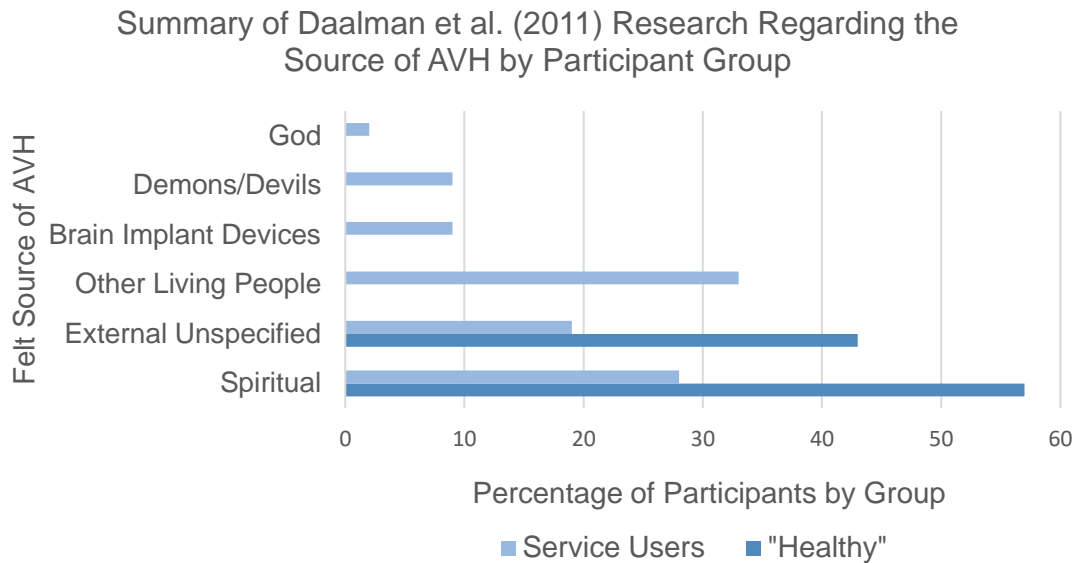


Figure 2.05 Graph Illustrating the Felt Source of AVH by Participant Group in Daalman et al. (2011).

To summarise the feeling of reality of AVH, such feelings regard a feeling of presence or entity and a feeling of what voices are in relation to one's own conscious experience (of externally created sensations or, moments of reliving one's own past memories). The feeling of reality of AVH also seemed to relate to the location of voices in space and in time.

2.03.3.2 Feeling Situated Within Space and Time.

Throughout the SR1b literature, there were discussions surrounding the location of voices in terms of bodily space and whether voices were located inside or outside of the body; with externally located voices described as traditionally indicative of true psychosis or hallucinations. Notably, this claim was not supported by the systematic review literature, with Upthegrove et al. (2016, p. 92) reporting voice location "may indeed be the least clinically useful" aspect of AVH. Daalman et al. (2011) found no difference in perceived voice location between clinical and non-clinical voice-hearing samples. Nayani and David (1996) consistently reported insight regarding voices experiences did not vary between internal and external hallucinators.

Voices were described as heterogeneous phenomena both within and between individuals, with "experiential nuances that exceeded traditional divisions between external and internal space" (Jones & Luhrmann, 2016, p.

196). For example, some voices were reported to move within one's body or between external and internal space. This research suggests although voices are often experienced spatially in terms of one's body, there may be high variability in terms of where voices are heard. In Nayani and David (1996) 49% of participant's voices were heard as external, 38% internal and 12% experienced a mix of both. All but 2 internal voice hearers located their voices within their bodies; typically their head and centre forehead. In McCarthy-Jones et al. (2014), the majority of external voice hearers (75%) heard sound in both ears. The location of the voice was stable over time for 65% of Nayani and David's (1996) participants, and the source did not tend to move; although voices were reported to move in other studies (Jones & Luhrmann, 2016).

The phenomenological online survey by Woods et al. (2015) reported the range of voices of 3 kinds displayed in Figure 2.06. AVH seemed to vary on a spectrum within the SR1b literature between thought-like non-auditory voices to clearly auditory literal voices (indistinguishable from other external speech sounds). This provides a sense of how feelings such as the location, felt source, and sound qualities of what we call voice-hearing may interrelate. It seems the colloquial meaning of terms such as voice hearing and hearing voices, may not fit the phenomenological properties of many kinds of AVH. As such, they may orientate understandings of AVH towards certain kinds of experiences and away from others. Earlier discussions noted established understandings of AVH as most valid when externally located and indistinguishable from other outside speech sounds. Favouring the term hearing voices may inadvertently perpetuate this orientation, which does not necessarily reflect many AVH experiences, nor contemporary research on hallucinations.

The SR1b research challenges established understandings of AVH as being solely externally located and literally auditory, by highlighting AVH experiences as varied both within and between individuals. The range of voices described, potentially suggests an interrelationship between the feeling of both internal and external spaces and sources. Established understandings of AVH are further challenged by 9-15% of participants reporting experiencing exclusively thought-like voices (Jones & Luhrmann, 2016; Woods et al., 2015). Notably, just 17.5% reported exclusively literally auditory voices (Jones &

Luhrmann, 2016). The often thought-like non-auditory experience of voices, provides a further nuance of how voices are experienced as characterful, relational and real; voices may not always be as auditory-verbal as the terms AVH and voices typically suggests.

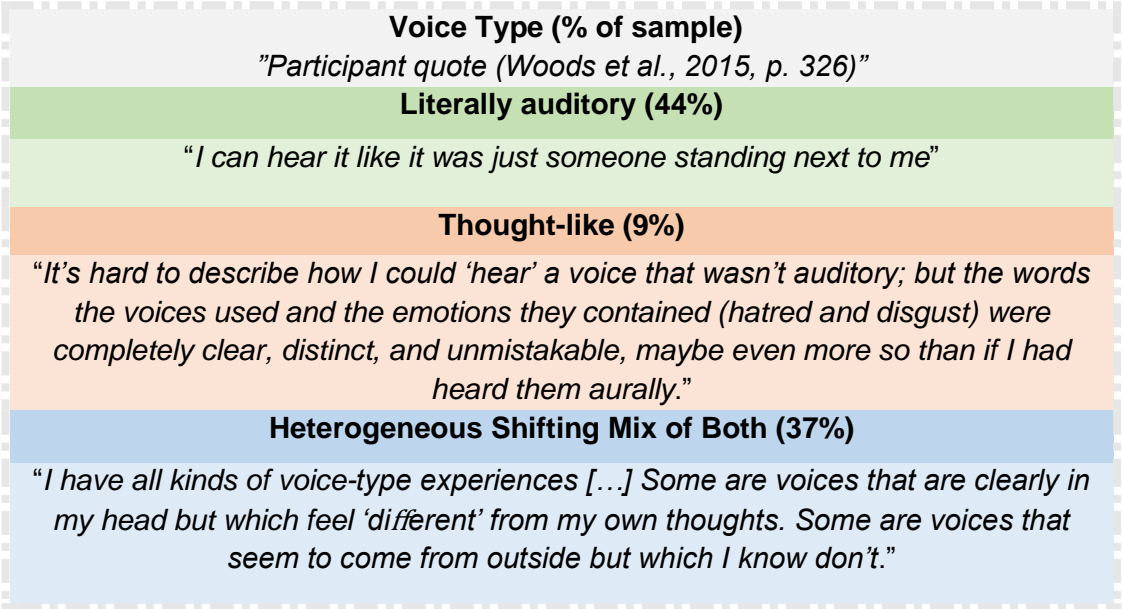


Figure 2.06 Examples of types of voices described by participants of Woods et al. (2015).

There was mixed research regarding the interrelationship between the location of voices, their auditory qualities and their feeling of reality. Nayani and David (1996) described those who reported greater feelings of reality, were more likely to hear external voices, and internal voice hearers were more likely to experience voices of an ideational quality. Upthegrove et al. (2016) however reported a lack of association between voice location, sound quality and feeling of realness, providing an inconsistent overall picture. With much of the research reporting outcomes in terms of statistical calculations, it was difficult to learn about how the texture of feelings interrelate and vary. Future research drawing upon qualitative analysis and sharing first-person expressions of hallucinations, may support in shedding more light upon the complexities of hallucinations.

The analysis of AVH's reality has explored how voices feel in terms of: feelings of presence and entity, feelings in relation to one's own consciousness, and feelings in terms of source and spatial location. The last element of the feeling of reality of hallucinations to explore is their feeling in terms of time. The

aforementioned memory-like quality of some AVH pointed to some of the ways in which feelings of time, consciousness and presence may interrelate.

Hallucinations were most often described as experientially situated in time in terms of their frequency, duration, as well as their repetitiveness over time and capacity to change over time. AH were experienced frequently for Nayani and David's (1996) sample ranging from constant (15%), most of the day (37%), several times a day (36%) to a couple of times per day (12%). McCarthy-Jones et al.'s (2014) participants reported the duration of AH lasted seconds (for 12%), minutes (for 31%) or hours (for 59%), with the researchers noting the duration of AH varied during the day for 59% of participants, something which had not been accounted for within research and may warrant further exploration. Further to AVH often being long in duration and frequent, voices were described as repetitive across much of the research. Voices were often described as being stuck on a theme of content, with almost half the sample reporting experiencing the same words and phrases repeatedly.

McCarthy-Jones et al. (2014, p.231) described an overall picture where most participants "heard the same voice, most or all of the time, saying the same things", with new voices continuing these themes. The voice tone and content in addition to its form of address, had stayed the same over time for 70% and 85% of their sample. Consistently, they reported an AVH subtype of constant, commanding and commenting voices, fitted 86% of participant's experiences. This feeling of constancy was also a common theme in Upthegrove et al. (2016), where voices were reported as unrelenting although they varied from being in the background to harassing in the foreground. Nayani and David (1996, p.187) also reported hallucinations repeated "across illness episodes"; 66% of their sample provided examples which were often vulgar simple insults. Perhaps the repetitiveness and constancy of AVH, also elicits the feeling of memory described earlier by McCarthy-Jones et al. (2014).

Although some experiences of AVH were described as repetitive and constant over time, some changed. 35% of Woods et al.'s (2015) sample described changes in the number and presence of voices; for 19%, voice content, frequency or emotional impact changed. Within their sample, women were more

likely to report change over time and just 1 participant described no change over time. Figure 2.07 summarises Nayani and David's (1996) research on change over time. They proposed AVH evolve and internalise over time, through becoming increasingly intimate, personified and complex, with evermore detailed dialogue about or with the hearer. Nayani and David (1996) described the price of reduced distress, is greater encroachment upon one's life and incapacity. These experiences fit with descriptions of Suryani et al.'s (2013) participants which are discussed in more detail in the later emotions section of this review. In their research participants reported deep confusion and difficulty functioning in relation to command voices, which were contradictory to one-another or one's own beliefs. The commonplace experience of change over time in AVH is in contrast to experiences of visions, which remained stable over time for 90% of Gauntlett-Gilbert and Kuipers (2003) sample.

Recent Onset of Voices	Longer History of Voices
<ul style="list-style-type: none">• Fewer and Less Complex Voices• Voices Less Likely to:<ul style="list-style-type: none">• Encourage Dialogue• Comment on Thoughts• More Distressed by Voices• More External Voices	<ul style="list-style-type: none">• More Frequent Voices with:<ul style="list-style-type: none">• More Words• More Emotional Range• More Styles of Address• More 'Delusional' Understanding of Voices• More Internal Voices

Figure 2.07 Summary of Nayani and David's (1996) research on the change in voices over time.

Figure 2.08 summarises the feeling of reality of AVH, including their feeling of presence, entity and realness; their varying feelings of arising from an internal or external source; their feeling of being experienced within and connected to one's consciousness; their feeling of being materially or spatially located; and their feeling of being experienced within and across time. The multi-faceted picture of this concept is fitting with Nayani and David (1996, p.185) conclusions "that 'reality' may include several overlapping constructs".

AVH Feel Real		
• Presence (Entity, Powerful, Real)	• Space and Location (Body, Internal, External)	• Source (Internal, External)
• Consciousness (Thought-like, Attention, Memory, Insight)	• Time (Frequency, Duration, Repetition, Change)	

Figure 2.08 Summary of the feeling of reality of auditory verbal hallucinations.

SR1b’s analysis has built a picture of AVH as an AH subtype holding identifiable characteristics, quantities, and varying levels of characterful qualities: an experience that holds relational capacities and has a multifaceted feeling of reality to them. In sum, AVH often feel characterful, relational and real. This review continues by mapping the emotional and multimodal picture of AVH.

2.03.4 Emotions of AVH.

Daalman et al. (2011) studied the extent to which AVH’s phenomenological features could predict whether their voice hearing participants were ‘healthy’, or current service-users with a psychotic spectrum diagnosis. This could be predicted with 88% accuracy, by one feature; the emotional valence of voice content (with negative content being indicative of having been given a psychotic spectrum diagnosis). This indicates emotions may substantially contribute to the lived experience of AVH. Consistently, a subtheme of Upthegrove et al. (2016, p.93) was the threatening experience of voices; one participant described they were “really aggressive or angry, shouting”.

Woods et al. (2015) also explored emotions and voice-hearing. Their online sample was split into clinical and non-clinical groups. Their clinical group were more likely to describe fear, depression and anxiety in association with voice-hearing (though the anxiety was not statistically significant). Woods et al. (2015) provided an overview of the emotional feelings associated with AVH, summarised in Figure 2.09. Most of the emotions were difficult or negative including fear, depression, anger, stress, and shame. Further difficult feelings were described by Suryani et al.’s (2013) participants, as AH elicited feelings of confusion, fright and uncertainty.

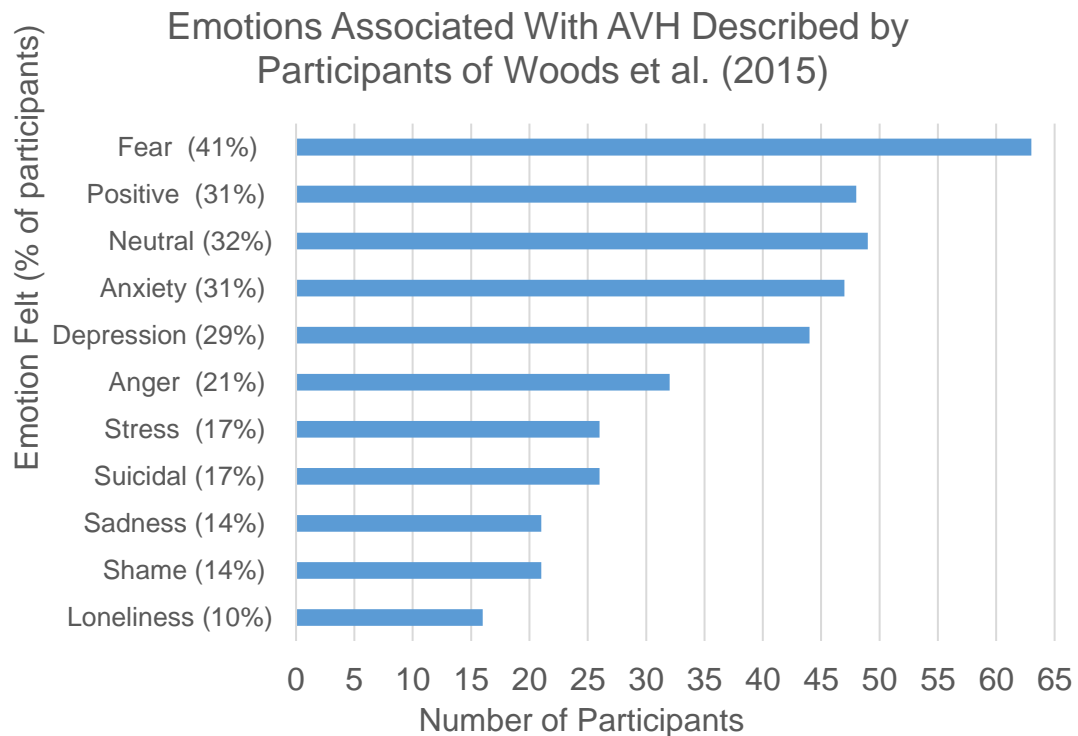


Figure 2.09 *Graph illustrating Woods et al. (2015) research regarding AVH's emotional feelings.*

Notably in Woods et al. (2015) positive and neutral emotions were also described by 31% and 32% of their sample respectively. This may reflect both the variation in voice-hearing experiences and the online sample. With regards to managing the emotional experience of AH, Suryani et al. (2013) reported for some participants, normalising AH as part of everyday life was the most effective way to navigate experiencing them.

In some studies, emotions were described as able to shape or precipitate AVH. In Jones and Lurhmann (2016), heightened stress was described as a cause for thought-like voices to become audible. Furthermore, in Nayani and David (1996), reported hallucinations were precipitated by emotions including sadness (52% of participants), fear (16%) and anger (8%). Sadness (at times alongside being alone or lonely) was described as forming a context where hallucinations emerge. The role of emotion in precipitating hallucinations is akin to SR1's research on stress, distress and loneliness as precipitating VH. To summarise this section thus far, emotions (and particularly negative ones) may be experienced in association with AVH or as a precursor to them.

Some of the research studied voices' emotional tone and content. Within McCarthy-Jones et al. (2014), more negatively emotionally toned voices were common (50% of participants), however 40% mostly experienced positively toned voices. Within Smith (2006) evaluating oneself negatively, low self-esteem and depression were associated with experiencing AH with negative content more often and with more intensely negative content. This is consistent with Daalman et al. (2011) where the content valence, provided clinical predictive value.

The relationships between voice content and feelings such as doubt, uncertainty and confusion were described by Suryani et al. (2013). These feelings were described when voice commands were contradictory or challenged the values (religious or otherwise) and integrity of the voice hearer. For example, voices may both command and prohibit prayer, or instruct hearers to eat and throw food away. Participants described feeling incapacitated; unsure what to do and pulled in opposite directions. This was described as eliciting anger; uncertainty and confusion were also amplified by the breakdown of familial and interpersonal relationships. Participants described feeling "inferior and ashamed. I seemed to talk alone like a crazy man", that relationships with marital partners had broken down, and fathers felt "embarrassed for not being able to provide" for their families (Suryani et al., 2013, p.315). This research was both novel and useful in highlighting how the emotional aspects of AH may interrelate both with their content and the broader lived circumstances in which they occur. Chapter-3 explores the relevance of circumstances in the feeling of hallucinations.

The reviewed research summarised in Figure 2.10 suggests multiple nuanced emotional aspects of voices including emotions: during AVH, before AVH, after AVH, and AVH with emotional tones and textured content. The SR1b research also points to the potential for emotions to interrelate with the broader lived circumstances and values of voice hearers. The complexities of AVH as emotional experiences, is further exemplified by McCarthy-Jones et al. (2014) reporting 39% of participants would miss their voices if they stopped. This is consistent with the TH case study in SR1a, where the presence of the shadow-man was missed.

AVH Feel Emotional	
• Emotions Felt in Time (Before, During, After AVH)	• Emotion of Voice (Content, Tone)
• Emotions Felt (Anger, Anxiety, Confusion, Depression, Embarrassment, Fear, Inferior, Loneliness, Low Self-Esteem, Normal, Positive, Sadness, Shame, Stress, Suicidal)	

Figure 2.10 Summary of the emotional feelings of auditory verbal hallucinations.

The anticipated experience of missing a voice, draws together the qualities of AVH mapped so far: of emotion, character, relationality and reality (in being and time). Although research such as Woods et al. (2015) is useful in providing an overview of the kinds of emotions that are associated with AVH, more research is needed to shed light on the texture and emotional feeling of lived experiences of hallucinations (both AVH and otherwise) and how this interrelates their other qualities.

2.03.5 Embodiment of AVH.

In addition to exploring AVH’s emotional features, some articles considered broader feeling states associated with AVH. The somatic, embodied or bodily feeling of AVH, ranged from sensory heard aspects to feelings in further senses and body parts. Some aspects of AVH’s embodied feelings merge with ideas of multimodality, further explored later.

Participants of Upthegrove et al. (2016) described AVH’s heard dimensions such as (such as sensations of volume), varied by the content and felt intent of voices. This harks back to their aforementioned textures of shouting, aggression and threat. Nayani and David (1996) also reported a relationship between content valence and volume; with third-person commentary as conversational volume and angry voices as louder. A spectrum of voices’ most common volume was reported to range from whispered or soft (14%-31% of participants), conversational volume (35-73%), loud, yelling, screaming or shouting (13-27%) (Nayani & David, 1996; McCarthy-Jones et al., 2014). Sounds were typically described as clear to hear and made sense (i.e. not gibberish);

with 52% of those hearing multiple voices, each voice had the same volume (McCarthy-Jones et al., 2014).

Upthegrove et al.'s (2016, p.90) participants described voice hearing as akin to people standing behind oneself talking in a pub, and when it becomes loud it's a "struggle not to hear it", that one may "stand up and think...what was that?". The experience of volume and clarity, builds upon the sense of presence described in terms of the reality of voices and the experience as often being forced upon or done to voice hearers. As explored in the reality of voices, the SR1b research varied regarding the extent to which AVH were literally heard in this way, with many experiences feeling more akin to thoughts.

Upthegrove et al. (2016, p.93) described AVH as physically imposed, as participants likened the experience to being: "possessed", "held down" and "constantly caged in by voices". These feelings of physical force, pressure, pull and imposition were further nuanced by participants describing bodily feelings in relation to AVH. Participants described feeling "sick", of itching "for ages" and of AVH "giving me physical pain", "a push on the shoulder", "pressure on my neck and the back of my head" and AVH "poke and prod me" (p. 94). Upthegrove et al. (2016) therefore reported feelings and sensations from varying modalities may interrelate to form AVH.

Further research documented AVH's more than auditory feeling. Participants of Woods et al. (2015, p. 327) described feeling "on fire" during AVH, feeling "heat and a strong irritation in the right frontal part of my brain", "tingling sensations throughout my extremities and shock-like sensations in my solar plexus" and one's body feeling "more distant ...dreamlike (like living a dream), surreal, other worldly". 66% of their participants reported bodily feelings during AVH. These participants had some distinct characteristics. They were more able to anticipate their voices, their voices were less positive or useful, more violent and abusive, more associated with shame, and their first voice experiences were more associated with traumatic circumstances.

Further to experiencing bodily feelings during AVH, they were also described as a precipitating feature. 50% of Nayani and David's (1996) sample cited somatic triggers of voices including: the intention to eat, eating, and the

urge to defecate. 45% described butterflies or a churning stomach sensation before AH or at its onset. This section of SR1b formed a thicker picture of AVH as an experience which alongside linguistic/heard/speech-like qualities, is often felt within one’s broader body. Figure 2.11 summarises AVH’s embodied feeling. This demonstrates AVH may be composed of complex symphony of interrelationships between sensory and somatic feelings, beyond a unimodal perceptual experience.

AVH Feel Embodied	
• Volume (Whisper, Soft, Conversational, Loud, Shout)	• Forceful (Pull, Imposition, Forced Upon)
• Bodily Feelings (Butterflies, Churning, Dreamlike, Heat, Irritation, Itching, On Fire, Pain, Poking, Pressure, Prodding, Pushing, Shock, Sickness, Tingling)	

Figure 2.11 Summary of the embodied feelings of auditory verbal hallucinations.

2.03.6 AVH as Multimodal Hallucinations.

Building upon this broader view, some research explored AVH as multisensory or multimodal (of perceptions involving more than one sensory modality). 10% of Jones and Luhrmann (2016) sample reported predominantly multisensory AVH, most often also involving visual features. Consistently, 18% of Woods et al.’s (2015) participants, reported multi-sensory voices. Combined with the striking somatic features of AVH described by 66% of their sample, there is strong evidence to suggest AVH is often more than a unimodal experience; a proposition in keeping with the conclusions of Upthegrove et al. (2016).

Though MMH were not prominently discussed in the SR1 literature, their relevance within hallucination research was documented almost 40-years-ago. In Lowe’s (1973) study which explored the utility of hallucinations for differential diagnosis, participants described as paranoid had mostly MMH (AH with VH). Those given a schizophrenia diagnosis were characterised by experiencing MMH in “all modalities, including the most rare...hallucinations of the self, originating in the body”, with “clearly specified causes” (Lowe, 1973, p. 623). Overall, 18% of the hallucinations documented in their research were simultaneous MMH.

Serial MMH have also been reported in the literature, 28% of Woods et al.'s (2015) sample experienced hallucinations in other modalities as well as AVH. In Nayani and David's (1996) AH sample, uncommon or transitory hallucinations were experienced in other modalities including visual (51%), olfactory (51%), visceral (40%), tactile (31%) and gustatory (18%) senses. Collectively the research suggests hallucinations may frequently occur in multiple modalities at simultaneous or separate points in time.

Woods et al. (2015) proposed the high prevalence of multi-sensory and somatic features of voices were scarcely attended to in clinical interventions; which may of course reflect the scarcity of their address in research. The research in this review raises questions of how bodily and multi-sensory features can be conceptualised in relation to AVH; of whether they are part of AVH phenomena, adjuncts or distinct separate sensations and so on. Figure 2.12 summarises the multi-modal experience of AVH. To better appreciate the nuance what hallucinations feel like, perhaps the lens of research should be zoomed outwards to study the body as a whole (including its many sensory modalities). Limiting the remit of hallucination research to focus on single sensory modalities may be a hindrance in understanding how many hallucinations are lived.

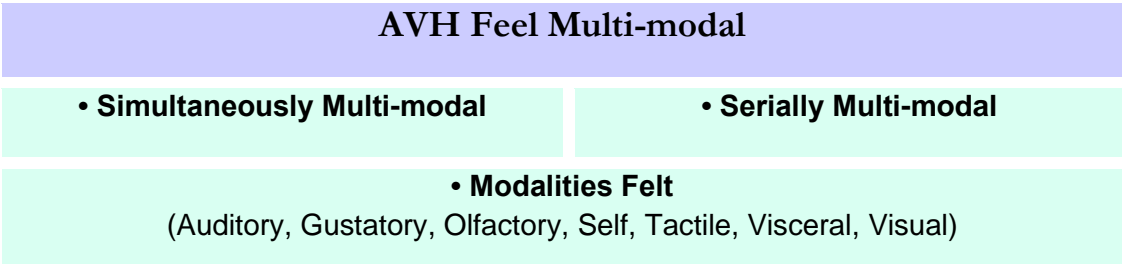


Figure 2.12 Summary of the multimodal feelings of auditory verbal hallucinations.

2.03.7 How do AVH Feel?

Figure 2.13 has collated SR1b's analysis on the feeling of AVH. AVH can be described as holding identifiable qualities, which were often characterful, with relational and interactive properties in addition to a feeling of reality (with presence in consciousness, space, and time). AVH were also often characterised by emotive, embodied and multimodal features, suggesting a more than simply auditory experience overall. Research regarding the emotional, bodily and

multimodal features of AVH was compelling, yet these areas were not a predominant focus within SR1 literature. These features in particular warrant further research, as do the way in which the multi-modal, emotional, bodily and sensory features of AVH interrelate to form a full lived experience.

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AVH Feel Characterful		
• Age	• Gendered	• Un/Familiar
• Language (Same or Different)	• Accent (Class and Region)	• Identifiable Quantity (Total)
AVH Feel Relational		
• Identifiable Quantity (Talking at Once)	• Relationship	• Relational (Ignore, Influence, Interact, Power)
• Content (Abusive, Brief, Commands, Commenting, Conversing, Criticism, Demands, Guiding, Personal)		
AVH Feel Real		
• Presence (Entity, Powerful, Real)	• Space and Location (Body, Internal, External)	• Source (External, Internal)
• Consciousness (Thought-like, Attention, Memory, Insight)		• Time (Frequency, Duration, Repetition, Change)
AVH Feel Emotional		
• Emotions Felt in Time (Before, During, After AVH)		• Emotion of Voice (Content, Tone)
• Emotions Felt (Anger, Anxiety, Confusion, Depression, Embarrassment, Fear, Inferior, Loneliness, Low Self-Esteem, Normal, Positive, Sadness, Shame, Stress, Suicidal)		
AVH Feel Embodied		
• Volume (Whisper, Soft, Conversational, Loud, Shout)		• Forceful (Pull, Imposition, Forced Upon)
• Somatic Feelings (Butterflies, Churning, Dreamlike, Heat, Irritation, Itching, On Fire, Pain, Poking, Pressure, Prodding, Pushing, Shock, Sickness, Tingling)		
AVH Feel Multi-modal		
• Simultaneously Multi-modal		• Serially Multi-modal
• Modalities Felt (Auditory, Gustatory, Olfactory, Tactile, Visceral, Visual)		

Figure 2.13 Overall summary of the feeling of auditory verbal hallucinations.

2.03.8 The Feeling of AVH and Predictors of ‘Psychotic Illness’.

The research and clinical context of hallucinations is entwined with experiences described as psychosis; this section explores research which has studied this interrelationship. This builds upon earlier arguments regarding AVH location and psychopathology. Figure 2.14 illustrates a summary of Daalman et al.’s (2011) research outcomes on the predictors of ‘psychotic illness’ from AVH. Qualities reported as predictive included the age voices started, their frequency, form of address, controllability, emotional valence and the explanation held for voices.

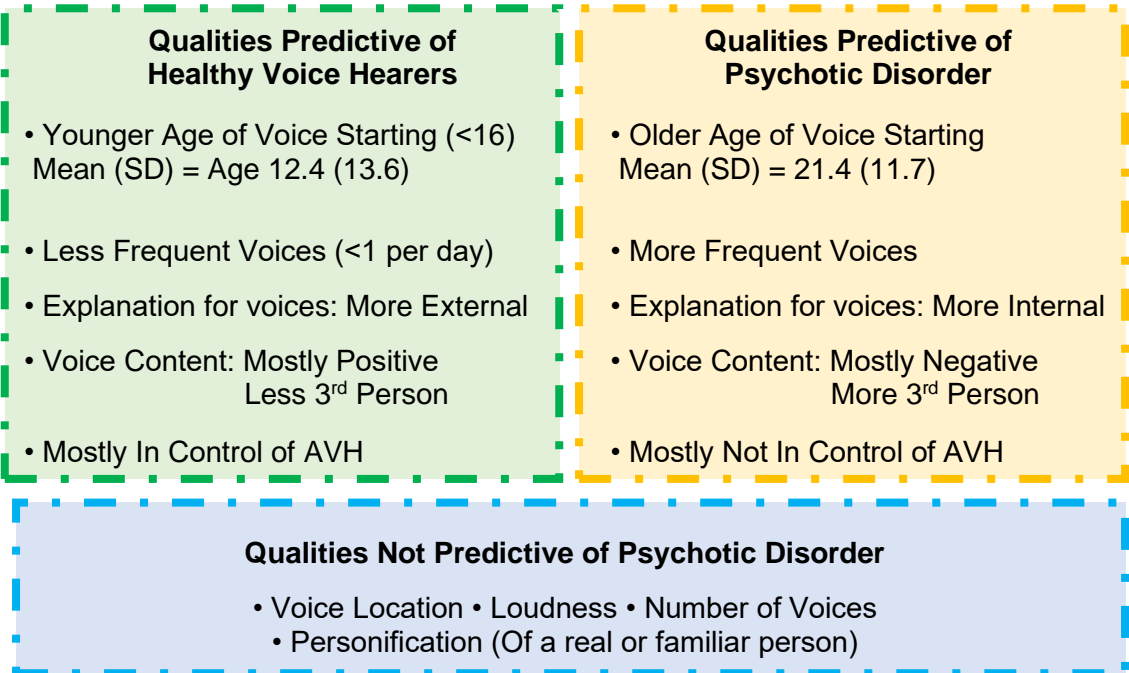


Figure 2.14 Predictors of Psychotic Disorder from Daalman et al. (2011).

It may be worth reflecting however that more internal explanations attributed by voice-hearers given a psychotic spectrum diagnosis, may be due to having been given an internal explanation (a diagnosis where one’s voices have been conceptualised as an internally embodied disorder/illness). Consistent with Daalman et al. (2011), Woods et al. (2015) reported voices of external, auditory or commanding qualities, were not predictive of having been given a diagnosis of schizophrenia or schizoaffective disorder within their research.

Overall within Daalman et al. (2011), the presence or absence of a psychotic disorder diagnosis could be predicted for 92% of participants by their age when voices started, voice frequency, degree of control and emotional

valence of content. The degree of control has also been associated with healthier profiles in other research. In Nayani and David (1996), those with more control over their voices, used more coping strategies, had more insight and were less distressed. Consistently, those reporting high levels of distress also described little control and fewer coping mechanisms.

As previously noted, Daalman et al.'s (2011) most notable finding was emotionally negative voice content alone could predict whether or not someone had been given a psychotic disorder diagnosis in 88% of their sample. This strong finding is all the more noteworthy, as emotional feelings have been seldom explored in research on AVH, hallucinations and psychosis. An example, of the relationship between voice valence and one's own emotions and functioning was described by a participant of Woods et al. (2015, p.326):

I heard the voices of demons screaming at me, telling me that I was damned, that God hated me, and that I was going to hell...The voices were so frightening and disruptive that much of the time I was unable to focus or concentrate on anything else.

It is understandable that those who experience more emotionally negative AVH, may be more likely to seek support through healthcare systems and may thereby be given a psychiatric diagnosis. Suryani et al. (2013, p. 317) proposed AH "need to be reconceptualised as a human experience and not always or only as signs and symptoms of schizophrenia".

The outcomes of the analyses of SR1b and SR1 more broadly, have demonstrated studying specific experiences such as hallucinations and exploring how they feel (beyond their relationship to psychopathology) is fruitful. This research suggests that to understand hallucinations, studying their emotional feeling should be a primary area for research concern.

2.04 SR1: How do Hallucinations Feel?

SR1 aimed to map knowledge of what hallucinations feel like. Hallucinations were described as heterogeneous lived experiences although they varied in terms of shared qualities. Hallucinations were described in terms of identifiable quantities and qualities, in terms of their occurrence within sensory

modalities and of holding characterful properties. Hallucinations were often described as relational and associated with emotional, real, and somatic feelings. Hallucinations were described as unimodal and serially or simultaneously multimodal. The multifaceted aspects of hallucination experiences which have been explored in terms of these qualities are summarised in a final concept map in Figure 2.15.

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Hallucinations often Feel Identifiable and Characterful		
• Distinct Content or Type (Varying by Modality)	• Sensory	• Distinct Qualities (Aged, Gendered, Familiarity)
• Identifiable Quantity (Total)	• Type of Being, Entity or Source (Animate, Humanoid, Inanimate, Natural, Supernatural)	
Hallucinations often Feel Relational		
• Identifiable Quantity (At Once)	• Relationship	• Known/Unknown (Acquaintance, Stranger)
• Relational (Ignore, Influence, Interact, Power)		• Powerful (Mythical, Supernatural, Real)
Hallucinations often Feel Real		
• Touchable	• Presence (Concrete, Conscious, Entity, Power, Real, Unsure, Vivid)	
• Source (External, Internal, Novel)	• Dimensional Form (3D, Edges, Moving, Opaque, Static, Surface Bound)	
• Consciousness (Attention, Memory, Insight, Thought-like,)		• Time (Change Over, Changed Sense of, Duration, Frequency, Repetitiveness, Stable Over)
• Location (Beyond Touch, Both Hemifields, External, Internal, Midline, Size Constancy)		
Voices often Feel Emotional		
• Emotion of Hallucination (Content, Tone)	• Emotions Felt in Time (Before, During, After AVH)	
• Emotions Felt During (Anger, Anxiety, Confusion, Depression, Embarrassment, Fear, Importance, Inferior, Loneliness, Low Self-Esteem, Miserable, Normal, Overwhelmed, Positive, Prompted Towards Action, Sadness, Safe, Shame, Soothed, Stress, Suicidal, Surprised, Worry)		
• Precipitative Feelings (Acute Distress, Loneliness, Stress, Tiredness)	• Feelings After (Belief-Changing, Frozen, Inquisitive, Safety Seeking, Precautious, Un/certain, Wishing for More)	
Hallucinations often Feel Embodied		
• Embodied Feelings (Butterflies, Churning, Dreamlike, Heat, Imposition, Irritation, Itching, Forced Upon, On Fire, Pain, Poking, Pressure, Prodding, Pull, Pushing, Shock, Sickness, Tingling)		
Hallucinations often Feel Unimodal and Multi-modal		
• Unimodal	• Serially Multi-modal	• Simultaneously Multi-modal

Figure 2.15 Overall summary of the feeling of hallucinations.

2.05 Feeling of Hallucinations: Areas for Research Development

This review and the associated summary concept map illustrates that although research has been successful in exploring many of the felt qualitative aspects of hallucinations, there is much still to learn. Despite there being little research on the emotional and embodied dimensions of hallucinations, in studies where they were explored interesting insights were generated. Insights which could shift contemporary understandings of hallucinations. Furthermore, despite much of the research being focused towards single sensory modalities and AH, indicators of the relevance of hallucinations outside of the auditory modality and MMH continued to shine through. The primary areas for further research therefore include studying:

- Hallucinations beyond the auditory modality.
- The emotional and embodied dimensions of hallucinations.
- The multimodal experience of hallucinations.

It may be worth considering the predominance of hallucination literature on AH and AVH by taking VH as an example. In 2003 Guantlett-Gilbert and Kuipers (p.203) wrote VH are:

Poorly understood...There is no systematic research on what people with psychiatric conditions see or how they respond to these visions. In contrast, auditory hallucinations have been subject to detailed phenomenological study.

Sixteen-years-later, these experiences are still rarely studied and poorly understood. At that time, they cited the lack of research could not be due to their rarity, as research had long since evidenced VH's common prevalence (experienced by 56% of an inpatient sample given a schizophrenia diagnosis [Bracha, Wolkowitz, Lohr, Karson & Bigelow, 1989]). Consistently, in Delespaul, deVries and van Os (2002) experience sampling research, VH were more-often experienced in daily life than AH which were reported by 62.5% and 49.1% of their clinical sample respectively. The available evidence does not seem to justify the lack of research on VH experiences, nor the extent of the bias towards studying AH within hallucination research. It is reasonable to question both the focus on AH and on unimodal hallucinations more broadly.

Rupert, Hollender and Merhof (1961) reported hallucinations described as rare, were much more common than thought within clinical practice. They described such experiences were not reported, as they were not specifically asked about; a finding which Lowe (1973) confirmed. Clinical practice and research are still lacking in acknowledging the relevance and commonplace experience of many kinds of hallucinations. As described at the beginning of this review, Lim et al. (2016) reported a lifetime prevalence of unimodal hallucinations within their schizophrenia sample of just 27%. MMH were reported by a much higher 53% of their sample, as 29% of participants had hallucinations in two modalities, 17% in three and 8% in four.

Figure 2.16 illustrates Lim et al.'s (2016) research on the lifetime prevalence of hallucinations by modality. MMH of various kinds were most common overall, and the auditory sense was the most common for both unimodal and MMH. Notably, AH and auditory-visual hallucinations were almost as prevalent as one another. Lim et al. (2016) proposed AH form a perceptual hub, from which hallucinations involving additive senses arise. The level of the bias in the literature towards unimodal AH, or unimodal hallucinations in general does not seem to be justified in light of the research. This prevalence research alongside the multimodal and somatic indicators described within this review, form a clear rationale to research the multimodal experience of hallucinations regarding which there is still much for research to learn.

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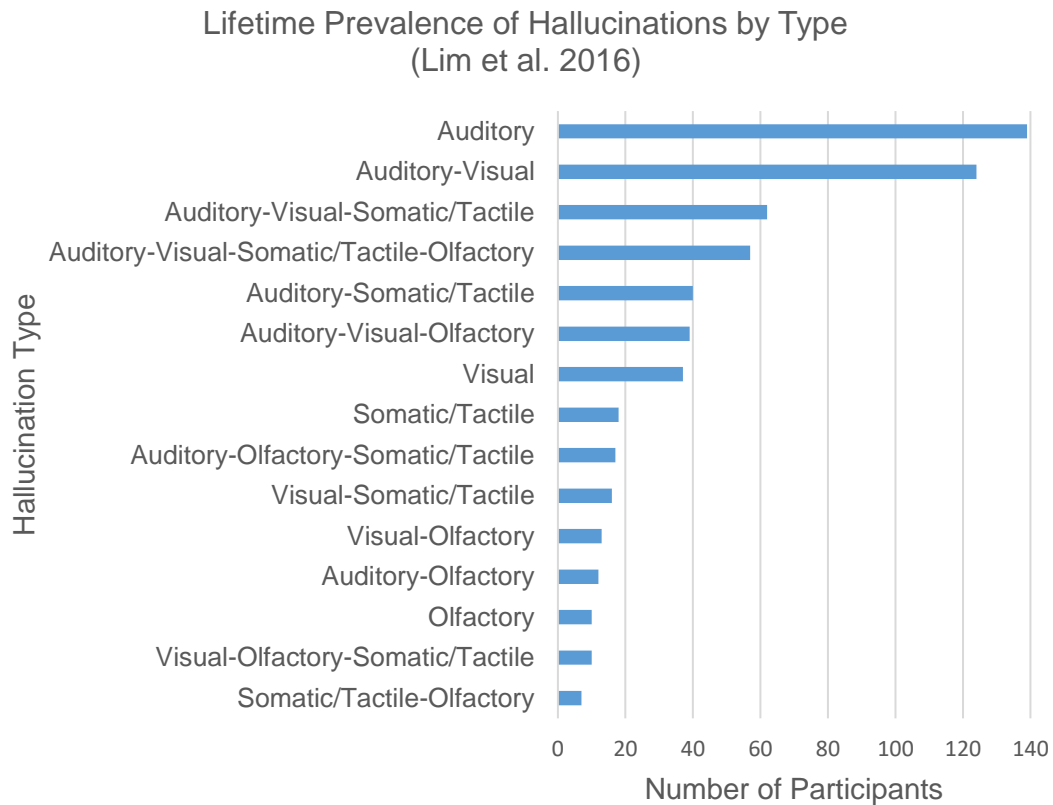


Figure 2.16 Graph illustrating Lim et al.'s (2016) research regarding the modality of hallucinations.

The overwhelming focus on AH in research and clinical work, perhaps reflects the comparative ease of identifying and communicating perceptual variations in this modality, and particularly so for AVH. In research and clinical work, as AVH and interpersonal communication share characteristics of speech and linguistic form, perhaps heard voices arise in a form more available to description and understanding. For perceptual variations in somatic fluctuations, nonverbal, visual, olfactory, gustatory senses and so on, their content cannot be shared verbatim. Sharing them may be difficult. This is consistent with the Lowe's (1973) writings that reported issues of communicability were most prominent in hallucinations involving more than one modality. A proposition fitting with their comparative neglect within research in the decades since.

It may not always be possible to communicate hallucinations in the modality in which they occur, and transforming experiences into a communicable form may be difficult. As such non-auditory-verbal hallucinations may not be as easily identified as hallucinations, or described to a loved one, clinician or

researcher. Equally upon attempting to research hallucinations which are not AVH, they may be harder to study, write about and share. The vast array of research tools and analytic methods designed to study the qualities of experience are often developed for speech and linguistic data, but not bodily feelings, visions and so on (Ellingson, 2017; Reavey, 2011). Perhaps utilising novel research methods may support in breaking new ground in hallucination research.

The quality review of the SR1 literature, stated concerns regarding the way in which scholarship surrounding the feeling of hallucinations, appeared mostly without reference to these experiences arising within a body, an ongoing lived personal history, or a context. These concerns were maintained throughout the analyses and are reflected in the concept map of how hallucinations feel. Although some of the studies did report some of the emotional and somatic feelings of hallucinations, they rarely provided any detail regarding the texture of these feelings or how they were experienced for the participants. What feelings of anxiety, depression and so on felt like as embodied experiences, in the context of the other felt aspects of hallucinations, and the participants' broader lived circumstances. This lack of qualitative description may be in part be due to the literature's methods and their write up in predominantly statistical terms.

Upthegrove et al.'s (2016) research which incorporated visual methods seemed better able to report on somatic feelings and some of the meaningful ways feelings intertwined. Semi-structured interview methods used by Suryani et al. (2013) seemed able to generate understandings of how hallucinations were lived within the context of participants' broader lives. This points to some of the ways in which future research designs could be better designed to study the feelings and circumstances of hallucinations. This thesis continues by systematically reviewing the circumstances hallucinations arise in.

3. What are the Circumstances of Hallucinations? A Systematic Review



Figure 3. Still Photographic Image of a Painting from the Feeling-In-The-World Art Series during Gallery Exhibition at Attenborough Arts Centre in Leicester, 2018.

Recognising circumstances in relation to hallucinations' feeling, echoes Nayani and David's (1996, p.188) concluding remarks regarding AH as "repetitive, emotive utterances which are context dependent, spatio-temporally organized and appear to originate from stereotypical personifications...evolve by accretion and, increasingly, come to invade the patient's private life". Over twenty-years-later, limited research has studied the context of hallucinations. To generate a thicker understanding of hallucination phenomena, this chapter reviews research on the circumstances of hallucinations. The chapter opens with an exploration of literature from the prior SR1 which commented upon circumstances and some broader research from the field. The chapter continues by detailing the procedure and analytic outcomes of a second systematic review (SR2) on the circumstances of hallucinations.

3.01 Prelude to the Review: The Contribution of Circumstances in the Feeling of Hallucinations

This section explores literature regarding the circumstances of hallucinations as mentioned within the SR1 literature. Table 3.01 presents some SR1 literature which pointed to the role of circumstances hallucinations' feeling. Hallucinations' content and feeling were reported as shaped by interpersonal relationships, gender and social circumstances. Further SR1 research reported on hallucinations in light of age, gender and trauma. Within Daalman et al. (2011), those who first heard voices at a younger age were less likely to be accessing clinical services for AVH as an adult. Interestingly, Woods et al. (2015, p.327) reported first voice experiences most-often arose in childhood. Childhood voices most-often first appeared in negative or "explicitly traumatic" circumstances and were more likely to be reported by women. First voice circumstances varied though, as 11% of participants' first voices were reported to arise in neutral or positive circumstances. This variation and the potential interrelationship with trauma, provides a rationale to further investigate the relationship between circumstances and hallucinations.

Woods et al.'s (2015) results were consistent with Read, Agar, Argyle and Aderhold (2003) research of 200 community mental-health service-users medical records. Read et al. (2003) reported childhood sexual abuse (CSA), childhood

physical abuse (CPA) or adult sexual assault (ASA) were predictive of experiencing hallucinations (particularly AVH or TH). CSA, CPA, ASA and adult physical assault (APA), were significantly related to TH, VH, commenting AVH and command AVH to harm or kill oneself. Their research reported OH were significantly associated with having experienced CSA, or both CSA and CPA. The research suggests experiencing physical and sexual traumas may be precipitative circumstances interrelated with the emergence of hallucinations (Read et al., 2003; Woods et al., 2015).

Table 3.01

Outcomes from SR1: In What Way do Circumstances Shape Hallucinations?

<u>First Author (Year)</u>	<u>Reported Association Between Circumstances and Hallucinations.</u>
Nayani (1996)	Abusive voice content of AVH may be gendered. AVH may be of familiar people and loved ones. With accents often of a higher social class, or akin to one's cultural heritage.
Stevenson (2011)	The most bothersome OH typically occurred at home. 34.2% described they were related to their past.
Gauntlett-Gilbert (2003)	VH often first start during periods of loneliness or relationship difficulties.
McCarthy-Jones (2014)	AVH's message may be linked to influential people in one's life. The voices may be similar to people one's spoken to.
Woods (2015)	Women are more likely to report voices changing over time.
Suryani (2013)	Marital breakdown and familial difficulties amplified feelings of doubt, confusion and uncertainty from contradictory command hallucinations
Upthegrove (2016)	The location of voices varied by situations and over time (details of this were not documented within their article).

Hallucinations were associated with circumstances in ways not explored in earlier chapters. 45% of Jones and Luhrmann's (2016) sample reported transformed voices of overhearing gossip or comments about oneself in public areas; ranging from feeling the topic to hearing the content. The researchers and participants explored how this may overlap with delusions and mishearing. Upthegrove et al.'s (2016) participants described similar difficulties of hearing

voices through people in public, outside, or around groups of people. Although transformed sound was typically from humans and speech, traffic, mechanical and natural noise (e.g. wind in trees) also transformed into voices (Jones & Luhrmann, 2016). Consistent with broader AVH literature difficulties were reported in elucidating how content was heard (e.g. as speech, emotions, or influences).

Further to hallucinations being felt in terms of one's immediate context, circumstances were also reported to precipitate hallucinations. Many of Gauntlett-Gilbert and Kuipers (2003) participants reported triggers of low stimulation including being alone (75%), quietness (65%), and dim-lighting (55%). Consistently, 80% of Nayani and David's (1996) sample reported being alone worsened their AH. AH were also reported as precipitated by sadness and loneliness. A specific social-material AH trigger reported by one participant, was a nagging voice when a nurse approached with medication. Watching the TV (particularly the news) was a further trigger; ranging from voices providing TV commentary, to the presenter's voice transforming to address the hearer. The researchers proposed the news' hallucinogenic properties may be associated with excess arousal and emotion. The research illustrates one's social and material circumstances may precipitate or shape hallucinations.

More complex circumstantial precipitative factors were described in Heveling et al.'s (2004) case study. TH was precipitated by her only child moving out from their shared flat. The TH shadow man was described as a partner needed due to the separation. This suggests an intimate interrelationship between TH's feeling and circumstances. Nayani and David's (1996) conclusions reflected this intimacy, by proposing AH may form part of one's apprehension of objective reality, rather than being unpredictable or random phenomena. The SR1 outcomes, alongside the research discussed here, contrasts with biomedical and individualised models outlined in chapter-1 (Bracken et al., 2012; Wade & Hilligan, 2004). Hallucinations do not appear to be random outcomes of pathology, but rather intimately connected to one's feelings and circumstances.

Nayani and David (1996, p.183) studied the association between activities and AH frequency; with patterns holding variability as summarised in Table 3.02.

Most activities except watching TV tended to make things better; with talking to somebody else being most helpful. Those using more than four coping activities reported less distress; although it may be less distress enables better capacity for activity. Upthegrove et al. (2016) described voices made activities of daily life a battle; with simple tasks becoming difficult, lives were described as destroyed by voices. The interrelationship between activity and hallucinations may benefit from further study.

Table 3.02

The relationship between AH and Activity.

<u>Activity</u>	<u>Frequency</u>	
	<u>Better %</u>	<u>Worse%</u>
Talking to Somebody	63	1
Going to Sleep	43	0
Thinking About Something Else	39	0
Listening to Music	30	3
Shouting to the Voice to Go	28	0
Sitting or Lying in Bed	23	1
Relaxing	19	1
Radio	17	28
Hobbies	16	0
Loud External Ambient Noise	14	0
Exercising	13	0
Watching TV	10	55

Consistent with AVH's difficult implications, 71% of Woods et al.'s (2015) sample, reported a negative effect of voices upon one's relationships due to stigma, fear, loneliness, and voices interrupting others or making it difficult to understand them. Consistently, Suryani et al.'s (2013, p. 316) participants, described difficulties with shame, the impact of "bizarre behaviours", family stress, the breakdown of intimate relationships, and struggles to provide for one's family. Suryani et al. (2013) reported broader interpersonal difficulties related to fearing rejection. One participant described "I cannot look them in the face, I feel inferior and ashamed...I rarely leave the house". Another explained "we have no family...no friends...isolated from our loved ones unable to share with them the joy and fun of family life. Our behaviour is completely different from that of other people" (Suryani et al., 2013, p. 315). Such research demonstrates one's

circumstances can be negatively affected by AH. The value of activities described by Nayani and David (1996) such as talking to somebody, may not account for voice hearer's capacity or opportunity to engage in such activities; or how the benefits of activities may vary over time.

The research suggests hallucinations may be precipitated, shaped, worsened or improved by one's circumstances and hallucinations may in turn negatively impact upon one's circumstances. Although overall discussion of circumstances was limited, the SR1 literature provided an empirical basis for further study. As explored in chapter-1, evidence regarding the interrelationships between circumstances and experiences described as psychosis or schizophrenia are well documented in research. As argued there, research regarding narrower experiences like hallucinations, is more limited. Therefore, in aiming to understand what it may be like to experience hallucinations, the following novel systematic review 2 (SR2) explored what is known about the circumstances of hallucinations arising within any modality.

3.02 SR2 Procedures

The SR1 protocol was applied with new search terms fitting SR2's review question. The outcomes of the initial literature database search are summarised in Table 3.03, with a 95 article yield.

Table 3.03
Systematic Review 2. Hallucination Literature Search Outputs.

Web of Science Core Collection Literature Review 2, Stage 1	
<u>Search Terms Applied</u>	<u>Number of Journal Articles</u>
"hallucinat*" AND "circumstan*"	0
"hallucinat*" AND "context*"	26
"hallucinat*" AND "psychosocial"	1
"hallucinat*" AND "social"	30
"hallucinat*" AND "life"	29
"hallucinat*" AND "cultur*"	20
Total: 106 Articles with 11 Duplicates. Revised Total: 95 Articles.	
PubMed (NLM) Literature Review 2, Stage 1	
<u>Search Terms Applied</u>	<u>Number of Journal Articles</u>

"hallucinat*" AND "circumstan*"	0
"hallucinat*" AND "context*"	0
"hallucinat*" AND "psychosocial"	0
"hallucinat*" AND "social"	0
"hallucinat*" AND "life"	0
"hallucinat*" AND "cultur*"	0

Total: 0 Articles.

Medline Literature Review 2, Stage 1

<u>Search Terms Applied</u>	<u>Number of Journal Articles</u>
"hallucinat*" AND "circumstan*"	0
"hallucinat*" AND "context*"	0
"hallucinat*" AND "psychosocial"	0
"hallucinat*" AND "social"	2
"hallucinat*" AND "life"	0
"hallucinat*" AND "cultur*"	0

Total: 2 Articles with 2 Duplicates. Revised Total: 0 Articles.

SR2 Stage 1 Hallucination Yield: 95 Articles.

Figure 3.01 charts a steady publication increase accelerating to a contemporary peak. Perhaps this reflects the accumulating evidence regarding the contribution of circumstances to mental health (as reported in chapter-1).

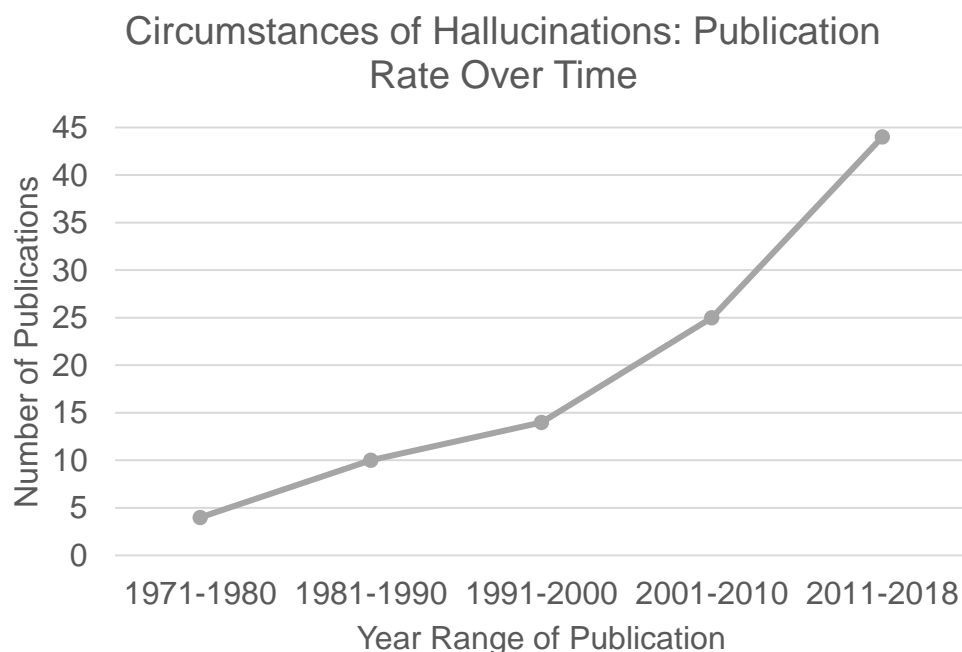


Figure 3.01 Graph Illustrating the Publication Rate over Time of Articles Retrieved through the Systematic Review 2 Literature Search

Consistent with SR1, Table 3.04 summarises the repeated searches with the SR2 keywords with “hearing voic*” instead of “hallucinat*”.

Table 3.04

Systematic Review 2. Hearing Voices Literature Search Outputs.

Web of Science Core Collection Literature Review 2, Stage 2	
<u>Search Terms Applied</u>	<u>Number of Journal Articles</u>
“hearing voic*” AND “circumstan*”	0
“hearing voic*” AND “context*”	1
“hearing voic*” AND “psychosocial”	1
“hearing voic*” AND “social”	3
“hearing voic*” AND “life”	1
“hearing voic*” AND “cultur*”	2
Total: 8 Articles with 1 Duplicate.	
PubMed (NLM) Literature Review 2, Stage 2	
<u>Search Terms Applied</u>	<u>Number of Journal Articles</u>
“hearing voic*” AND “circumstan*”	0
“hearing voic*” AND “context*”	0
“hearing voic*” AND “psychosocial”	0
“hearing voic*” AND “social”	0
“hearing voic*” AND “life”	0
“hearing voic*” AND “cultur*”	0
Total: 0 Articles.	
Medline Literature Review 2, Stage 2	
<u>Search Terms Applied</u>	<u>Number of Journal Articles</u>
“hearing voic*” AND “circumstan*”	0
“hearing voic*” AND “context*”	0
“hearing voic*” AND “psychosocial”	0
“hearing voic*” AND “social”	0
“hearing voic*” AND “life”	0
“hearing voic*” AND “cultur*”	0
Total: 0 Articles	
SR2 Stage 2 Hearing Voices Yield: 7 Articles.	
SR2 Final Total Yield: 102 Articles.	

With a final 102-article yield, exclusion criteria were applied serially. As Table 3.05 summarises, 82 articles were removed, leaving 20 articles for quality review.

Table 3.05
Number of Papers Excluded by Exclusion Criteria.

<u>Reason For Exclusion</u>	<u>Number of Articles Removed</u>		
	<u>Brief Screening</u>	<u>Full Screening</u>	<u>Total (%)</u>
Health Condition	10	0	10 (12%)
Induced Hallucination	5	0	5 (6%)
Intervention Study	6	0	6 (7%)
Did Not Collect Data	17	1	18 (22%)
Not Within Review Remit	28	2	30 (37%)
Conference Abstract	10	1	11 (14%)
Unable to Access	0	2	2 (2%)
Total	76	6	82 (100%)

3.02.1 SR2 Quality Review.

The quality screening was repeated using SR1's framework and procedures. Consistent with SR1, articles ranked in the lowest quality quartile were removed from the review database; based on SR1, any further articles scoring below a weighted-total of 30 were removed. Appendices B1 documents SR2's quality review scoring. SR2 was composed of 13 articles rated of the highest quality and contribution. Table 3.06 summarises their basic features.

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Table 3.06

Systematic Review 2: Study and Participant Details.

<u>Author</u> <u>(Year)</u> <u>Location Author</u> <u>[Research]</u>	<u>Hallucination</u> <u>N</u>	<u>Clinical</u> <u>Mean Age</u> <u>(Range)</u>	<u>Modality</u>	<u>Focus</u>
Siegal (1984) USA	N= 8	No 35 (18-61)	VH	Hostage Situations
Grimby (1993) Sweden	N= 41	No Not Stated	Uni- modal	Grief
Wickham (2014) UK	N= 68	No Not Stated	AVH	Social Deprivation
Andrade (1988) India	N= 1	Yes 28	Multi- Modal	Culture
Bless (2018) Norway	N=135	No 40	AVH	Adverse Life Events
Waite (2016) UK	N=10	Yes 39 (19-65)	AVH	Sleep Problems
Reynolds (2010) UK	N= 32	Yes 34 (18-56)	AVH	Social Rank
Bauer (2011) Austria [Austria, Georgia, Lithuania, Nigeria, Pakistan, Poland]	N= 1080	Yes 32 (18-62)	Uni- modal	Culture
Janaki (2017) Malaysia	N= 60	Yes 40 (18-60)	AVH	Quality of Life
Ma (2016) Taiwan	N= 189	Yes 47 (20-65)	AVH	Social Interactions
Varese (2011) UK	N= 21	No 40	AH	Daily Life
Delespaul (2002) The Netherlands	N= Not Stated	Yes Not Stated	AVH VH	Daily Life
Kent (1996) UK [Saudi Arabia, UK]	N= 75	Yes (20-65)	AVH	Culture

3.03 Literature Overview: What are the Circumstances of Hallucinations?

All studies recruited adult samples, with 8 (of 13 studies) using clinical populations. Consistent with SR1, the research was predominantly based in the global north, although more studies were in based in the global south (Figure 3.02). Consistent with SR1, research was focused towards unimodal and AH; some studies considered other unimodal hallucinations (especially VH) and MMH. Appendix B2 documents demographic characteristics regarding participants reporting hallucinations, which were inconsistently reported across the literature. Notably none of the studies documented the religion of their participants.

Where participant demographics were reported, there were interesting features. Consistent with chapter-1's observations regarding high prescribing rates, 90-100% of participants were prescribed anti-psychotic medications (Bauer et al., 2011; Kent & Wahass, 1996; Janaki et al., 2017; Ma et al., 2016; Varese et al., 2011). Participants had most often been given a schizophrenia or paranoid schizophrenia diagnosis (60-100% of participants), with 91-100% given psychotic spectrum diagnoses (Bauer et al., 2011; Kent & Wahass, 1996; Janaki et al., 2017; Ma et al., 2016; Reynolds & Scragg, 2010; Varese et al., 2011; Waite et al., 2016). Most studies reported the majority (74-81%) of participants were unemployed (Janaki et al., 2017; Ma et al., 2016; Varese et al., 2011). Bless et al. (2018) however reported most participants were employed (46-66%), with the upper figure representing a group of participants whose hallucinations had not been precipitated by an adverse trigger.



Figure 3.02 *Geo-graph illustrating the Concentration of Hallucination Research in the Global North, Though Less so than SR1.*

Table 3.07 summarises that SR2 articles could be organised by three categories; these are not proposed to function separately in the flow of experience, although the research did not appear to study their interrelationships. The remainder of SR2 documents an exploration regarding what can be learnt about the circumstances of hallucinations from the empirical literature.

Table 3.07
Systematic Review 2. Categories of Research.

<u>Category</u>	<u>No. of Articles</u>	<u>Contents</u>
Difficult Life Events and Circumstances	4	Adverse Life Events, Bereavement, Hostage Situations, and Social Deprivation.
Daily Life	4	Problems with Sleep, Daily Living and Quality of Life.
Social and Cultural Circumstances	5	Social Rank, Communication and Interaction, and Culture.

3.04 Difficult Life Events and Circumstances

3.04.1 Adverse Life Events.

Bless et al. (2018) studied whether adverse life events occurring when AVH start, influenced AVH characteristics later. This study exemplifies research teasing apart the interrelationships between the feelings and circumstances of hallucinations. Their 135-participant sample from Norway's general population included 76 people (56%) who experienced an adverse life event when AVH started and 59 (44%) who reported AVH starting without a notable circumstantial situation; participants were split into these two groups. Adverse life events included marital or relationship problems, heartbreak, bullying, divorce, bereavement, depression, leaving home, accidents, violence, war and alcohol or drug use.

The research reported significant differences in the emotional valence and emotional experience of voices between these two groups. Adverse life events were associated with both more negative and positive voices, as well as hearing less neutral voices and feeling more troubled by one's voices. Daily AVH were most common among the adverse trigger group whereas AVH of yearly or less, were most common among the no-adverse trigger group; suggesting AVH's

emotional content, feeling and frequency may vary in relation to the initial circumstances they arise within. Bless et al. (2018) studied the modality of first hallucinations, in relation to the adversity of their circumstances. As Figure 3.03 demonstrates, a substantial proportion of participants reported experiences of hallucinations in visual, tactile and olfactory modalities (31-73.3%) and a substantial proportion reported MMH. Bless et al. (2018) reported all hallucination types were more common among those who first hear AVH in adverse circumstances.

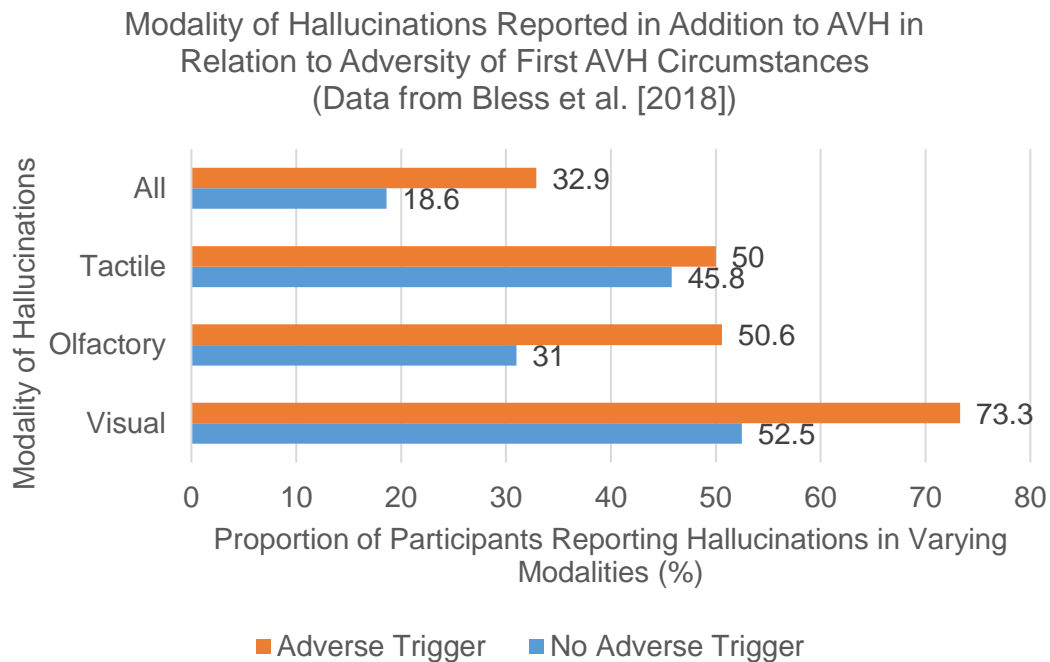


Figure 3.03 Graph Illustrating the Modality of Current Hallucinations in Relation to The Adversity of the Circumstances During a First AVH.

In terms of AVH’s broader circumstances, the adverse trigger group were older when AVH first started (aged 21 versus 12). This is consistent with Daalman et al.’s (2011) SR1b research where ‘healthy’ voice hearers first heard voices at a younger age. Consistently, Bless et al. (2018) reported 45.8% of the no adverse trigger group reported very good mental health status compared to just 9.2% of the adverse trigger group. More of the adverse trigger group reported having used medications for psychological problems (52.3% versus 21.4%), having significantly more contact with health professionals due to AVH difficulties, and worse overall mental health. Bless et al.’s (2018) regression model indicated group membership could be predicted at 66.3% accuracy based

upon whether voices were predominantly neutral, and medication use for psychological problems (not related to AVH). Consistent with chapter-1's arguments regarding psychosis, Bless et al.'s (2018) research demonstrates an interrelationship between the circumstances of distress and experiences of mental health care.

Bless et al.'s (2018) study suggested AVH first arising in adverse circumstances, are likely to be more severe (in terms of their emotional and multi-sensory dimensions). Bless et al. (2018, p.235) proposed "hallucination-proneness in itself may not lead to troublesome voices, but rather, that it is the presence of an adverse trigger at first onset of AVHs in addition to hallucination-proneness that may result in troublesome AVHs". They suggested adverse triggers may be risk factors or pre-morbid psychosis markers; this chimes with chapter-1's arguments regarding psychosocial risk factors of distress. The relevance of circumstances in shaping hallucinations, provides supportive evidence for the thesis' direction.

3.04.2 Bereavement.

1 SR2 article studied hallucinations among bereaved spouses in their 70s, with one semi-structured interview of 1.5-2 hours (Grimby, 1993). Although marriage length was not reported as associated with hallucination incidence, 76% of participants had been married over forty-years. Among those reporting hallucinations 36% reported one sensory modality being involved, 30% two, 12% three and 2% four or five modalities. These findings illustrate the relevance of unimodal and MMHs; with MMH being more common overall. Figure 3.04 summarises hallucination incidence by modality type at 1, 3 and 12 months post-bereavement. Notably, a spouses' presence after their death was most common, followed by speaking and hearing experiences, seeing and experiences of touch with their spouse.

1 month post-bereavement, 82% of participants reported hallucinations (57% of men [n=8], 89% of women [n=32]). This decreased slightly over time, with 71% reporting hallucinations at 3 months (78% of women, 50% of men) and 52% at 12 months (54% of women, 46% of men). Over time, hallucinations reduced, although all kinds remained at 3 and 12 months except touch. The

variation in gender was notable. Significantly more female participants reported hallucinations at each time point. Interestingly, men were most likely to report touch experiences and between 1 and 12 months, the proportion of men experiencing hallucinations decreased by 9%, compared to 35% for women; suggesting although at first hallucinations were more prominent among women, proportions are more similar after a year. Overall, hallucinations appeared a common experience among bereaved spouses. The relevance of felt presence, harks to Upthegrove et al.'s (2016) participants in SR1b, where presence formed a core phenomenological aspect of AVH.

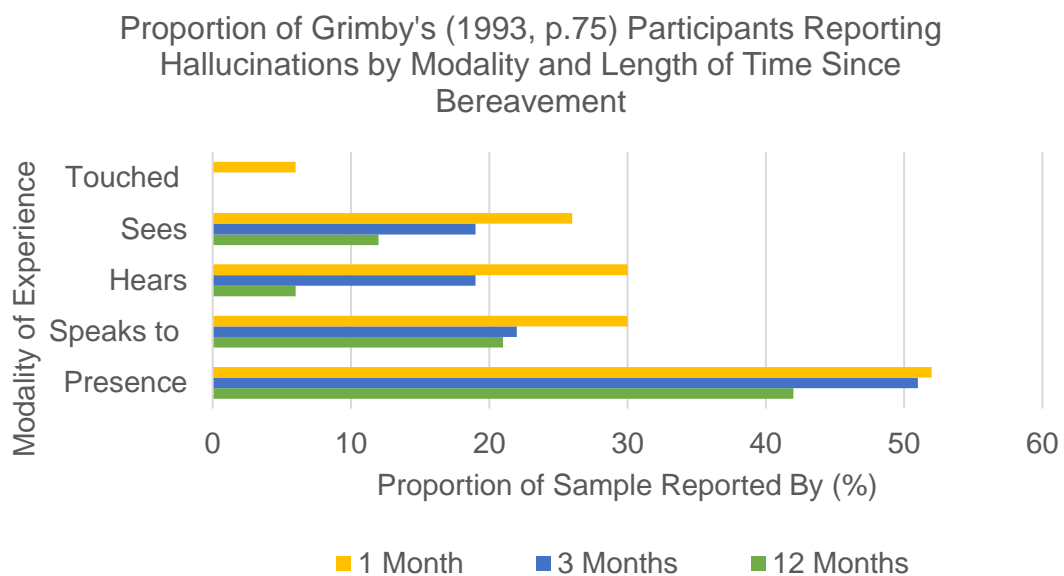


Figure 3.04 Graph Illustrating the Modality and Time Point Post-Bereavement of Hallucinations.

Grimby's (1993) research also considered the relationship between hallucinations and emotions. At 1 month post-bereavement, hallucinations were more common among those who reported crying and severe loneliness. SR1 also reported experiences of loneliness in relation to hallucinations. Interestingly, more intense grief reactions were associated with more pleasant hallucinations. Hallucinations of presence were associated with pleasant feelings by all but one widow, hallucinations of other kinds were felt to be pleasant by all widowers and 75% of widows. This contrasts to the reported feeling of presence in SR1 and illustrates the relevance of studying both the feelings and circumstances of hallucinations. Despite most participants reporting hallucinations of a lost spouse as pleasant, they were experienced as unpleasant or frightening by some; 50%

of these cases were of hearing and 50% were of seeing; indicating a potential interrelationship with the modality and emotional feeling of bereavement hallucinations.

Grimby's (1993) research considered the role of further circumstantial factors in relation to post-bereavement hallucinations. Hallucinations were reported to be correlated with low-life-satisfaction (VH, overall sample) and low-self-esteem (AH, men). At one and three months post-bereavement, happier marriages were correlated with the good quality of hallucinations and hallucination frequency. This research illustrates the importance of significant long-term romantic relationships and bereavements in shaping perceptions and feelings in the world; including potential experiences of hallucinations. The common incidence of post-bereavement hallucinations demonstrates the role of difficult life events and meaningful social relationships in hallucinations. Hallucinations within this article were not of random perceptions, they were meaningfully understood and experienced in terms of one's lost spouse.

The relationship between cultural norms and conceptualisations of hallucinations was evident within Grimby's (1993) research as just 1 participant freely disclosed experiencing bereavement-hallucinations. The remainder reported them only after being informed bereavement-hallucinations were common, with 1 participant describing relief due to fear they may become or already be considered insane. Given most research and understandings surrounding hallucinations regards their interrelationship with madness, mental illness and psychiatry, such a view is understandable. It is interesting that in bereavement, hallucinations may be considered as normal, common, or understandable experiences and not signifiers of madness or psychosis. Whereas in the case of other hallucinations within daily life or experience of other life-changing events (e.g. CSA), the same may not be true.

3.04.3 Hostage Situations.

Siegal (1984) interviewed 31 people who had been held hostage; all except prisoners of war were interviewed within 6 months. 25.8% (n=8) reported experiencing hallucinations whilst being held hostage, Siegal's (1984) reports of their experiences are summarised in Table 3.08. 100% of those who experienced

hallucinations reported VH including geometric patterns, light flashes and tunnel formations. 87.5% (n=7) reported tactile-kinaesthetic hallucinations, 25% (n=2) heard voices, 62.5% (n=5) reported seeing complex imagery of scenes of familiar places, people and childhood memories and 50% (n=4) described auditory perception as intensified. This provides a core of varied perceptual and sensory experiences experienced during hostage situations.

Hostage-hallucinations were described as co-occurring with light sensitivity, difficulty focusing one's eyes, lapses of attention (associated with negative hallucinations), dissociation, disorientation and being preoccupied with body imagery; further to this 4 reported out-of-body experiences. Considering the vivid perceptual experiences described during out of body experiences (which one assumes were not associated with a tangible material source), it seems uncertain the extent to which these differ from somatic hallucinations or MMHs. Overall, the co-occurrence of feelings and sensations in hostage-hallucinations provide an enveloping sense of swarming feelings which transform one's reality; both of their feeling body and situated circumstances.

VH were reported as starting as flashing white light, these may hold shapes, vibrate or pulsate and were reported to last a short amount of time (1 to several seconds). Patterns (typically in periphery of vision) were reported, often geometric, kaleidoscopic, of tunnels, webs, curved lines, lattices and often moving horizontally. These were reported as colourful, intensely bright, varying in size and located ~2feet away, and seen as tunnels, cones, funnels, vessels, alleys, corridors and pits. Tunnel-like VH were often accompanied by body feelings of falling or floating through them; this supports SR1's outcomes of the relevance of MMH, interrelating feelings and non-AH. After hours or days of being held hostage VH included complex experiences of seeing recognised objects, scenes and people; described as concrete, vivid and 3D. Overall hostage-hallucinations display some similar phenomenological features of VH described in SR1a by Gauntlett-Gilbert and Kuipers's (2003) clinical sample.

Table 3.8 Reports of Hostage Hallucinations by Siegal's (1984) participants.				
<u>Who?</u> Age (Sex) Detail	<u>How</u> <u>Long?</u>	<u>What</u> <u>Circumstances?</u>	<u>What Happened?</u>	<u>What Hallucinations or Perceptual Changes</u>
18 (F) College Student	60 hrs	Held for ransom by 2 men, imprisoned in a garage.	Blindfolded with hood; arms and legs bound with rope. Captors threatened to kill her periodically.	VH of flashing lights in front of eyes, small insects and animals in periphery. AH of whispers and strange sounds. Felt hypervigilant, thought she was going to die upon hearing approaching loud voices and "saw my whole life run off like a slideshow before my eyes....mostly childhood scenes and my parents". Voices were of rescuing police.
23 (M) "Street Gang" Member	32 hrs	Taken hostage and held in warehouse by rival gang.	Blindfolded, tied to chair, beaten severely. Recorded ransom demands.	VH of geometric colourful patterns in the air. Dissociation and out of body experiences; not feeling within one's body whilst being beaten, felt detached and floated to the ceiling; observed self being beaten outside of the body and without pain. Saw past memories flash and saw dreamlike/nightmarish cops and monsters.
32 (F) College Student	18 hrs	Held hostage by male burglar in her apartment.	Blindfolded and tied to her bed. Repeatedly raped and threatened to be killed.	Feelings of dissociation. VH of bright lights, colourful geometric shapes, vivid 3D VH images of boyfriend and his brothers in room to save her which were startling.
35 (M) Veteran	~1 wk	Held hostage as POW in southeast Asia.	Blindfolded. Hands and feet chained. Kept in bamboo cage.	VH of twinkling lights and a dark long tunnel. Improved sense of hearing. Felt detached and as if his body inflated.

<u>Who?</u> <u>Age (Sex)</u> <u>Detail</u>	<u>How</u> <u>Long?</u>	<u>What</u> <u>Circumstances?</u>	<u>What Happened?</u>	<u>What Hallucinations or Perceptual Changes</u>
61 (F) Grandma	4 days	Held hostage by male burglar in her house demanding drugs hidden there by her grandson.	Gagged, bound, threatened to be killed, stabbed ("minor...wounds") locked in dark closet at house; allowed to use toilet.	VH of lights and patterns of coloured lace. Saw scenes of a recent mountain holiday. Changes in feeling of material space in closet, such that it felt like a train tunnel with the door "hundreds of feet away". Felt invisible and "floated through the closet door and around the house". Sense of time was distorted such that the 4 days were felt to have been 2.
36 (M) Veteran	3 mo's	Held hostage as POW in southeast Asia.	Bound with ropes and blindfolded for periods of several days, kept in alone in a cell (~8x10 feet) with little to no light.	VH of "tunnels of lights and tall modern skyscrapers all lit up with colors". Saw images of home and friends, feeling almost able to touch them. Transformation of material space, "funny angles" and changing room. Disconnection of "wall between me and what was happening" and being "drained of feelings". Feeling more religious.
52 (M) Father 24 (M) Son	~7 hrs.	Driving in the desert at noon. Stopped and left car due to mechanical noise, both men saw a UFO hovering above the car and both reported floating and being forced onto the UFO. Held in an illuminated room and perceived "vague outlines of humanoid creatures behind the lights". Next reported being sat in car and it was night.	Reported being blinded and paralyzed by light before entering UFO. Both described "floating down a long tunnel-like corridor constructed out of metallic latticework", flashes of memories and pat lives projected upon a screen, last image was of their car stopping in desert. They did not see one another during the abduction.	Father reported AH of voices within head and muscle tremors. Both reported feeling dizzy.

VH reported by Siegal's (1984) participants VH were often meaningful in terms of the participants own lived history; seeing romantic partners or family for example. Sometimes these were experienced within the present moment (e.g. of being rescued) or describe as a slideshow/movie onscreen projection of images of childhood memories. Hallucinatory percepts were experienced in time as either of the present or past. Hostage-hallucinations demonstrate an emergent interrelationship between feeling and circumstances to generate experiences such as hallucinations, which gain increasing complexity over-time, so-long as the circumstances by which they are co-constituted are maintained. This is reminiscent of the experiences of AVH described by Nayani and David (1996), where AH were reported to increase in dynamic complexity over time. Chapter-4 returns to theoretical implications of this in terms of feeling-trap theory.

The immediate circumstances of hallucinations as summarised in Table 3.08 involved being held hostage, social isolation, restraint of movement, visual sensory deprivation (blindfolding, darkness or limited light), having one's life threatened, verbal abuse and physical abuse. Flashes of white light were reported to occur first in the corner of one's visual field, within 15 minutes of isolation. All hostage hallucinations were reported with co-occurring feelings of helplessness, isolation and feeling alone; with helplessness and life-threatening stress being emphasised as conducive of hallucinations. Siegal (1984) described the reported experiences and circumstances of the UFO abduction case were similar but difficult to disentangle. The two who described alien abduction, alongside the 32 year old female who was held hostage and raped by a burglar, were the only participants to report struggling to distinguish hallucinations from reality. This is consistent with Gauntlett-Gilbert and Kuipers's (2003) VH research reported in the previous review, where less than half of their psychiatric service-user sample felt their VH were real.

In Siegal (1984), the antecedent circumstances of those who reported hallucinations were similar to 2 further cases where hallucinations were not reported. One of these cases regarded a male attorney aged 50 held for ransom on a business trip; having been threatened in the past by one of the captors, the man anticipated being held hostage and was wearing a bulletproof vest. This case was reported as similar to most POWs who did not hallucinate; as such

anticipation was reported to “markedly reduced his stress, thus attenuating the emergence of hallucinatory phenomena” (Siegal 1984, p.268). The other case was of a man who reported being “full of cocaine” when captured and experienced withdrawal symptoms (sleep, lethargy, depression, fatigue) whilst held hostage. Siegal (1984, p.268) proposed perhaps this “dramatically tempered his stress and visual imagery”.

From this research it seems being held hostage is a circumstantial situation where hallucinations are much more likely to occur. Any of the following factors individually or in combination may be characteristic of situations which elicit hallucinations: visual deprivation, social isolation, physical abuse, restraint on movement, and having one’s life threatened; with Siegal (1984) emphasising the combination of social isolation and threat of death in particular. Some of these features are consistent with the outcomes of Gauntlett-Gilbert and Kuipers’ (2003) research, where low sensory and social stimulation were circumstantial features conducive of VH. To summarise, during hostage situations perceptual experiences and hallucinations varied; they were however likely to involve seeing things or changes in bodily feelings; with their incidence potentially mediated by circumstantial features such as anticipation, preparation and intoxication.

Experiences of hostage hallucinations seemed to be co-constituted by and intimately bound within one’s social and material circumstances; particularly with regards to the safety and conditions of one’s feeling body. The role of the safety of one’s body, is consistent with the growing empirical evidence surrounding the interrelationship between being subject to CSA, CPA and ASA and hallucinations. In Siegal (1984) complex VH were often closely tied to one’s personal history; providing a rationale for further research studying hallucinations to also investigate personal histories, difficult life events and the immediate social and material circumstances of hallucinations.

Though there were similarities between Siegal’s (1984) sample and Gauntlett-Gilbert and Kuipers’ (2003), the sample of the latter regards psychiatric service-users and the former regards a non-clinical sample. None of Siegal’s (1984) hostage-hallucination cases held psychiatric histories, except for the father reporting UFO abduction who had been given a paranoid psychosis

diagnosis two-years-prior. The son did not have a psychiatric history, although Siegal (1984) reported strongly rated belief in paranormal phenomena. Overall, hostage-hallucinations were described in terms of the meaningful material and social circumstances in which they occurred, rather than conceptualised as meaningless indicators of pathology, or symptoms of random content within a mental illness. This was consistent with the approach towards bereavement hallucinations. Such an approach is consistent with chapter-1's arguments and Suryani et al.'s (2013) proposals in SR1b; that hallucinations (and mental health more broadly) may be best understood as meaningfully related to the circumstances in which they arise. Given that hallucinations seem to be co-constituted by their immediate circumstances, future research may aim to identify further circumstances and life-events that elicit hallucinations.

3.04.4 Social Deprivation.

In addition to studies of life events' contribution to hallucinations, research investigated difficult socio-economic circumstances. Increasing income inequality in recent decades has gained researchers' attention, who have documented widespread negative effects on health, most notably for those most socio-economically deprived (Marmot, 2010). In Kirkbride et al.'s (2007) southeast London study, 23% schizophrenia diagnosis incidence was explainable through neighbourhood level risk factors. This included factors such as increased risk of schizophrenia in BME individuals' resident in neighbourhoods with smaller proportions of BME residents, or where neighbourhoods were more ethnically fragmented. Consistent with hallucinations literature being more limited (Bentall, 2014), this review retrieved 1 article on the relationship between AVH and social deprivation. Wickham, Taylor, Shelvin and Bentall's (2014) UK based study, used data from a large mental health survey. Within the survey, social deprivation was defined in terms of income, education, skills and training, living environment, employment, barriers to housing and services, health and disability, and crime.

Wickham et al.'s (2014) research suggested as social deprivation increases, mental health difficulties also increase; with neighbourhood-level deprivation predicting psychosis. Their more specific analysis proposed social

deprivation was not predictive of AVH but was predictive of paranoia, depression, stress, lack of trust and discrimination. Notably, both depression and stress were reported as associated with and/or precipitative of hallucinations in SR1. In Wickham et al. (2014), experiencing AVH had been applied as a binary code of selecting yes to “Did you at any time hear voices saying quite a few words or sentences when there was no one around that might account for it?” (p. 3). Any response outside of yes to this question, was not identified as AVH. Given that SR1b identified many variations in form and feeling of AVH beyond that described in their question, the research is unlikely to provide a comprehensive picture of the relationship between social deprivation and AVH. Given the results regarding the relationship between social deprivation and psychosis, perhaps future research may re-examine the relationship between social deprivation and hallucinations using a more comprehensive definition of hallucinations.

3.04.5. Category Summary: Difficult Life Events and Circumstances.

As summarised in Figure 3.05 difficult and traumatic life events appeared co-constitutive of hallucinations in many and multiple sensory modalities. The relationship between broader difficult circumstances and AVH was less clear and may warrant further investigation. Such outcomes suggest it may be imperative for research to continue studying the nuances of the interrelationships between difficult life events, hallucinations and distress, as well as identifying further events conducive to hallucinations. The evidence reviewed thus far demonstrates the value of research focused on hallucinations, feelings and circumstances, each of which may be neglected by individualised and biomedical conceptualisations of distress discussed in chapter-1. This review continues by exploring research of hallucinations in daily life.

Hallucinations, Difficult Life Events and Circumstances	
<ul style="list-style-type: none"> • Adverse Life Events (Accidents, Alcohol/Drug Use, Broken Heart, Bullying, Death/Grief, Depression, Divorce, Leaving Home, Relationship Problems, Violence, War) 	<ul style="list-style-type: none"> • Common Modalities of Hallucinations (AVH, MMH, OH, TH, VH)
<ul style="list-style-type: none"> • Adverse Life Event Trigger (AVH More Often, Less Neutral AVH, More Negative AVH, More Positive AVH, More Troubled by AVH, More VH) 	<ul style="list-style-type: none"> • No Adverse Life Event Trigger (AVH Less Often, Less Negative AVH, Less Positive AVH, Less Troubled by AVH, More Neutral AVH)
<ul style="list-style-type: none"> • Adverse Trigger and Health (More Contact with Health Professionals for AVH, More Use of Psychiatric Medications, Older at First AVH, Worse Mental Health) 	<ul style="list-style-type: none"> • No Adverse Trigger and Health (Better Mental Health, Less Contact with Health Professionals for AVH, Less Use of Psychiatric Medications, Younger at First AVH)
<ul style="list-style-type: none"> • Death of a Spouse and Incidence of Hallucinations (82% at 1 month, 71% at 3 months, 52% at 12 months, More Likely in Women) 	
<ul style="list-style-type: none"> • Bereavement Hallucinations More Likely (Crying, Happier Marriages, Lonely, Low Life-Satisfaction, Low Self-Esteem, Memory Problems) 	<ul style="list-style-type: none"> • Bereavement Modality (Hearing, Presence, Seeing, Speaking, Touched)
<ul style="list-style-type: none"> • Hostage-Hallucinations (26% of Those Held Hostage, Start After ~15+ Minutes) 	
<ul style="list-style-type: none"> • Descriptions of Hostage-Hallucinations (Geometric Patterns, Falling Feeling, Floating Feeling, Light Flashes, Seeing Objects and Scenes, Seeing People, Tunnel Formations) 	
<ul style="list-style-type: none"> • Hostage-Hallucinations Co-Occur With (Anhedonia, Attention Lapses, Body Imagery, Difficulty Focusing Eyes, Disorientation, Dissociation, Feeling Isolated, Helplessness, Light Sensitivity, Stress, Out-of-Body-Experiences) 	
<ul style="list-style-type: none"> • Circumstances of Hostage-Hallucinations (Life Threatened, Movement Forcibly Restrained, Physical Abuse, Social Isolation, Visual Sensory Deprivation, Verbal Abuse) 	
<ul style="list-style-type: none"> • Social Deprivation (More Social Deprivation Associated With More Mental Health Difficulties and Psychosis, Paranoia, Discrimination, Depression, Stress but not AVH) 	

Figure 3.05 Summary of Research Regarding Hallucinations and Difficult Life Events or Circumstances.

3.05 Daily Life

Four articles studied three aspects of daily life; sleep problems, hallucinations within the flow of daily life and quality of life. This review section explores each of these in turn.

3.05.1 Sleep Problems.

One article by Waite et al. (2016) explored the relationship between sleep problems and AVH through semi-structured interviews with 10 participants. All participants were from a cognitive behavioural therapy for insomnia (CBT-I) trial. Despite being related to an intervention trial, this article remained due to its exploration of circumstances in terms of sleep.

Within their study, most participants reported sleep problems and tiredness were negative exacerbating factors for their wellbeing and functioning. There were however two participants who reported adjusting to and engaging in daily life despite sleep disturbance. Sleep problems were associated with fatigue, distress (agitation, anxiety), lost opportunities for activities of daily living and a negative effect on social relationships, and described as having a bidirectional interrelationship with AVH by Waite et al. (2016, p.186); AVH “wrecked” sleep and sleep problems negatively impacted wellbeing and reduced participant’s ability to cope with AVH. Participants described AVH worsened when they were tired as they didn’t “have the strength to fight them as much” and conviction in fears related to persecution became stronger (Waite et al., 2016, p.187). Furthermore, sleep could improve voices as “voices would be better from sleeping as well” and sleep offered an escape and coping strategies for AVH. Both the sleeping state and the experience of being in bed were described as beneficial; one participant described hearing voices continued but “doesn’t affect me in bed. It is the only place it doesn’t” and sleep itself was respite as voices “fly out of your head when you’re asleep” (Waite et al., 2016, p.187). Their research suggests a close interrelationship between sleep and AVH.

Being unable to fall asleep despite trying was “frustrating” (p.185) and associated with AVH, threatening command voices, thoughts of being killed and worrying (about finances, daily tasks, medication, living situations and concerns about relapse and one’s wellbeing). The onset of sleep was described in relation

to voices' distracting and distressing qualities; which were also described as associated with feelings of frustration, annoyance, hyperarousal, fear and anxiety which prevented falling asleep. This is consistent with negative emotions reported in association with voices described in SR1b and Woods et al.'s (2015) research. In Waite et al. (2016), one participant described a distracting voice which spoke and created shadows as they were trying to fall asleep, they described it:

Makes you want to pull your hair out, especially when you're trying to sleep at night and he [the voice] won't shut up... if he is in one of his annoying moods...although I am not trying to concentrate on him, when someone speaks you automatically hear what they are saying. (p.186)

These descriptions are reminiscent of the sense that AVH are done to and forced upon hearers, as described in Upthegrove et al. (2016) in SR1b.

Waite et al. (2016) reported post CBT-I trial improvements in sleep, mood, wellbeing, functioning, ability to cope with AVH and reduced tiredness. The therapeutic relationship was also reported as beneficial. Beneficial relational aspects included being listened to, connecting with someone, ease of talking with someone, experience of someone who was "open and honest" and experience of where someone "really did care... actually did want to help, which I had never really got... before" (Waite et al., 2016, p.190). Such outcomes are consistent with Nayani and David's (1996) results that talking to someone was the activity which eased AH most. Such research reinforces and builds upon the sense of the role of meaningful social relationships in experiences of hallucinations. In bereavement-hallucinations, meaningful relationships (or moreover their loss) were a precipitating factor, here social relationships supported voice hearers in navigating these experiences.

3.05.2 Daily Life.

Further to research sleep problems, two SR2 articles studied hallucinations within the flow of daily life; one in general (Delespaul et al., 2002) and one in relation to dissociation experiences specifically (Varese, Udachina, Myin-Germeys, Oorschot and Bentall, 2011). The majority of Delespaul et al.'s (2002) analysis regarded participants given a schizophrenia diagnosis and

similarly, Varese et al.'s (2011) sample was composed of people given schizophrenia spectrum diagnoses. Both studies used experience sampling methods (ESM) where participants complete a structured diary in response to a randomly signalling beep sound over 6-7 days. Except those continuously experiencing hallucinations, Delespaul et al., (2002) estimated that between the hours of 7:30am and 10:30pm, AH were experienced for 4 hours and 59 minutes and VH for 3 hours and 57 minutes. Consistently, within Varese et al. (2002), AVH were reported at 64.7% of beeps, ranging from reports on 2.4% of occasions, to reports of AH at every beep. Such research, consistent with SR1, suggests for some, hallucinations compose a substantial part of everyday life.

Regarding the modal form of hallucinations Delespaul et al. (2002), assessed VH and AH. Overall, more participants in their sample reported experiencing VH at least once and interestingly, 18% of participants reported experiencing AH but no VH, and equally 18% reported VH but no AH. Consistent with the arguments of the previous chapter, their research supports the position that VH (as well as AH) are commonly experienced and warrant adequate study. Interestingly, their analysis identified although VH were more common in daily life, AH were more intense.

The intensity of hallucinations was monitored over time (Delespaul et al., 2002). Over the course of an AH episode, the intensity would increase until a rounded peak, with a drop at the end; VH intensity however was reported as not affected by the phase of the episode. Anxiety and intensity were reported as co-varying as the feeling of anxiety was the strongest predictor of intensity; consistently, in the closest diary entries prior to AH, anxiety was reported as elevated, this was not reported for VH. During VH participants reported themselves as more obsessive, de-realised, hearing AVH more often, and more fearful of losing control. Statistically significant results were not generated regarding VH and cognition, mood, activity or social interaction. Similar outcomes were identified during AH, where participants reported more thought control and more VH. Overall, Delespaul et al. (2002) reported mood fluctuations (particularly anxiety) co-varied with hallucinations.

VH intensity was reported to vary in relation to one's activities. Interestingly, hallucination intensity varied by social company; when alone, at the episode beginning intensity was greater but this depleted at the end; when in social situations intensity was more consistent over time. Working was reported as reducing the hallucination intensity, and over the course of an AVH episode, intensity decreased whilst working. In contrast, hallucinations were more intense during leisure activity (e.g. watching television for 70% of participants) or more-so during no activity. However, during leisure activity, the intensity worsened over time, whereas intensity slightly dropped for those doing nothing. Delespaul et al. (2002, p.103) proposed:

Social withdrawal decreased hallucinatory intensity (AH > VH). Engaging in work activities (AH > VH) and, to a lesser extent, doing nothing (VH > AH) led to decreases in hallucinatory intensity over time. In contrast, passive leisure activities increased intensity of hallucinations (AH > VH)... Our data indicate that – in daily life – both maximal engagement (work) and maximal disengagement (being alone and doing nothing) are coping situations for hallucinatory intensity.

This builds upon Nayani and David's (1996) research, regarding the relationship between hallucinations and activities, where engaging in activity (except for watching TV) eased AH. Watching television in both systematic reviews seemed to be a binding circumstance precipitative of hallucinations. Broader contemporary digital activities were not a focus for exploration within the review literature and may warrant further study.

Delespaul et al.'s (2002) research suggested hallucinations may be inter- relationally co-constituted and sustained both by feelings (e.g. anxiety) and circumstances (e.g. TV). Due the diary's level of structure and statistical results reporting, appreciating the nuance of the hallucinations' feelings and circumstances was somewhat limited. Their research provides a substantial empirical basis further research can build upon. Delespaul et al. (2002) described primary areas for future research, including studying hallucinations' context (time of day, places, company, activities and coping strategies), particularly within daily

life. Almost twenty-years-on, these may still be an under-studied research priority areas.

More recently Varese et al. (2011) explored AVH within daily life, with a focus on dissociation. Their sample included ‘healthy’ controls, two schizophrenia spectrum diagnosis groups (non-hallucinating and hallucinating). Experiences of paranoia, dissociation and experiential avoidance were highest among hallucinating participants; a positive association was also identified between experiential avoidance and dissociation. Within their analysis, AVH were predicted by greater paranoia, greater dissociation, or greater experiential avoidance (though experiential avoidance was only statistically significant whilst paranoia was part of the model). Interestingly, stress was predictive of dissociation; this relationship was strongest among those hallucinating. Further analysis indicated stress severity strengthened the relationship between AVH and dissociation, with the association between AVH and dissociation being greatest under high stress. Their research illustrates an association between AVH and dissociation, with voice hearers experiencing a greater general tendency towards dissociation.

The relevance of the interrelationship between AVH, dissociation and stress, is highlighted by research regarding a bi-directional association between psychosis and increased stress-reactivity (or negative emotional reactivity) within daily life; such that stress sensitivity has been proposed as an affective pathway to psychosis (Myin-Germeys & van Os, 2007). Such research is useful in understanding what feelings may interrelate with regards to hallucinations in daily life. Research on dissociation in relation to hallucinations elicits interesting questions on the way in which perceptions which are additive to ‘objective’ reality (e.g. hallucinations) can be differentially understood, compared to experiences which deplete or disconnect perceptions of ‘objective reality’. Perhaps the relationship between AVH and dissociation may relate to their shared phenomenology of transforming perceptions of ‘objective’ reality and one’s connection to it. This points to feelings of reality which chapter-4 further explores.

Within Varese et al.’s (2011) research, the material and social features which characterise daily life are somewhat absent. To further build upon

Delespaul et al.'s (2002) research aims, appreciating the nuance and details of both feelings and circumstances of hallucinations within daily life may be beneficial. Varese et al. (2011) proposed given the association between stress and dissociation with stressful life events (including trauma), future research should build upon their results with consideration of potential trauma histories. Their further research did just that. Varese, Barkus and Bentall (2012), demonstrated the relationship between childhood trauma and hallucination-proneness, was positively mediated by dissociation; especially for sexual abuse. Given the relationship between hallucinations and difficult emotions, sleep problems and engaging in activity, it makes sense that research has investigated quality of life among people experiencing hallucinations

3.05.3 Quality of Life.

One review article studied the relationship between AH and quality of life (QOL). Janaki et al. (2017) used standardised quantitative measures with a sample of 60 patients in Malaysia given a schizophrenia diagnosis. Their research reported a significant relationship between AH and QOL, with voice frequency, duration, loudness, controllability, disruption to life, amount and intensity of distress all having a negative relationship with QOL. Voice frequency and controllability were predictive of QOL. To study this relationship from another perspective, their research also considered the relationship between voice hearer's demographic circumstances and QOL but did not generate significant outcomes. This suggests AH's experiential features may be more useful in predicting QOL. It may be interesting to further research to study the interrelationships between QOL, AH experiential features and demographic characteristics.

3.05.4 Category Summary: Daily Life.

Figure 3.06 summarises the overall picture of hallucinations in daily life research, which highlights a close relationship between hallucinations and sleep, dissociation, anxiety and stress among other features. Hallucinations comprised a substantial feature of day to day life, taking up significant portions of time and impacting negatively on QOL.

Hallucinations and Daily Life		
<ul style="list-style-type: none">• Sleep Difficulties (Bidirectional Relationship, Disrupted Sleep Pattern, Falling Asleep, Napping, Staying Asleep, Waking Early)		
<ul style="list-style-type: none">• Difficulty Falling Asleep (Distracting Voices, Distressing Voices, Fear, Frustration, Hyperarousal)	<ul style="list-style-type: none">• Sleep Avoidance (Fear of Threats, Nightmares)	
<ul style="list-style-type: none">• Consequences of Sleep Problems (Agitation, Anxiety, Fatigue, Lost Opportunities, More Fearful, Social Difficulties, Reduced Ability to Cope with Voices, Tiredness)		
<ul style="list-style-type: none">• Consequences of Good Sleep (Escape from Voices, Improved Coping, Improved Voices)		
<ul style="list-style-type: none">• Modality (AH, VH, VH > Often)	<ul style="list-style-type: none">• Time (~4-5 hours of day)	<ul style="list-style-type: none">• AH (Thought Control, >VH)
<ul style="list-style-type: none">• Intensity (AH > Intense, Anxiety Covariance, Phase of Episode [AH Peaks])	<ul style="list-style-type: none">• VH (>AVH, De-realised, Fear of Losing Control, Obsessive)	
<ul style="list-style-type: none">• Activity x Intensity (Decreased by Working and Doing Nothing, Increased by Leisure Activities, Less Likely to Employed in General)		
<ul style="list-style-type: none">• AVH (Dissociation, Experiential Avoidance, Paranoia, Stress Strengthens Dissociation)		
<ul style="list-style-type: none">• AH make QOL Worse (Controllability, Disruption To Life, Distress [Amount & Intensity], Duration, Frequency, Loudness)		

Figure 3.06 Summary of Research Regarding Hallucinations and Daily Life.

3.06 Social and Cultural Circumstances

This category discusses two articles on hallucinations' social circumstances, before exploring three articles focused upon culture.

3.06.1 Social Circumstances.

The two articles on social circumstances included 1 studying AH beliefs and social interaction (Ma, Beckstead, Lo & Yang, 2016) and another on voice power and command compliance in relation to social rank (Reynolds and Scragg,

2010). These papers are considered in each in turn. Ma et al.'s (2016) sample of 189 psychiatric service-users given a schizophrenia diagnosis, completed a questionnaire before and after a 3-month period. Their study did not appear to detail what proportion of participants reported AH; reporting of their demographic information within SR2 was limited. Ma et al. (2016) considered AH beliefs (e.g. influence of AH on participants), AH characteristics (e.g. clarity, reality, loudness) and the emotional behaviours of AH consequences. They reported AH beliefs were associated with AH characteristics and emotional behaviours. Where AH became less influential, emotional behaviour and AH characteristics scores improved compared to participants who reported no AH belief change. Although those with less influential AH beliefs improved during the study, those with more influential AH beliefs, had improved social interaction scores at 3 months; this was the case for those believing their AH were beneficial.

Overall, their research reported social interactions over time did not vary in terms of AH belief changes. This conclusion may be associated with recruiting in-patients from rehabilitation centres aimed at improving social skills and increasing social interaction; their daily lives may be inherently more social. Outside of this study's living situation, the relationship between AH belief and social interaction may differ. Given medication's prominence in treating hallucinations, a further notable result was AH beliefs, characteristics and social interactions improved without increased anti-psychotic medication. Ma et al. (2016) proposed opportunities for social interactions are beneficial for voice hearers.

Reynolds and Scragg (2010) also studied hallucinations' social circumstances with a rather different focus. They interviewed 32 men using forensic services who had heard command AVH to harm others. Hearing voices started at age 23 on average (ranging from age 5–51), with voice hearing episodes lasting 2-years-16-weeks on average. 65.6% (n=21) of participants 'compliers' reported complying with harm-other AH, 34.4% (n=11) were 'resisters' having reported never complying. Reynolds and Scragg (2010, p. 129) reported "no significant differences between the two groups in age, ethnicity, the age they finished education, highest educational level, employment status and

relationship status” or psychiatric diagnosis, age voices started or length of voice hearing episodes.

Regarding compliance among ‘compliers’ 42.9% always complied/never resisted, 19% rarely resisted, 33.3% sometimes resisted and 4.8% often resisted. The study explored social rank perception in relation to others and one’s voices. There were no differences between groups on perception of social rank compared to others. Compliers however perceived voices to be more powerful and of a higher social rank than resisters. These findings nuance SR1b outcomes of AVH’s powerful feeling. The relevance of perceived social rank of complied harm-other AVH was a novel result, yet reminiscent of Nayani and David’s (1996) participant’s AVH’s higher class accents.

Reynolds and Scragg’s (2010) compliers reported more AVH and command AVH than resisters; hearing more command AVH may therefore increase compliance. Their research highlights interesting areas of nuance in terms of voices’ perceived power, social rank, frequency, and content. Reynolds and Scragg (2010) proposed the reported greater feeling of power or social rank of AVH among compliers may have been retrospectively recalled, due to being aware they complied. Methodologically this may be a difficult problem to overcome.

SR2 articles on hallucinations’ social circumstances illustrate not only are people who hallucinate experiencing social-relational circumstances of ‘objective’ consensual reality, they are also navigating complex social and relational dynamics of hallucinations; as exemplified in the relational experience of voices in SR1b. The social circumstances of hallucinations can be described as dynamic, complex and multifaceted.

3.06.2 Culture.

Experiences of daily life, social interactions, and hallucinations arise within cultural circumstances. Although the prior articles did not examine such interrelationships, three SR2 articles studied hallucinations and culture. Bauer et al. (2011), commented on the experience of hallucinations across societies and their differing conceptualisations; ranging from contact or possession with spirits, to symptoms of illness. They documented hallucination prevalence over 1 year

across samples in 7 countries. Table 3.09 summarises their results, countries with the highest prevalence are shaded in orange and the lowest shaded in blue. AH and VH were most common in Ghana; TH, OH and gustatory hallucinations (GH) were most common in Lithuania; and VH, TH, OH and GH were least common in Pakistan. AH was most common, followed by VH and cenesthetic hallucinations (CH) (also called somatic, body or visceral hallucinations).

Table 3.09

Bauer et al.'s (2011, p.322) Research Outcomes Regarding Hallucinations by Modality and Culture. (NS=Not Stated)

Mod- ality	Austria (n=350)	Poland (n=80)	Lithuania (n=73)	Georgia (n=74)	Pakistan (n=103)	Nigeria (n=324)	Ghana (n=76)	Total %
AH	66.9%	83.3%	82.2%	71.6%	72.8%	85.4%	90.8%	74.8
VH	39.1%	45.0%	37.0%	9.5%	3.9%	50.8%	53.9%	39.1
CH	36.3%	28.8%	31.5%	20.3%	23.3%	18.8%	18.7%	28.9
TH	5.1%	7.5%	11.0%	8.1%	2.9%	10.6%	6.6%	NS
OH	8.6%	10.0%	12.3%	6.8%	—	8.3%	6.6%	NS
GH	3.7%	8.8%	13.7%	8.1%	—	8.3%	6.6%	NS

Bauer et al. (2011) demonstrated hallucination modality varying and co-varying across cultures. They reported unlike prior research, substantial proportions of West African and European participants reported VH; further analysis documented participants of West African origin more often reported VH. Time and modality were discussed in terms of age and frequency: younger participants reported more VH, those younger when hallucinations started reported more AH, and those who experienced hallucinations for a long time reported CH. In terms of frequency, AH was similar across countries, whereas VH were significantly more frequent among African participants.

Kent and Wahass' (1996) SR2 article compared AH among psychiatric service-users given a schizophrenia diagnosis in the UK and Saudi Arabia using a structured interview and standardised questionnaire. By focusing on 2 cultures and one modality type, their study provided further information on how the cultures and hallucination phenomenology varied. Both Bauer et al. (2011) and Kent and Wahass (1996) studied the proposition hallucinations held cross-

cultural similarities; noting AH content was shaped by culture (rather than ethnicity). Between cultures, voices held similar characterful properties with no significant differences in terms of voice gender, whether they had a name (or not), whether they were familiar (or not) and the form of address in which the voice spoke (100% heard 2nd person voices of you/your, 66-68% heard 3rd person voices of he/she/they). Samples had similar voice “frequency, loudness, distress caused, difficulty in ignoring the voices, validity, source and perceived reality” (Kent & Wahass, 1996, p. 434). Differences between samples included UK hearing voices more clearly and variations in thematic content; Table 3.10 presents participant quotes to summarise content themes.

Table 3.10
Kent and Wahass’ (1996, p. 435) Themes of AVH Content.

<u>Theme Name</u>	<u>Theme Description</u>
Religious	“the relationship between the patient and his god, e.g. instructions to read a holy book, chastisement after death, or mention of paradise”
Instructions	“the ordering or forbidding of certain activities, e.g. telling patients to kill somebody or to harm themselves, or disallowing particular behaviours”
Animosity	“animosity, including threats, accusations, criticism, and reviling of patients”
Cultural	“politics, sports, and family affairs”
Superstitious	“mention of demons, magic and spirits”
Friendly	No definition provided
Sounds	“sounds such as whispering, whistling and laughing”
Comment	No definition provided

Figure 3.07 summarises the percentage of participants reporting experiencing voices by theme, form of address and country. In the UK, instructional content was more common (particularly within second person voices) as were 3rd person running commentaries. In the Saudi sample, religious and superstitious themes voices were significantly more likely, both within second and third person voices. The researchers proposed this may be due to religious and supernatural thought and religion’s greater role within Saudi culture.

Figure 3.07 also illustrates cultural similarities including levels of 3rd person instructional content; 2nd and 3rd person AH, sounds, voices of animosity, friendly and cultural content.

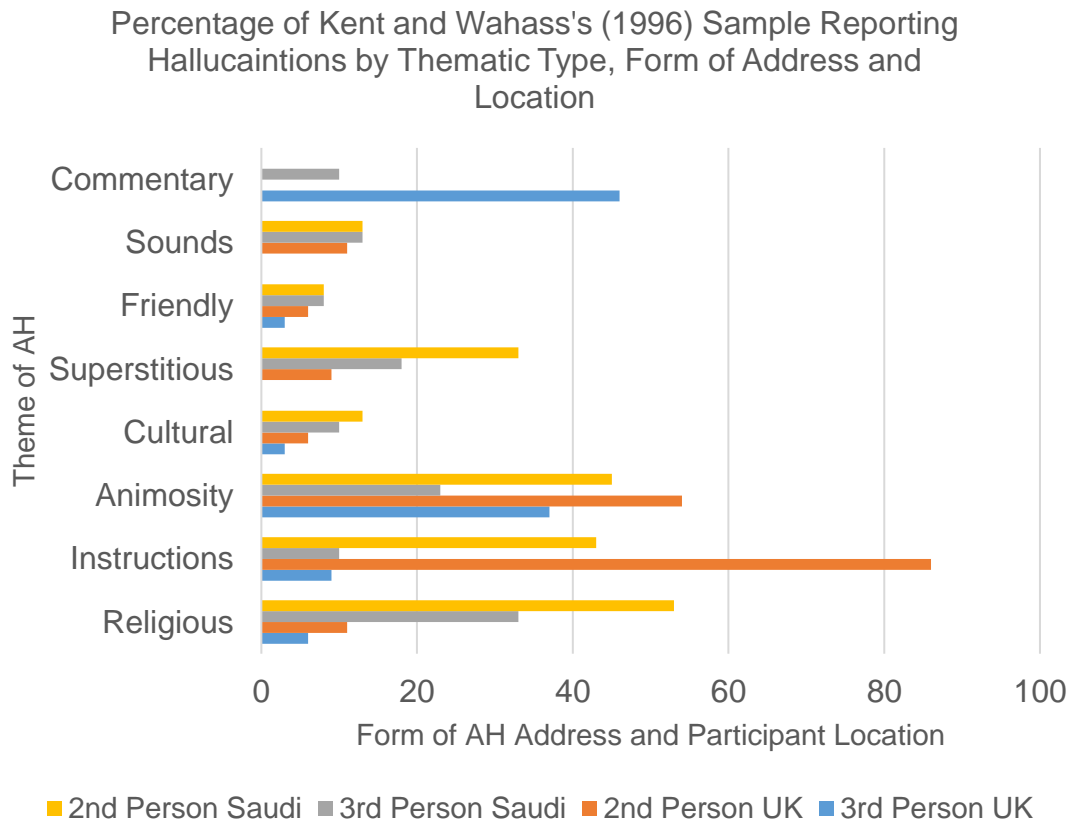


Figure 3.07 Summary of Research Regarding AVH by Theme Content, Form of Address and Country.

Given the cultural similarities and differences, Kent and Wahass (1996) proposed psychological interventions may need adapting to address variations in content and aspects of hallucinations considered salient. Notably, both Bauer et al. (2011) and Kent and Wahass' (1996) participants had been given a schizophrenia diagnosis and antipsychotic medication. Similarities may therefore be partially mediated by shared psychiatric conceptualisation and management of AVH.

Culture's contribution in hallucinations is further illustrated through Andrade, Srinath and Andrade (1988) case study retrieved through SR2. Within their Indian context, paranormal phenomena and religious folklore were described as mostly culturally accepted; including prophecy, evil eye, possession from gods and demons, mystical trance, rebirth, faith-healing, witchcraft, divine

revelation and ancestral spirits. Cultural explanations may enhance veridicality and objective feeling; they are culturally 'true' perceptions. This was proposed regarding a male aged 28, 'K', who experienced a vivid MMH of seeing a woman sitting upon his bed. He reported hearing her speak about her difficulties for two hours before vanishing; co-occurring feelings included fear and surprise the interaction did not wake his brother who slept throughout the encounter. The experience was described as happening "in clear consciousness and in objective space", without ability to influence the perception and "despite intact reality-testing, K was unshakeably convinced of the veridicality and objectivity of the experiences" (Andrade et al., 1988, p. 838). The conviction, vividness and reality of the experience was reported as closely interrelated with the Indian cultural context. K's family were reported to share his views and temple exorcism rites were conducted to cleanse K of the evil eye. Andrade et al. (1988) concluded clinicians must assess hallucinations on the terms of their socio-cultural circumstances. This illustrates that experiences described as madness and mental illness are conceptualised through the extent to which one deviates from cultural norms. Hallucinations are tied to cultural circumstances, as they are actualised as such by their deviation from consensual perceptions of reality (which culturally vary).

3.06.3. Category Summary: Social and Cultural Circumstances.

Figure 3.08 summarises the overall outcomes of research on hallucinations' social and cultural circumstances. The research illustrates people experiencing hallucinations navigate and manage dual planes of social relations; of both hallucinations and 'objective' consensual reality. Voices' influence and power appeared to influence hearers' emotional and social experience, and the likelihood of complying with voice commands. Across cultures hallucinations varied and co-varied; with hallucinations being indexed through shared phenomenological properties by which they were similar or differed. Overall, hallucinations seemed to be meaningfully shaped by and experienced through their situated culture.

Hallucinations and Social and Cultural Circumstances	
<ul style="list-style-type: none"> • Less Influential Voices (Improved AH Characteristics, Emotions) 	<ul style="list-style-type: none"> • More Influential Benevolent Voices (Improved Social Interactions)
<ul style="list-style-type: none"> • Social Interaction and AH Beliefs Over Time (AH Belief Changes may not Change Social Interaction) 	<ul style="list-style-type: none"> • Social Interaction (Recommended)
<ul style="list-style-type: none"> • Antipsychotic Medication Increases Not Necessary for Improvements 	
<ul style="list-style-type: none"> • Compliance With Harm-Other Commands (34.4% Had Never Complied, 65.6% Had) 	<ul style="list-style-type: none"> • Compliers Resisted (4.8% Often, 19% Rarely, 33.3% Sometimes, 42.9% Never)
<ul style="list-style-type: none"> • Compliers Heard (More AVH, More Command AVH) 	<ul style="list-style-type: none"> • Compliers Voices (More Powerful, Higher Social Rank)
<ul style="list-style-type: none"> • Differences and Similarities Across Cultures 	<ul style="list-style-type: none"> • Modalities Cross-Culturally Most Common (AH 74.8%, CH 28.9%, VH 39.1%)
<ul style="list-style-type: none"> • Countries Where Hallucinations Were Most Common By Modality (Austria [CH], Ghana [AH, VH], Lithuania [GH, OH, TH]) 	
<ul style="list-style-type: none"> • Countries Where Hallucinations Were Least Common By Modality (Austria [AH], Ghana [CH], Pakistan [VH, GH, OH, TH]) 	
<ul style="list-style-type: none"> • Cross-Cultural Similarities of Voices [UK & Saudi] (Difficulty Ignoring, Distress Caused, Form of Address, Frequency, Gender, Having Name, Loudness, Reality, Source, Validity) 	
<ul style="list-style-type: none"> • Cross-Cultural Similarities AVH Content [UK & Saudi] (Animosity, Cultural, Friendly) 	<ul style="list-style-type: none"> • Cross-Cultural Differences AVH Content [UK & Saudi] (Saudi More Religious and Superstitious, UK More Clearly Heard, UK More Instructional and Commentary)
<ul style="list-style-type: none"> • Hallucinations Are Meaningfully Related to the Culture Within Which They Arise 	

Figure 3.08 Summary of Research Regarding Hallucinations and their Social and Cultural Circumstances.

3.07 The Circumstances of Hallucinations

To summarise SR2's outcomes, the circumstances of hallucinations regard the flow of daily life (including sleep and dissociation), may relate to adverse life events (past or present), one's activities, material circumstances, living situation, and situated cultural and social-relational experiences. Circumstances appear to influence hallucinations' occurrence, maintenance and feeling. Past and present circumstances shaped hallucinations' feeling in terms of modality, complexity, emotional valence, emotional impact, frequency, complexity and the sense that was made of them. Consistent with SR1, feelings themselves seem to precipitate hallucinations, particularly stress, isolation, loneliness, dissociation and altered connection to reality. There was some evidence of a bidirectional relationship with adverse life events being associated with the hallucinations' feeling, and subsequently shaping ongoing circumstances (e.g. healthcare professional contact for AVH). Although the field of research regarding hallucinations' circumstances was small, circumstances appeared relevant in shaping lived experience.

The circumstances of hallucinations regards many multifaceted features of one's surrounding environment alongside a temporal element; of one's present, prospective future and past. The term circumstances used in this thesis points to the ongoing temporally-situated features and events comprising one's environment; this may involve past, present or anticipated future material, social, cultural, political, historical and relational aspects (among others). SR2 provides clear empirical grounds for further research to develop.

3.08 Areas for Development

Primary areas for study include interrelationships between feelings and circumstance; with a broader conceptual focus (e.g. more modalities or circumstantial features); including consideration of hallucinations' socio-economic, material and digital circumstances. Consistent with SR1, studying interrelationships between hallucinations' feeling and circumstances was not a prominent focus in SR2's articles. This is consistent with Chapter-1's opening arguments, wherein dominant models of distress often place feelings and circumstances beyond their attention; such issues may be exacerbated as the

available hallucination research is limited. Building upon the daily life research using broader conceptualisations may facilitate in-depth research by prospectively studying situated examples of hallucinations. Drawing upon feeling theory may support in developing more comprehensive empirical studies of the feeling and circumstances of hallucinations.

SR2 literature paid minimal attention to hallucinations' socio-economic or material circumstances. Wickham et al. (2014) studied the socio-economic circumstances of hallucinations most and reported AVH in particular did not appear associated with deprivation. Given the broader literature on the association between socio-economic factors and wellbeing, further research seems warranted (Kirkbride et al., 2017; Marmot, 2010). Research on hallucinations' circumstances held a narrow focus towards selected aspects of lived contexts. Waite et al. (2016) for example reported on sleep difficulties without exploring the situated circumstances of participants' sleeping arrangements. An advantage of selective research focus may enable more specific data generation and refined research reporting. However, it pulls apart the multifaceted aspects of situated experience, that for example sleep is always situated in a place, in relation to objects and other living beings, and within an ongoing lived history of situated experiences. Research may benefit from studying hallucinations' circumstances with a broader scope. This may facilitate understandings of how combinations of circumstances relate to hallucinations.

Consistent with minimal attention on hallucinations' material circumstances, contemporary technological circumstances were seldom considered. Mention of technology was largely in relation to TV, yet modern life is characterised by living with and through multiple mobile available technologies (TV, computers, mobile smartphones, tablets, laptops, social-media, virtual assistants, smart-speakers, activity trackers), with new digital and social realities emerging rapidly. The 'objective' material and social circumstances of hallucinations are now lived within and through a context involving parallel, dynamic and emerging digital realities. Further research of hallucinations' circumstances may wish to pay attention to material circumstances and their socio-technical features, regarding which there is much to learn.

Regarding hallucinations' socio-cultural circumstances, there was more available literature on culture's contribution than social relationships. The role of culture was studied at different levels from comparing the primary modality between several cultures (Bauer et al., 2011), to more detailed phenomenological comparison between 2 cultures (Kent and Wahass, 1996), to exploring in 1 case in detail (Andrade et al., 1988). Further to the research described at the beginning of this chapter, some articles documented the relevance of social circumstances to hallucinations' short term (Delespaul et al., 2002) and longer-term trajectory (Ma et al., 2016), the social-relational features of AVH (Reynolds and Scragg, 2010) and precipitation of hallucinations by adverse life events including bereavement and hostage situations. The contribution of social circumstances to hallucinations forms a research priority area; interrelatedly, as do adverse life events which were reported to elicit hallucinations rapidly for some. The circumstances of hallucinations are characterised by many interrelated social aspects including culture, politics, history, religion, interpersonal relationships and so on, for ease of communication, these are referred to as 'social' circumstances; with economics spanning socio-material circumstances.

Based on SR1a, SR1b and SR2's outcomes, Table 3.11 summarises a series of future research priority areas. To build upon the reviews' research, studying hallucinations with a wider scope of their circumstances and modalities may be beneficial. Circumstance focused research needs to develop in terms of understanding experiences both as it's lived within daily life and within an ongoing lived history. The body of literature to guide research's specific directions to explore these key areas is limited. Future research designs should facilitate participants to bring their perspectives of what is salient to guide research.

Table 3.11
Priority Areas for Future Research.

<u>Priority No.</u>	<u>Priority Areas</u>
1	What Theories May Help in Conceptualising Feelings and their Interrelationship with Circumstances?
2	What Do Hallucinations Feel Like (Particularly in terms of their Emotional and Bodily Feelings)?
3	What Life Events Are Associated With Hallucinations?
4	What Are the Material Circumstances of Hallucinations?
5	What Are the Social Circumstances of Hallucinations?
6	How Do Hallucinations Feel within One's Lived Circumstances?
7	In What Ways Do the Circumstances of Hallucinations Relate with How They Feel?

The systematic review articles relied on self-report measures. Self-report measures raise methodological difficulties as explored in SR1; they also provide access to situated experiences key to this research area. To combat methodological difficulties such as memory's reliability, drawing upon prospective methods such as diaries may build upon the success of the daily life articles. Drawing upon the growing scholarship on visual and arts-based methods, may be fruitful to facilitate research flexible enough to empower participants to contribute to the research direction, whilst maintaining reliable and robust methodological rigour. Chapter-5 explores methodologies fitting with such aims.

Before exploring potential methodologies and methods to develop the research literature, Chapter-4 explores theoretical scholarship on feelings. The systematic review literature was developed, conceptualised through and discussed in terms of other empirical studies. Having systematically reviewed empirical literature on the feeling and circumstances of hallucinations, Chapter-4 documents an investigation of theories on varieties of feelings; of feelings and circumstances; and of feelings, circumstances and distress.

4. Theories of Feeling



Figure 4. Still Photographic Image of a Portrait of Susanne Langer from the Feeling-In-The-World Art Series during Gallery Exhibition at Attenborough Arts Centre in Leicester, 2018.

This chapter begins by overviewing the research's theoretical context by considering the affective turn and associated terms. The linguistic meaning and analytic structure of the term feeling is considered, before working to develop a process account of feeling and outlining its implications for research. A theoretical framework built from Langer (1967) and Cromby's (2007; 2015) conceptualisation of feeling is taken forward to guide the thesis and its associated practice. After building a theoretical lens of feeling, a specific theory of feeling-traps is considered (Cromby & Harper, 2009; Scheff, 2012). These feeling theories were drawn upon to conceptualise hallucinations and distress. This chapter concludes with a discussion of the implications feeling theories may have for empirical hallucination research.

4.01 Terms and Turns: Affect, Emotion and the Affective Turn

The rise of scholarship on affective and emotive matters in recent decades has been described as the affective turn (Leys, 2011). Affect in Massumi's (1995) terms may be understood as an unqualified, bodily intensity, and conceptualised as nonconscious, pre-linguistic, pre-personal and separate from meaning and intentionality. Massumi (1995) wrote of the autonomy of affect from the linguistic and discursive; constructs which held such a dominant focus, that academics argued the material matters of the body had been conceptually marginalised out of the frame of much academic study. Brown et al. (2008, p. 202) described:

The body and its sensed felt engagement with the world around it is rarely represented as such in discursive work in psychology. When it is, it must be converted into either talk around the body or as the embodied grounds of talk.

Affect scholarship has produced a conceptual language through which literature and theory of embodiment can be explored. The affective turn has supported qualitative and social researchers to shift academic perspectives away from a sole focus on discourse, whilst affording interdisciplinary collaboration and scholarship (Cromby & Willis, 2016). The affective turn has worked to pull consideration of neuroscientific and psychological research into disciplines across the social sciences, arts and humanities; with promising potential for interdisciplinary understandings of experience.

Ley (2011) argued much affective turn scholarship holds parities with or draws directly upon approaches associated with basic emotion theory (BET), which dominates affective and emotion research in psychology and neuroscience. In BET, emotions are conceptualised as evolutionary, rapid, automatic physiological reactions and corresponding behavioural expressions, which are activated by genetically inherited neural affect programs; similar to Massumi's affect, emotion occurs independently of socio-cultural meaning, cognition and intentionality. In the neurobiological research drawn upon by affect scholars such as Massumi (1995), the body's affective processes are conceptualised as responding at a pace too quick for cognitive functions, meaning, or intention to have played a part, these matters of 'mind' are described to come 'after the fact'. The primacy of affect and body in such a kind of sensual knowing or action (prior to meaning or intentionality), pulls the human sensing bodily being-in-the-world into centre view for academic study. Concepts of affect and emotion informed by approaches consistent with Massumi (1995) and BET, have been used to inform much scholarship; promisingly bringing embodied materiality into focus, but, some of the assumptions by which it is underpinned, may have problematic implications.

Ley's (2011) critique of the affective turn and BET, describes where physiological bodily responses (affect and emotion) are separated from the meaning of the triggering object, a dichotomous dualism is imposed between affect and emotion on the one hand and meaning, thought, intention, language, ideology, and subjectivity on the other. Ley's (2011) arguments highlight how affect scholarship may invoke dualisms of mind and body; as the primacy of the body (through a pre-personal, pre-linguistic affect), separates out the function of mind as something of a reviewer, or conceptualising after-effect.

Further critique by scholars such as Burkitt (2014) and Wetherell (2012) argue conceptualising affective and emotive phenomena in this way, problematically places them beyond the realms of the meaningful, discursive, socio-cultural and historical influences, which are argued to relationally form them. With affect separated from meaning, and emotion pre-deterministically triggered, recognising an interrelationship between affective experiences and circumstances may become problematic. So not only is affect separated from

thought and meaning, and body separated from mind, but such conceptualisations may separate individuals from their circumstances.

A conceptualisation of hallucinations under such a framework may accommodate a corporeal concern for the fluxes of the body but akin to strong biomedical approaches discussed in chapter-1, such fluxes would be asignifying, with the content, context and subjective feeling and meaning of these experiences potentially moved out of the frame of study. Such an approach may neglect the nuances of how experiences such as hallucinations may be framed by, entangled within, relationally infused with and meaningfully formed through one's socio-cultural-material-discursive circumstances.

The affective turn has pushed across a range of disciplines, with heterogeneous conceptualisations and approaches invoked at each turn. In Wetherell's (2012) work on affective practice, the discursive is interwoven with affect, by arguing language shapes what we come to know of the world and how we form meanings of our experiences. By drawing on Goodwin (2006), Wetherell (2012; 2013) describes that during embodied interactions in situated activities, flows of embodied activity are often bound up with talk in some way. This may be through talk in the moment or in subsequent communication to make sense of the experience. Furthermore, Wetherell (2013) highlights how affect, embodiment and action are already entangled in the discursive, as affect and practice in the present are meaningfully orientated, modulated and organised by the past (including understandings socially constructed [in part] by language). Such conceptual moves work to integrate affect with studies of language, rather than placing affect in opposition to language (Cromby & Willis, 2016). An integration between affect and the discursive, or the contextual has also built up elsewhere in academic literature. For example, Brown and Reavey's (2015) vital memory understands affect in subjectivity, memory and remembering, as interwoven in arrangements of contextual interrelations. Further work by Burkitt (2014) forms a concept of emotion as a complex of social relations; intersubjectively elicited and relationally co-constituted through contextually situated social relations (with permeating cultural and historical influences).

This brief overview of some of the numerous ways in which ideas of affect and emotion are being taken up and understood, highlights a corporeal concern for the fluxing states of the body can be held in view alongside a concern for their circumstances, discursive interrelations and meaning. Overall, contemporary scholarship on affect and emotion are used in a variety of interrelated yet different ways with varying connections and disconnections to concepts such as discourse, subjectivity, social relations, meaning and materiality.

Academic literature on affect and emotion, often use another interrelated term: feeling. Consistent with the academic moves of scholars such as Cromby and Willis (2016), this thesis continues by prioritising feeling and builds a process understanding of feeling, informed by Langer (1967) and Cromby (2015). As described by Cromby (2007, p.96), such an approach to feeling “differs somewhat from the notion of affect within cultural theory, although it indexes many of the same phenomena”. Langer (1967) and Cromby’s (2015) concepts of feeling deftly cut across numerous dualisms. It does so by developing a process account of feeling, as a phase of the multifaceted interrelationship of being a material bodily organism in the world (including its interweaving discursive, socio-relational and historical trappings). In this same sense, feeling is understood as the stuff of experience, the raw material from which the thoughts and attributes of what we may call mind branches. This chapter continues by examining this concept of feeling which the thesis takes forward.

4.02 Of Feeling

‘Feeling’ is used in a colloquial sense in numerous ways including describing:

- Sensations, reactions, and emotions;
- A way of acting or an aspect of one’s being or character;
- Beliefs, attitudes, ideas or opinions;
- An understanding, intuition or sensitivity for something;
- Sense-experiences such as touching or being touched.

This vast breadth in the ways feeling is used colloquially, reflects the great potential feeling affords as a concept within human research. Although in colloquial language, one may speak of ‘having’ ‘a feeling’, such talk may be deceptive. Consistent with Langer (1967), Cromby and Willis (2016, p.484) argue

feeling is a “verbal noun- a verb made into a noun- and, as such, precipitates an entity out of a process”. Feeling can be understood as a phase of the interrelating activity within the human body, finely adjusting to its circumstances; as such to feel is to do, not to have.

Following from Wierzbicka and Goddard (1994), Shweder’s (2004) work argues that for the sake of enabling comparative and cross-cultural scholarship on human experience, the study of feeling should be privileged, over for example studies of emotion. Linguistic study has suggested “feeling” (alongside thinking, knowing, wanting and valuing things as good or not), is a natural language prime. This means every known human language, is encoded with a single lexical word-like item for feeling. Emotions are understood as lexically synthetic complex terms, composed of combinations of wants, values, beliefs and feelings. Although emotions may be synthesized across the world in similar forms, the complexity of this synthesis is yet to be consistently acknowledged or understood in research. As such, Shweder (2004) argues the universality of human emotional functioning or experience cannot be assumed or claimed to be existent. These scholars propose, to progress in studies of human mental functioning (with capacity for cross-cultural research), theoretical development and empirical studies should focus on prime constructs such as feeling. Consistently, a bottom up research approach beginning from consideration of feeling may be beneficial. Anthropologists such as Shweder (2004) argue use of top-down complex constructs is not necessarily inappropriate, but their utility cannot be assumed. Having considered feeling in a colloquial and linguistic sense, exploring the analytic structure of feeling, may provide an insight into what a focus on feeling means for research.

4.03 Taxonomies of Feeling: A Theoretical Development of Cromby (2007)

Theoretical work mapping the construct of feeling may help to organise empirical analysis and provide remits of what studies of feeling regard. Cromby (2007) broadly categorised feeling into three elements explored in this section. Despite taxonomic categorisation, different feelings are not proposed to occur in isolation. The categories are proposed as interrelated analytic facets of feeling,

which may support empirical research in providing a refined and precise account of the felt experiences under study. To support in elucidating the theoretical context of such an approach, some parities with other theorists are noted.

The first category is emotional feelings: embodied aspects of emotions such as the glowing energetic warmth of happiness or the cool dark lethargy of sadness. As previously explored, the concept of emotion which lacks universal use or definition, can be understood as indexing complexity on both linguistic (Shweder, 2004) and social-relational levels (Burkitt, 2014). This analytic category of feeling, can thereby be seen as the somatic, bodily aspect of emotion; despite being indexed by complexity, their somatic aspects infuse a linguistic prime and a key aspect of feeling-in-the-world. In SR1b AVH were associated with numerous emotional feelings: from fear, anger and depression, to positive or neutral emotions (Woods et al., 2015); Daalman et al.'s (2011) research notably indicated voice hearing participants could be predicted as accessing services (with 88% accuracy) by voice content being emotionally negative. Emotions were a focus area for future research from SR1.

The second category is extra-emotional feeling: bodily impulses, senses, and drives, which often have emotional aspects to them yet further embodied textures beyond their emotionality examples could include: pain, sexual desire, hunger, tiredness and comfort. As described by Cromby (2007), if the emotional aspects of the feeling were somehow separated out, meaningful aspects of the feeling would remain. The combination of emotionally charged and fluxing somatic aspects of the feeling, may modulate the texture of how the feeling is experienced and may also afford particular responses (e.g. a covering of ones ears due to a loud unpleasant noise). For the purposes of research exploring hallucinations for example, extra-emotional feelings would include feelings such as pain or itching that could co-occur with AVH (Upthegrove et al., 2016). These feelings (often described as somatic or bodily) were an SR1 focus area for future research.

The third category is feelings of knowing: akin to Shotter's (1993) knowing of the third kind and gut feelings such as the resistant tension of reluctance. Described by Cromby (2007, p.100) as "the more subtle and fleeting feelings that

arise in social interaction, discussion, deliberation and decision-making. These are the feelings associated with half-formed desires, inarticulate refusals, the imperfect sense of significance not yet realised or a judgement only partially made". This analytic category of feelings, may be less readily described in terms of their bodily aspects and are proposed to often pass unnoticed or unnamed. These feelings may be understood as akin to the valences afforded in the gut feelings of decision making; invoking an idea of rationality akin to Damasio's (1994) somatic marker hypothesis. These kinds of feelings did not appear to have been the focus of study in phenomenological hallucination research.

A further novel analytic category potentially relevant to hallucination research, is feelings of reality: the textured feelings of being a body, a conscious thing, in space and time; including feelings of connection and disconnection to reality, materiality, to oneself, one's body and one's circumstances in time and space. Such feelings may incorporate aspects of hallucinations described by Upthegrove et al. (2016) like the texture of a feeling or perception being 'real' or genuine. Feelings of reality may be relevant to dissociative experiences of disconnection from oneself or the surrounding world, typically relating to changes in feeling, and potentially memory or identity. Interestingly, some contemporary theoretical work and review exploring voice hearing, has described such experiences as "a primarily dissociative process" (McEnteggart, Barnes-Holmes, Dillon, Egger & Oliver, 2017, p. 575). Indicating that beginning to explore hallucination experiences with a lens considering these feelings of reality may be particularly interesting. The relevance of feelings of reality was indicated by SR1b's exploration of AVH phenomenology in terms of reality, including: feeling of presence and entity, situated within conscious experience, and feeling situated within space and time.

The analytic category of feelings of reality could also support the study of experiences of flashbacks and experiences associated with psychoactive substances, or psychotropic medications, where partial or complete transformations in reality may occur; through changes in quality and texture of one's feeling-in-the-world or, through hallucination. Some examples may include, the vividness of absorption of connection to a situation, the blurred feeling of disconnection or distance to reality and one's circumstances, the loss of time,

slowness of time, feeling present and not present, and out of body experiences. The analytic category of feelings of reality may be understood as feelings which in some way disrupt or qualitatively alter the texture of reality, its stability, continuity, or our connection to it. Such that our experience of the world is in some way qualitatively different to consensual reality held by those around us, or held by ourselves during the usual flow of events. This novel proposed category will be explored in relation to Cromby's (2007) existing analytic categories before continuing the chapter which builds a process account of feeling.

4.03.1 Novel Analytic Category Review: Feeling of Reality

The fourth category of feelings of reality, holds analytic interweaves with Cromby's (2007) established categories; these are explored in order of feelings of knowing, extra-emotional feelings and emotional feelings. Feelings of reality could interrelate with feelings of knowing as the way in which reality feels, may transform attempts to navigate social-material circumstances. Disruptions to feelings of reality which in some way destabilise the security and trust in the feeling of reality and ourselves, would likely correspond with floods of feelings of uncertainty with disruptions to feelings of knowing. Changes in feelings of reality may form shaky felt grounds upon which to make decisions, hold social interactions and attempt to rationally navigate the world. Conversely, stable and secure feelings of reality, with a genuine and valid feeling of connection to reality and oneself, may support in trusting and harnessing feelings of knowing; to make decisions, understand and interact in the world. In this way, feelings of reality are in some way known and texture ways of knowing.

As much as feelings of reality are known, they are embodied; felt through fluxing bodily states to form a textured thread of a feeling of reality. An example may be the feeling of being very much in our social-material circumstances in time and space, to the derealised feeling of this no longer being as real or feeling less connected to it. This visceral, sensed aspect of feelings of reality harks to an interrelationship with Cromby's (2007) analytic category of extra-emotional feelings. A further example can be seen in Upthegrove et al. (2016) where participants described bodily feelings of imposition and control alongside AVH.

In this example the sensory extra-emotional feelings, co-occur with vivid feelings of a conscious present entity; with these sensations feel as though they correspond to an imposing and existent facet of reality despite lack of a tangible stimulus. These AVH experiences illustrate an analytic interweave between a sense of extra-emotional feelings and of vivid feelings of reality; seemingly of one's own feeling body generating an experience of an imposing, controlling presence. Cromby's (2007) emotional feelings could interweave through these experiences, a vivid feeling of imposition may be felt as real and experienced with an emotional hue such as fear or distress. A further documented interrelationship between feelings of reality and emotion, may be exemplified in how varying emotional feelings can distort our experiences of time such that it seems to speed up or slow down (Droit-Volet & Gil, 2009).

Alongside Cromby's (2007) three analytic categories of feeling, the fourth novel category may support in providing a refined analysis to understand some of the feelings which may interweave through experiences of hallucinations. Utilising theories and taxonomies of feeling may support empirical hallucination research through providing shared conceptual understandings, and structures with which to study different modal kinds of hallucinations. This chapter continues by building a process understanding of feeling and mind.

4.04 Feeling Body and Mind: Emotion and Thought

Feeling is a concept which affords numerous possibilities, including conceptualisation of experience as always and continuously dynamically co-constituted between our bodies and our circumstances. This chapter continues by building a process understanding of feeling primarily informed by Langer (1967). This approach is also consistent with Cromby (2015) and Cromby and Willis' (2016) arguments. Langer's (1967) work focused on a process philosophy of mind with a focus on feeling; this work provides a broad and fitting conceptual basis for research.

For Langer (1967), feeling is understood as a phase of the multi-faceted aspects of the body and environment, interrelating in such a way and to such an intensity that they are felt; known to the body, although not necessarily noticed. As feelings are proposed to form the very fabric of our experience, they are

conceptualised to most often go by unnoticed. Feelings may be more likely to be noticed when they are of an intensity, complexity or form that they highlight or elicit changes to the normative feeling of the flow of events in everyday life; whether that be due to changes in one's circumstances, a change in one's body or a change in how one can relate to their circumstances through their body. For example, the feeling of the middle of the upper side of one's left foot may rarely be noticed when in a resting state or walking. Should a blister develop in this area, it's likely that attention and awareness would be drawn to this typically unnoticed area, due not only to the feeling of discomfort, but also in terms of the alterations in how circumstances and surroundings can be engaged with; changes in how one feels-in-the-world.

A core aspect Langer's (1967) feeling, is that it is not an entity in and of itself, feeling is not a product, an excess, nor an addition to nature but a phase of relations in process. Langer's (1967) example is of the redness of an iron when it's hot. The redness is not an entity of itself, nor an excess that must be released elsewhere, the redness disappears as the iron cools. Redness is to an iron, as feeling is to a body; a phase of relations in process. There is a pragmatic sensibility which weaves through Langer's (1967) work, which in its simplest terms understands feeling as a phase of the body. There are many complex aspects of Langer's (1967) conceptualisation of feeling, including its implication for how humans are interrelated with their circumstances and how processes of mind can be understood. The role of circumstance is considered later in this chapter but for now, the breadth of Langer's feeling and mind is further explored.

An interesting implication of Langer's (1967) work is by conceptualising feeling as a physiological phase, rather than a product, by-product or something metaphysically different, difficult paradoxes and dualisms between the physiological objective processes of body and psychological subjective processes of mind are deftly cut across and may no longer seem so important. Langer (1967, p.31) describes:

Any felt process may be subjective at one time and objective at another, and contain shifting elements of both kinds all the time...Since organic

functions have dynamic forms, which they build up and melt down again constantly, their identifiable properties are transient.

A more recognisable example of a relational process simultaneously composed of subjective and objective elements, may be the sound of music. When an orchestra of instruments are correspondingly engaged with in harmonious ways, the sound of music transiently emerges from flows relational material activity. Much like feeling, this process is fusion of subjective and objective elements; of tangible bodies engaging with material instruments, which generate sound waves which touch a listener's ear, and the synchronicity or familiarity of the orchestra's interrelated engagements with these instruments eliciting the experience of hearing a melody. It is the entwined emergence of these subjective and objective elements through which music emerges, small changes in this interrelated process may lead to a mess of sound, without any music or melody heard. The sound of music then is to the relational process of an orchestra, as feeling is to the relational processes of the body. In this way, feeling can be understood as emerging at the transient intersections of the continuous interrelationships of the physiological processes of the human body.

The process orientation of Langer's (1967) work emphasises notions of transiency, flux and an understanding of feeling as continuously emerging, forming and changing. Langer (1967) argues that mind emerges through this very same process of feeling, as a phase of the interrelationships of physiological systems of the body (including the brain). This provides a process-relational ontology of human mind, feeling and experience.

In an approach consistent with Langer (1967), feeling may be understood as the raw material of experience and the basis of what is called mind; with feelings branching and interrelating to form ever-more complex mental functions. For Langer (1967, p.22) "the entire psychological field- including human conception, responsible action, rationality, knowledge- is a vast and branching development of feeling". The processes of mind such as thought, reason and decision making, can be understood as elaborate complex organisations of feeling. These weaving branching interrelationships of feelings, can fuse through, draw on, build upon and be entrained by sense-making made available from

previous felt experience and learned sign systems. In a conceptualisation of mind and experience where the primacy of feeling holds a centrality from which other aspects branch, the commonplace divisions of mental faculties such as the separation of thought from emotion, find themselves fused in roots of the very same stuff; of feeling. Considering processes of knowledge generation in a way consistent these arguments could be described as an embodied-feeling epistemology. Langer's (1967) scholarship may reorganise or reframe the conceptual foundations of studies of experience and mind.

Langer's (1967) conceptualisation of mind contrasts with the implicit and explicit dualisms inherent in most western conceptualisations of mind, psychology, and human experience. In the west, individualistic norms and culturally reinforced divisions between body, mind and different mental functions (such as the separation of thought from emotion), may be conceptualised as taken for granted matters of fact (Lutz, 1988). However as previously discussed, aspects of mind like emotions, may be cultural norms often erroneously construed as human universals (Shweder, 2004). The psychology of the Pacific Ifaluk culture highlights conceptualisations of mind vary between cultures and interestingly, theirs holds parallels with Langer's (1967) proposals for feeling and mind.

The work of Lutz (1988) and Cromby (2015), highlights the united conceptualisation of oneself in Ifaluk culture. This culture has been studied with interest by anthropologists due to its isolation in the Pacific Ocean sub-region of Micronesia. Here, people describe themselves in terms of 'niferash' loosely translated as 'our insides', which is used to talk about both psychological and physiological matters. This highlights the first similarity to Langer's (1967) feeling, which implicates both physiological and psychological processes within one system. Furthermore, the western distinctions between conscious and unconscious matters and the head and the heart are not similarly made in Ifaluk culture. Interestingly, matters of (western) mind are conceptualised as embodied; they are not necessarily being attributed to the head or the brain, but are attributed throughout the body, including the heart, gut and stomach. Similarities to Langer's work can be seen in the most predominant ways niferash is

discussed, in terms of 'nunuwan' and 'tip'; in a western sense respectively refer to collective combinations of thought and emotion, and will, emotion and desire.

Like Langer's (1967) feeling, both *nunuwan* and *tip*, are conceptualised to be aspects of the same phenomenon. Furthermore, akin to Langer's (1967) feeling, the term *Nunuwan* describes events ranging from what we may call thought to emotion, and these concepts are completely linked in *nunuwan*; not accompaniments nor things which trigger one another; they are one. Further still, emotion is an inherent part of *tip*, with emotion consistently fused through one's wills and desires. Akin with Langer (1967), the Ifaluk's culture's conceptualisation of mind is understood as composed of united, interrelated functions; embedded both in the physical body and in moral and social life.

If an approach to the study of hallucinations draws on Langer (1967) and insights from Ifaluk culture, there are interesting implications for how hallucinations may be differently understood. A process feeling conceptualisation of hallucination would encourage consideration of how the physiological processes of the body interrelate to appear in such transformative ways. A focus on feeling would understand hallucinations by looking across and between the systems of what we often describe as body and mind; seeing all of these processes as interweaving and interrelating to appear as a hallucination. Hallucinations could be understood as a mode of appearance within a complex, multi-faceted, continuously emergent tapestry of feeling. Hallucination in this way is a mode of feeling-in-the-world; with modes of feeling-in-the-world being continuously enmeshed within social and material relations, that themselves dynamically elicit, shape and entrain the feelings from which hallucinations emerge.

These theoretical, conceptual and cross-cultural considerations of mind challenge taken-for-granted assumptions of research. The conceptual basis of academic psychology (or the neglect thereof) was something Langer (1967) addressed in her work. She was critical of how laboratory methods (with associated emphases on isolation, control, repeatability and objectivity) were (mis)applied in psychology, and how in turn psychological subject matters can be blindly accepted or rejected on their basis. Langer's (1967) criticisms hark

warning signals of what's contemporarily dubbed as the replication crisis in psychological research (Pashler & Wagenmakers, 2012). Langer's (1967) work, challenged empirical researchers to philosophically develop the concepts of mind, such that a robust science could develop.

The primary aspects of Langer's (1967) feeling taken forward to further explore her propositions and contemporary psychological theory are that:

- Feeling forms the raw material of mind;
- Feeling forms the root of mental functions such as thought, emotion and perception;
- These are interrelated processes of feeling and so are referred to using this primary term;
- Feeling is formed through the interrelationships of physiological processes, and feeling can be understood as a phase of process. Ever-present yet continuously emerging.

This way of knowing the world, is an embodied-feeling epistemology; further applied in chapter-5. This chapter continues by considering how feelings and the physiological process of the body are moved and influenced by one's circumstances.

4.05 Feeling as a Process: Interrelated with circumstances

Langer (1967) proposed humans are always influenced by and influencing their surroundings in a vital relational process, where every aspect of the human organism, is continuously and finely adjusted to its surroundings. Drawing upon Langer (1967) and taking a process perspective, forms a lens which understands feeling as an emergent phase of bodies, dynamically related to circumstances, and continuously transforming in process. Feeling is co-constituted between the permeating influence of the characteristics of the external environment and the physiological capacities of the internal body. This dynamic, relational, socio-material process is revealed through the body and feeling, as a personal, situated, and unique revelation of one's body and the world. Through this interpermeating process, the body and environment are ever changed and continuously ever changing.

Feelings are understood as co-constituted by circumstances. In this way feelings gain and hold meaningful implications through their relationship to all aspects of the embodied-relatio-socio-material system. Feelings, perceptions and meanings are afforded and entrained by our bodily being within the world, with this felt knowledge developing through our interactions with the world. The strength of feeling in shaping our world is described in an example of the rose-coloured glasses of those madly in love (Cromby, 2015). The world can be so transformed by such a feeling, that otherwise unsuited partners may become objects of infatuation; herein is the phrase that love is blind. Cromby (2015) argues these commonplace linguistic notions and phrases, are recognitions of the centrality of the body in generating our experiences of our world.

Our experience of the world is meaningfully orientated by our feelings of it; we notice, we ignore, are absorbed by, un-phased by and sensitised to, those things which our feeling bodies and circumstances have entrained us to engage with and feel. This approach is consistent with the work of Merleau-Ponty, (1962, 2002, p.60), who used the example that “light of a candle changes its appearance for a child when, after a burn, it stops attracting the child’s hand and becomes...repulsive.” Consistent with the work of Langer (1967), this example illustrates how humans are always feeling, knowing, acting and existing out of and into their circumstances, and the possibilities feeling bodies and circumstances afford.

To explore how we can conceptualise some of the implications of a concept of feeling developed through Langer (1967) and a process orientation, drawing on the work of Shotter (1993) may be helpful. Shotter argued (1993, p. 110) “our ‘inner’ lives are structured by us living ‘into’ and ‘through’, the opportunities or enablements offered to us by the ‘otherness’ both around us and within us. Thus our mental life is never wholly our own. We live in a way which is both ‘within us’ in some way, but which is also ‘other than’ ourselves”. In this sense, the composition of how one feels can be understood as a boundary phenomenon, which is meaningfully afforded, forged and entrained in a co-constituted process between one’s body and circumstances.

Building a process understanding of feeling, implies private individual experiences (thoughts, inner speech, ways of feeling -our inner worlds-), are not neutral private spaces, they're irrevocably and continuously related, orientated and nuanced by our lived social and material circumstances. Emotional feelings for example in the work of Baerveldt and Vostermans (2005, p.470), can be understood as "expressive responses to breaches of the obvious or the taken-for-granted normative structure of everyday life. Yet they can also be seen as ritualized and stylized ways of restoring the obvious normativity of everyday life". In this way, feelings and emotions are meaningfully interrelated and co-constituted by circumstances, and akin to Merleau-Ponty's candlelight, they form entrained ways of meaningfully interacting with and navigating our circumstances. Feeling and the processes of western mind, can be conceptualised as always embodied and circumstantially situated in a continuously emerging interrelationship through time.

This thesis takes forward the conceptualisation of feeling, which has been developed through this chapter, as a theoretical lens with which the research was approached. Mind becomes an emergent phase, a constellation of processes, composed of branching elements born of feeling. Feelings are always embodied and always interrelated with surrounding circumstances. Through this co-constitution feelings interweave to form rich, enveloping tapestries of not just our being-in-the-world but our feeling-in-the-world. These landscapes of feeling and the landscapes of our circumstances co-constitutively form experiences.

4.06 Feelings and Mind in Distress: Implications for research and our conceptualisation of madness and mental health.

Reflecting on chapter-1, an approach rooted in Langer's (1967) process philosophy holds striking differences to biomedical and individualistic research frameworks. Research using a process-relational approach would not seek single cause and effect relationships in isolated systems, but would map interrelated processes, looking for constellations of co-occurrences defined by the characteristics of their constituent parts, and how these come to exist through their interrelationships with one another. By conceptualising all experiences including hallucinations, as constituted by a history of time and circumstantially

situated, felt, relational occasions, research can be encouraged to take a broad process-relational focus. Researching experiences of hallucinations with a process-relational approach, which seeks to contextualise experiences within feeling bodies and social and material circumstances, may support in considering arguments explored in chapter-1 and build upon the systematically reviewed hallucination research.

Chapter-1 considered arguments of UK psychologists who have proposed experiences described mental health problems and mental illnesses, may be conceptualised as understandable responses to difficult circumstances, and meaningful ways of trying to understand and navigate them (Bentall, 2003; Cromby, Harper & Reavey, 2013). Arguments which were echoed by researchers such as Suryani et al. (2013) in their studies of AH phenomenology. Langer's (1967) scholarship and conceptual lens built in this chapter has numerous interesting implications for understandings of madness.

Feeling can be understood as providing the means by which difficulties arising from socio-material circumstances and life trajectories, can be known and experienced through the feeling body; with branching inflections and transformations through what may be described as the processes of mind. Looking to empirical research of hallucinations, feeling would be the link by which circumstances such as the death of a spouse or of being held hostage, elicit and sustain experiences of hallucinations (Grimby, 1993; Siegal, 1984). Some hallucination research has studied the link between trauma and hallucination content (Hardy et al., 2005). With such research suggesting the content of hallucinations may resemble the trauma directly (e.g. threatened with a knife and later seeing a knife) or indirectly (e.g. hearing voices of threatening themes). To understand the interrelationship between circumstances and distress, scholars such as Cromby and Harper (2009) and Scheff (2012) have worked on theories of feelings and feeling-traps.

Cromby and Harper (2009) proposed feelings may provide the means by which experiences of traumatic, chaotic and adverse circumstances are internalised. In an approach consistent with the notion of feeling developed in this chapter, Cromby and Harper's (2009, p.366) social account, understands

distress as “relationally, societally and materially co-constituted”. Patterns of feeling are described as sculpted by and relationally nuanced and entrained through flows of events of life trajectories, situated in interrelating material conditions (e.g. housing, financial resources, and urbanicity), social structures (e.g. gender, ethnicity and class) and relational influences (e.g. family life, friendships, peer relationships). In the approach of Cromby and Harper (2009), socialised feelings both dynamically provide, and orientate experience of the world; such that feelings of persecution for example, may be associated with experiencing discrimination.

Paranoia in their terms, can be understood as a mode or tendency. A proposition akin to Langer’s (1967) description of feeling as a phase of relations in process. In this way, presentations of distress may share commonalities and differences nuanced through the fluxing interrelationships of feeling and socio-material circumstances in relational process. Cromby and Harper’s (2009) arguments are consistent with the conceptual lens of feeling developed in this chapter and chapter-1’s exploration of service-user and psychosocial understandings of distress. Experiences such as hallucinations could be conceptualised within this same lens, as complex multi-faceted organisations of feelings, inflected and forged through perceptions, experiences and the entangled interrelationships between body and social- material circumstances.

Conceptualising feeling in this way, may support in providing a thicker lens with which to research empirical first-hand accounts of hallucinations such as those described in the systematic reviews. The feeling and embodiment of these experiences can be emphasised, as can the complexity of how they are meaningfully entangled through and situated within circumstances. This may help to bring the distressing and transformative experiences of hallucinations, into the empirical and conceptual conversations of the literature discussed in chapter-1. Perhaps theoretically informed empirical investigation of the feeling and circumstances of hallucinations, may advance research in understanding these experiences and appreciating their nuanced presentations.

4.07 Feelings, Feeling-Traps and Hallucinations

Recent hallucination research has documented novel feelings associated with AVH. Chapter-2 described interesting reports of feelings such as heat, tingling and being in a dream-like state alongside AVH (Woods et al., 2015) and co-occurring feelings during AVH such as pain and itching, alongside feelings of control and imposition (Upthegrove et al., 2016). As chapter-2 argued, these outcomes indicate that there is more to learn about the ways in which embodied feelings arise within hallucinations. A theory of feeling-traps from emotion scholarship, may shine a light on the co-occurrence of feelings in hallucinations.

It is theorised that circumstances can generate two or more feelings which co-occur self-perpetuate one-another within sustaining circumstances. Self-perpetuating feelings were referred to as feeling-traps by Lewis (1971) and researched by Scheff (1990, 2012), both of whom observed difficulties in acknowledging shame (which is commonly disavowed) often results in anger, only producing more shame, in a recursive loop. For example, should a person be subject to a shameful act, they may feel ashamed, they may feel angry about what has happened and angry at themselves for feeling ashamed, this may lead to further feelings of shame, and so on. This recursive loop of shame-anger feelings may be sustained by circumstances within which for example:

- Feelings of shame and anger continue to be generated (e.g. through subjection to further shameful acts),
- Someone is without the resources or opportunity to acknowledge or safely express feelings of shame or anger, or
- Someone is unable to access more nourishing circumstances wherein feelings of shame and anger are less likely to be sustained or generated.

The pain of acknowledging this increasing, yet disavowed backlog of feelings, further reinforces avoidance of acknowledging or expressing them, such that the feeling-trap sustains. Scheff (2012) described how painful emotional backlogs of prior unresolved emotions could be elicited through similar (yet potentially much more trivial) experiences. In sum, within feeling-traps, feelings co-occur, catalyse, and intensify one another such that they sustain over time and generalise past their prompting circumstances. Serving to colour and shape

experiences and understandings of the world. Considering feeling-traps may therefore help in studying unshared perceptions such as hallucinations.

Within their social account of distress, Cromby and Harper (2009) proposed feeling-traps could produce embodied modes or tendencies, such that experiences and perceptions seemingly depart from a shared reality. With the prior feeling-trap example of being subject to a shameful act, these enveloping feelings may dominate perceptions, such that circumstances feel difficult to connect with or navigate. Scheff (2012, p.89) argued there may be “no natural limit” to the recursive interactions of feelings with the possibility they can spiral endlessly. As feeling-traps self-perpetuate within sustaining circumstances, they generalise past the trigger situation, such that navigating life may become more difficult, which in turn, has its own social and material consequences. Further still, when threats or circumstances repeat or persist, one’s perception and feeling of the world may depart from a consensual reality shared by those without such experiences. An example of this is Scheff’s (2011) proposition of the disastrous consequences of humiliated fury, wherein acts of multiple killings (e.g. Columbine) often seem precipitated by engulfing relationships, isolation, and shame-shame and shame-anger feeling-traps.

An important implication of feeling-trap theory (Cromby & Harper, 2009; Scheff, 2012), is feelings, feeling-traps and associated modes of distress, are not due to individualised pathology, illness, neural fault or disease. They can be understood as being generated relationally, through processes of the feeling body within dynamic, social and material circumstances. These theoretical perspectives would argue for the value in acknowledging the power of feelings, and the difficulties within the circumstances through which they form.

Cromby (2015) and Cromby and Harper (2009), have theoretically applied feeling-traps to experiences described as paranoia. They theorised unpredictable surges of feelings, may produce overwhelming and intense experiences which disrupt one’s feeling of stability and continuity. By illustrating the fragility of our feeling landscapes, Cromby and Harper (2009) proposed context enmeshed feelings and feeling-traps may form the basis of florid states in experiences described as psychosis. In this way, feelings and feeling-traps

hold their own implications as Cromby and Harper (2009, p.351) argued “the apparent security and solidity of the world, usually given to us effortlessly by our embodied engagements within it, is suddenly, shockingly, revealed as a somewhat fragile achievement”. Alongside the difficulty of managing and navigating these feelings in and of themselves, they occur (as all things do), relationally within social and material circumstances, this too may have its own implications.

In moments of such high levels of arousal, feelings may dominate understandings and perceptions of the world, transforming conceptualisations of social-material circumstances and ways of interacting with them. These moments may have negative implications such as stigma, employment difficulties, and fear due to distress’ associations with deviance, non-conformity and illness pathology. Associated with this, the potential for and experience of enforced and voluntary hospitalisation and psychiatric treatment such as sedation, seclusion and restraint, may reinforce feelings of panic, fear, helplessness, loss of control, and victimisation (Morrison, Frame and Larkin, 2003). This insecurity of feeling-in-the-world may highlight the salience of florid moments and have a dynamic catalysing interrelationship with distress, such that it further sustains and generalises past its initial circumstances. As the feeling-trap continues in a mode of feeling-in-the-world, one’s seeing, hearing, understanding, acting, interacting and so on, may continuously depart from the experiences and understanding of reality shared by those around us. This points to the potential relevance of the novel feeling of reality analytic category to experiences of hallucinations.

4.08 Feeling Theories and Hallucinations

Utilising theories of feeling and feeling-traps, could provide conceptual guidance for hallucination research through a conceptual lens within which to link hallucinations with circumstances, and understand how hallucinations may be sustained over time. These theories thereby hold a close conceptual relevance to the key areas of future research stated at the end of chapter-3. The relevance of feelings and circumstances to hallucinations was indicated throughout the systematic reviews. Examples can be seen in Stevenson et al.’s (2011)

participants reporting the most bothersome OHs were often described by participants as related to one's past and almost always occurred when at home or that VH were often precipitated by relationship problems and feelings of loneliness, tiredness and stress (Guantlett-Gilbert & Kuipers, 2003). A further clear example of how our social and material worlds and our feelings co-constitute each other is in bereavement hallucinations such as those described by Grimby (1993), which have a prevalence of 30-60% among widowers (Castelnovo, Cavallotti, Gambini & D'Agostino, 2015). Further still, in 'healthy' populations, commonplace hallucinatory experiences associated with feelings of hypervigilance include hearing the phone or doorbell ring in the absence of any such sound (García-tacek, García Azorín, Sanchez Salmador, Cuadrado and Porta-Etessam, 2013). This research points to ways in which hallucinations may be understood in terms of interrelating feelings and circumstances.

There may be much value in looking across modalities of hallucinations to consider the feeling of hallucinations, learning from the insights of people who experience them first-hand. The earlier discussion of linguistic primes (Shweder, 2004), illustrated consideration of linguistically complex notions (such as feeling-traps) to experiences (such as hallucinations), must be done so with care; their utility and relevance cannot be assumed. Interestingly, feeling-traps scholarship has primarily looked at emotional feelings. The conceptualisation of feeling worked up in this chapter has conceptualised feeling as much broader. The extent to which the conceptualisation of feeling and feeling-traps worked up in this chapter, may be useful for understanding experiences of hallucinations, can be investigated through empirical research. Theoretical literature outlined in this chapter, is yet to be applied hallucination research; doing so may support in developing these theories and empirical understandings of hallucinations.

Concepts of feeling (Cromby, 2007; Cromby, 2015; Langer, 1967) and feeling-traps (Cromby and Harper, 2009; Scheff, 2013) and the form of feeling worked up here, is a conceptual basis which affords vast potential to melt limiting dualisms which implicitly and explicitly permeate much research in contemporary psychology, neuroscience, psychiatry and the human and health sciences more broadly. This includes dualisms of internal body and external world; of mind and body; of affect and language; and of the multi-faceted separation of the

processes of mind, most notably the division of thought from emotion. There is exciting potential for researchers to better appreciate nuanced presentations of distress such as hallucinations through feeling.

The conceptual lens built from theories of feeling and feeling-traps can be applied to understand hallucinations in terms of a history of continuous situated relational processes, co-constituted and maintained between the multi-faceted, fluxing, interrelationships of feeling bodies and socio-material circumstances. This may advance studies of the feeling of hallucinations within lived circumstances, and potentially learn more about how, where, why and for whom these experiences arise. Appendix C holds a brief reflective note on feminism and feminist theories which resonated with this chapter's theoretical lens. This chapter continues by proposing a series of research questions built from the empirical and theoretical literature review. After this a methodology chapter further explores scholarship from Langer (1967) and other theorists to build an approach with which to study these questions. The thesis then continues by outlining the methods and analytic outcomes of empirical study, before concluding.

4.09 Rationale and Research Questions

In seeking more reliable, valid and clinically useful research, researchers have proposed specific experiences associated with distress such as hallucinations should be studied (Bentall, 2014; Vanheule et al., 2013). The systematic reviews analysis proposed hallucination research can progress by studying their feelings and circumstances. Such hallucination research could inform advances in empirical research and clinical practice through more nuanced and precise understandings of hallucination experiences and their potential causes (Woods et al., 2014). Applying theoretical literature described in this chapter may support in developing conceptual approaches to hallucination research and refining its analysis. Existing scholarship may be developed in four primary ways:

(1) Research has much to learn about hallucinations, particularly those outside of the auditory modality and MMH which seem much more common than previously thought (Clark et al., 2017; Lim et al., 2016; Waters et al., 2014). To my knowledge, this is the first empirical study to prospectively research the

feeling of hallucination experiences arising in any sensory modality.

(2) Recent hallucination research (Upthegrove et al., 2016; Woods et al., 2015), can be developed by exploring feelings in-depth. As far as I am aware, this was the first empirical study to prospectively research experiences of co-occurring and combining feelings during hallucinations (arising in any modality).

(3) There is much for researchers to understand about how hallucinations feel for the person having them; within the context of their current circumstances and their personal history. To my knowledge this was the first empirical study of the life history of people experiencing hallucinations in Britain; in terms of their ongoing lived circumstances and feelings.

(4) This empirical research approach is guided by theoretical research of feeling and feeling-traps; as far as I am aware, this was the first empirical study to apply theories of feeling-traps to experiences of hallucinations.

The research questions as summarised in Table 4.01 are designed to satisfy the following research objective; to map the feeling of hallucinations and what circumstances they arise in. By studying numerous novel research areas, no methodology, research methods or protocol existed to study them. Consistent with previous hallucination research which chartered new fields of study (such as Hardy et al.'s [2005] research on associations between trauma and hallucination content), the direction of study was guided by the literature. The methodology chapter now explores methodological literature of how these novel research areas could be studied.

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Table 4.01
Thesis Research Questions.

<u>Question Number</u>	<u>Question</u>
1	What do participants express their hallucinations feel like?
1a	Do participants express an interaction between these feelings?
1b	If so, what is the form of this interaction?
2	What circumstances do participants express their felt experiences of hallucinations are situated in?
2a	What material circumstances do participants express their felt experiences of hallucinations are situated in?
2b	What social circumstances do participants express their felt experiences of hallucinations are situated in?
2c	From participants' expressed perspective, what does it feel like to experience a hallucination within these circumstances?
3	What autobiographical experiences are associated with hallucinations?
4	To what extent is the concept of feeling-traps useful in understanding the experience of hallucinations?

5. Methodology



Figure 5. Still Photographic Images of an Installation from Feeling-In-The-World Art Series during Gallery Exhibition at Attenborough Arts Centre in Leicester, 2018.

Building on the empirical and theoretical literature, this chapter documents the methodological approach which facilitated the development of the research design to answer the research questions. The methodological approach was built through engaging with further theoretical and methodological literature and a self-practice self-reflection process. This chapter begins by describing an embodied-feeling epistemology before exploring scholarship of embodiment, feeling and art.

5.01 Embodied Knowledge

Chapter-4 developed a conceptual lens where the fabric of experience is formed of tapestries of feeling; that experience of the world is provided by embodiment, yet always dynamically interrelated with and co-constituted by circumstances (past and present). Consistent with Langer (1967), feeling is conceptualised as a phase of the interrelationships of the physiological processes of the body; feeling is proposed to be the basis of mind and the root of psychological processes such as knowledge, reason, emotion and thinking.

The primacy of feeling and the body in coming to know the world and navigate through it, can be seen in contemporary neuropsychological research and reflects a growing mass of literature on embodied cognition (Anderson, 2003; Glenberg, 2010; Wilson, 2002; Wilson & Golonka, 2013). The affective prediction hypothesis, for example, proposes ways of understanding the world through visual perception, involves parallel simultaneous support from both the visual sensory systems and the affective systems (relating to an object's value, salience and relevance) at once from the moment of stimulation (Barrett & Bar, 2009). Our perception is bound up with predictions of what has been sensed and knowingly felt before, from the continuous dynamic interrelationships of our brains, bodies and environments. Such research alongside the theoretical literature of chapter-4, points to the continuous, emerging interrelationships between intertwined body, circumstance and 'mind'.

Consistent with Langer (1967) and Chapter-4's arguments, Johnson (2008), proposed our situated embodiment, senses, and sensori-motor capacity for movement, form our primary modes of understanding our world. Johnson (2008, p.ix) describes how:

Meaning grows from our visceral connections to life and the bodily conditions of life. We are born into the world as creatures of the flesh, and it is through our bodily perceptions, movements, emotions and feelings that meaning becomes possible and takes the form it does.

Johnson (2008) argues that from the concrete-material to abstract-conceptual, systems of knowledge, understanding and meaning derive from our embodiment within the world and our embodied engagements with it. This chimes with Chapter-3's arguments, where the characteristics of the relational processes of the multifaceted aspects of our bodies and circumstances, produce feelings which afford experiences and knowledge production. Conceptualising knowledge generation in this way emphasises felt process. This is referred to as an embodied-feeling epistemology. This chapter continues by drawing upon Johnson's (2008) arguments due to its harmonious parallels with Langer (1967). These arguments form the foundations of the methodological approach of the empirical research activities and as such it is these arguments this chapter continues to consider.

5.02 The Art of Sharing Felt Knowledge of Process Relations

Langer's (1967) philosophy may be as much a philosophy of art as it is a process philosophy of feeling and mind. Langer (1967) pulls together all these aspects of her philosophy by arguing:

Feeling is a dynamic pattern of tremendous complexity. Its whole relation to life, the fact that all sorts of processes may culminate in feeling with or without direct regard to each other, and that vital activity goes on at all levels continuously, make mental phenomena the most protean subject matter in the world. Our best identification of such phenomena is through images that hold and present them for our contemplation; and their images are works of art. (p.67).

Langer's (1967) arguments highlight that much like feeling emerges over time at the dynamic intersection of processes between bodies and circumstances, works of art can be understood as holding a relational capacity to show multi-faceted aspects of composition at once. Langer (1967, p. xix) argues any work of art is expressing "felt tensions, rhythms and activities, expresses their unfelt

substructure of vital processes of life” and in this way “art is the objectification of feeling” (Langer, 1967, p. 65). The process of creating art and the material objects it produces, were anticipated to be an appropriate way through which an embodied-feeling epistemology, could generate data and produce artefacts for research study. These anticipated potentials of visual and arts-based research methods (ABRM) were actualised through the empirical research activities which chapter-6 outlines.

Both Langer (1967) and Johnson (2008) argue for the value of art in capturing and expressing feeling through the arts in a broad sense. Qualities of feelings and the dynamics of relational process may be artistically expressed through colour, structure, texture, tension, pitch, amplitude, sharpness, blur, density and sparsity in complementary or unnerving compositions. Drawing upon the work of John Dewey, Johnson (2008) argued expressive artwork such as music or a painting provide integrated, intensified and heightened experiences of meaning and feeling, communicated by harnessing our ordinary resources for embodied and sensory meaning-making. Langer (1967) and Johnson (2008) propose art has the capacity to abstract the phenomenal character of feeling. Visual and ABRM were therefore suited in studying the feeling and circumstances of hallucinations as this thesis aimed to do.

Guiding people who experience hallucinations in using visual and ABRM, offered the potential of enriching research understandings of hallucinations through objectified maps of feelings. Langer (1967, p.67) argued art:

Presents the semblance of feeling so directly to logical intuition that we seem to perceive feeling itself in the work... a form which is subtly but entirely congruent with forms of mentality and vital experiences, which we recognize intuitively as something very much like feeling; and this abstract likeness to feeling teaches one, without effort or explicit awareness, what feeling is like.

In this way, works of art, may hold resemblance or resonance with the viewer’s lived experience of the relational processes of feeling.

Interestingly, these kinds of moments are depicted in popular culture. A televisual example includes an episode of *It’s Always Sunny In Philadelphia*

(Ledgin, & Biermann, 2016). As part of a plan to illustrate that art is meaningless, a lead character experiences a moment of connection with a painting. In a mesmerised state, the original scene blurs with only the painting staying in focus; this scene is replaced with a rapid montage, of a flashback-esque series of audio-visual clips, seemingly representing a flurry of meaning and feeling. Such moments of connection to works of art, have been documented in empirical research. In Csikszentmihalyi and Robinson's (1990) exploring experiences of encountering artwork, participants described feeling a heightened awareness, a loss of self, and experiences of being outside oneself. One participant described, "I think it absorbs, it involves all of the senses in a unifying manner" (Csikszentmihalyi & Robinson, 1990, p.68).

Some of Csikszentmihalyi and Robinson's (1990) participants described works of art and its constituting features (colours, shapes, the scene depicted), could elicit feelings, sensory associations, and feelingful memories of past experiences. As one participant described:

The feeling of hope that might be generated by some little area in some painting just by the colors it might have...Now if I stood in front of that painting, I might remember some sensation of that joy that I felt at seeing that tree of that color. But as living individuals we have so many experiences, so our possibilities, our potential, is so great for having those feelings. You know, the vocabulary is in there, the visual vocabulary, or the sensory vocabulary. Practically, you would almost think without end. (Csikszentmihalyi & Robinson, 1990, p.67)

The researchers highlighted how participants often described encountering artworks as a process of non-verbal communication, which evoked lasting exchanges of feelings over time. Csikszentmihalyi and Robinson's (1990) suggests art has the relational capacity to share and elicit feelings for viewers of art. Having considered conceptual and methodological arguments for art's value in capturing, expressing and sharing feelings, this chapter continues by considering research methods literature regarding arts-based and visual approaches to data generation.

5.03 The Art of Research

With growing prominence over the past twenty-years, visual and ABRM are recognised for their value across the social sciences, health sciences and psychology (Reavey, 2011). In visual and ABRM, artistic and expressive processes form modes of enquiry. Consistent with Langer's (1967) and Johnson's (2008) respect for the arts in the broadest sense, ABRM may refer to use of a wide range of art forms in the research process; including for example drawing, painting, collage, poetry or song (Knowles and Cole, 2008). Use of the term visual methods often implicitly refers to the use of photograph and film in research but can also refer to the uptake of visual tools, and visual media too. This thesis refers to visual and ABRM to signal the literature bases that this project builds upon. Visual and ABRM can use creative media and tools in novel ways. This thesis has focused on approaches typically described as participant-generated visual and ABRM (Guillemin & Drew, 2010) or researcher-initiated-participant-generated methods (Pauwels, 2010). These terms describe visual and ABRM data generation strategies wherein a researcher facilitates participants in generating original expressive creative pieces for research purposes. This visual and ABRM approach appeared suited to research of first-person perspectives of hallucination experiences.

These visual and ABRM are valued for their utility in studying feelings and situated lived experiences (Reavey, 2011). Visual and ABRM achieve this value in three primary ways: firstly, by providing different modalities and mediums through which data can be generated; secondly, by facilitating novel researcher-participant interactions through potentially more equal levels of power; and thirdly, by affording innovative methods of research dissemination. The following section of this chapter discusses further benefits of using visual and ABRM.

5.03.1 Benefits of Visual and Arts-Based Methods.

5.03.1.1. Novel Modes of Communication.

One of the most prominent strengths of visual and ABRM, is their opportunity to harness meaning-making resources beyond language. The opportunity to use visual and arts-based tools of communication, is proposed to be helpful in maintaining an embodied and feeling focus to the data generation

process and can support the communication of experiences difficult to capture using words alone (Chadwick, 2017; Gillies et al., 2005; Harris & Guillemin, 2012). Where someone does not have the resources, opportunity or capability to utilise language in a way which fits or communicates their experience, visual and ABRM can provide tools to sensitively focus on the participant's situated and embodied feelings and insights. In the context of hallucination research, visual and ABRM provided unique opportunities for participants to document their experiences in the sensory modality in which they were occurring. The novel use of visual and ABRM in this study supported VH to be documented in their original sensory mode, through creative practices such as painting and drawing.

An empirical data generation strategy built upon Langer (1967) and Johnson's (2008) conceptual arguments did not need to be limited to a specific art form. This afforded the conceptual potential that participants could be empowered to choose their creative medium of choice and are hereon be described as 'open ABRM'. The limits regarding the breadth of their choices related to the available material resources, ethically safe art-practice, and the creation of artworks which could be stored, and shared by the researcher. The notion of open ABRM may sound simple, but this represents a distinct departure from traditions in visual and ABRM research, where the researcher decides the creative medium through which participants respond. It was felt that participants should be empowered to make the choice whether to use visual and ABRM to participate, they could choose their creative medium of response and be provided the resources to express their situated experiences and perspectives. This provided an opportunity for participants to express themselves in the mode and medium which they felt most confident and comfortable in. This had in turn potential benefits of maximising the outputs of the data generation methods and increasing the effectiveness of the overall research strategy.

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5.03.1.2. Generating Situated Insights.

Visual and ABRM have gained favour in research practice for their capacity to communicate situated human experience (Knowles and Cole, 2008). This is consistent with the arguments of Langer (1967) and Johnson (2008) of the strength of art in capturing and sharing complex tapestries of feeling-in-the-world. Visual and ABRM are proposed to elucidate the nuances of lived experience for those subjugated and marginalised by dominant discourses (Knowles & Cole, 2008). Consistent with the philosophical arguments of Langer (1967), this may be due to art's capacity to capture, abstract or objectify the compositions of embodied relational processes; processes which can be lived from different perspectives.

The value of visual and ABRM may be afforded by providing participants with the space, time and the resources to bring their own agendas, insights and steering into the research process. This may support in orientating the dynamics and interactions between the researcher and participant, towards a focus on the participant's insights, experience and feelings (Packard, 2008). This may be useful when studying aspects of human life which are novel in the literature, or where understandings of these experiences may be discursively organised in ways which may ill-fit the lived experiences of those with first-hand situated knowledge. For both of these reasons, visual and ABRM were suited to the study of feeling and circumstances of hallucinations.

In standpoint epistemology knowledge is situated through one's unique perspective within social interrelations (Haraway, 1988; Harding, 2004). Shotter (1993) described those who lack power, and are closer to the margins of social life, experience and are most aware of the nuanced resistances of power, and the dynamics of the social world. Arguing those with power at the centre of social life, are those who "experience it's workings the least, in their world, opportunities open themselves up before them, to have power is to find no resistance to the realisation of ones desires". In this same sense, those people who are recruited as participants in many studies of health, wellbeing, and madness, whose own perspectives of their experiences are often not gathered, likely hold unique and relevant insights which could (if documented), advance knowledge and practice.

Researchers have argued visual and ABRM can generate fresh perspectives and novel insights on topics which may be familiar to the researcher, by facilitating research to focus on participant's situated viewpoints and experiential expertise (Mannay, 2010; Mannay 2016). Novel perspectives may have the capacity to disrupt dominant discourses and understandings. Perhaps incorporating these methods can bring fresh situated insights into academic and clinical conversations, such that they could disrupt the dominant discourses used to discuss experiences such as hallucinations. Using participant generated visual and ABRM methods, offered an ideal conceptual and methodological fit for investigating the feeling and circumstances of hallucinations.

Alongside utility in sharing situated experience, visual and ABRM can support in sharing information to diverse audiences, particularly regarding emotionally and politically charged topics (Leavy, 2018). Visual and art-based research outputs, have different capacities in holding and sharing information. Unlike other data, visual and arts-based media can be displayed in original participant generated form to the research viewer. This breaks down swathes of data reduction and transformation inherent in most methods. Participant generated creative expressions also afford novel opportunities for dissemination such as exhibition, zines, picture-books and online blogs. This overcomes barriers to consuming research, such as journal access, academic literacy, and time to read lengthy literature. Alongside potential public engagement benefits, alternative dissemination methods can empower researchers to hold expressive control whilst sharing their research (Lovata, 2008). The potentials of visual and ABRM to innovate in public engagement and research dissemination, compliment the thesis aims of improving understandings of the lived experience of hallucinations.

Although visual and ABRM are being utilised across the health and social sciences, in disciplines such as psychology, psychiatry and the health sciences, they are still on the margins (Reavey, 2011). A process-relational and embodied-feeling methodological approach, incorporating visual and ABRM, was a novel hallucination research strategy with exciting potential. Recent advances in the field have incorporated contemporary methods into research. In their AVH study,

Upthegrove et al. (2016) incorporated photo-elicitation and a diary to stimulate interview discussion. Their data generation approach did generate novel and thick insights into experiences of AVH, it is unclear however whether the photographs were analysed as part of the data-set. The theory enriched broader empirical approach has been able to build upon these empirical advances, to further understand the feeling and circumstances of hallucinations. This chapter continues by considering, how arts-based and visual media may be understood.

5.04 Fluidity of the image: Interpretation of Data

Image-based communication can be seen in the commonplace use of digital languages like emoji's and gifs, and the generation of memes on websites such as twitter.com, imgur.com or reddit.com. Like language, the visual image may also be understood as unable to have a fixed meaning and that meaning arises through a continuous process of interpretation; a process composed of time and situated dimensions which change (Hall, 1997). In the context of research, visual and arts-based data have been associated with historical concerns surrounding their credibility, rigour and utility; visual and ABRM research may be disregarded on such grounds (Prosser & Loxeley, 2008). As with all data, participant generated visual and arts-based data, are analytically interpreted and translated into a given research context. During this process there is fluidity in what the data can mean and what the research can report as outcomes within the research context.

Consideration of fluidity and ambiguity in data generation highlights two important things: firstly, consistent with a process-relational framework, when participants encounter any research methods of data generation (e.g. visual methods, interviews, questionnaires, neuroimaging), the data generated by these methods produce a situated version of reality holding situated meanings (rather than for example a singular, true, comprehensive recording of reality in its objective, natural, consistent state of affairs). Secondly, consistent with a process-relational framework, the fluid meaning of data illustrates the inherently interpretative process of its analysis. Researchers must always be aware of the fluidity in the meaning of data, and to *mind the gap* between the characteristics of the collected data and what this data can mean.

These issues surrounding the ambiguity and fluidity of data's meaning and interpretation are discussed to highlight they are not unique to visual and ABRM. This thesis argues that although issues of fluidity in data's meaning and interpretation present in different ways for different methods, these are common among research methods in social and health sciences and should be recognised for effective application of research. As visual and ABRM are less familiar, the issues they bring may seem more problematic, but perhaps this is not the case. Perhaps they encourage us to recognise the situatedness of all research and the ever-present influence of interpretation, which may otherwise go unspoken or unnoticed.

The spotlight of concern surrounding visual and arts-based data's fluidity of meaning and interpretations, shines a light on the perspectives, viewpoints and biases that flow through research. Researchers such as Frith et al. (2005, p. 188) argue the "apparent fluidity of readings/interpretations of visual data should not discourage us from engaging with this data; rather we should embrace the opportunity to consider issues of 'translation' which permeate our understanding of verbal data in a different mode". Visual methods highlight the inherent gap between the participants' lived experience, what the researcher is able to capture or generate as data and what the researcher can say about experience, in light of the available data. The spotlight is thrown on research as the embodied-feeling relational-process that it is.

Thus far this chapter has illustrated the strengths of visual and ABRM and their fit for the studying the feeling and circumstances of hallucinations. In light of the fluidity in interpretation of arts-based and visual data, two research practices aimed to ensure the data generation strategy was robust: firstly methodological pluralism and secondly reflexivity. This chapter continues by exploring each of these in turn.

5.05 Methodological Pluralism

Until this point the chapter has focused on visual and ABRM. This focus was chosen firstly due to their suitability to the research questions and secondly, to account for the application of novel methods, in a field which (as SR1 described) is characterised by interviews, surveys and standardised

questionnaires. Methodological pluralism describes the research practice of using a collection of different methodological tools to consider a research question. A triangulated pluralistic research strategy using multiple methods to study the feeling and circumstances of hallucination, could produce diffractive perspectives of the research questions to generate a comprehensive dataset. For example, written and verbal data collected alongside arts-based and visual data, could capture participant's own interpretations of their expressions or diary entries, which could orientate the analysis process towards this.

Consistent with embracing methodological pluralism, researchers have argued to enhance the application of visual and ABRM, they should be applied alongside methods which allow for verbal description and interpretation from the participant themselves (Kearney & Hyle, 2004). The fluidity for art's interpretation, may mean without reference to participant's situated context through shared language, their intentions and expressions could be misrepresented. As people described as experiencing psychosis are often denied the opportunity to communicate the feeling, circumstances and meanings of their experiences (Dillon, 2010), a comprehensive empirical approach seems essential.

Using visual and ABRM, with parallel written or verbal descriptions from the participant, provided the opportunity for a triangulated and thereby more robust analysis of the dataset. Availability of linguistic data can support traditional forms of research dissemination which is typically through written and verbal communication. The vast majority of existing research on the feeling and circumstances of hallucinations (systematically reviewed in chapters 1-3), illustrate self-report and interview methods can be effective methodological tools. Pluralistic methodological approaches are less common however, but have been argued to be effective in studying embodied experiences such as sensing presences (Steffen & Coyle, 2010), adaptation to first episode psychosis (Attard, Larkin, Boden, Jackson, 2017) and AVH (Upthegrove et al., 2016).

Academic movements such as the discursive turn and social constructionism have demonstrated the role of language in organising and sharing cultural meanings (Burr, 2015). Alongside language's strength in sharing

information, words may still be charged with feeling and can be incorporated within embodied-feeling epistemologies. Langer (1967) argued that feeling words often reflect physical qualities such as bright, sharp, deep or heavy. Furthermore, Johnson (2008) argues grammar may convey feeling patterns and language tools such as metaphor gain meaning through embodied understanding. In the arguments of Johnson (2008), language is incorporated into the processes of coming to know and understand the world through our bodies; arguments which were considered in depth at the beginning of this chapter. Feelings seem woven into discourse through word choice and expression; yet feelings are not reducible to discourse or language (Cromby, 2007). Feelings are embodied and situated and arising from fleshy bodily matter in flux with co-constituting circumstances. Although feelings may be understood as beyond capture in words, still language can be used as a tool to point to aspects of feelings and how they are experienced within circumstances, such that they might be understood.

Chapter-4 held a lengthy discussion of how the influence of language and ongoing discursive circumstances weave through, entrain, organise and orientate our feelings. Within a process-relational approach, language can be understood as one of the ways bodies and feelings are socialised within and into the world. Language can be understood as a transformational element both within the constitution of reality and one's expressive life. Such perspectives are consistent with the work of Wetherell (2012; 2013) explored in chapter-4; where language shapes and entrains embodied experiences of the world. This transformational aspect of language is akin to the value attributed to art in the arguments of Johnson (2008, p. xiii), where he argued for the capacity of art to "help us grasp, criticize, and transform meaning and values".

Earlier within this chapter, the art's value was emphasised in terms of its capacity to capture features of embodied feeling, meaning, and the composition of process relations. In this way, abstract and compositional aspects of art, may be able to objectify and make visible the visceral and embodied experience of feeling-in-the-world. To complement the utility of visual and arts-based data, oral and written language can be used as a tool for documentation and expression with many potential benefits: this could include attempts to semantically point to aspects of feeling using shared linguistic meanings or use of language which

attempts to elicit feelings in the listener, this may include abstract descriptions using metaphor and simile, to share for example the texture of bodily sensations during a hallucination. Language may also be used for clear descriptions of concrete or tangible elements of experiences, such as the geographical location and whose company one was in at the time of a hallucination. Akin to art, use of language can point to aspects, qualities or elements of felt experiences. In this sense, the process of collecting written and verbal data, recognises the relationship between language and feeling, and the potential for language to shed light on feelings and circumstances.

Empirical literature provides a contemporary example of how methodological pluralism can be effectively applied in hallucination research. Upthegrove et al.'s (2016) in SR1b research studied the phenomenology of AVH and was most empirically similar to the research activities of this thesis. They investigated similar kinds of experiences (hallucinations) in a similar situated context (modern day English midlands); as such this is the empirical paper which this thesis most closely builds upon. Within their study, participants kept a diary for 1 week to document their AVHs, during this time participants were also welcomed to take photos of salient things which may represent their experiences. After this time, a semi-structured interview was used to map experiences of AVH, in terms of the diary content and the content of images. Upthegrove et al. (2016) study provided an empirical foundation to build upon to study the research questions of this thesis. This thesis' aims however were different, due to: the broader definition of hallucinations, a focus on feelings and a focus on past and present circumstances (including autobiographical life events). The design for this study was developed to account for this. Based on the empirical and methodological research, it was felt a thicker picture of hallucination experiences may be generated through using broader visual and ABRM, by holding a second interview which could both prospectively study change over time, and mapping the participants' life history. The data generation strategy has been documented in much more depth in chapter-6.

A pluralistic data generation strategy was developed to utilise linguistic data from diaries and interviews as an interpretive anchor, with which to hold the participants intentions of the meaning of visual and arts-based data. With

language as the traditional means of sharing research and clinical information, a multi-modal strategy provides a welcome broader scope for gathering and sharing the research. The means by which the role of researcher can be acknowledged and understood in the research process taps into a literature of reflection and reflexivity.

5.06 Reflexivity and Reflection

Terms of reflection and reflexivity are often used interchangeably to describe processes which shine a light upon the researcher's role in shaping the research process (Finlay, 2002). Reflection and reflexivity are often described as opportunities to gain a more comprehensive, critical, credible or in some way better view of the research process and its content (Finlay, 2002). Consistently, reflective practice is a marker of quality and rigour within contemporary qualitative research. Consistent with Burkitt's (2012) arguments, use of terms such as reflect, reflection or reflexivity are not used to invoke notions of static or distant viewpoints, they are used for two purposes: to signal the acknowledgement of embodied and relational processes which formed the research, and to support in describing this acknowledgement within the thesis' own academic context. Reflecting throughout the research, was a practice of seeking diffractive perspectives and reinterpretations of the research process.

This thesis is not isolated in its approach, a harmonious example can be seen in the contemporary qualitative psychology work of Boden, Gibson, Owen and Benson (2015). They argued for the value for researchers to acknowledge feelings and their influence, as they flow through the research process, particularly surrounding encounters with participants. The feeling of these moments are conceptualised as co-created through felt intersubjective experience, where "researcher and participant are intertwined and feelings are coconstructed" (Boden et al., 2015 p.3). A reflexivity focused on feeling seems consistent with the theoretical lens of this thesis. Reflexivity focused upon feelings and emotions has been argued to be suited for research topics which may challenge or disrupt the researcher's own emotional equilibrium (Boden et al., 2015; Jackson, Milburn and Newall, 2013). Researchers such as Burkitt (2012) and Boden et al. (2015), have emphasised feeling and emotion should be

a primary focus in reflexivity; this thesis draws upon reflexivity and reflection, consistent with their use by these authors. This supports recognition of the researcher as an embodied feeling person, with wellbeing, in a place and time, with a situated standpoint, and an experience of the research process.

Drawing upon a feeling-focused process of reflection alongside the research, supported in navigating the sensitive content and distressing feelings associated with the research. A reflexive visual diary formed an adjunct to the research design, data generation and analysis process. Reflexivity also served to monitor the double hermeneutic lens which arose through the research process, both between the participants' conceptualisations of their experiences and my own conceptualisation of the participants' descriptions. Consistent with Boden et al.'s (2015) suggestions, diary entries were made before and after each participant meeting, and at any point where feelings or circumstances were felt to an intensity or of a quality that they warranted consideration or documentation. To support in monitoring researcher wellbeing, the reflexive diary was also used to document life events outside of the research process as they formed core parts of its situated context.

Consistent with Boden et al. (2015), a reflexive diary seemed to support the research process in developing more sensitive understandings of participant's experiences and their relationship to the research questions. The reflexive diary also provided tangible material from which monitor researcher wellbeing. Consistent with existing scholarship on visual and ABRM (Reavey, 2011), incorporating art into reflective practice supported in researching in feeling and embodiment focused way. Such practices built the foundations from which the embodied process analysis (described in full in Chapter-6) developed. In addition to keeping a reflective diary throughout the research process, reflective practice was also undertaken in the form of self-practice self-reflection. The process is reported upon before closing this chapter.

5.07 A Brief Report from Self-Practice Self-Reflection: Abstracting Feelings into Art and Putting Feelings on Display

A process of self-practice and self-reflection formed a bridge between the literature and the empirical design; the pieces of art imaged at the beginning of each chapter so far, were generated during this process. Self-practice self-reflection is a contemporary psychotherapeutic training technique, whereby practitioners engage in self-directed practice of the therapeutic strategies which their future clients are asked to use. Outcomes of a meta-synthesis by Gale and Schroder (2014) proposed self-practice self-reflection increases levels of empathy and an appreciation of the client's perspectives of therapeutic activities and their challenges. The principle of self-practice self-reflection was applied by engaging in art practice whilst developing the conceptual basis of the thesis and the design of the empirical research activities. To appropriately report on the reflective aspect of this experience, this report is written in first person.

Application of self-practice and self-reflection involved trying out the protocol on myself (e.g. creating a life-timeline, keeping a visual diary) to experience what this was like. Prior to this, I wanted to gain a sense of three things: of what it would be like to put my own feelings into art, to share this art with others, and placed on public display. The next section of the chapter documents two self-practice processes, before discussing the reflections they prompted and their associated implications for the research design.

5.07.1 Self-Practice.

5.07.1.1 Self-Practice Process One.

I wanted to abstract my understanding of the feeling and circumstances of distress and put the art/my feelings on display. I felt a close investment in the academic and personal journey of exploring the feeling and circumstances of distress. I abstracted my understandings into an art series named Feeling-In-The-World including paintings, drawings, a zine and two installations. It was exhibited in February and April 2018: first at a public exhibition in Attenborough Arts Centre's main gallery during an arts festival on mental health ('Destress Fest'), the second exhibition was at Aston University for an academic event

called 'Exploring Culture and Experience' by the Phenomenology of Health and Relationships research group.

5.07.1.2 Self-Practice Process Two.

I expressed my feelings of emotional experiences through art, collaborated with artists and put the collaborative artworks on display. I collaborated with artist Jenny Hibberd to develop and create artworks exploring different ways feelings could be shared through art. Our collaboration named MadArt produced five art installations, one poem, and fourteen paintings from two interactive installation concepts and one static/performance installation concept. The static/performance installation concept "Thought Traits" involved arts-based expressions of past experiences Jenny and I found emotional or difficult. We created this in private and performed it in public when the artworks were exhibited.

Jenny and I were awarded a Wellcome Trust funding grant to cover the costs of her time and the initial art materials. Gurdeep Sian provided monetary and in-kind funding support for the artworks to be exhibited as part of his Arts Council Change Maker role. Further in-kind support and materials were provided by Emma Fay and Charlotte Faulkner. Emma Fay supported the works to be exhibited as part of her Portraits of the Mind Exhibition which ran throughout March 2018 at Attenborough Arts Centre. Two installations were exhibited on the University of Leicester main campus (in the students union and library) for the winter-spring semester of 2018.

5.07.2 Self-Reflection.

Self-practice provided of experience of developing and sharing art; both on my own, and in collaboration with other artists and stakeholders. This process of collaboration and the feeling of vulnerability in making and sharing art, supported in approaching the research design and data generation activities with an empathetic approach and realistic expectations. The process of self-practice and self-reflection supported in guiding decision-making whilst forming the research design; reflections and their corresponding design impacts are summarised in Table 5.01. I feel self-practice contributed greatly to developing an empirically effective research design. After a series of photographs from self-

practice self-reflection processes (Figure 5.01), the thesis continues with a chapter summary before the next chapter outlines the methods of the empirical research activities.

Table 5.01

Summary Extracts of Reflections from Self Practice Self Reflection and Their Impact on the Research Design.

<u>Reflection</u>	<u>Impact on Research Design</u>
I felt able to share complex concepts in more accessible and concise forms in art than in writing. Spoken and written language was helpful as a supplement to the artwork and as a mode of communication in its own right.	Written and oral as well as visual and arts-based data generation options were present throughout the empirical research activities.
I anticipated Process One would all be ink paintings, but felt some aspects of my feelings could be better captured using different art forms.	Consistent with Chapter-4, participants chose their medium of arts-based communication, this was agreed through a shared decision to ensure feasibility and safety.
Despite previous experience and feeling comfortable making art, abstracting my feelings into art in a form which felt right was challenging.	The study design held flexibility for participants to choose the extent to which they engaged in visual or arts-based activities. There was no minimum or maximum necessary number of submissions. Participants could take part without completing the visual or arts-based parts of the study.
During Thought Traits, myself and Jenny found translating our feelings into art was harder whilst being observed than whilst in private.	Participants completed the visual diary and arts-based activities at home in their own time.
Collaborating with others worked best when channels of communication were open and transparent.	The participant information sheet was detailed and care coordinators who supported recruitment were worked with closely. An on-site presence at the clinical research site was maintained to support in disseminating study

	information and facilitating the study procedures for both care coordinators and participants. Participants were provided many opportunities to ask questions and could meet with the researcher (one or more times) before deciding to take part.
Abstracting my art into feelings took time and revision.	Participants engaged with arts-based activities at home (with materials pre-provided) and had 3-7 weeks between interviews to engage in arts-based activities.
The resources needed to engage in both developing and displaying artworks was substantial and composed of many months of intensive activities with numerous stakeholders (including myself, collaborating artists, festival organisers, gallery staff, and funders). It felt difficult to remove myself or reduce my involvement within this process. I reflected on the massive potential participant burden of continuing their participation in arts-based research activities (including research dissemination) past the point of the data generation procedures.	Participant's involvement with and obligations to the study stopped at the end of data generation.
I felt vulnerable putting my feelings on display. I felt this was both due to being recognisable as the artist and knowing that the art pieces were static, whereas the feelings they represented were dynamic and could change. I felt less able to openly share and express my feelings due to this.	Participants who submitted visual or arts-based materials remain anonymous, could opt out of their materials being on public display, and would never be named as the creators of the artworks.

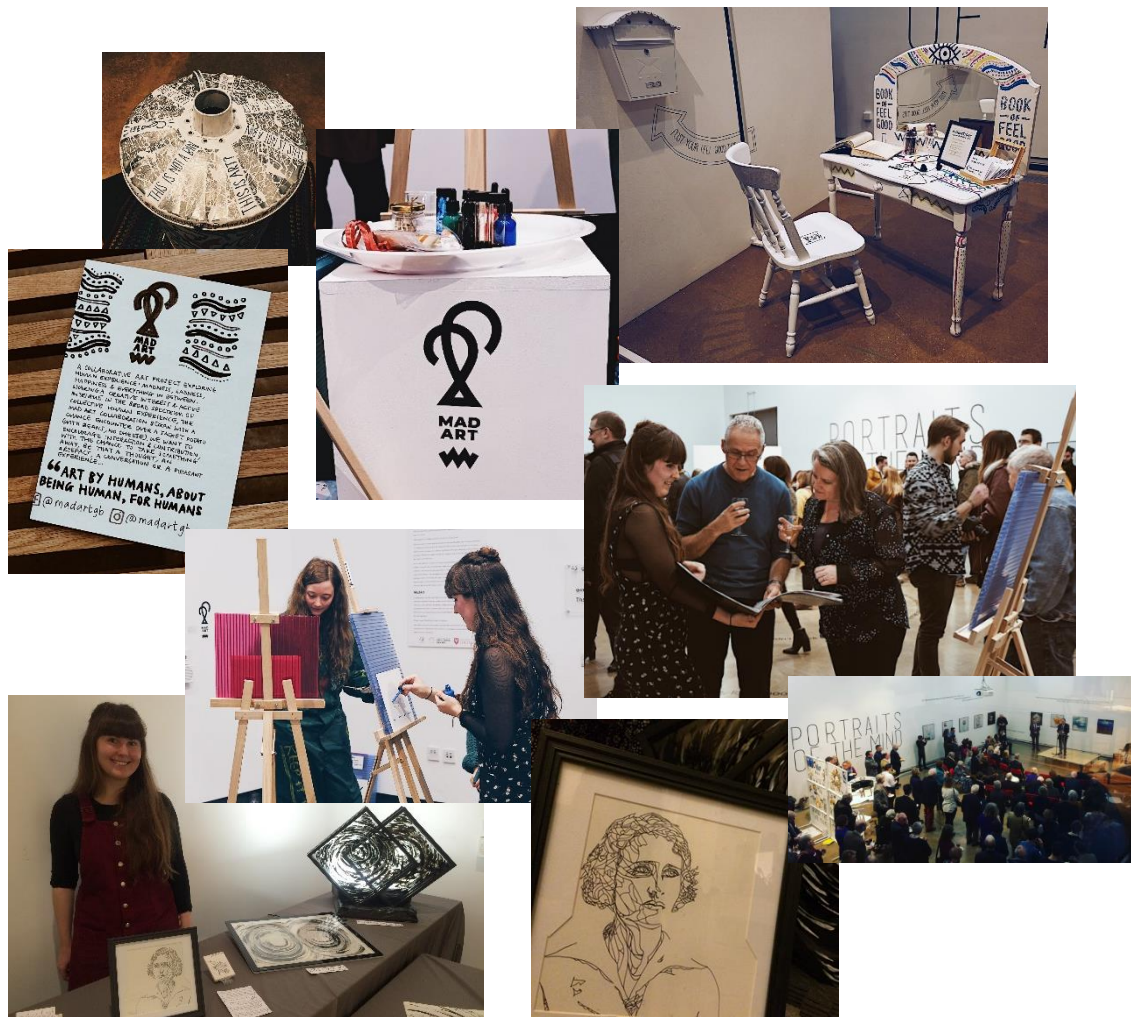


Figure 5.01 Still Photographic Images from Exhibitions of the Solo Feeling-In-The-World Art Series and the Collaborative Artworks with Jennifer Hibberd as 'MadArt' displayed within Emma Fay's Portraits of the Mind Exhibition. Attenborough Arts Centre, Leicester February-April, 2018 (Mobbs, Garcia & Melvin, 2018).

5.08 Chapter Review

This chapter has continued building a lens for this thesis which has a primary focus on feeling, embodiment and a recognition of these as situated in time, place, and personal histories. The methodological approach affords an opportunity to empirically apply Langer (1967) and Johnson's (2008) theoretical works regarding the value of art as a form of meaning making and communication. An embodied-feeling epistemological approach was described, with a recognition of the value for the arts to create material expressions of feelings and share situated felt perspectives. Facilitating participant generated creative pieces, may serve to make the invisible visible in some way. By

producing a diverse range of materials in research outputs, visual and ABRM thereby afford the potential to engage with creative methods of research dissemination.

Pluralistic methods offered the potential to develop multimodal personal accounts of lived experiences of hallucinations. The pluralistic creative research approach built upon contemporary methods advances in hallucination research. An in-depth qualitative research strategy served to comprehensively study the research questions which aimed to map the feeling of hallucinations within multifaceted current circumstances and a life history. A reflective practice process was documented as supporting the development of the research design and research process; it served acknowledge how researcher's lived experiences are interweaved through the research process. Innovating within, between and beyond conventional use of traditional research methods is consistent with contemporary qualitative embodiment research, as well as some social and health sciences research. Having documented the methodological approach of the thesis, the following methods chapter holds a record of the practicalities and procedures of how the methodological approach was applied to answer the research questions.

6. Method



Figure 6. Still Photographic Image of Feeling-In-The-World Art Series during Gallery Exhibition at Attenborough Arts Centre in Leicester, 2018.

6.01 Overview

The empirical research activities of this thesis applied and developed modern qualitative methods in hallucination research. This methods section demonstrates having built upon:

- The existing use of ecological diary methods to study hallucinations in daily life (Delespaul et al., 2002; Varese et al., 2011).
- The use of visual methods to study the textures of hallucination experiences (Upthegrove et al., 2016).

This methods chapter also demonstrates a novel:

- Use of open arts-based methods to study hallucinations.
- Use of 2 follow up interviews to understand participant's diary content and monitor any changes over 4-8 weeks.
- Use of life-timelines to study the trajectory of life events and hallucinations.
- Development of a visual diary.
- Development of micro body-mapping of feelings during hallucination experiences.

Consideration of ethics and engaging with the formal research ethics process formed a substantial part of the activities through which this thesis was delivered. As such, to foreground the empirical research methods, this chapter begins with a report on research ethics.

6.01.1 A Report on Clinical Mental Health Research Ethics.

Contemporary research ethics are infused with principles of minimising potential risk of harm or discomfort for participants. Within the context of research studying the experiences of mental health service-users, a prominent concern regards the level of potential participant benefits, in light of the potential for increased distress or worsened mental states, and, consideration of the extent to which such populations can appropriately decide to partake in the research. Fortunately, empirical studies of the experiences of research for such populations was available during the development, design and completion of the project.

Systematic review by Jorm et al. (2007), argued although distress can arise in research for populations with a psychiatric diagnosis, this occurs in a

minority of participants (including research exploring trauma). Distress can co-occur with positive reactions to the research, and overall, Jorm et al.'s (2007) analysis highlights reactions to research were more-often positive than negative. Recent UK-based research by Taylor et al. (2010), qualitatively studied research experiences among people with a diagnosis of schizophrenia, with findings consistent with Jorm et al. (2007). Participants primarily outlined positive experiences of the research process; that it was interesting and enjoyable, they were happy to help the research and happy the research may in turn help others (Taylor et al., 2010). Many participants described feelings of relief alongside beneficial therapeutic and cathartic experiences of being able to talk with the researcher. Other participants saw the research as valuable and necessary, with some participants highlighting research provided them a voice and a platform to be heard. Some negative experiences included distress and difficulty talking about experiences and difficulties, however these were often described alongside the research being acceptable (Taylor et al., 2010). The available research supported the notion that for people given mental health diagnoses (including schizophrenia), participation in research is mostly a beneficial experience.

In the UK where the thesis is based, mental health service-users are conceptualised as a vulnerable population for research. Keogh and Daly (2009, p. 277) argue complications in seeking ethical approval and recruiting participants may arise from “misconceptions about the nature of mental illness and negative assumptions about individuals’ ability to understand the research process and provide informed consent”. In America, Roberts and Kim (2014) investigated whether perspectives surrounding research and its ethical dimensions (e.g. it’s risks, burdens, ethical acceptability), were different between people described as physically ill, healthy, and mentally ill (people given diagnoses including schizophrenia, depression, anxiety or post-traumatic stress disorder).

Roberts and Kim (2014, p.8) reported “a remarkable general pattern of ethical perspectives emerged” with similar views held throughout their sample. Similar ethical perspectives included the ethical acceptability of research and perspectives surrounding protocol burdens. Roberts and Kim (2014, p. 9)

described hopes that the results may help to: diminish “exceptionalism” and stigma of mental illness and mental illness investigation, by providing data that begin to address questions of whether people with certain diagnoses should be viewed as intrinsically different from other research volunteers and/or require additional safeguards. Although this field of research is still growing, the outcomes were in favour of a proportional rather than an exceptional approach to researching mental health service-users.

Consistent with Keogh and Daly (2009) arguments, the ethical approval process for this thesis’ empirical research was resource intensive. This may be too great a barrier for some mental health service-user research to take place. Keogh and Daly (2009) described researchers may also be discouraged from conducting research with mental health service-users due to the potential complications in receiving ethical approval for research with populations described as vulnerable. Without mental health service-users being recruited as participants or working as researchers themselves, their experiences and insights may not be present in the research literature and clinical care developments.

Drawing upon research ethics literature supported in building an effective research design, with a proportionate approach to risk. In the context of this thesis (which recruited a sample who may described as vulnerable, to study on topics which may be conceptualised as sensitive) access to guidance to robustly develop and precisely plan the study, alongside thorough ethical screening was a complex but useful process. Although logistically difficult, developing research protocols and procedures in the depth was an asset in enacting the empirical research activities. It also facilitated a transparency of the intent and procedures of the research. Safeguards built into the ethical review process were difficult to navigate but helped to refine the design and moreover are present for a valid reason; to uphold and maintain the dignity, rights and safety of participants.

Drawing upon ethical literature, supported the research design. Following Taylor et al.’s (2010) research, the potential benefits of the research were included in the participant information sheet. The ethics of reimbursing participants for their time and travel expenses were also considered (Shore,

2006); such that participants of this research were refunded public transport travel, offered creative materials to keep, refunded for any creative materials purchased during the study, and provided £15. Consistent with existing research practice, to explore how the participant's found their experiences of the data generation methods (Jorm et al., 2007), participants were asked for their views of the data generation procedures (which are shared at the end of this chapter). Asking participants to evaluate the procedures can support monitoring whether generation methods are experienced in ethically sound ways. This was important to the research activities of this thesis, due to the novel data generation materials and design. This chapter continues by outlining and discussing the research methods.

6.01.2 Doing Data Generation: Pluralism and Triangulation.

The term data generation used within this thesis acknowledges the data were generated through a relational process. Notions of data generation are often adopted in arts-based and visual methods literature (Mayaba & Wood, 2015). Pluralistic methods and their associated materials facilitated interactions with participants to generate the dataset. The pluralistic data generation strategy facilitated flexibility for participants to bring their own insights and agendas to the research. The pluralistic data generation process also enabled triangulated study of the research questions, which (as chapter-5 discussed) has been argued to improve the validity of qualitative health research (Yardley, 2000).

6.02 Design

The design was developed to avoid the 'drive-by' interview, and 'off-the-shelf' methods (Chamberlain, 2012 p.4) often used in qualitative research; including most of the qualitative hallucination systematic review studies. The research utilised an idiographic, pluralist approach with an arts-based and visual methods data generation strategy. The study generated primary data with a sample of sixteen mental health service-users using an empirical, observational, longitudinal qualitative design, composed of 4 complementary stages. The methods generated multimodal prospective and retrospective maps of participants experiences as summarised in Figure 6.01.

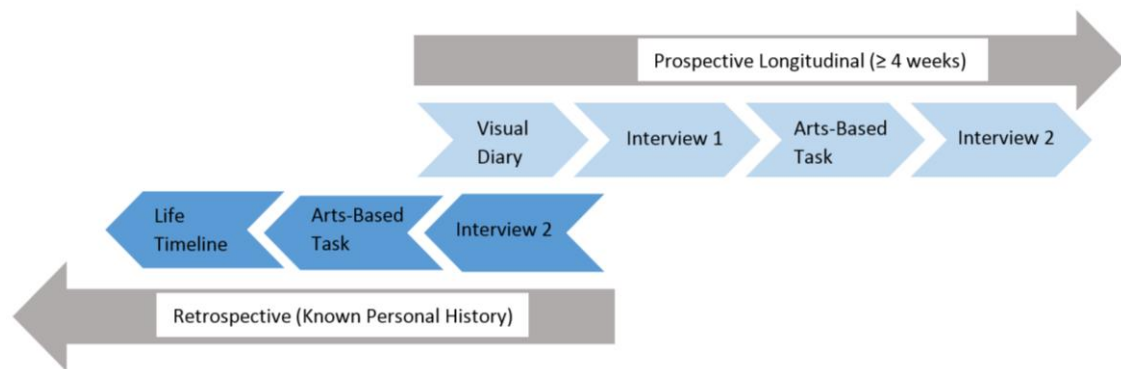


Figure 6.01 Prospective and Retrospective Data Mapping Strategy.

The design was developed for each participant to be worked with over at least 4 weeks, including at least two face-to-face one-to-one interviews (two interview schedules which could be asked over two or three meetings). The data generation strategy included a novel combination of innovative methods, of a visual diary (with micro-body-maps), an arts-based task and a life-timeline, alongside established methods of semi-structured interviews and a demographics form.

6.02.1 Service-user Review.

Prior to finalising the research strategy procedures, the proposed study and design were reviewed and approved through a service-user reference group. The written copy of their feedback in Appendix D1, illustrates the feedback was positive in relation to the arts-based and diary methods. Their feedback provided a prelude to comments which were echoed by almost all the participants of the study that “arts based diaries and work produced can help the participants in a therapeutic way whilst undertaking the task, but at the same time being useful to test for the aims of the study”. The service-user feedback also emphasised hallucination experiences may change over time, the design of the study was supportive in being able to capture this.

Consistent with the outcomes of the self-practice self-reflection, the service-user feedback illustrates the anticipated potential for ethical concerns arising from the interrelationship between anonymity, distress and the dissemination of ABRM research data. The recruitment process procedures

encouraged consideration of the potential for distress to arise in relation to the research topic and the data generation methods. Furthermore, during data generation participants could: participate without doing the visual or ABRM activities, opt out of having their work shared beyond the data generation process, and were encouraged to reflect on what ABRM materials they submitted to the study (and encouraged to keep any creative expressions for themselves if they wished).

6.02.2 Setting and Population.

The research was conducted at a single clinical site in collaboration with a multi-disciplinary outpatient and community NHS early intervention in Psychosis (EIP) service based in the midlands of England. The team provides a statutory service to people aged 14-64, who are described as experiencing a first episode of psychosis. All contact between the researcher and participants for data generation took place at the EIP service's outpatient clinic during clinic hours; there was a duty practitioner available who could manage any urgent difficulties or supervision needs. No such difficulties arose during the process of data generation.

Recruiting EIP service-users and generating the data in a clinical setting facilitated conducting the research safely, with numerous benefits summarised in Table 6.01. Collaborating with a statutory EIP service and recruiting service-users as participants had been a successful empirical strategy in the field (Upthegrove et al., 2016) and was a success for this thesis too. Further to the practical and ethical benefits listed in Table 6.01, there were also empirical benefits which supported the rigour of the research. Consistent with Upthegrove et al. (2016), working with EIP service-users facilitated the generation of data at a time potentially closer to when these experiences had started and were still unfolding. This provided 3 primary benefits: firstly, participants could self-report recent and present experiences where memories are more likely to be clear and reliable. Secondly, although the impact of medication use and psychiatric or psychological framing of hallucinations was anticipated to be somewhat unavoidable (and a relevant part of hallucination experiences as they are lived), the impact of this was hoped to be reduced as EI service-users were likely to be

early on in their 'psychiatric careers'. Thirdly, as the experiences were ongoing, they could be studied using both prospective and retrospective qualitative methods, further supporting the breadth of the research findings.

Table 6.01
Benefits of Collaborating with an EIP service.

<u>Benefit</u>	<u>Details</u>
1. Sample	1. Access to a sample of participants with current lived experience of hallucinations to explore the research questions with.
2. Setting	2. Access to clinical rooms at an NHS site provided an appropriate, safe and familiar setting to meet prospective participants and hold interviews.
3. Safeguarding: Recruitment	3. Able to recruit only those participants who were perceived by their care-coordinators as able to safely engage with the research procedures and having the capacity to consent.
4. Safeguarding: Data Generation	4. The participants already known to a clinical support-network who were providing on-going support to the participants throughout the duration of the study.
5. Researcher Wellbeing	5. Regularly working on-site in the clinical setting throughout recruitment and data generation provided safeguards of a professional and peer support-network.

6.02.3 Access.

To research on an NHS site it was necessary to gain multiple levels of permissions and provide extensive and detailed plans, materials and procedures for the research. Appendix D2 holds brief reflections on the labour of gaining permissions including details of the timescale are included in. The permission seeking process began with a Letter of Access (LoA) (see Appendices D3), after providing a clear screening from the Disclosure and Barring Service, curriculum vitae (CV) and occupational health screening.

6.02.3.1 Initial Access: Clinical Staff Review and Feasibility Checking.

Once initially designed, the research procedures were brought to a clinical team meeting at the collaborating site. This supported building some initial rapport with the clinical site staff, and in evaluating the design's practical feasibility; the process of ensuring feasibility was also supported by one of the thesis supervisors (Dr Jon Crossley) being a Clinical Psychologist within the EI team. The design was positively reviewed and felt to be feasible by the clinical staff present.

6.02.4 Ethical Approval.

The research was sponsored and insured by the University of Leicester (Sponsorship Number 0660), and was reviewed and approved by the Health Research Authority (HRA) and an independent research ethics committee (REC). The research was approved by London Camden Kings Cross REC (see Appendix D4). Confirmation of capacity and capability of the Leicestershire Partnership NHS Trust to host the research study was then provided. The ethical principles of the British Psychological Society (BPS) and advice of the HRA were adhered to throughout the research (BPS, 2014). The following thesis sections document the empirical research activities undertaken to apply the research design before outlining the analysis, and methods evaluation.

6.03 Participants: Recruiting, Sampling, Sample

6.03.1 Recruitment Strategy and On-Site Presence.

Empirical recruitment and data generation activities were completed over 7 months at the EIP site. An initial 2-pronged recruitment strategy involved attending clinical team meetings and maintaining an on-site presence by working at a desk in a large open-plan office alongside the clinical team. Below is an extract sketch from a research reflective diary (Figure 6.02). This illustrates the location of the researcher in the collaborating site base during the empirical research; the brown arrows document the walking routes of staff through the clinic. This location of sitting at the yellow spot marked X, maximised potential

staff interaction as they moved through the clinic and took breaks for tea and food.

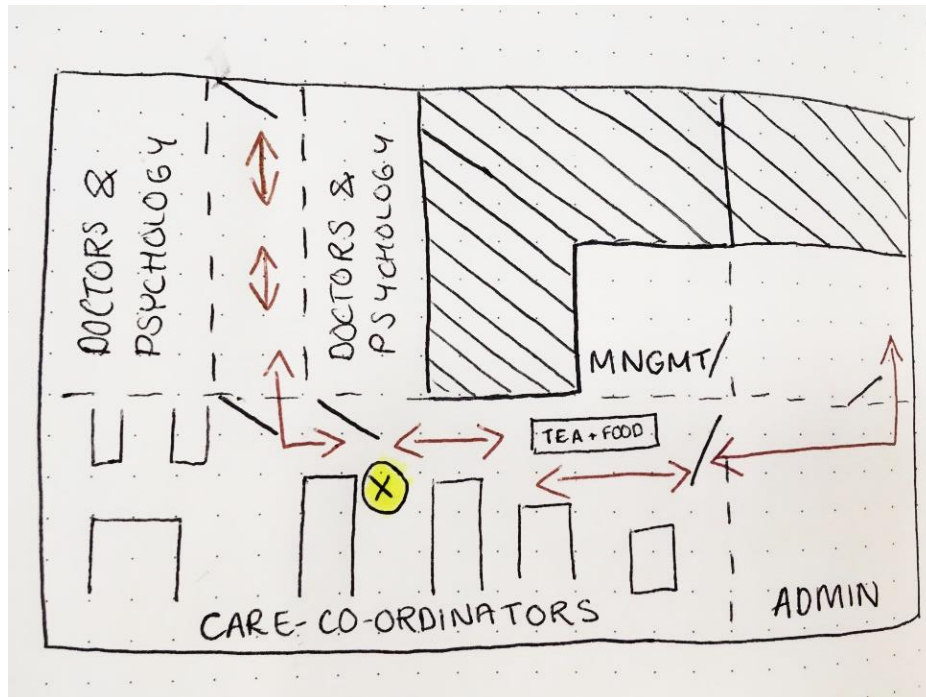


Figure 6.02 Extract sketch from reflective diary.

The recruitment strategy of attending clinical team meetings and maintaining an on-site presence supported:

- Meeting the large clinical team,
- Building rapport with staff,
- Providing opportunities to disseminate study information,
- Promoting the study was open for service-users to take part,
- Sharing information regarding the participant inclusion criteria (Appendix D5),
- Liaising with care-coordinators regarding participants and,
- Meeting prospective interested participants when they attended appointments.

The onsite presence seemed crucial for supporting the recruitment; by building staff rapport and being a present reminder the study was underway. The clinical care team were welcoming and helpful in supporting the study.

6.03.2 Sampling.

To support in studying the research questions, a purposive sampling strategy ensured recruited participants could safely engage in the data generation procedures. At the point of recruitment to the study participants were:

- Aged 18-64 (service upper age limit),
- Experiencing hallucinations frequently (daily or every-other day) and,
- Currently accessing the EIP service.

Consistent with empirical literature, participants could be experiencing hallucinations in any modality and they were not recruited on the basis of having been given a particular psychiatric diagnosis. To support the clinical relevance of the research, hallucinations could not be due to another health condition, current medication or substance use. Appendix D5 holds further details of the inclusion and exclusion criteria.

During routine clinical care, care-coordinators provided suitable service-users with study information including the participant information sheet summary (Appendix D6.1). Participants interested in taking part were provided with the full participant information sheet (see Appendix D6.2), with time to consider it in full and had the opportunity to ask questions. Before deciding to take part, participants had the option to meet with and speak to the researcher to discuss the study and ask questions. Before signing the consent form (Appendix D7), all participants had the opportunity to ask questions and were informed that: participation was anonymous and voluntary, their information would remain confidential, and they could withdraw from the research until one week after the final interview.

6.03.3 Participant Sample.

6.03.3.1 Age, Gender, Ethnicity.

A purposive sample of sixteen participants was recruited. Participants completed a demographics form during their first interview (Appendix D8). Participants were given an open question entitled 'Gender' within which participants self-identified as 75% male (n=12) and 25% female (n=4). This open question aimed to address the binary approach to gender from the systematic reviews. Participants' ages ranged from age 18-37 with a mean age of 27.25; this is similar to existing EIP research (Upthegrove et al., 2016). The sample self-identified nationalities of 87% British and 13% British-Indian, and self-identified ethnicities of 69% white British ethnicity (n=11), 19% Indian (n=3), 6% Afro-

Caribbean (n=1), and 6% mixed African and European (n=1) heritage. All participants were fluent in English.

6.03.3.2 Occupation, Diagnosis and Medication.

Participants occupational status was 63% (n=10) unemployed, 13% (n=2) part-time employed, and 19% (n=3) full-time employed, and 6% (n=1) full time student. This is consistent with SR2's outcomes, where people experiencing hallucinations were most-often unemployed. Of the 3 participants in full-time employment, 1 was self-employed and 1 was being made redundant. As participants were all EIP service-users, the psychotic-spectrum diagnoses in Figure 6.03 is unsurprising. This is consistent with Chapter-1, that experiences of hallucinations may be experienced among people given different diagnoses.

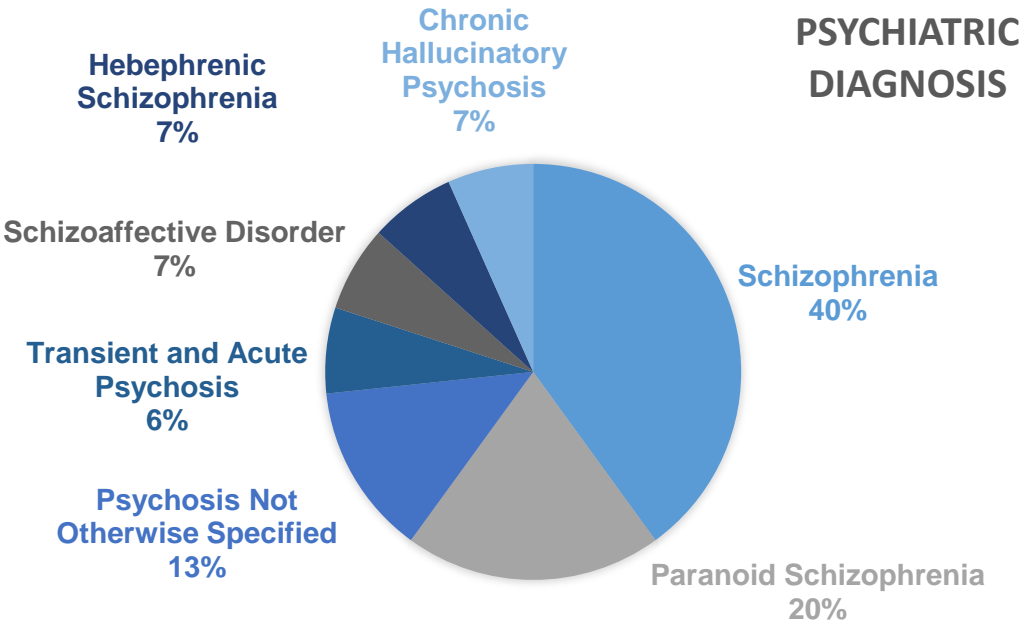


Figure 6.03 Pie Chart of the Participant Sample's given Psychiatric Diagnosis.

Table 6.02 summarises participants' self-reported health conditions and antipsychotic medications. Participants reported a range of other health conditions, most notably Two self-reported Asperger's, one of whom reported having been formally diagnosed; previous research has suggested psychotic disorder diagnoses are uncommon within this population (Lugnegård, Hallerbäck & Gillberg, 2011). Two participants self-reported anxiety as a condition, although

experiences of anxiety were commonly reported in the data generation process too. The contributing role of anxiety is consistent with SR1 research and is explored further in chapter-7.

Most participants were currently prescribed antipsychotic medications, this is consistent with research in chapter-1 and SR2. Although notably, within SR2 0-10% of participants were reported to not be prescribed antipsychotic medications, whereas within this study, 38% of participants reported being on no psychiatric medications.

Table 6.02
Participant's Self-Reported Health Conditions and Prescribed Psychiatric Medication.

<u>Other Health Condition</u>	<u>n, %</u>	<u>Antipsychotic Medication</u>	<u>n, %</u>
None	9, 56%	None	6, 38%
Hay fever	2, 13%	Quetiapine	3, 19%
Anxiety	2, 13%	Lurasidone	2, 13%
Asperger's (Diagnosed)	1, 6%	Risperidone	1, 6%
Asperger's (Suspected)	1, 6%	Haloperidol	1, 6%
Chronic Back Pain	1, 6%	Olanzapine	1, 6%
Depression	1, 6%	Aripiprazole	1, 6%
Iritis	1, 6%	Anti-psychotic NOS	1, 6%
Arthritis	1, 6%		
Dyslexia	1, 6%		

6.04 Data Generation

This chapter has described the overarching design, setting, ethics, recruitment, and participant sample. The remainder of this chapter explores the data generation tools and analysis.

6.04.1 Data Generation Tools.

Data generation tools were tailor made by the researcher to study the research questions. The tools included: a demographics form, a visual diary with a micro body-map (Appendix D9), two semi-structured interview schedules (Appendix D10), a life-timeline (Appendix D11) and arts-based task guidance

(Appendix D12). The data generation tools were designed to:

- Prospectively study the feelings and circumstances of hallucinations. This included embodied reports of the immediate feeling and circumstances of hallucinations in the first week using the visual diary (stage 1) and interview 1 (stage 2), documentation at participant's discretion over the following ≥ 3 weeks through the arts-based expression task (stage 3), with a follow-up interview 2 (stage 4) to explore any changes during the study.
- The arts-based task (stage 3) and interview 2 (stage 4) were designed to encourage participants to reflect upon and express the broader feelings and circumstances of hallucinations; including use of a co-created life-timeline to consider historical life events and the trajectory of hallucination experiences over time.

6.04.2 Data Generation Procedures.

The research was structured with a pluralistic four stage design. The study was designed with flexibility such that visual and ABRM activities were optional (to suit participant's availability and preferences). The data generation procedures could be completed within four weeks or extended up to a total of eight weeks (as participants could have up-to seven weeks for the arts-based task) with the final interview at the end. Participants could attend a third interview if they needed to leave a prior session early; this was used by one participant. This flexibility facilitated participation at a pace which best-suited participants with the available study resources. The procedures were designed such that data generated at each stage were relevant to different research questions. This meant participants could stop the study part way though, and their data still made a useful contribution.

6.04.2.1 Data Generation Pilot.

The data generation procedures were successfully piloted with 2 participants. This process generated a wealth of information relevant to the research questions. No amendments were made to the data generation tools. Sixteen participants took part in the study, with thirteen participants completing the final research stage (81% participant completion, 19% attrition).

6.04.2.2 Stage 1: Visual Diary (At Home, In Participants' own Time).

Participants were asked to complete a visual diary each time they had a hallucination for the week preceding the first interview. Twelve participants completed the visual diary. The visual diary included opportunities and prompts to respond in both written and visual modes of expression to document details of the feelings and circumstances of hallucinations. The guided visual diary was designed to generate specific kinds of data itself as summarised in Table 6.03 (as well as being used to generate interview verbal data). The visual diary generated quantitative data (data type 1-4) and qualitative data (data type 5-11) from open prompts with the exception of some binary options to indicate modality type.

Table 6.03

Data on the Immediate Feelings and Circumstances of Hallucinations Generated by the Visual Diary.

<u>Data Type</u>	<u>Details of Data Generated</u>
1. Binary	Modality of Hallucinations Binary Options Including: 'Hearing', 'Seeing', 'Smelling', 'Tasting', 'Feeling Touched' and 'Bodily Feeling'. One open option of 'Other' where text could be written.
2. Ratio [or Text]	Number of Modalities Involved in Hallucination Using data from section 1.
3. Ratio [or Text]	Length of Time of Hallucination
4. Interval or Ordinal	Time of Day
5. Text	Where the Hallucination Happened
6. Text	Who They Were with at the Time
7. Text & Visual	What the Sensory Experience Was
8. Text & Visual	What Feelings Were Felt at the Time
9. Text & Body-map	What was Felt in the Body at the Time
10. Text & Visual	What the Circumstances of the Hallucination Were
11. Text & Visual	An Open Space for Expression or Further Information

The visual diary was designed by drawing upon the systematic reviews and methodological literature. The diary was could address aspects of daily life warranting further study described by Delespaul et al. (2002) including: what times of day, places, company, and activities co-occurred with hallucinations.

The novel visual diary further built upon existing research by using a diary to:

- Study hallucinations arising in any sensory modality,
- Use visual methods to study hallucinations of any modality,
- Study the sensory, bodily and emotional feeling of hallucinations, as well as their immediate circumstances,
- Visually map bodily feelings during hallucinations using micro body-maps.

Participant's visual diaries (including micro body-maps) were discussed in an interview to further understand and contextualise the data generated. Before discussing the remainder of the stages of data generation, the body-mapping methods are discussed.

6.04.2.2.1 Body-Mapping.

Body-mapping methods were built upon within this thesis through using an analogue micro body-map, upon which participants could illustrate the location, form and texture of embodied feelings during hallucinations. This builds upon both existing analogue and digital body-mapping methods. Analogue body-mapping methodologies are a qualitative ABRM for embodiment research. Within this ABRM, a full-scale body-map is often created by drawing around the participant's body and worked with creatively to support people to reflect on their embodiment (de Jager, Tewson, Ludlow & Boydell, 2016; Dew, Smith, Collings & Savage, 2018). Since the development of this study's research protocol, body-mapping has been a successful method in studying physical health experiences among young people described as experiencing first episode psychosis (Boydell et al., 2018). Parallel to arts-based analogue body-mapping, digital body-mapping tools have been used in research too. Smaller scale generic body-maps are used to study the subjective bodily location of emotions. These methods have been used within the general population and people given a diagnosis of schizophrenia (Torregrossa et al., 2018).

As discussed in Chapter-4, feelings may often go by unnoticed as they are fleeting and form the fabric of experience. Use of body-mapping sought to bring the 'background' experience of feelings to the foreground for study. Existing body-mapping methods were developed in three interrelated ways by:

- Applying body-mapping to study the feeling of hallucinations,

- Using body-maps in a diary to study feelings and emotions in the flow of daily life,
- Combining the generic and micro aspect of digital body-maps with the analogue form of ABRM body-maps.

To understand what the context and experience of these feelings within hallucinations was like, body-mapping methods were applied within the broader novel pluralist qualitative data generation strategy being described.

6.04.2.3 Stage 2: Semi-Structured Interview (In Clinic, With Researcher).

All participants completed stage 2. The interview schedule (Appendix D10.1) of open questions included an opening statement, restating information regarding what the session would involve and their right to withdraw. Participants were asked about their daily life (e.g. “Can you talk me through an average day for you, what happens from when you wake up until you go to bed?”) and their current material and social circumstances (including living situation, support-network, finances). Participants who completed the visual diary were asked to talk through what they documented, and all participants were asked open questions about their current circumstances and experiences of hallucinations.

At the end of the interview, the stage 3 Arts-Based Task was discussed using the participant arts-based guidance sheet in (Appendix D.12). Options of artistic expression were discussed. Participants were provided arts materials of their choosing from a stock of study art materials, and/or refunded for any artistic materials bought during the study. Art materials kept in stock included a range of: pens, pencils (including coloured and water-colours), paints (acrylic and water colours), clay, collage materials, card, canvases, sketchbooks, and painting tools (paint brushes, pallets, plastic pallet knives and sponges).

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6.04.2.4 Stage 3: Arts-based Task (At Home, in Participants' own Time).

11 participants completed the novel arts-based task. In the time between interviews, participants were invited to reflect on their life history, circumstances and the feeling of their hallucinations; they were asked to create arts-based expressions from their reflections. Unlike the stage 1 visual diary's guided format, during stage 3, participants could document their reflections at their own pace and their options for what experiences they documented and how they documented them were broader. Participant's planned creative technique or medium to create arts-based expressions were discussed and agreed at the end of the stage 2 interview to ensure they had materials and their plans would not put them at undue risk. No such concerns surrounding risk arose. Participants brought their Stage 3 arts-based expressions to interview.

6.04.2.5 Stage 4: Semi-Structured Interview (In Clinic, With Researcher).

13 participants took part in stage 4. Participants were asked open questions from interview schedule 2 (Appendix D10.2) about how their feelings, circumstances and hallucinations had been since Stage 2. Where relevant, participants were invited to talk through their creative pieces. After this, participants were asked open questions to understand more about their circumstances, personal history, and hallucination experiences. This included the option to make a life-timeline together. The end of this interview formed the end of participation in the research. Participants were thanked for their contribution to the study, reminded they would be provided a summary of the research outcomes once they were developed and given the opportunities to ask any questions they had. Having outlined the data generation procedures, the following section of the thesis describes data preparation and analysis.

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6.05 Data Preparation

Once data were generated or consent were provided at the clinical site, the data were securely transferred and stored at the University of Leicester. The dataset includes interview audio recordings, the written and visual data of the visual diary (including body-maps), arts-based data submitted for the arts-based task, life-timelines (including visual and written data), and written information from the demographics forms.

In qualitative embodiment research, the role of the transcript and of transcription is being increasingly questioned (Ellingson, 2017). With some researchers arguing a transcript is to knowing a field of research, as a map is to knowing a city (Warr, 2004). To translate heard, spoken words into letters on a page is an active process of interpretation from one form of communication (spoken) to another (written), which represent qualitatively different forms of information (Ellingson, 2017). During the initial process of transcribing data (interviews, diary contents, scanning images), reflective concerns developed regarding the process of translation this involved and whether beginning the analysis with a transcript was appropriate to understand participants' embodied experiences. An initial primary data preparation strategy of verbatim transcription and analysing data from transcripts generated a feeling process of becoming ever-separated from the data. Uncertain feelings grew surrounding making valid analytic decisions at this distance.

The transcript held a very different kind of data than those the audio recordings. The words on a page bore little resemblance to the dynamic tonal conversation and sound of an interview. Many of the feelingful markers important to guide the analysis direction were lost in transcription. Where analysis hinges primarily on the reading and reviewing of written transcripts, the sensory mode of the data has been transformed from words heard through participant's speech, to words relived through gazing at black and white symbols heard through one's own inner voice(s). When listening to the sound of the audio without typing, a feeling of re-immersion in moments lived with participants grew. Upon transcribing the focus shifted towards to flurries of accurately pushing keyboard buttons, editing misspelled text, stopping, rewinding, relistening and retyping.

The loss of so many textured feelings was noticed with each focused keyboard push.

The study was designed to create a rich multimodal dataset, and the data generation activities achieved this aim. Yet after this time, when focused upon creating transcripts, there was a feeling of erasing core parts of the embodied dataset which had been sought to be co-created with participants. A break was taken from data preparation to understand how best to manage and address this issue within the research. Returning to reading Ellingson's work (2017, p. 137, 138), the following sentiments resonated with these difficulties, as:

- “the rhetorical choices inherent in transcription typically erase bodies completely” and
- “writing down oral speech renders it a different entity altogether. People do not process oral speech the same way we read it; we encounter and make sense of language in vastly different ways”.

In the early stages of analysis, whilst encountering and making sense of the dataset, working primarily with transcripts did not feel right. Consistent with the writings of Warr (2004), the embodied power of the participants' voice was diluted.

To explore the dataset generated by this study, a novel analytic strategy was developed which is detailed in the following sections. To support this data analysis strategy and sharing the dataset, verbatim transcripts were generated for each interview. Based on the reflections which arose within data preparation, these transcripts were understood as one part of a broader dataset for analysis, rather than the primary data or sole source of data for analysis.

6.05.1 Starting Data Analysis.

Listening to understand the transcripts and looking at the physical pieces of artwork, diaries and timelines, provided an embodied closeness to the data analysis process. Although some scholars argue transcribing interviews and analysing transcripts reflects a closeness to the data, health researchers have argued for reflexive, iterative data management processes (Halcomb and Davidson, 2006). In such processes an emphasis is taken towards listening and generating reflective journals and notes. Approaches such as this have also been

endorsed by transcript-focused analysts such as Wengraf (2001). Wengraf (2001, p.217) wrote of the value of the “holistic sense of the whole” which arises from the process of listening to interview audio-recordings and argued the ideas, memories and understandings which flood through this process, can form theoretical memos richer and more useful than a perfect transcript. Consistently, a much greater closeness to the data was felt by starting the analysis through looking at the visual materials and listening to the sounds of the audio. Having documented the approach to the data and its preparation, the next section describes the analytic method.

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6.06 Embodied Process Analysis (EPA)

The multi-modal dataset was analysed as an interrelated whole. Appendix D.13 holds EPA extract. EPA aimed to understand and share a sense of the feeling and circumstances of participants' lived experiences. Applying the writings of contemporary embodiment qualitative research scholarship (Ellingson, 2017), and building upon procedures in qualitative health research (Halcomb and Davidson, 2006), the research identified areas of analytic focus before undertaking a novel EPA.

6.06.1 Focus of analysis.

The research questions were drawn upon to identify analytic focus areas which formed the three analysis chapters. Participant responses to the analytic anchor questions regarding key stakeholders, provided reference points around which streams analyses could flow. Table 6.04 summarises this process.

Table 6.04
Analysis process and presentation details.

<u>Focus of Analysis</u>			
<u>Analysis Focus Area</u>	<u>Included Participants</u>	<u>Data Source</u>	<u>Chapter Number</u>
Immediate Feelings & Circumstances of Hallucinations.	Participants who prospectively completed the Visual Diary (n=12).	Visual Diary (including body-maps) & Interview 1 Recordings.	Seven
Change in Hallucinations Over Time.	Participants who attended the final interview (n=13).	Visual Diary (including body-maps) & Interview 1 and 2 Recordings.	Seven
Broader Feelings & Circumstances of Hallucinations.	All participants (n=16).	All data.	Eight
Feeling-Traps and Hallucinations.	All Participants (n=16) with case-examples.	All Data.	Nine
<u>Analytic Anchors</u>			
What do you hope I have learned from your experiences?			
What do you wish members of the public knew about hallucinations?			
What do you wish clinicians knew about hallucinations?			
If you could give advice to someone who is experiencing hallucinations, what would you say?			

6.06.1.1 Streams over Themes

Compared to traditional themes, EPA analytic streams are more specific than themes but more analytically developed than codes. In a practical sense, a stream refers to a sub-titled document section, under-which a cluster of related multi-modal content are collated (e.g. felt reflections, data extracts and written implications for existing scholarship). Stream names point to aspects from the focus of analysis process (research questions, analytic anchor question responses) and delineate features of participants' experiences including feelings, embodiment, circumstances, and activities. The term stream also harks back to the process orientation of the analytic method, which emphasises the importance of acknowledging emergent flows through time, the role of interrelating systems, and the connection of the dataset to the material, natural world.

6.06.2 EPA Stage A. Sensing and Feeling.

This analysis stage (summarised in Table 6.05) was guided by the 'Focus of Analysis' process. Analytic Levels A1-3 were completed by immersing and re-immersing oneself in the dataset at each level, with each subsequent level drawing upon the last to build an overall understanding (reviewed in Level A4). For the body-map data, digital illustration software was used alongside digital word processing for collation. After EPA-Stage-A, the analysis refined through Stage-B.

Table 6.05

Description of EPA Level A's Analytic Activities and Focus.

<u>Level No.</u>	<u>Analysis Activity</u>	<u>Level of Analysis</u>
Level A1	Re-listening to the interview through headphones with any visual data laid out on the desk and using a reflective diary to document feelings, memories of the interview and ideas which arose (in a written or arts-based form).	This level of analysis was focused at the level of each participant.
Level A2	Akin to A1, whilst revisiting the dataset and reflective diaries (via listening and looking), initial analytic stream titles were generated using the "Styles", "Heading" functions in Microsoft word processing document. Streams were initially worked into through documenting reference points to key data (e.g. art pieces or interview time points), and	This level of analysis began to build initial interrelated understandings within and between participants.

	documenting streams of ideas (e.g. reflections in relation to feelings and within or between participant comparisons).	
Level A3	At this stage, interview transcripts and digital copies of arts-based data (diary, arts-based data or life timelines) were reviewed for each participant. During this process, analytic streams were worked into further by inputting data extracts which resonated or flowed with them or had been referred to in Level A2. As the dataset was reconsidered, additional streams were added to comprehensively accommodate the dataset.	Initial analysis of streams considered how participants' experiences: spoke to the RQs, compared to existing literature, or the experiences of other participants.
Level A4	Reviewing the streams to ensure the entire relevant dataset were considered.	Review streams.

6.06.3 EPA Stage B- Organising, Refining, Writing.

The organising and refining process as summarised in Table 6.06 was guided by the research questions, analytic anchors and the feeling of the data. Reflective discussions with the researchers supported in validating and enriching the analysis. This refining stage was followed by re-interpretation in Stage C.

Table 6.06
Description of EPA Stage B's Analytic Activities.

<u>Level No.</u>	<u>Analysis Activity</u>
Level B1	Guided by the content of the streams and the research questions and analytic anchors, streams were organised into a serial order which reflected their interrelationships and flows as best as possible with written language. The "Navigation" pane in word can provide an overview of headings. which can be selected and ordered as needed (re-organising the content of the analytic document). Creating a table of contents offers a simple means of overviewing the stream composition.
Level B2	To ensure appropriate analysis of the data, independent analysis of data-extracts was sought from 2 researchers independent of the research study. Two extracts of analysis and stream composition process were reviewed and discussed with no discrepancies. Had discrepancies arisen, this would have been explored collaboratively with consideration of differing reflective positionalities of the researcher and reviewer.
Level B3	The content of the streams were refined, with data appropriately collated depending upon its type, and written into academic analytic prose. The stream names became the analysis write-up sub-titles.

6.06.4 EPA Stage C- (Re)Interpreting.

As Table 6.07 summarises, in this stage the analytic prose and streams were reviewed with a critical eye. The lengthy analytic prose arising from this process formed both the structure and detail upon which the thesis analysis was written.

Table 6.07
Description of EPA Stage C's Analytic Activities.

<u>Level No.</u>	<u>Analysis Activity</u>
Level C1	Looking for what was missing, reflecting on disconfirming cases and building critical re-interpretations on the analysis.
Level C2	Reworking and reviewing the content of the streams, in relation to the empirical and theoretical literature.
Level C3	Evaluation of the research activities and analytic process.

6.06.5 Putting EPA in its Place.

Though the EPA strategy was novel, it drew upon qualitative research methods scholarship. Specific examples can be seen in stage A, which drew upon Gleeson's (2011) polytextual thematic analysis, where images are looked at again and again, and where the relevance of feeling in analysis is recognised. Stage A was useful in writing chapter-7 on the immediate feelings of hallucinations. The development of working into analytical streams draws from memo writing in grounded theory, which forms an analytic bridge between initial understandings of the data and a drafted paper. Parallels can be seen in Charmaz's (2008, p.166) writing which described memos as "capturing ideas in process and in progress...to learn about the data rather than just summarizing material". The process of identifying areas of focus and developing streams informed by research questions, and then using these to frame and shape the analysis, mirrors some aspects of template analysis (Brooks, McCluskey, Turley & King, 2015). A simultaneous desire towards a closeness with the data and of identifying patterns which are generated through immersing and re-immersing oneself in the data, mirrors some parts of interpretative phenomenological analysis (IPA, Larkin & Thompson, 2012). Akin to IPA, experience is the focus of analyses, however compared to IPA's focus on meaning-making, within EPA the

centre-stage is held by attending to what feelings and experiences arise in what circumstances, and in what ways these may interrelate.

EPA also drew upon qualitative research rigour through processes such as multiple coding involving independent researchers (Level B1) and disconfirming case analysis (Level C1) (Yardley, 2015). Level C1 also draws upon Langdridge's (2004) writings on the hermeneutics of suspicion of bringing an interpretative critical gaze to the analysis. The Stage C levels of analysis were most relevant to the analysis of feeling-traps reported in chapter-9. Holding the perspective of participants as experts of their own experiences, the analysis tried to be transparent in (re)interpretations from other perspectives whether they be theoretical, critical or otherwise.

6.07 Evaluation of Novel Research Protocol and Tools

Consistent with existing research practice (Jorm et al., 2007), before closing the chapter this section examines data regarding the methods; including participants engagement with and reported experience of them. Consideration of methods will be returned to in the final chapter's discussion through consideration of mental health service-user research ethics.

6.07.1 Engagement with Data Generation Tools.

Though completion of the data generation stages varied, each participant contributed insights to the research questions from their lived experience to explore the research questions. Table 6.08 visually summarises procedure completion. 'Partial' completion indicates rather than using the timeline (verbally and visual life-history), life-history was provided verbally without use of the timeline. There were four dominant patterns of participation in the research procedures:

- Pattern A (63%,n=10): Completed all stages,
- Pattern B (19%,n=3): Completed first 2 stages (visual diary and interview 1),
- Pattern C (12%,n=2) Completed only stages 2 and 4 (the interviews),
- Pattern D (6%,n=1) Completed all stages except stage 1 (visual diary).

There were some noticeable demographic clusters as 100% (n=4) of female participants were in Pattern A, compared to 50% (n=6) of male participants; 100% (n=6) of Patterns B, C and D were male. 80% (n=4) of BAME participants

were in pattern A, compared to 54% (n=6) of white British participants. These comparable demographic patterns chime with existing literature arguing visual and ABRM support marginalised groups in expressing their experiences (Knowles & Cole, 2008).

Table 6.08
Visualisation of Methods of Data Generation Completed by Each Participant.

Participant No.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Pattern	A	C	A	A	B	B	D	A	A	A	A	C	A	B	A	A
S1. Visual Diary																
S2. Interview 1																
S3. ABRM Task																
S4. Interview 2																
Life-timeline																

Visual Key: Level of Completion		Full	Partial	None
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Within the ‘open’ ABRM approach, participants chose their creative medium(s). Participants used between one and three creative mediums for the arts-based task. Figure 6.04 illustrates drawing and painting were by the largest number of participants, with further unique contributions of a comic, information leaflet, story-telling (visual and written), a rap/rhyme and a found image. Participants were advised not to submit found images; however, for the one participant who brought along a found image, this supported their sharing of an aspect of their experience at interview. Overall the variety of creative mediums used provides evidence of the relevance of an open ABRM approach to the study of lived experiences. Furthermore, there was no specification of the number of artistic pieces to be submitted. This was appropriate as (consistent with expectations) the way participants generated expressions varied in terms of the number of pieces produced. For example, a series of expressions could be shared over numerous pieces or combined in a single piece. The open ABRM approach seemed to facilitate the uptake of creative data-generation options and the sharing of experiences.

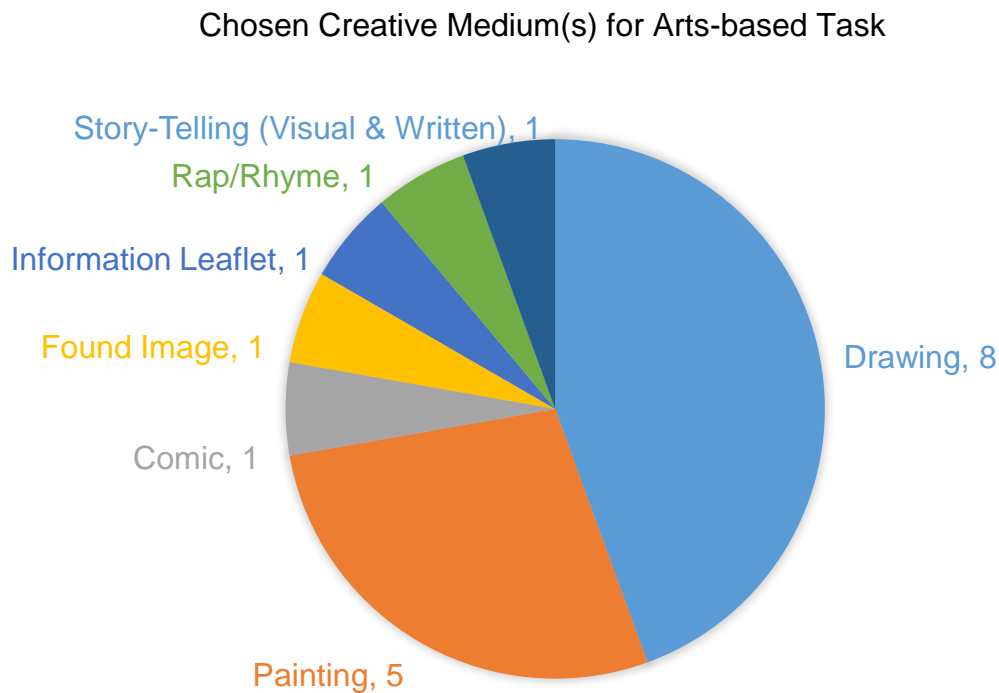


Figure 6.04 Visualisation of the number of participants who used each creative medium for the arts-based task.

If each data generation tool was conceptualised as producing a map of participants' experiences, this study held 64 maps of: 13 visual diaries, 16 first interviews, 11 arts-based tasks, 13 second interviews and 11 visual life-timelines. This was a manageable amount of data, which could comprehensively explore the research questions with an EPA approach. The varied pattern of completion of data-generation stages was accounted for the design. As stages and tools were mapped onto research questions, participants could contribute to the study so long as they attended stage 2 (interview 1). In this way, the study's precise design was flexible in supporting participant's availability and preferred communication style. Visual and 'open' ABRM design, with optional data generation tools, can be considered useful for future study of experiences of mental health service-users, and people experiencing hallucinations.

6.07.2 Reported Experience of Data Generation Tools.

The overall process was described by participants as useful in sharing and expressing lived experiences, of hallucinations such that participants reported feeling understood. Some participants described the data generation tools as "therapeutic" and the overall process generating benefits like "what I

used to get from therapy”. The positive responses to the tools and reported benefits of the design have been summarised in Table 6.09 (full participant quotes in Appendix D.14). Although the visual and ABRM options were not used by the participants, those who did use them described them as useful in facilitating communication; the visual diary with body-map seemed particularly helpful in sharing simultaneous MMH. The flexibility seemed to support the research design in adapting to participant’s preferences and needs.

Table 6.09

Reported benefits of taking part in research and aspects of research design which facilitated sharing.

<u>Data Generation Stage</u>	<u>Benefit Summary</u>	<u>Example Participant Quote</u>
Full Protocol	<ul style="list-style-type: none"> ●Enjoyable ●Relieving ●Felt Understood ●Supported Reflection ●Opportunity to Help Others 	“Just being able to talk... someone to listen to everything that I go through and understand it...just feels a relief and understanding and like that’s what I want from someone, so I’ve got that”.
Visual Diary	<ul style="list-style-type: none"> ●Document Experiences ●Communicate to Presence ●Express and Offload 	“It was really helpful, everything fit, every description that I wanted to write down”.
Body-Map	<ul style="list-style-type: none"> ●Helped to Describe MMH 	“This was perfect because...everything is to do with my body”.
ABRM	<ul style="list-style-type: none"> ●Felt Good ●Sharing ●Making Sense of Experiences ●Using Creative Skills to Share ●Expressing Feelings ●Becoming Relatable ●Achievement ●Evidence of Recovery ●Opportunity to Express ●Flexible Communication ●Art Resources to Keep 	“I think that helps explaining to people what’s happening, so you can see what I’m seeing or what it would feel like to see. You’ve got the ears and the nose so you can picture what it might be like or what I’m feeling when I’m hearing or seeing these things”.

Visual Diary & ABRM	<ul style="list-style-type: none"> •Communicating (Hallucinations) •Communicating (Psychosis) 	"I think the visual aspect really helps explain to people who don't suffer from psychosis".
Interviews	<ul style="list-style-type: none"> •Cool to Share •Building Relationship 	"Being able to talk about it has definitely been a good thing...being able to speak about things and it not be sort of like, weird, you know it's cool".
Life- timeline	<ul style="list-style-type: none"> •Helped to Share •Describe Event Sequence •Organise Chronology Events •Feeling Better About Life History 	"I feel a lot better now because I can see how my life has gone as well. I had it in my head jumbled up, but now it's all in order."

Appendix D.15 shares quotes of features which reportedly hindered sharing for some participants. This included the omnipresence of hallucinations (n=1), the personal content under study (n=1), and it being "a bit tougher just to talk about experiences" in a context where in the past sharing "scares people" (n=1). Nonetheless, each of these participants took part in all data generation stages and contributed a wealth of valuable insights to the study. The reported experiences regarding the research processes, reflect what the participants felt able to share and as such may be a partial reflection of their lived experience. Still, these outcomes point to ways in which an open and flexible ABRM design may be experienced among a mental health service-user sample. Overall the design successfully generated a comprehensive dataset to explore the research questions.

6.08 Moving Forwards

This chapter has detailed the design, ethics, procedures, data generation strategies and analysis of the empirical research which mapped the feelings and circumstances of hallucinations. The following chapters of the thesis document the data analysis outcomes, before concluding.

7. Empirical Analysis: The Immediate Feeling and Circumstances of Unimodal and Multimodal Hallucinations

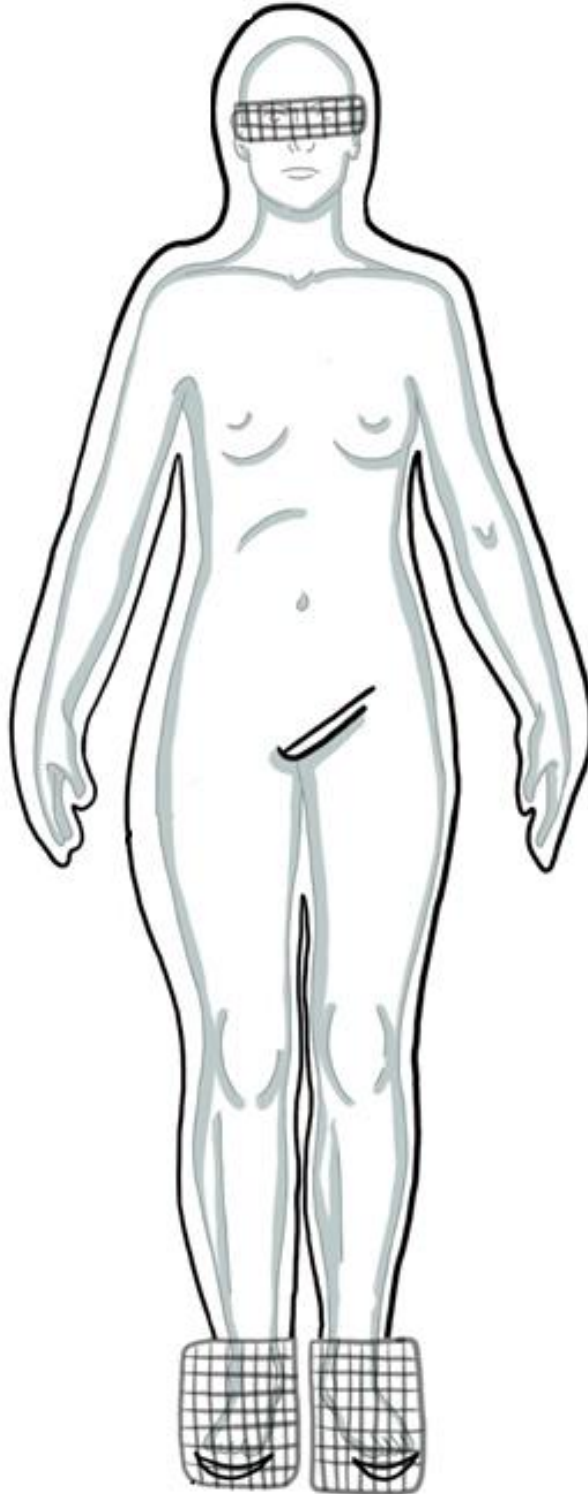


Figure 7. Participant generated body-map digitally re-generated by researcher.

7.01 Analysis Chapters Overview

The following three chapters present and examine the data analysis. These chapters follow EPA's sequential focus on different research questions and data. Chapter-7 examines prospective data on the immediate feelings and circumstances of hallucinations, while chapter-8 explores retrospective data on the ongoing feelings and circumstances which surrounded hallucinations (including participants' ongoing lived histories in Britain). Chapter-9 reviews the extent to which feeling-traps theory was useful in understanding the research. The final chapter-10, reaches the conclusion.

7.01.1 Chapter-7: Introduction

This chapter explores the immediate feelings and circumstances of hallucinations through the analysed prospective data. Chapter-1 argued research on feelings, circumstances and specific distress experiences appeared neglected due to dominant biomedical, diagnostic and individualised research approaches. Consistently, the systematic reviews struggled to shed much light on the feeling of hallucinations (beyond unimodal AVH), or the circumstances which may precipitate or surround them. Existing research about the content and experience of hallucinations can be built upon with the novel prospective data this chapter presents (summarised in Table 7.01 with sources). The evidence to be presented suggests hallucinations seem characterised by a broad range of immediate feelings and co-constituting circumstances. The outcomes of the analysis propose hallucinations appear more than a simply sensory experience.

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Table 7.01
Summary of the Novel Data and Data Sources Presented in Chapter-7.

<u>Novel Prospective Data</u>	<u>Data Sources</u>
Immediate feeling of hallucinations across modalities (emotional, extra-emotional, of knowing, of reality, localised, generalised).	The visual diary (including body-maps). Semi-structured interview questions about diary.
Immediate social and material circumstances of hallucinations, (company, location).	The visual diary. Semi-structured interview questions about diary.
Temporal features of hallucinations, (duration, time of day, change during the study).	The visual diary. Semi-structured interview questions about diary. Semi-structured interview questions about change during study in final interview.

7.02 The Immediate Feeling and Circumstances of Hallucinations:

Visual Diary and Follow-Up Interview Data

This section presents the analysed data from 42 diary entries including: written and visual data, with 42 body-maps and data generated by the semi-structured follow-up interview questions. 81% of the sample (n=13) submitted diary entries. One participant's diary data was excluded from diary analysis, as their hallucinations reportedly stopped between recruitment and beginning data generation; as such, they documented a past hallucination. The 12 participants included in this section's analysis, submitted between one and eight diary entries (average of three).

A novel outcome of the prospective visual diary method was reported hallucinations were predominantly MMH (of varying categories), the extent to which the data can be compared to existing research is limited by this. Consistent with AH having a higher lifetime prevalence than other unimodal hallucinations (Lim et al., 2016), AVH were the only unimodal experiences reported. As the later 'what senses' section explains, all analytic sense categories were involved in a range of MMH. As existing research predominantly studied hallucinations reportedly involving one modality, the comparative analysis has been written to

reflect this. This analysis section reports on the immediate circumstances and then feelings of hallucinations. The analysis has been structured to mirror the visual diary sections, with subtitles to reflect the data sources.

7.02.1 The Immediate Circumstances of Hallucinations.

This sub-section explores reports of how long hallucinations lasted, what time of day they happened, where they happened, who participants were with and what situations they were in. This covers primary areas for future hallucination research proposed by Delespaul et al. (2002), regarding the need to study the context of hallucinations (particularly within daily life) in terms of places, activities, social-company and time of day.

7.02.2 It Lasted?

Each diary page had an open question-box with the phrase “It lasted”, to generate hallucination duration data. Most diary entries (67%,n=28) had numerical values from which duration could be calculated. Some entries provided non-specific phrases for duration (19%,n=8), such as “all day” or “all night”. A minority of entries had no duration data (14%,n=6). The data with a breakdown of unimodal and MMH is available in Appendix E. This data suggested variability in the specificity of felt time, with some participants providing more specific lengths of time, particularly when the duration was shorter. Where numerical values were provided hallucinations lasted between 1 minute and 14 hours. The difference in the length of time stated for hallucinations involving one sense (unimodal hallucinations) and hallucinations simultaneously involving multiple senses was interesting. Documented unimodal hallucinations lasted between 1 and 30 minutes (10 minutes on average), whereas simultaneous MMH lasted much longer, at between 2 minutes and 14 hours, (3 hours and 29 minutes on average).

Where numerical values were provided, diary entries of AVH (n=11 entries, either unimodal or part of serial MMH), lasted between 1 and 30 minutes (7 minutes on average). This is consistent with approximately a third of McCarthy-Jones et al.’s (2014) sample who reported AH duration in the minutes range, although 12% reported they lasted seconds and 59% for hours. With AVH experiences often arising repetitively (Nayani & David, 1996), perhaps they may

be recalled as holding durations spanning over hours. In Gauntlett-Gilbert and Kuipers (2003) study, 65% of their sample's hallucinations lasted minutes or seconds; this is comparable to the 1.5-minute-long VH reported by a participant in the current study. The extent to which the discussed outcomes can be compared may be limited by existing research's use of retrospective methods and the broad time-phrasing; in the case of VH it may also be limited by existing research's unimodal VH focus and the current study's reported VH being part of serial MMH experiences.

The current study's analysis suggested duration varied by the number of simultaneous senses. Figure 7.01 illustrates the novel outcome that the more senses simultaneously involved in a hallucination, the longer the hallucination reportedly lasted (up to a peak of four modalities). This outcome may reflect the lower quantity of diary entries for hallucinations involving higher numbers of simultaneous modalities. The notion of combining feelings recurrently sustaining over time, points to feeling-traps which chapter-9 explores. With AVH being the most common contributing hallucination type to simultaneous MMH, perhaps the longer durations reported by McCarthy-Jones et al.'s (2014) participants, may reflect simultaneous contributions of undocumented senses. The novel outcome regarding hallucination duration and the number of senses simultaneously involved warrants further prospective study with a larger sample.

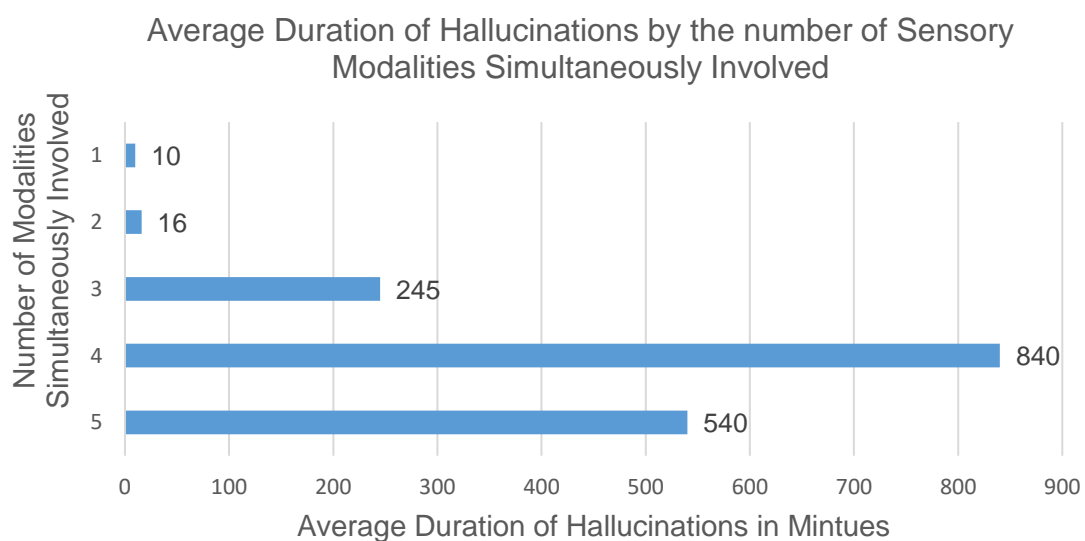


Figure 7.01 Exploration of the Duration of Hallucinations by the Number of Modalities Involved.

7.02.2.1 The feeling of frequent and long hallucinations.

All participants who reported hallucinations during data generation (n=15), described experiencing hallucinations daily, often repeatedly and for substantial periods of the day. This is consistent with Delespaul et al.'s (2002) prospective hallucination research where hallucinations were estimated to take up four to five hours each day. This generated difficult immediate and broader feelings of: confusion; presence and entity regarding felt sensory sources; and disruptions of one's feeling of reality and what is 'real'. In the current study, a participant who experienced serial and simultaneous MMH explained hallucinations typically lasted "4 to 6 hours. It can go on for a long time...it's a big like war of the worlds...it's really surreal". This generated a "struggle to know what reality is, what's real and what's not". This suggests a disruption or flux in feelings of reality in frequent or enduring hallucinations. Overall the data points to interrelationships between duration, frequency, feeling of reality and number of simultaneous senses. Chapter-8 further explores these broader feelings of hallucinations with focus upon reality and presence.

7.02.3 Time of Day?

Delespaul et al. (2002) proposed studying the time of day of hallucinations was a key future research area. The visual diary was designed to generate data to explore this. Like the duration data, most entries held numerical times (69%), some had linguistic temporal phrases such as "all morning" (24%) and a minority of cases had missing data (7%). The time of day data was mapped onto 24-hour graphs. To generate Figures 7.02, 7.03 and 7.04, linguistic phrases were transformed into numerical times by drawing upon the broader dataset (duration data, other diary entries, interviews); Appendix E2 holds the numerical coding.

Figure 7.02 illustrates how many hallucinations were experienced each hour; reported hallucinations often spanned multiple hours and thereby multiple time-points. Figure 7.02 suggests hallucinations typically arose between 8am and 11pm; reflecting participants' sleeping and waking cycles. Consistent with existing hallucination definitions (Blom, 2015), hallucinations were mostly reported as occurring whilst awake. One diary entry was an exception (2% of total), by reporting a simultaneous MMH (VH+BH) upon waking alongside an

experience described as “sleep paralysis”. Section 7.02.6.1 explores this further. This overall data trend suggests hallucinations may occur at any time whilst awake, although hallucinations seem most likely soon-after waking, in mid-afternoon and soon-before sleeping.

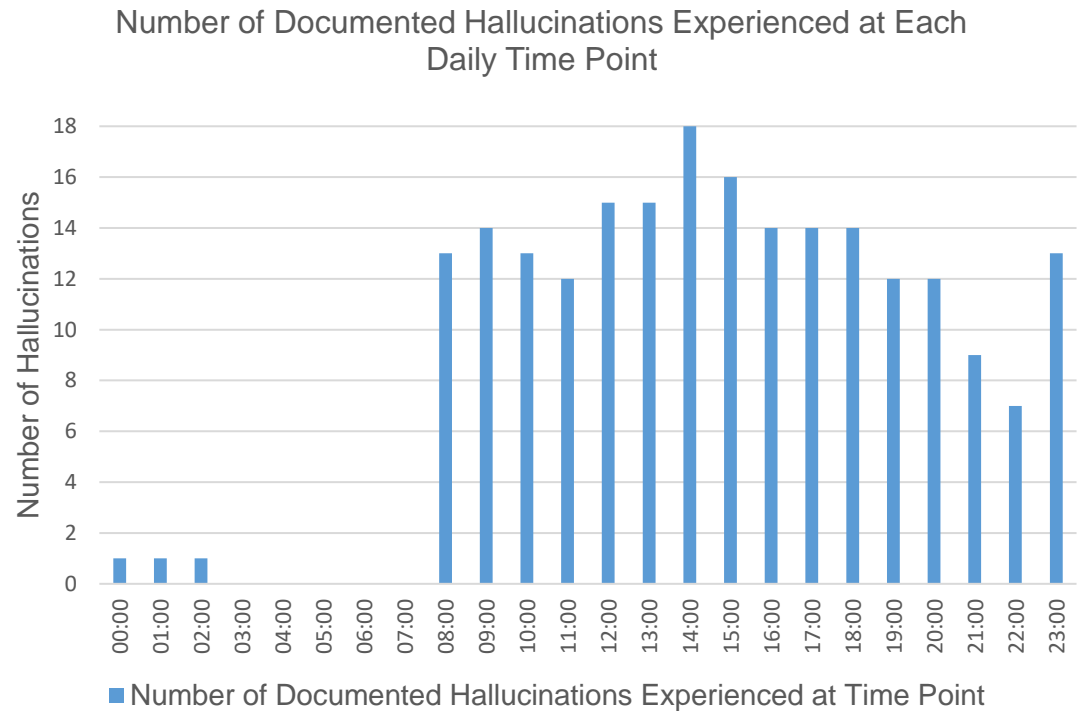


Figure 7.02 Visualisation of the Time of Day of Diary-Documented Hallucinations.

As the systematic reviews reported, existing hallucination research has focused on those involving one modality. With this in mind, the data was graphed separately in Figures 7.03 and 7.04; they have been combined in Figure E.1 (Appendix E). These figures suggest hallucinations involving one modality may be experienced fairly-steadily throughout the day (with the exception of a sudden peak at 14:00), with experiences declining through the evening, with a peak before sleep. In contrast, Figure 7.04 suggests simultaneous MMH seem increasingly present from waking until a peak between 13:00 and 15:00, after which time they decline, until a familiar peak before bed. These graphs indicate the time of day of hallucinations, may vary by their sensory kind.

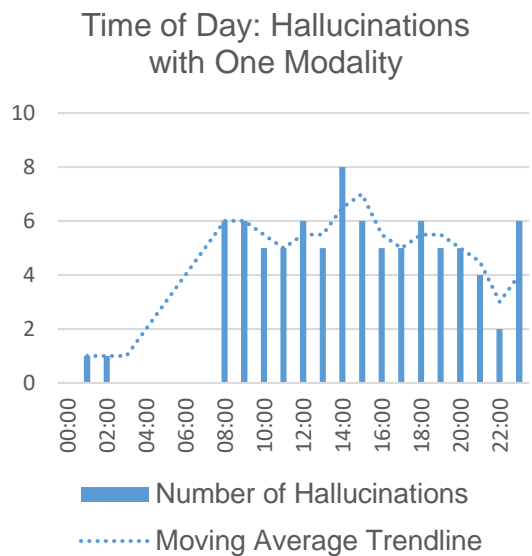


Figure 7.03 Time Visualisation for Diary-Documented Hallucinations involving One Modality.

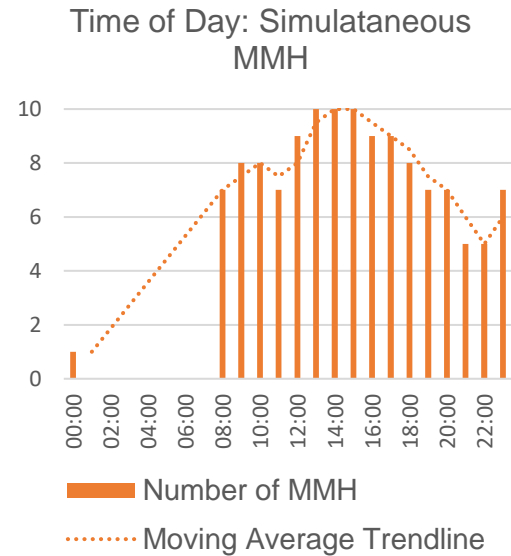


Figure 7.04 Time Visualisation for Diary-Documented Hallucinations involving Multiple Modalities.

The data suggested the prominence of hallucinations may vary throughout the day (particularly so for simultaneous MMH). The novel outcomes shared here could facilitate the development of interventions or practices aiming to manage hallucinations. For example, coping strategies could be used, developed or adapted for specific times-of-day; service-providers and organisations should inquire how people's experiences vary over the time of day to support them in a way which reflects their needs best. For example, managing peak hallucination times could be supported by adjusting working times, healthcare appointment times or use of pre-emptive coping strategies. The interesting analytic outcomes and the trends identified, provide an empirical basis for further time of day research with a larger sample (Delespaul et al., 2002). It may be fruitful to explore time trends in relation to more specific hallucination types, the activities underway at different times of day, and how hallucinations may be best managed at different time-points. The features of the generated data are discussed before continuing the temporal data analysis.

7.02.3.1 Temporal Data Types: Words and Numbers.

The temporal data diary sections were open for participants to provide data in a form which best fitted their experience; whether precise quantified times or more open qualitative descriptors. Consistent with the duration discussion, this

variation in data may reflect the variation in the experience of time within hallucinations and the experience of boundaries in their starting and stopping. The reliability of the data reflects this aspect of the phenomena and the temporal data analysis should be understood in light of this. Considering the specificity and reliability for temporal data raised queries over the validity of existing temporal data (duration and frequency), generated with solely retrospective methods. Within the diary there was a mix of use of numerical and linguistic temporal terms, however in the interview, participants predominantly used non-specific linguistic temporal terms. This may reflect the different specificity of retrospective recall in interviews, or the way in which temporal information may be communicated differently in speech compared to writing. To support the quality of temporal data (e.g. duration, frequency, time of day) in future hallucination research, it may be crucial to use prospective methods and to highlight the potential limitations of generating temporal data.

7.02.4 Where?

Delespaul et al. (2002) argued exploring where hallucinations happened was a key future research area. 93% (n=39) of diary entries reported where the hallucination happened. Most were experienced at home (64%,n=27). This could be due to: the circumstantial features of home spaces; that this may be where most time is spent (particularly to cope), or home was where hallucinations could be documented easiest. The outcome was similar to Stevenson et al. (2011) where bothersome OH typically occurred at home. Other common places included work (12%,n=5), being outdoors (12%,n=5) and being indoors but away from home (7%,n=3). Table 7.02 provides further detail on where hallucinations happened.

The varied places where hallucinations happened reflected the varied places where participants spent their daily lives. Although participants described places where hallucinations were more difficult (which chapter-8 further explores), there was a sense they could arise anywhere. One participant said their experiences tended to be worst and arise most at their city flat, and so “If I need a break from my area I go and sit at my sisters. It feels like it follows me there though. It’s everywhere I go”. This reflects a feeling of omnipresence and

an element of experiences generalising and sustaining beyond their initial circumstances which chapters 8 and 9 explore further.

Table 7.02
Further Details of Where Hallucinations Happened.

<u>Home Areas</u>	<u>H-N</u>	<u>Outdoors</u>	<u>H-N</u>	<u>Indoors (Away from Home)</u>	<u>H-N</u>
"Bed"	3	"Park"	1	"Parents House"	1
"Kitchen"	3	"Woods"	1	"Charity Shop"	1
"Living Room"	2	"City Centre"	1	"Yoga" Class	1
"Bathroom" or "Toilet"	2	Near Family's House	1		
"Upstairs"	1	"Walking"	1		
"In Garden"	1				

H-N: Number of diary documented hallucinations which occurred in each material location.

7.02.5 Who With?

Further to time of day and places, the company of hallucinations were a priority research area (Delespaul et al., 2002). 93% (n=39) of diary entries documented social company. Where reported, hallucinations were most often experienced whilst alone (67%,n=27); either throughout the hallucination (64%,n=26) or both alone and with a friend (3%,n=1). Participants were also quite likely to be with people in their social support-network (26%,n=10) including: colleagues (8%,n=3), their dog (5%,n=2), friends (3%,n=1) and immediate family members (10%,n=4). Two participants reported being with strangers during hallucinations, due to a home-delivery and being at an exercise class. Variation in social circumstances of hallucinations often reflected the social opportunities and connectedness of participants' daily lives. With over a quarter of documented hallucinations happening whilst with members of one's support-network, it may be beneficial to extend research, care and information to them. The novel outcomes generated here may warrant further study to understand what hallucinations are like for different people within a social situation, and what may help to support them. Chapter-8 explores support-networks further.

Akin to the high rate of hallucinations reportedly happening at home, the results of hallucinations mostly arising whilst alone could be due to numerous reasons such as:

- Being alone eliciting or sustaining hallucinations;
- Time often being spent alone, so increasing the likelihood of hallucinations arising then;
- Hallucinations were easiest to document alone.

Each of these could have contributed to the analytic outcome. Furthermore, the way participants felt in relation to other people may have impacted the result. For example, a participant reported being alone whilst in circumstances of a “busy” shop with “lots of people”. This points to the varied ways in which one may feel alone. Although participants reported hallucinations could potentially arise in any circumstances, one participant captured the common trend that “I don’t know why it happened, it’s just because I was home...by myself”. The social-material circumstances of diary-documented hallucinations were characterised by many features further to their timing, location and company. The analysis next explores the diary’s further section to generate written and visual data on the immediate circumstances of hallucinations.

7.02.6 What circumstances?

The situations hallucinations reportedly happened within were summarised into five data-streams including: social and leisure activities, material circumstances, difficult social-material circumstances, activities of daily living and managing hallucinations. These have been summarised in Table E.3 (Appendix E4) with examples from participant quotes. The most common circumstances of hallucinations included preparing to leave the house (n=4), sleep difficulties (n=4), walking (n=4), working (n=3) and talking back to hallucinations (n=3). These differing circumstances reflect the broader variety of situations in which hallucinations arose across the dataset. Consistent with the previous sections, the immediate circumstances of hallucinations were characterised by the relative spaces, places, activities and social relations which formed participants’ daily lives.

Looking across the sample, clusters of similar circumstances of hallucinations mirrored similarities among some participants' daily lives. For the working participants ($n=3$), the physical and social demands of work were circumstances of hallucinations, although the situations varied from "being on my feet" and interacting with "customers", to "trying to meet deadlines", or organising tasks of "deciding who does what". In this way, similarities in the circumstances of hallucinations varied further by the unique features of situations and participant's relational positions within them. In contrast to the participants who experienced hallucinations at work, or upon preparing to leave the house, for other participants ($n=2$), hallucinations arose in moments of social isolation of "being alone feeling low". This reflected struggles of their daily lives and previous analysis of documented hallucinations most often arising whilst alone.

Hallucinations seemed to arise within daily life as it flowed by, although they often caused disruptions and diversions. Hallucinations most notably disrupted the flow of activities whilst reading for people experiencing AVH who "couldn't read...because of the voices" ($n=2$). For many participants, hallucinations themselves and their management often formed the circumstances of further hallucinations. This reflects the remaining priority area of Delespaul (2002), of the coping strategies used for hallucinations in daily life. Within this study this included talking back to hallucinations aloud, shouting out to other people who were felt to be sources of stimuli at the time, self-soothing TH through touch, and managing one's home space through "covering covert cameras" and "checking all doors and windows". These examples point to the emergent processes of responding to hallucinations, which may impact upon one's immediate material and social circumstances (and one's feelings and so on). The activities reported to manage hallucinations in daily life were also more varied than those reported in existing research such as Nayani and David (1996). This may reflect the prospective and ABRM used in the current study; chapter-8 further explores activities of coping.

Overall, the further data on the circumstances of hallucinations further illustrated their variety and nuance. The broad data suggested in attempts to understand experiences of hallucinations and support people in managing them,

the unique activities, situations, relationships and burdens which characterise peoples' lives must also be attended to.

7.02.6.1 A Brief Note on Sleep.

As the temporal data indicated, participants' hallucinations often occurred around sleep. This aspect of the circumstances of hallucinations points both to the temporal circumstances in which hallucinations arise and the continuously changing states of bodies. This understanding is consistent with Langer's (1967) writings of the co-constitution of feelings in environments of bodily systems and one's broader world. Within this study, disconfirming case analysis highlighted in contrast to most hallucinations which happened whilst awake, one participant had a difficult experience upon waking. Alongside the expression in Figure 7.05, they described "I woke up with sleep paralysis and could see the same entity ["genie"] that has been haunting me for months". Hallucinations in waking states and around sleeping are often conceptualised as different phenomena; however, for this participant this was "a recurring hallucination but this is the first time this happened alongside sleep paralysis". Although some contemporary research has explored the experience of AVH in hypnagogic and hypnopompic states in participants described as healthy (McCarthy-Jones, Fernyhough & Larøi, 2010), and sleep problems among people experiencing hallucinations (Waite et al., 2016) further research may benefit from studying hallucinations experiences around sleeping and waking for people with waking hallucinations. This may help to further understand the interrelationships between the experience of hallucinations, sleep, fatigue and varied states of consciousness.



Figure 7.05 Visual diary illustration of a "haunting" "genie".

7.02.7 Immediate Circumstances of Hallucinations: Key Outcomes.

The data shed light on numerous research priority areas regarding hallucinations in daily life (Delespaul et al., 2002), and provides an empirical basis for future research. The analysis explored how long hallucinations lasted, the time of day they happened, where participants were, who they were with, and

further aspects of the circumstances which were salient to participants. The analysis generated many novel outcomes, some of which Table 7.03 summarises. Consistent with the conceptual approach to feeling proposed in earlier chapters, within the analysis hallucinations seemed to arise within immediate multifaceted and varied webs of temporal, social and material circumstances. The chapter continues by exploring the immediate feeling of hallucinations and before considering change in hallucinations over time.

Table 7.03

Summary of Key Analytic Outcomes Regarding the Immediate Circumstances of Diary Documented Hallucinations.

<u>Analytic Area</u>	<u>Analytic Outcome</u>
Temporal	Hallucinations lasted between 1 minute and 14 hours.
Temporal & Modal	Simultaneous MMH typically lasted substantially longer than unimodal hallucinations, with average respective durations of 3 hours and 29 minutes, compared to 10 minutes.
Temporal & Modal	Further analysis indicated that the more modalities involved in a hallucination, the longer they seemed to last up to a peak of 4 simultaneous modalities.
Temporal	Although hallucinations arose throughout the waking day, overall, they peaked soon after waking, declined before their greatest peak at 14:00 and declined until a peak before sleep.
Temporal & Modal	Further analysis suggested different time of day trends for hallucinations involving one modality compared to simultaneous MMH; although both had peaks after waking and before sleeping.
Temporal & Modal	Simultaneous MMH had an inverted u-shape time-trend curve, with an increase to a rounded peak (13:00-15:00) and decline thereafter. Whereas hallucinations of one modality were relatively stable over the day, with a sharp peak at 14:00 and a decline after 8.
Material	Hallucinations happened most often when at home, although they also happened at work, whilst outdoors and whilst indoors but away from home.
Social	Hallucinations most often happened whilst alone, although they also commonly happened whilst with members of one's support-network and on occasion whilst with strangers.
Social-Material	Participants described the circumstances of hallucinations happened in in terms of social and leisure activities, material

	circumstances, difficult social-material circumstances, activities of daily living and managing hallucinations.
Social-Material	The data varied greatly, although clusters of similar circumstances of hallucinations mirrored similarities among some participants daily lives. Still the particular features of these circumstances and participants' relational positions within them varied further.
Social-Material	Overall, hallucinations arose within a variety of immediate social and material situations, which reflected participants' unique broader lived circumstances.

7.03 The Immediate Feeling of Hallucinations

SR1's investigation of the feeling of hallucinations pointed to priority research areas including: hallucinations beyond the auditory modality, multimodal experiences, and the emotional and embodied dimensions of hallucinations. The study was designed to address each of these areas. The diary held four sections to generate nominal, visual, written and (at interview) audio data titled: 'what senses?', 'the sensory experience was', 'during this time I also felt' and 'during this time my body felt'. These are considered each in turn in the following sub-sections of this chapter. Data on the immediate feeling of hallucinations was analysed using Cromby's (2007) analytic feeling categories of emotional feelings, extra-emotional feelings, and feelings of knowing; as well as the fourth proposed novel category of feelings of reality.

7.03.1 What and How Many Senses?

All sensory modalities SR1 examined (AH, VH, TH and OH), were documented in the prospective dataset; of the three explored AH subtypes, non-verbal AH (NVAH) and AVH were reported in the diary, however MH were not. Further senses were reported in the diary by three participants, including: sexual hallucinations, gustatory hallucinations (GH) and disruptions to one's sense of time. The analysis of senses examined the extent of multimodality (the number of senses experienced) and what the senses involved were. Guided by the systematic reviews, the sensory analytic categories were NVAH, AVH, BH, VH, OH and GH. The sexual hallucinations have been included within BH and the disruption of time has been abbreviated as 'Te' for the analysis.

With regards to the senses within diary documented hallucinations, the outcomes varied from the systematic review literature focused towards unimodal and AVH experiences. In contrast as Table 7.04 illustrates, all analytic sense categories were predominantly involved in a range of MMH. AVH were the only unimodal experiences reported; this is consistent with existing research which suggested AH have a higher lifetime prevalence than other unimodal hallucinations (Lim et al., 2016). This contrasts with existing prospective research, where unimodal AH and VH were reportedly experienced at equal rates (Delespaul et al., 2002). Consistent still with Lim et al. (2016), was the overall greater rate of MMH experiences, with most AVH arising within MMH. Unimodal AVH were reported in the diaries of just two participants. These results were consistent with contemporary research on MMH's prominence, despite phenomenological literature's unimodal focus. These multimodal outcomes may reflect the propositions of researchers such as Uptegrove et al. (2016), of AVH's seemingly more than auditory qualities.

Table 7.04
Summarising the Modality Involvement in Unimodal and Multimodal Hallucinations.

<u>Modality</u>	<u>Uni-</u> <u>modal</u>	<u>Serial MMH</u>		<u>Simultaneous</u> <u>MMH</u>		<u>Total</u>
	<u>P-N</u>	<u>M-N</u>	<u>P-N</u>	<u>M-N</u>	<u>P-N</u>	<u>P-N</u>
Auditory (NVAH)	0	1	1	0	0	1
Auditory(AVH)	2	1	1	10	9	12
Bodily (BH)		2	2	8	7	9
Visual (VH)				7	4	4
Tactile (TH)				6	4	4
Gustatory (GH)				3	2	2
Olfactory (OH)				1	1	1
Temporal (Te)				1	1	1

P-N: Number of participants who experienced hallucinations in that modality.
M-N: Number of MMH modal combination types, the sensory modality was involved in.

The analysis explored the extent of multimodality in reported hallucinations. MMH involve two or more modalities and can either be simultaneous (multimodal at once) or serial (different modes at different times) (Lim et al., 2016). Figure 7.06 illustrates diary data multimodality. Notably, 83% of participants (n=10) reported MMH which included simultaneous and serial MMH. This chimes with Lowe's (1973) research which emphasised MMH as commonplace and characteristic experiences of participants described as paranoid or given schizophrenia diagnoses. In contrast to Figure 7.06 and Lowe (1973), contemporary research in SR1b reported lower MMH rates of 10-28% of participants (Jones & Luhrmann, 2016; Woods et al., 2015). Although higher rates of serial MMH ($\geq 70\%$ of participants), were reported in Gauntlett-Gilbert and Kuipers (2003). In Nayani and David's (1996) unimodal AH research, and although many participants ($\geq 51\%$) reported serial MMH, non-AH experiences were described as transitory and uncommon by the researchers; whereas they appeared very commonplace within the current analysis.

Proportion of Participants Reporting Unimodal or Multimodal Hallucinations

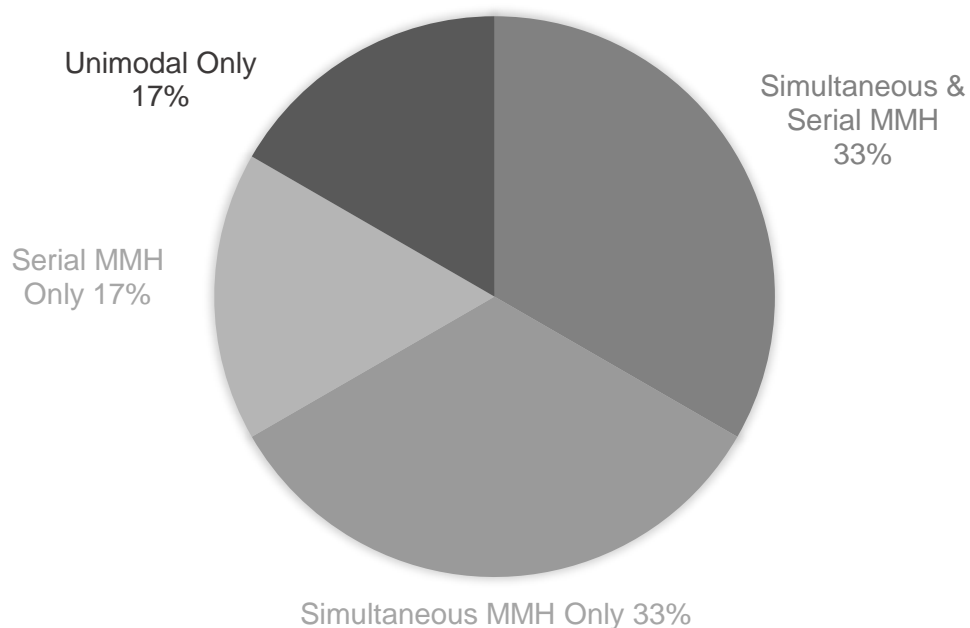


Figure 7.06 Summary of the Modal Types of Hallucinations.

Overall, although SR1 highlighted the potential for MMH, the analytic outcomes here suggest MMH may be much more common. This is consistent with Lim et al.'s (2016) reports among people given a schizophrenia diagnosis,

that lifetime prevalence of MMH was much more common than unimodal hallucinations. Based on the data, it is reasonable to propose hallucinations may often be characterised by multimodality. The remainder of this section explores what modalities were involved in the MMH.

7.03.1.1 Modalities of Multimodal Hallucinations.

Participants reported experiences of MMH in three ways: serial only, simultaneous only, or serial and simultaneous. AH and BH were the most commonly experienced modal form for each of these (with all but one AH being AVH). This contrasts with existing research which emphasised auditory and visual combinations (Gauntlett-Gilbert & Kuipers, 2003; Lim et al., 2016). However, this outcome may shed light on Woods et al.'s (2015) research, where 18-28% reported MMH experiences but a much higher 66% reported co-occurring bodily feelings whilst hearing voices. With feelings often being fleeting and passing by unnoticed (Cromby, 2015), perhaps the prospective diary methods of the current study and broader conceptualisation of hallucinations supported in generating data on AH+BH MMH. This may have clinical implications for the assessment of hallucinations. Continuing the AH+BH trend, for the 17% (n=2) who documented serial MMH only, their experiences solely involved BH and AH (AVH, n=1 and a NVAH "closed book noise", n=1). For participants reporting simultaneous MMH, and both serial and simultaneous MMH however, the modal picture was more varied; the modal combinations have been summarised in Appendix E5 (Figure E.2 and E.3).

Consistent with existing research, Table 7.05 illustrates MMH involving greater numbers of co-occurring modalities were experienced less often (Lim et al., 2016). It is interesting that the MMH which included Te was of AVH+BH+VH+Te, given that a relationship between notable changes in one's sense of time and MMH of AH+VH had been reported by Lowe (1973). This perhaps points to an interesting interrelationship between multimodal experiences and time which may warrant further study. Within the current simultaneous MMH dataset, AVH was the modality most often involved. This reflects Lim et al.'s (2016) propositions that AH may form a perceptual hub, from which hallucinations involving additive senses arise. This contrasts with existing

prospective research however where unimodal AH and VH reported at equal frequency. Interestingly, Table 7.05's bottom two modal combinations may provide dis-confirming evidence to propositions of AH's centrality. Furthermore, BH and VH were present in many modal combinations and only slightly less common than AVH; further still, the greater frequency does not necessarily equate to greater subjective dominance of this sense.

Table 7.05

Modality Combinations of Simultaneous MMH: Horizontally and Vertically Ordered by Frequency of Modality Involvement.

Participant N	Modalities	
5	AVH	↔ BH
1	AVH	↔ BH ↔ VH
1	AVH	↔ BH ↔ VH ↔ Te
1	AVH	↔ BH ↔ VH ↔ TH
1	AVH	↔ BH ↔ VH ↔ TH ↔ GH
1	AVH	↔ BH ↔ TH
1	AVH	↔ BH ↔ GH
1	AVH	↔ VH
1	AVH	↔ VH ↔ TH
1	BH	↔ VH
1	TH	↔ GH ↔ OH

To summarise the sensory data analysis:

- Participants' reported hallucinations as arising in many varied modalities, their report-rate (highest-lowest) was: AH, BH, VH, TH, GH, OH and Te.
- Participants' experiences typically involved multiple modalities either simultaneously or at separate time points.

Future research may benefit from further prospectively studying the modal combinations of hallucinations and the subjective experience of how these modalities interrelate to form a hallucination. This analysis section closes by exploring the content and congruency of MMH in the prospective data analysis.

7.03.1.1.1 Content of Multimodal Hallucinations.

Although hallucination content was not a focus of this research, it seems noteworthy that MMH content was typical akin to unimodal hallucination content when considering the same modalities (summarised in SR1). Multimodality did however (particularly when simultaneous), present these familiar features in increasing complexity; with participants having to process, navigate and manage

the experiences and demands of each modality (often at once). Perhaps these similarities reflect potential under-documentation of MMH in prior research, or shared phenomenology between unimodal and MMH. The phenomenology of MMH warrants further study. The following section explores the feeling of hallucinations in further depth, after considering multimodality and congruency.

7.03.1.1.2 Is Felt Multimodality a Function of Congruency?

All participants reported bodily sensations as co-occurring with hallucinations. Interestingly, 75% of participants (n=9) documented hallucinations involving BH. Perhaps the extent to which unusual sensory experiences are reported as multimodal, may reflect the extent to which co-occurring feelings were experienced as an entwined whole experience. Notably, all the diary documented simultaneous MMH were congruent; defined by Lim et al. (2016, p.498) as MMH which add “up to a coherent whole”. No incongruent MMH were reported. Perhaps among participants reporting unimodal or serial MMH, their co-occurring bodily sensations could be conceptualised as part of an overall incongruent simultaneous MMH. With all participants reporting bodily sensations co-occurring with hallucinations, it may be interesting for research to compare the experiences and needs between those who report bodily sensations as co-occurring yet separate from hallucinations, and those which form part of the hallucination.

7.03.2 What Feelings?

Having examined the circumstances and senses of hallucinations, this analysis sub-section explores feelings during hallucinations. Thereafter the chapter explores feelings described in relation to the body, and lastly change in hallucinations over time. Cromby's (2007, 2015) analytic feeling categories (discussed in Chapter-4) were used to guide the analysis, which explored visual, written and audio data generated from the “During this time I also felt” diary section. Consistent with arguments in Chapters 1-4, participants reported a variety of feelings during hallucinations. These feelings spanned each of the analytic categories including Cromby's (2007, 2015) emotional feelings, extra-emotional feelings and feelings of knowing, as well as the novel proposed category of feelings of reality. Data from the aforementioned diary section were

screened for single word, or two word feeling terms; 106 terms were generated as listed in Appendix E6. This data formed the Figure 7.07 word-cloud for an overall picture of how hallucinations feel (the size of the words corresponds to their frequency).



Figure 7.07 Diary data on the feeling of hallucinations.

With each of these feeling terms being quoted from participants, Figure 7.07 provides a picture of the immediate and difficult feelings which characterised hallucinations. This dataset goes far beyond the feelings studied in the systematically reviewed research. Examples of feelings include: “anxiety” and “frustration” (emotional feelings), “tiredness” (extra-emotional feeling), “overthinking” and feeling “alert” (feeling of knowing), and “confusion” and “paranoia” (feeling of reality). The data points to the kinds of feelings people may be navigating whilst experiencing hallucinations; this may be valuable given the

prospective data's quality and the broader range of feelings documented. Recognition of such feelings may offer support in providing relevant and improved information for both those experiencing hallucinations themselves, and people within their support-networks (professional and personal).

This section further explores the data in relation to the analytic feeling categories in order of: emotional, knowing, reality and extra-emotional. Consistent with Cromby's (2007, 2015) writings, the kinds of feelings the analytic categories referred to overlapped. The following subsections consider clusters of similar feelings and the modalities of hallucinations they arose within; for feelings of reality, it also explores how this analytic category related to Cromby's (2007) existing three.

7.03.2.1 Emotional Feelings.

Emotional feelings were used to describe hallucinations by 92% (n=11) of participants. 41 terms were collectively used 111 times to describe the feeling of diary-documented hallucinations. The prominence of emotional feelings is consistent with systematic review 1's outcome, which proposed hallucinations were (in part) emotional experiences. Table 7.06 presents data on the immediate emotional feeling of hallucinations; including their frequency and co-occurring hallucination modalities. Emotional feelings were experienced during a range of hallucinations; these involved between one and five modalities (simultaneously), in a variety of combinations of AVH, BH, VH, TH, GH, OH and Te. This data builds upon SR1, by illustrating the varied emotional feelings experienced during MMH.

By order of frequency, the clusters of emotional feelings could be described as: fear and anxiety; despair and powerlessness; abused and threatened; frustration and anger; loneliness; stress and distress; worry; and positive feelings. As the clusters of Table 7.06 demonstrate, the immediate emotional feeling of hallucinations was predominantly negative; just four positive feeling terms were reported, and these were all reported by one participant. The prominence of negative emotional feelings during hallucinations, was consistent with the existing literature on AVH, VH and OH (Gauntlett-Gilbert & Kuipers, 2003; Stevenson et al., 2011; Suryani et al., 2013; Woods et al., 2015).

Table 7.06

Summary of the Frequency of Clusters of Emotional Feelings and the Modal types of Hallucinations they were Experienced within; Clusters Vertically ordered by Participant Numbers.

<u>Clusters of Feelings</u>	<u>H-N</u>	<u>P-N</u>	<u>F-N</u>	<u>Hallucination Types</u>
Anxious, On-Edge, Scared, Frightened Nervous, Apprehensive	35	9	6	AVH + BH + TH AVH + BH + VH OH + GH + TH AVH + BH VH AVH
Powerless, Desperation, Despair, Turmoil, Trapped, Stuck, Worse, Wrong, Sad, Upset	11	6	8	AVH + BH + VH + TH + GH AVH + BH + VH + TH AVH + BH + VH + Te AVH + VH + BH VH + BH AVH
Abused, Attacked, Harm, Invaded, Touched, Manipulated, Uncomfortable, Vulnerable, Unpleasant, Threatened	11	5	10	AVH + BH + VH + TH + GH AVH + BH + VH + TH AVH + BH + TH AVH + VH + BH AVH
Frustrated, Irritated, Anger, Agitated, Annoyance, Wound-up	22	4	6	AVH + BH + VH + TH + GH AVH + BH + VH + TH AVH + BH AVH
Alone, Lonely	7	4	2	AVH + BH + VH + TH + GH AVH + BH + VH + TH AVH + BH + VH AVH + BH + TH AVH
Distressed, Stressed	7	3	2	AVH + BH + VH + Te AVH + VH + BH AVH + BH VH + BH AVH
Worried, Concerned, Pensive	10	3	3	AVH + BH + VH + Te AVH + VH + BH OH + GH + TH AVH + BH VH + BH
Happy, Excited, Funny, Smiling	8	1	4	AVH + BH AVH

Total	111	11/ 12	41
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H-N: Number of times a feeling within a cluster was used to describe a hallucination.
P-N: Indicates the number of participants who diary documented a feeling.
F-N: Indicates the number of feeling terms.

Within the aforementioned existing literature, examples of reported emotional feelings included those related to: fear, misery, depression, helplessness, intrusion and anger. Similarities can be seen within the current dataset. In Woods et al. (2015), their clinical group were more likely to describe fear, depression and anxiety in association with voice-hearing. This outcome was consistent with the commonplace experience of similar emotional-feelings within the current study's clinical sample. These outcomes regarding emotional feelings, seem interesting as existing research studied the experiences of unimodal hallucinations, whereas the majority of the hallucinations reported here were simultaneous MMH. This suggests although the form of hallucinations may vary greatly, service-users experiencing hallucinations may find common experiences in their emotional feelings.

Although the research outcomes regarding negative emotional-feelings were fairly consistent with the existing literature, the outcomes relating to neutral and positive emotions differed. In Woods et al. (2015), 32% of their mixed (clinical and non-clinical) online voice-hearing sample, reported neutral emotional feelings in association with hallucinations; in contrast, none of the participants of the current study described the experience as neutral. The current outcome regarding the rate of positive emotions (n=1 participant), also contrasts with existing VH and AVH research, in which positive emotions were reported by 31% of Woods et al.'s (2015) voice-hearing sample, and 45% of Gauntlett-Gilbert and Kuipers (2003) clinical VH sample. Interestingly, both aforementioned studies generated data retrospectively.

In the current study, when participants described their experiences in general (during retrospective data generation), some participants reported a relatively balanced picture: "there's two ends of the scale", of "how horrific they can be...how fantastic they can be". In contrast, within the prospective dataset

and when specific examples of hallucinations were reported retrospectively, the emotional feelings reported were rarely positive and never neutral. The contrast in outcomes regarding neutral and positive emotional feelings perhaps points to ways different research designs may generate different kinds of data (and thereby reach different outcomes). To generate valid outcomes, perhaps future phenomenological research should consider prospective diary research designs. Furthermore, clinical practice and assessment typically relies upon clinical interviews and retrospective self-reports to understand service-users experiences. Given the outcomes of the current study, clinicians may benefit from providing service-users with diaries to support in assessing their experiences and providing appropriate interventions of care.

Overall, the dataset suggested emotional feelings were a prominent, varied, though mostly negative feature of hallucinations. The analysis suggested similarities in difficult emotional feelings may be shared among people experiencing hallucinations of different modal kinds. Future study may benefit from looking towards strategies and developing interventions which support in easing and managing the difficult emotional feelings of hallucinations.

7.03.2.2 Feelings of Knowing.

Cromby (2007, 2015) proposed as feelings of knowing arise within the flow of interactions, they may be difficult to study due to more subtle felt textures and fleeting temporal attributes. Nonetheless, as Table 7.07 illustrates, 11 feeling of knowing terms were reported and collectively used 20 times to describe hallucinations by 6 participants. Feelings of knowing were reported during hallucinations involving one to four simultaneous modalities; hallucinations included a variety of modal combinations of AVH, BH, VH, TH and GH. In contrast to emotional feelings, feelings of knowing were not reported during diary-documented hallucinations involving NVAH, OH or Te. This may be due to the features of these feelings (e.g. fleeting, difficult to describe) or due to the smaller number of available diary entries for involving these modalities.

Consistent with existing research, the content of hallucinations were often characterised by repetitiveness. For some participants this generated feelings of disinterest and boredom. This chimes with McCarthy-Jones et al.'s (2014, p. 231)

AH research were participants “heard the same voice, most or all of the time, saying the same things”, with themes being continued by new voices. Although this cluster of feelings was reported by two participants within the diary, within the full dataset, all participants (n=16) reported recurrent and repetitive hallucinations. Still, the prospective dataset provided further evidence to support existing research, whilst demonstrating similar feelings can be generated by both AVH and simultaneous MMH. Furthermore, with these kinds of feelings having been neglected with regards to the phenomenology of hallucinations as explored in SR1; this data sheds new light on the immediate experience of hallucinations feels like.

Table 7.07

Summary of the Frequency of Clusters of Feelings of Knowing and the Modal Types of Hallucinations they were Experienced within.

<u>Clusters of Feelings</u>	<u>H-N</u>	<u>P-N</u>	<u>N-F</u>	<u>Hallucination Types</u>
Uninterested, Bored, Repetitive, Nagging	7	2	4	AVH + VH + BH +TH AVH
Pressure, Overthinking, Busy, Rushing, Organised	7	3	4	AVH+BH AVH VH
Alert, Concentration	6	3	3	AVH + GH + BH AVH + BH AVH
Total	20	6	11	
H-N: Number of times a feeling within a cluster was used to describe a hallucination.				
P-N: Number of participants who diary documented a feeling.				
F-N: Number of feeling terms per cluster.				

7.03.2.3 Feelings of Reality.

This analytic category was proposed in Chapter-4, as an extension of Cromby’s (2007, 2015) work. This development aimed to support the study of altered states of consciousness (such as hallucinations) and attune to feelings which in some way disrupted or qualitatively altered the texture of reality; such that it was different to the consensual reality held by those around us, or by ourselves during the usual flow of events. The analytic category of feelings of

reality held 31 feeling terms (listed in Table 7.08), which were collectively used 49 times to describe hallucinations by 92% (n=11) of diary-completing participants. Some feelings of reality regarded the watchful entity qualities of hallucinations and their malevolent atmosphere; some were feelings of disorientation and disconnection, others were the confusing and occupying pull of hallucinations, and the paranoia and overwhelming feelings of experiencing and making sense of it all.

Table 7.08

Summary of the Frequency of Clusters of Feelings of Reality and the Modal Types of Hallucinations they were Experienced within.

<u>Clusters of Feelings</u>	<u>H- N</u>	<u>P- N</u>	<u>F- N</u>	<u>Hallucination Types</u>	<u>Closest Related Analytic Category</u>
Nasty, Evil, Haunted, Curse, Derogatory	5	5	5	AVH + VH + GH + BH + TH AVH + BH VH + BH AVH	Emotional Feelings
Disoriented, Dizzy, Dreamlike, Floaty, Spacey, Zoned- out,	6	4	6	AVH + VH + BH + TH AVH + BH AVH BH	Extra- Emotional Feelings
Confused, Uncertainty, Unsure	12	4	3	AVH + VH + BH + TH AVH + GH + BH AVH + BH + TH AVH + BH	Feelings of Knowing
Watched, Under- Assessment, Judged, Monitored, Talked-About	8	3	5	AVH + VH + BH AVH + BH AVH	Feelings of Knowing
Distracted, Occupied	4	3	2	OH + GH + TH AVH + BH AVH	Feelings of Knowing
Real, Lost-Time, Confirmed	3	3	3	AVH + VH + BH + Te AVH + BH	Feelings of Knowing + Extra- Emotional Feelings

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Curious, Questioning, Critical	3	3	3	AVH + GH + BH AVH + BH NVAH	Feelings of Knowing
Overwhelmed, Intense	3	3	2	AVH + VH + BH +TH AVH + BH + VH + Te AVH + BH AVH	Emotional Feelings
Paranoia	4	2	1	AVH + BH + TH AVH + BH AVH	Emotional Feelings
Free	1	1	1	AVH + BH	Emotional Feelings
Total	49	11/ 12	31		

H-N: Number of times a feeling within a cluster was used to describe a hallucination.

P-N: Number of participants who diary documented a feeling.

F-N: Number of feeling terms per cluster.

Feelings of reality were reported during hallucinations involving between one and five simultaneous modalities, with a variety of modal combinations of AVH, BH, VH, TH, GH, OH, Te and NVAH. As such, these feelings were experienced in hallucinations involving each of the modalities documented within the study. As hallucinations are defined by their difference to consensual reality, it makes intuitive sense that feelings of reality would be reported across sensory modalities by the vast majority of participants. Some of the feelings of reality reported were consistent with the reported experiences in SR1. Participants in existing literature reported feelings such as confusion, uncertainty and being unsure in AH (Suryani et al., 2013), the evil sources of AH (Nayani & David, 1996) the vivid and intense experience of OH (Stevenson et al., 2011), the overwhelming experience of VH (Gauntlett-Gilbert & Kuipers, 2003) and “dreamlike” feeling of hearing voices (Woods et al., 2015, p. 327). The data presented within this section provides further evidence of the relevance of these feelings and the theoretical analytic category for studying hallucinations.

Chapter-4 proposed consistent with Cromby’s (2015, 2007) theory, feelings of reality would overlap with the existing categories. To present where

the conceptual boundaries of these categories may meet, an extra column was included in Table 7.08 titled “Closest Related Analytic Category”. Of the feelings clustered within this table, two clusters were proposed as close to extra-emotional feelings, four to emotional feelings and five to feelings of knowing. This provides a sense feelings of reality may be most closely analytically related to feelings of knowing and emotional feelings.

Before exploring the extra-emotional feeling data, the outcomes of the application of this novel category are summarised. The category was useful in attuning to feelings which characterised hallucinations as salient or distinct from the sense-experience of consensual reality. A broad variety of feelings of reality were reported by the vast majority of participants who completed the visual diary, and they were reported during hallucinations involving each modality documented in the study. The novel analytic category supported in studying the feeling of both unimodal and MMH. The feelings in Table 7.08 may provide insight into what experiencing hallucinations may feel like. The outcomes provide empirical evidence for the novel analytic feeling category which may benefit future research in studying the experiences of altered states of consciousness (including hallucinations).

7.03.2.4 Extra-Emotional Feelings.

Within the “During this time I also felt” section of the diary, 5 feeling terms were reported collectively on 15 occasions by 5 participants. As Table 7.09 summarises, these feelings were related to tiredness and heaviness; such feelings arose during hallucinations involving one to three simultaneous modalities, involving various combinations of the following modalities: AVH, BH and VH. Feelings such as those in Table 7.09 appear novel in relation to the existing literature. Research in SR1 such as Woods et al. (2015) indicated bodily feelings co-occurred with hallucinations for 66% of participants, and seemed relevant to their overall experience. An outcome of SR1, was for future research to study such bodily feelings in depth and this study was designed to do so. Most feelings which may be analysed as extra-emotional were documented within further diary sections of “During this time my body felt” and the micro body-map.

The chapter therefore continues by examining this data, wherein such feelings were reported either as localised to body parts or generalised across the body.

Table 7.09

Summary of the Frequency of Clusters of Extra-emotional Feelings and the Modal Types of Hallucinations they were Experienced within.

<u>Feelings</u>	<u>H- N</u>	<u>P-N</u>	<u>N-F</u>	<u>Hallucination Types</u>
Tired, Fed-Up, Weak, Deflated, Heavy,	15	5	5	AVH + BH + VH AVH + BH AVH + VH BH AVH

H-N: Number of times a feeling within a cluster was used to describe a hallucination.
P-N: Number of participants who diary documented a feeling.
F-N: Number of feeling terms.

7.03.3 Feeling Bodies.

Titled after Cromby's (2015) work on feelings, this substantial part of the analysis explores data generated from the "during this time my body felt" section of the visual diary and micro body-maps. As SR1 explored, recent research indicated bodily feelings were experienced during AVH in both clinical and non-clinical samples (Upthegrove et al., 2016; Woods et al., 2015). As SR1 concluded, limited data existed on feelings co-occurring with hallucinations. In the current study, novel use of body-mapping generated prospective data of bodily feelings during hallucinations. To support in analysing this data, two further analytic categories were used: localised feelings (when feelings were reported in terms of a specific body area) and generalised feelings (reported in terms of the body in general). For ease of understanding, the data within this section is primarily explored using these terms.

7.03.3.1 Feeling of Body Parts During Hallucinations.

This analysis section holds a series of digital body-maps of body areas. These digital illustrations by the researcher collated body-map data across the sample and across hallucination types. The body-maps illustrate: what feelings were experienced during hallucinations, where in the body the feeling was

localised and, during what kind of hallucination they happened. The following pages share the first series of digital body-maps. The figures shared on the following pages, illustrate the collation of all the body-map data, to share what feelings were reportedly experienced in particular body areas. The body-maps illustrate feelings localised to the:

- Head (Figure 7.08),
- Neck, shoulders, back and arms (Figure 7.09),
- Chest and abdomen (Figure 7.10), and
- Pelvis, legs and feet (Figure 7.11).

The black writing in the figures is of participant quotes of feelings (from the diary or post-diary interview); the grey writing is the sensory kind of hallucination (from the “What Senses?” diary section). To support in the analysis specificity, the body-map data was illustrated separately for participants who respectively identified as either male or female. After presenting the first series of body-maps, they are examined.

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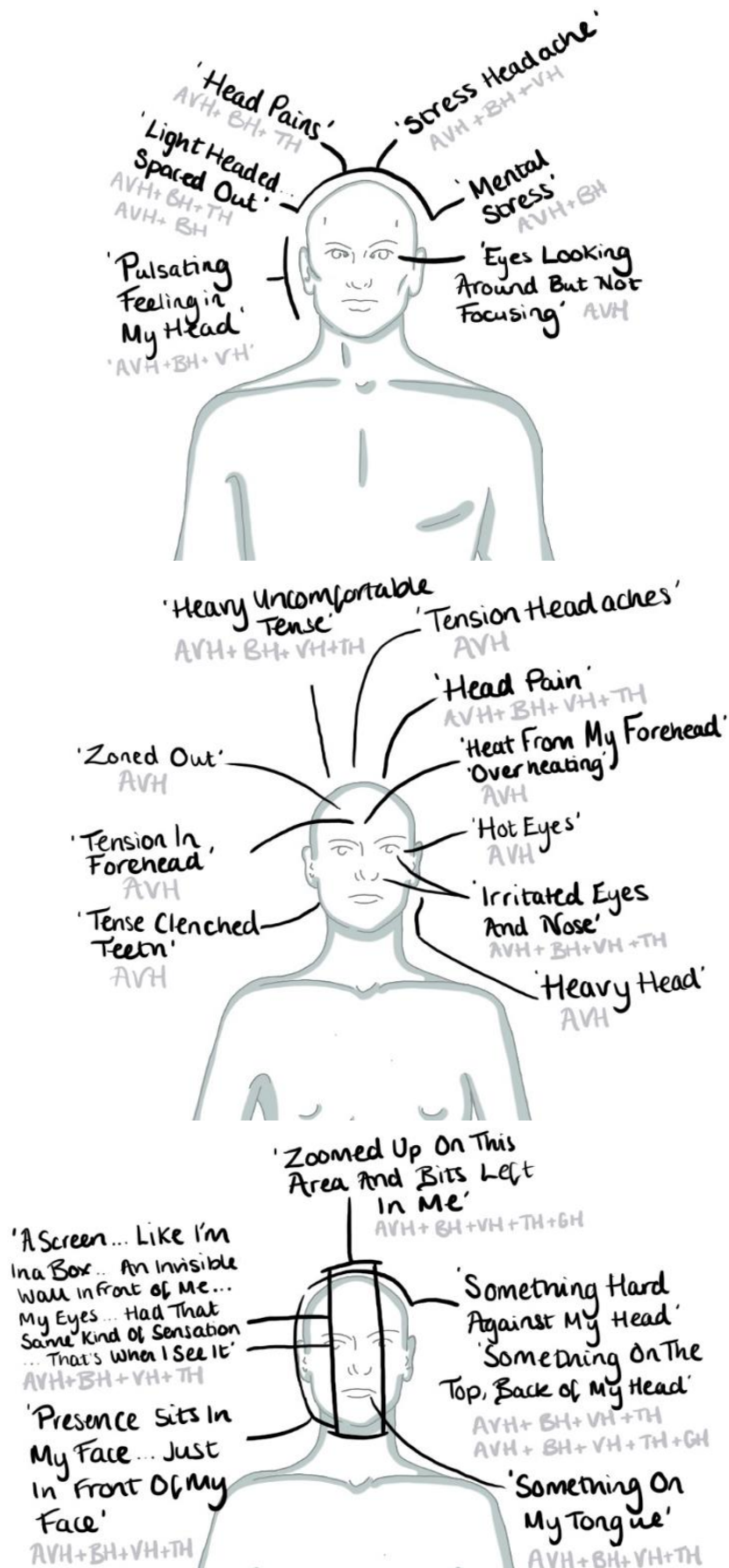


Figure 7.08 Illustrations of collated body-map data localised to the head.

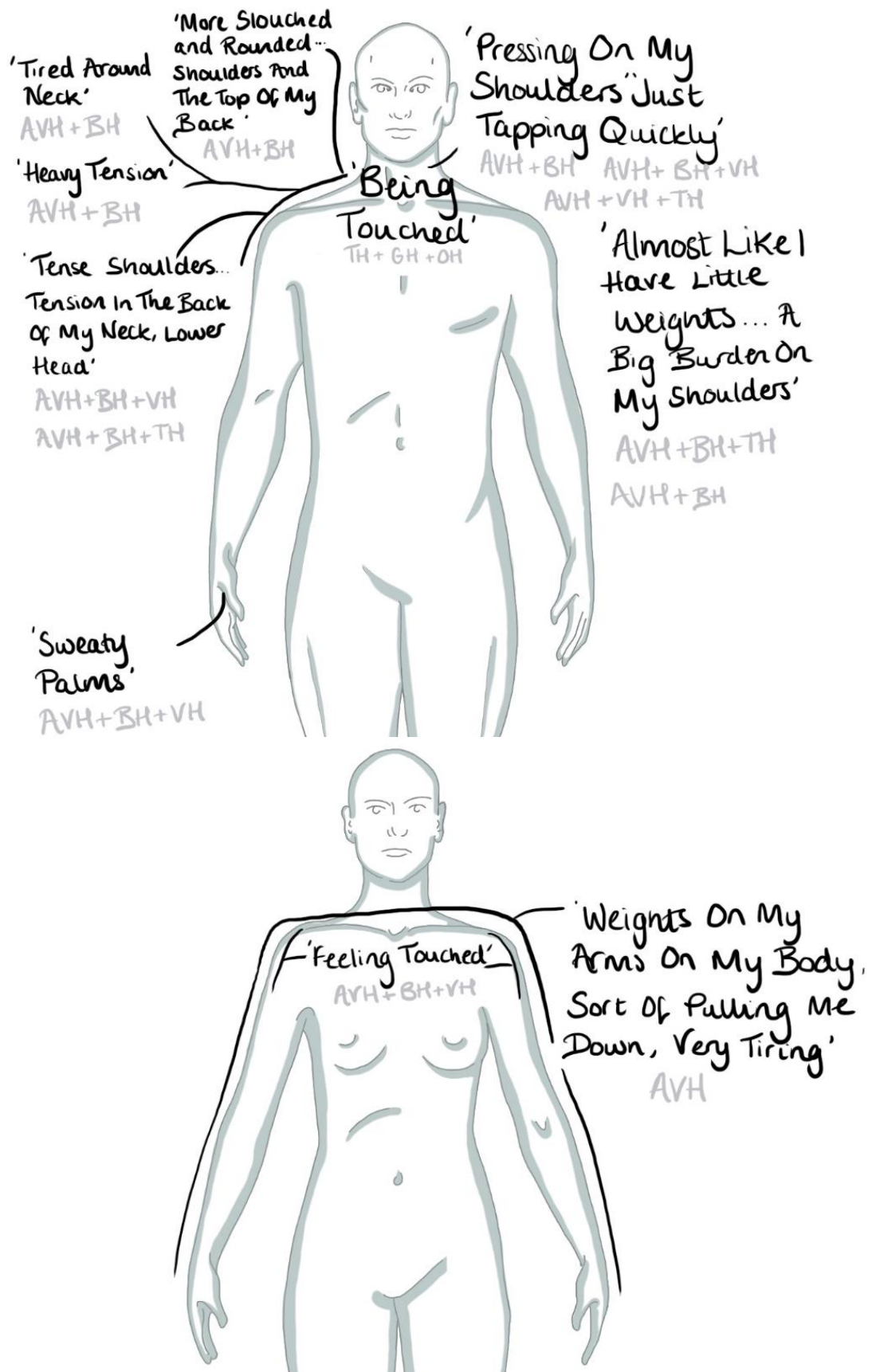


Figure 7.09 Illustrations of collated body-map data localised to the neck, shoulders and arms.

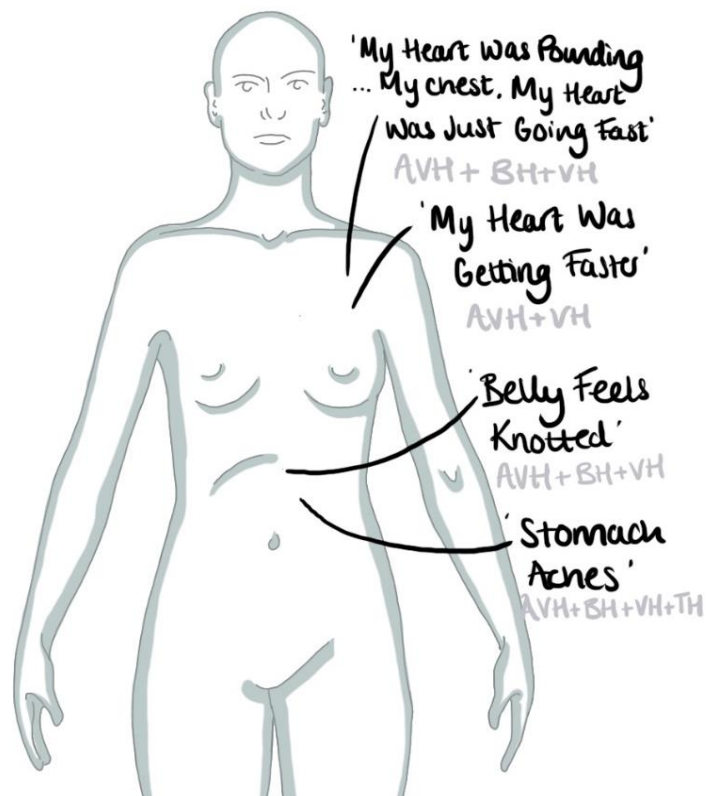
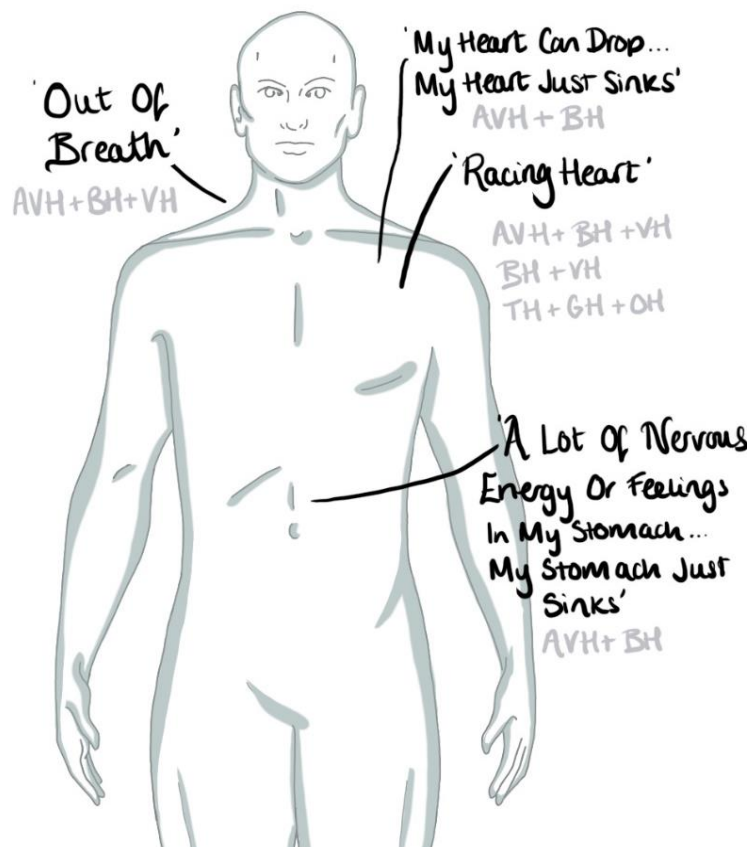


Figure 7.10 Illustrations of collated body-map data localised to the chest and abdomen.

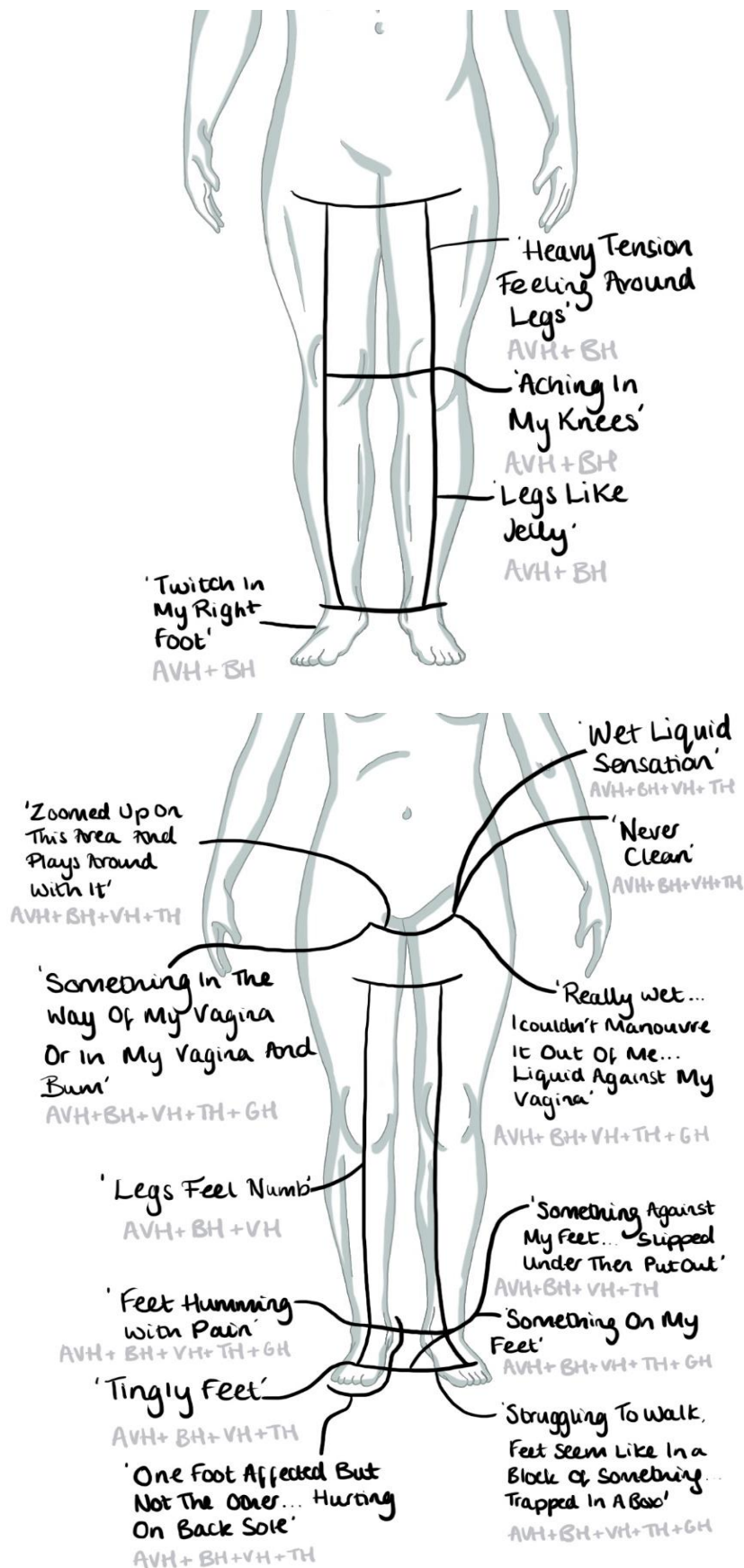


Figure 7.11 Illustrations of collated body-map data localised to the pelvis, legs and feet.

The head and shoulders seemed to be the areas where feelings were localised most for participants and across hallucination types. The chest, abdomen, legs and feet were also areas where feelings seemed concentrated. No male participants documented feelings within their genitals or pelvis; in contrast, for one female participant, many feelings were localised to these areas (this is further examined later). The hands and back were not frequent documented sources of localised bodily feelings. Please note, although the digitally regenerated body-maps are face-forward (which could discourage the documentation of feelings on one's back), as Figure 7.12 displays, the analogue diary body-map could be interpreted as a body front or back. Despite this, the vast majority of participants seemed to use the body-map as front-facing; future prospective research using body-maps may benefit from holding two body-maps (titled 'front' and 'back').

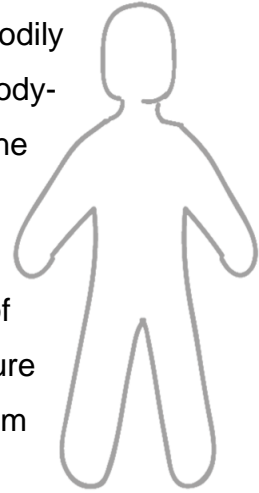


Figure 7.12 Body-map figure from visual diary.

The body-map data, suggested many specific bodily feelings in different body areas can be experienced during hallucinations. Some of the feelings documented chime with existing research. Similar to Upthegrove et al., (2016) AVH research, participants in the current study reported experiences of: "pains", "pressing on my shoulders", "tension in the back of my neck, lower head" and "being touched" on the shoulders. As the figures illustrate, each of these experiences were reported within simultaneous MMH, whereas they were reported within AVH by Upthegrove et al. (2016). This raises interesting considerations of how both researchers and participants may understand the modal form of hallucinations; and also of the similar feelings that may arise across different kinds of hallucinations.

Woods et al.'s (2015) hearing voices research also shared some of the bodily feelings reported by 66% of their participants. Interestingly, one of their participants described a "heat and a strong irritation in the right frontal part of my brain"; one of the two unimodal AVH participants of the current study similarly reported experiencing "heat from my forehead" as a distinct recurrent feature of her AVH experiences. Further experiences documented in existing research and

also by participants of this study included “tingly feet” and one’s “belly” feeling “knotted” (Nayani & David, 1996; Woods et al., 2015). Unlike the unimodal AVH and AH of the aforementioned research, within this study these feelings were respectively felt within simultaneous MMH of AVH+BH+VH+TH and AVH+BH+VH.

Some feelings documented in SR1, were not described within the prospective dataset, this included: nausea, itching, feeling on fire and shock-like sensations in one’s chest (Upthegrove., 2016; Woods et al., 2015). One participant did describe BH of itching in the retrospective dataset. The similarities and differences compared with existing literature points to the anticipated variety in experiences which would emerge from unique, emergent process-relations of bodies situated in circumstances (as discussed in the theoretical chapters). The modalities of the hallucinations indicated types of hallucinations, did not necessarily generate particular kinds of feelings; instead many varieties of localised bodily feelings may arise. The analytic outcomes suggest a complex interrelationship between the sensory and localised bodily feelings of hallucinations.

In summary, consolidating the relevance of bodily-feelings to AVH in existing research, all documented hallucinations co-occurred with localised bodily feelings; often of many varieties. The examples of feelings during hallucinations demonstrated in the body-maps, go far beyond those documented in existing research. The novelty of the dataset is due to documented feelings’ variety in form, location and their occurrence during many kinds of unimodal and MMH. To shed further light on the similarities and differences which may characterise hallucinations of various kinds, future research should study feelings during different modal types of hallucinations.

7.03.3.2 Feeling of the Whole-Body During Hallucinations.

The previous analyses explored what feelings were reported within specific body areas during hallucinations; to do so, the linguistic and visual data were drawn upon. This analysis section further examines the visual body-map dataset and presents visual data of where feelings were felt (in full bodies) during specific modal kinds of hallucinations. This following section therefore separately

shares body-maps of each documented hallucination type in Figures 7.13-7.18. To support data presentation, where possible body-maps were digitally collated; each figure title provides digital collation details. The body-maps are presented in order of one to five simultaneous modalities. After which they are examined and bodily feelings are discussed in relation to multimodality and BH.

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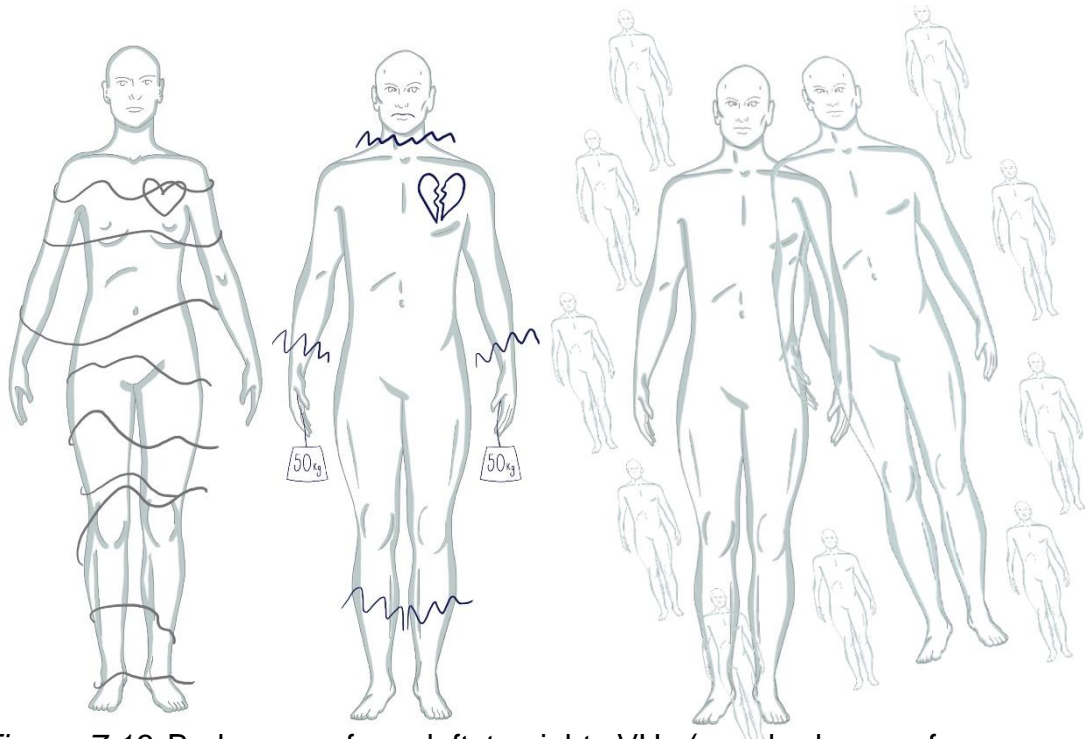


Figure 7.13 Body-maps from left to right: VH, (one body-map from one participant), BH (collation of two body-maps from one participant), AVH (one body-map from one participant).

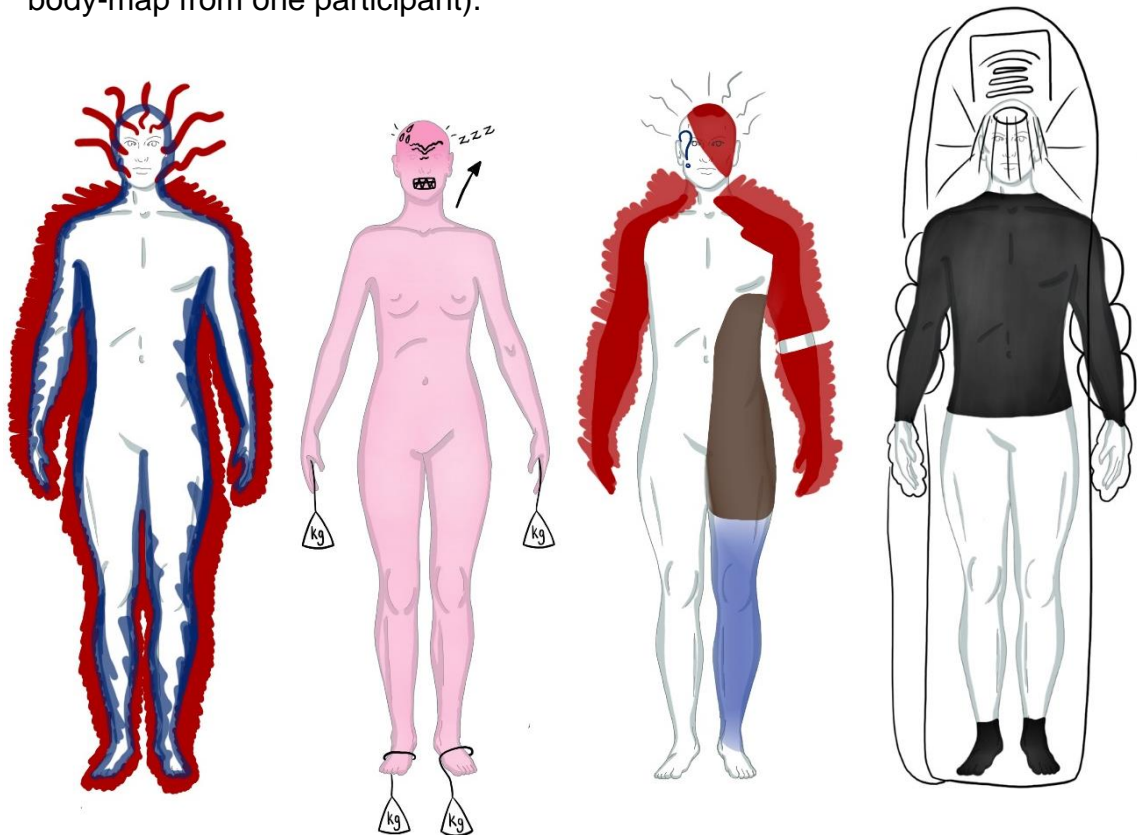


Figure 7.14 Body-maps from left to right: AVH (collation of two participant's body-maps), AVH (collation of seven body-maps, six from one participant, one from another), AVH (collation of two body-maps from one participant) and AVH (collation of seven body-maps, six from one participant, one from another).

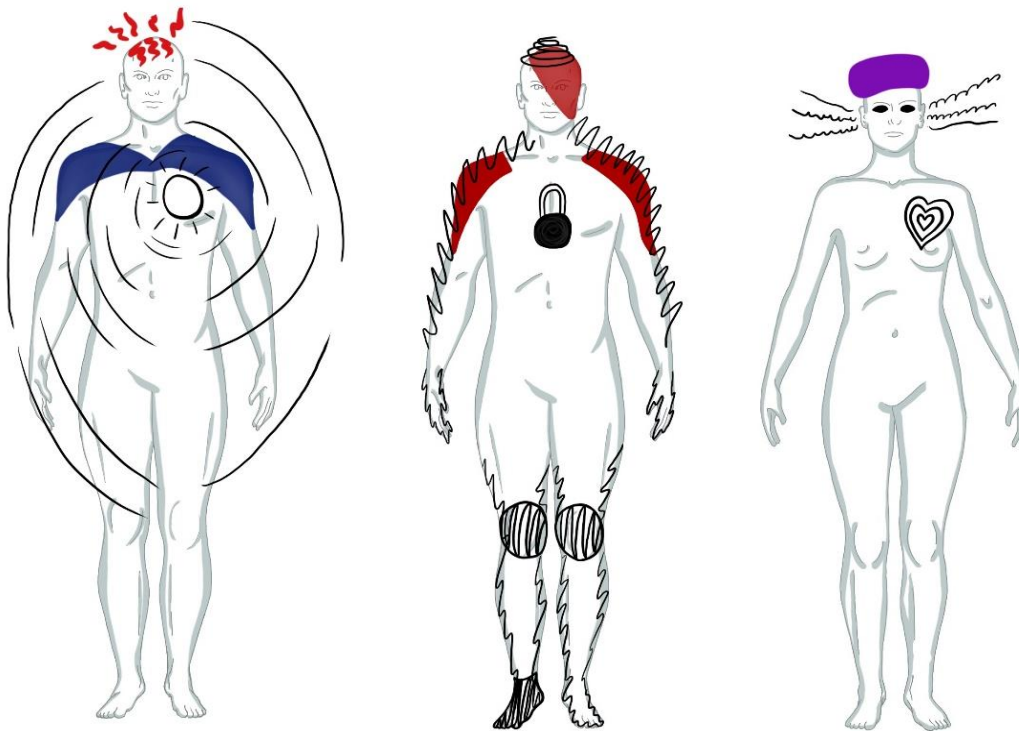


Figure 7.15 Simultaneous MMH with two modalities body-maps from left to right: AVH + BH (collation of two participant's body-maps), AVH + BH (collation of two participant's body-maps), AVH + VH (one participant's body-map).

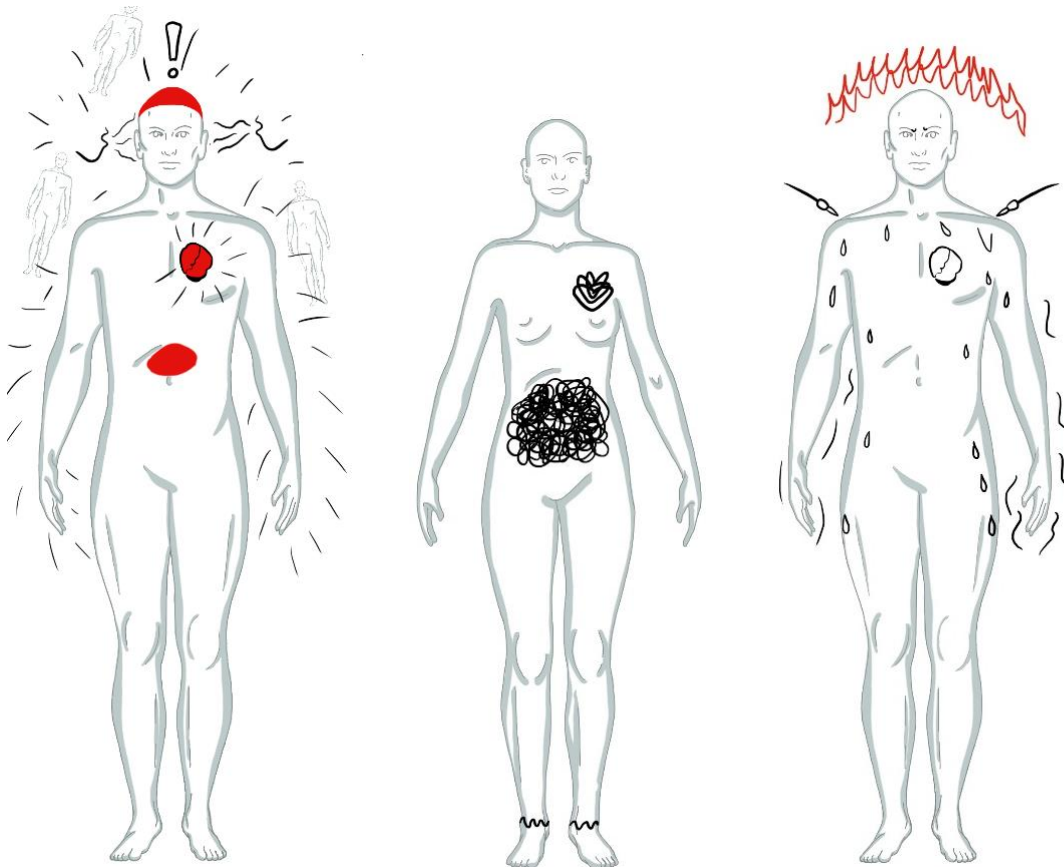


Figure 7.16 Simultaneous MMH with three modalities body-maps from left to right: AVH + BH + VH (collation of two participant's body-maps), AVH + VH + TH (one participant's body-map), TH + GH + OH (one participant's body-map).

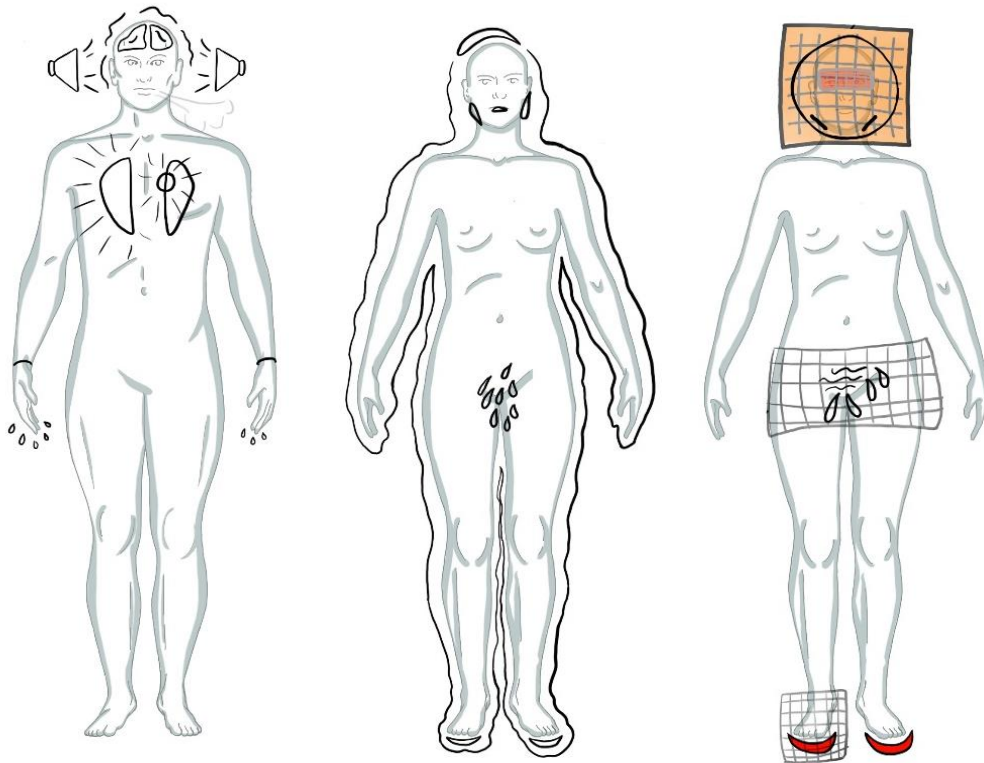


Figure 7.17 Simultaneous MMH with four modalities body-maps from left to right: AVH + BH + VH + Te (one participant's body-map), AVH + BH + VH + TH (one participant's body-map), AVH + BH + VH + TH (collation of one participant's three body-maps).

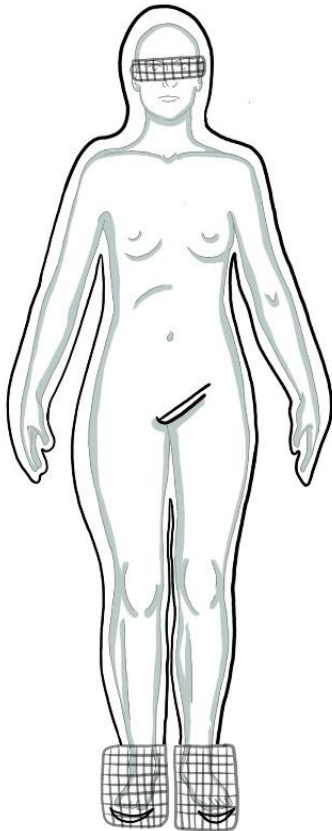


Figure 7.18 Simultaneous MMH with five modalities body-maps AVH + BH + VH + TH + GH (one participant's body-map).

The body-maps illustrate feelings may be experienced across many different body areas during a single instance or type of hallucination. Some feelings may be localised to particular areas (as reported in the previous section), whilst other feelings may be generalised across the body. Co-occurring feelings experienced within identifiable parts of the body, seemed to be characteristic of diary-documented hallucination experiences. The body-maps provided a novel and successful way of studying and communicating what experiences of hallucinations feel like.

The body-maps presented here and earlier in the chapter illustrated akin to simultaneous MMH, hallucinations identified by participants as involving one modality (e.g. AVH), were characterised by co-occurring feelings (often localised to body areas). The content of these feelings and their locations were comparable and often indistinguishable from those identified as BH (for example within simultaneous or serial MMH). This is consistent with the similarities described in the previous section between the bodily feelings reported in existing unimodal hallucination research, and the (mostly) MMH documented currently (Nayani & David, 1996; Upthegrove et al., 2016; Woods et al., 2015). The analysis raised interesting considerations of how the feeling of hallucinations described as unimodal (e.g. AVH with co-occurring localised bodily feelings) and multimodal (e.g. AVH+BH) may differ, or the reason for which they are felt or reported differently. Such considerations included whether the:

- Felt multimodality of some hallucinations was a function of their felt congruency; as all simultaneous MMH reports were congruent.
- Felt unimodality or multimodality of a hallucination, regards the extent to which the contribution of a modality dominates in comparison to others.
- Other immediate feelings of hallucinations (e.g. feelings of reality), influenced the feeling of bodily sensations (e.g. as one's own, as generated by a presence, or as experience of the spiritual or beyond-material qualities of one's world).
- Experiences of hallucinations which may be initially experienced as multimodal, could be reframed as unimodal due to the prominent conceptualisation of hallucinations as unimodal (as SR1 demonstrated) or due to issues of communicability of MMH (Lowe, 1973).

In any case, although the extent to which bodily feelings were experienced as part of hallucinations varied, the immediate experience of hallucinations was characterised by feelings in identifiable parts of one's body. These outcomes provide a novel evidence base of bodily feelings during unimodal and MMH upon which further research can build. Perhaps such research may shed light on the bullet pointed considerations. Having explored where feelings were localised, what feelings they were and the kinds of hallucinations they arose within, the final body-map series are presented. This section explores feelings experienced within body-parts, alongside feelings of other analytic kinds. After this, the prospective research analysis reaches its final section, regarding the change of hallucinations over time.

7.03.3.3 Co-Occurring Localised and Generalised Feelings.

Using the existing analytic categories (Cromby, 2007, 2015), many of the feelings reported in this section could be conceptualised as extra-emotional feelings. To describe the body-map data, this section however continues to use the analytic category terms of localised and generalised feelings. This section illustrates that:

- Localised, specific feelings were reported as co-occurring often during different areas of the body at once.
- Feelings localised to specific body-parts, often arose alongside other feelings which were experienced in a generalised form across the body.
- Localised and generalised feelings co-occurred alongside a broad range of further feelings during hallucinations.

The section concludes by proposing hallucinations appear more than simply sensory experiences, and visual and ABRM strategies may be ideally suited for their comprehensive study. This section's body-maps are of simultaneous MMH reported by one participant, these are presented in Figures 7.19-7.22 and then examined to demonstrate the co-occurrence of feelings during hallucinations; they are also further discussed in chapter-8. The black writing documents feelings which were localised to body areas during these MMH.

FEELING, CIRCUMSTANCES, AND HALLUCINATIONS

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FEELING, CIRCUMSTANCES, AND HALLUCINATIONS

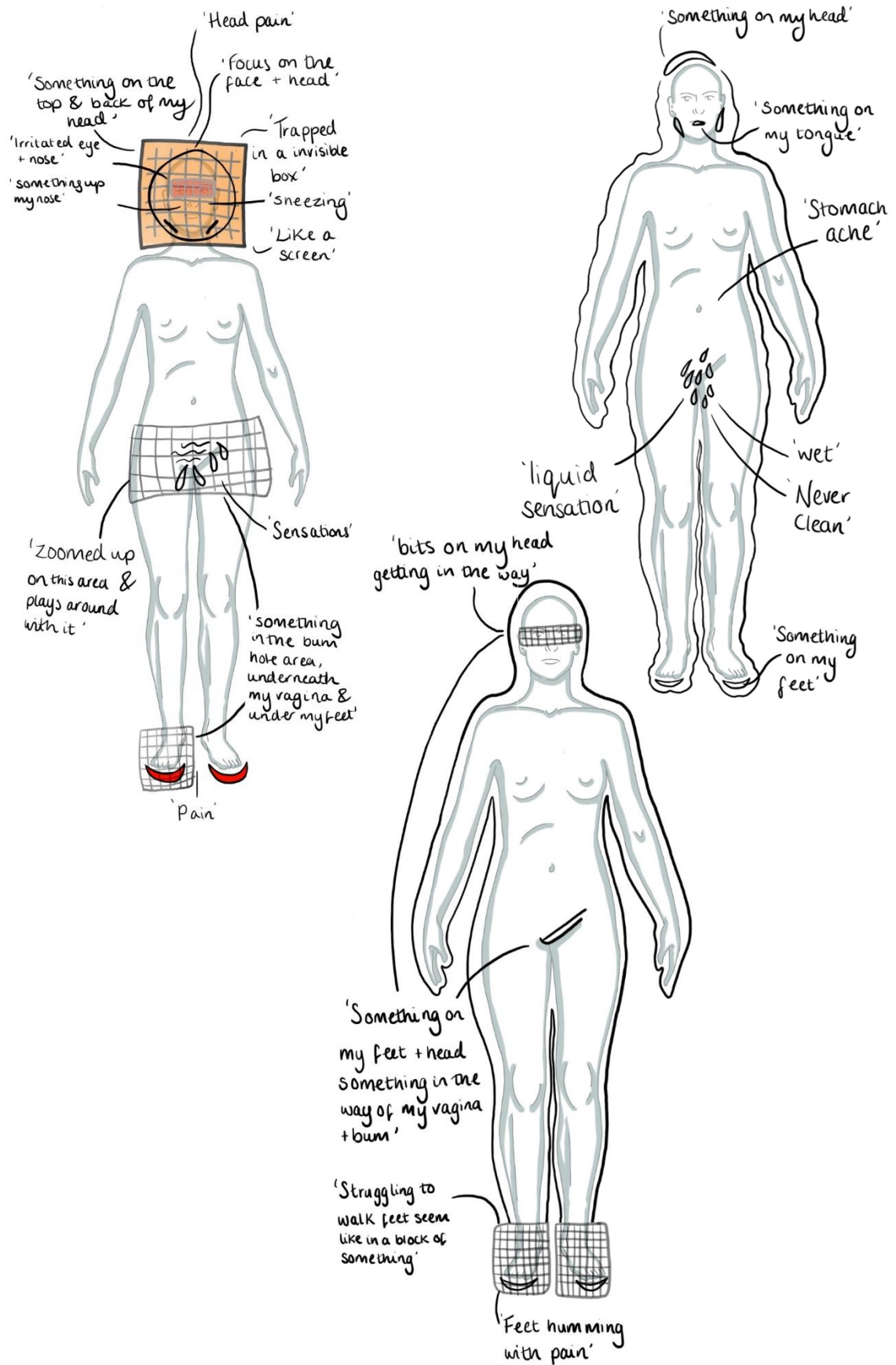


Figure 7.19 Digital illustrations of body-maps of simultaneous MMH.

As the body-maps illustrate, many specific, identifiable, localised feelings may be simultaneously felt in different areas of the body (from one's head to their feet) during hallucinations. Feelings seemed to be recurrently experienced in similar bodily parts. These areas of concentration would be repeated sources of feelings such as pain, heat or tension during hallucinations of different modal kinds. In this participant's case, their feelings were concentrated within their head, genitals and feet. Within participants, areas of concentration were recurrent, however across the sample areas of concentration varied greatly; this can be observed in the data shared in the first series of body-maps.

Alongside feelings localised within specific body areas, generalised feelings were reported too. Generalised feelings documented in Table 7.10 were reported within the "during this time my body felt" section, without referring to a body area. Akin to variety of the previous feeling data tables, 46 feeling terms were collectively reported during hallucinations on 54 occasions by 92% (n=11) of participants (who completed the visual diary). This suggests further to feelings localised to particular body areas, more generalised bodily feelings were also commonly experienced during hallucinations.

Table 7.10

Summary of the Frequency of Clusters of Feelings and the Modal Types of Hallucinations they were Experienced within.

<u>Clusters of Feelings</u>	<u>H-N</u>	<u>P-N</u>	<u>F-N</u>	<u>Hallucination Types</u>
On-edge, Tense, Pressure, Fight or Flight, Adrenaline, Agitated	12	8	6	AVH + BH + VH +TH AVH + BH + VH AVH + BH + GH AVH + BH AVH VH
Tired, Heavy, Weak, Exhaustion, Knackered, Weighted, Struggling, Solid	16	7	8	AVH + VH + BH +TH AVH + BH + VH AVH + BH AVH + VH AVH BH
Hot, Cold, Sweaty, Chills	6	3	4	AVH + BH + GH TH + GH + OH AVH + BH

FEELING, CIRCUMSTANCES, AND HALLUCINATIONS

				VH + BH BH
Wobbly, Dizzy, Shaky, Jumpy, Light, Tingly, Trembling	5	3	7	AVH + BH + TH + GH + OH AVH + VH VH + BH AVH VH
Daren't move, "I couldn't move because my body was too in shock", Stuck	3	2	3	AVH + BH + VH VH + BH VH
Energised, Conscious Energy	2	2	3	AVH + BH AVH
Unresponsive, Not Real, Disconnected, Like Air, Not in Myself just Watching Myself	2	1	5	BH AVH
Something Against my Body All Over...Placed On the Top. It Feels like a Heat.	2	1	2	AVH + BH +VH + TH + GH AVH + BH + VH +TH
Subtle pain, Severe Discomfort	1	1	2	AVH + VH + BH +TH
Feeling of Someone Watching	1	1	2	AVH + VH
Wet	1	1	1	AVH + BH + VH + TH
Relaxed, Kind of High	2	2	2	AVH + BH + VH AVH + BH
Like There was Something Inside of me Pushing Outwards.	1	1	1	AVH + BH
Total	54	11/ 12	46	

H-N: Number of times a feeling within a cluster was used to describe a hallucination.

P-N: Number of participants who diary documented a feeling.

F-N: Number of feeling terms.

The analysis suggested similar kinds of feelings (e.g. pain, tension) could be experienced in different ways. Some of the feelings reported here as generalised, were described as localised by other participants; for example,

tension throughout the body versus tension in the neck. Use of the visual (body-map) alongside linguistic (diary and interview) data generation methods, seemed to support participants in sharing the experience of feelings in terms of their localisation or generalisation.

Some generalised feelings reported in Table 7.10 were consistent with reports in existing research. Feelings such as pain and heat, mirrored existing AVH research (Woods et al., 2015); although here they arose within a broader range of hallucinations. Further similarities with existing research can be seen in the feeling of being unable to move; this had been reported by 25% of Gauntlett-Gilbert and Kuipers (2003) sample. Both in their research and the current study, the hallucinations involved the visual modality. Interestingly, some of the feelings relating to “disconnection”, “not in myself just watching myself”, are akin to the out of body experiences reported during hostage situations in SR2 (Siegal, 1984). Such experiences could also be described in terms of dissociation, which Varese et al. (2011) research indicated was associated with AVH. Such feelings chime with the previous discussions of how feelings may be differentially conceptualised during hallucinations.

In addition to those feelings which had been documented in existing research, the evidence base was built upon further by reports of numerous novel feelings during hallucinations. Generalised feelings relating to anxiety and exhaustion seemed to be most common; these were experienced within a context of many other feelings such as feeling “disconnected”, watched, “relaxed” or “kind of high”, feeling “wet” or as though “there’s something against my body all over” or “something inside of me pushing outwards”. Overall, the data suggested hallucination experiences were characterised by both localised and generalised identifiable feelings in the body. A further novel insight generated from the research was of how feelings co-occurred together.

Earlier within this sub-section, 3 body-maps generated from one participant were shared. These were worked upon further to include a grey surrounding line upon which the rest of the feelings reported during the hallucination were written. This included feelings which have been analytically described within this chapter as: emotional feelings, feelings of knowing, feelings

of reality, extra-emotional feelings and localised and generalised feelings. These body-maps are presented as examples of the dataset regarding the co-occurrence of feelings; after their presentation, they are discussed and the analysis of the feeling of hallucinations closes.

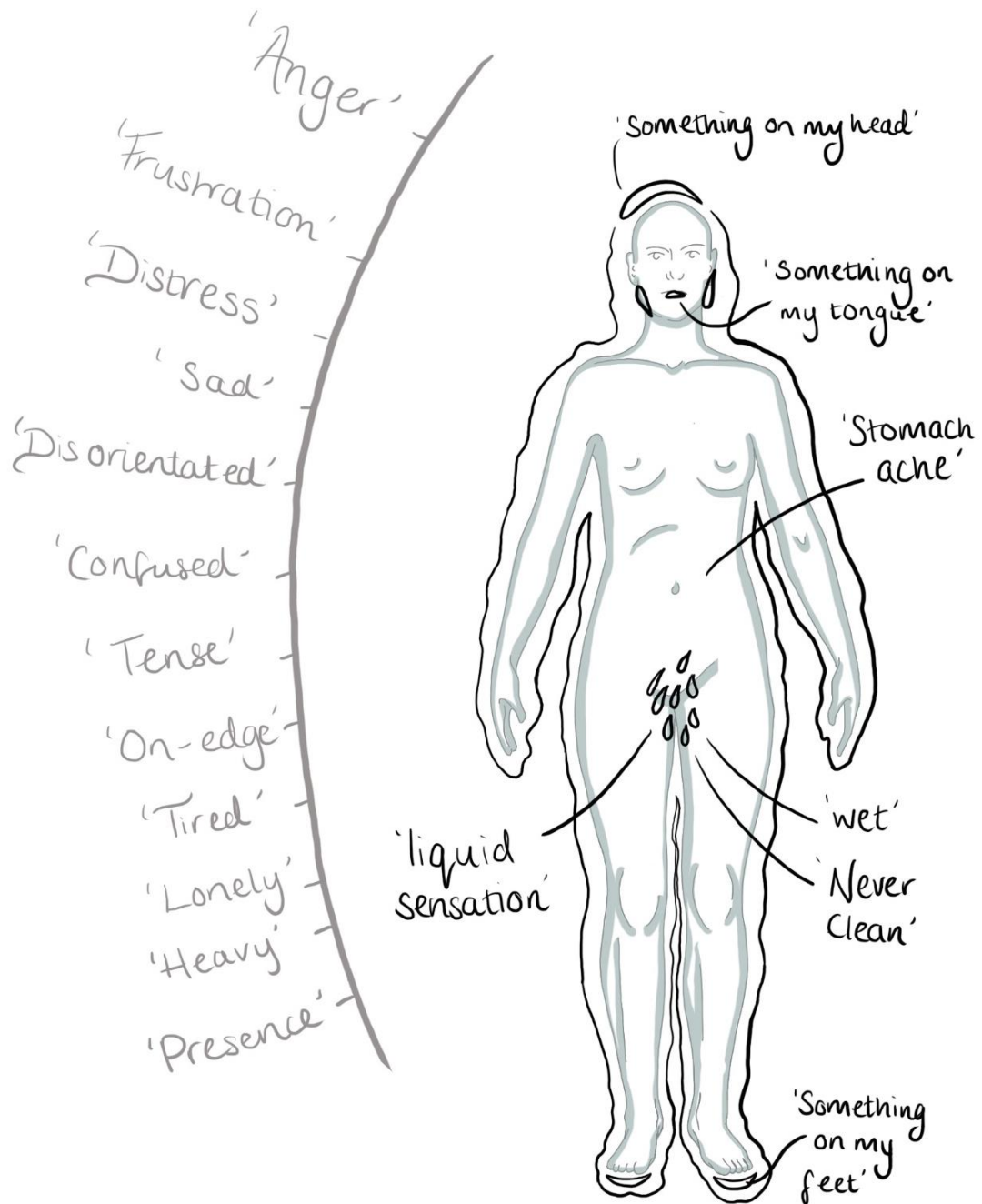


Figure 7.20 Digital illustration of immediate feeling of AVH+BH+VH+TH.

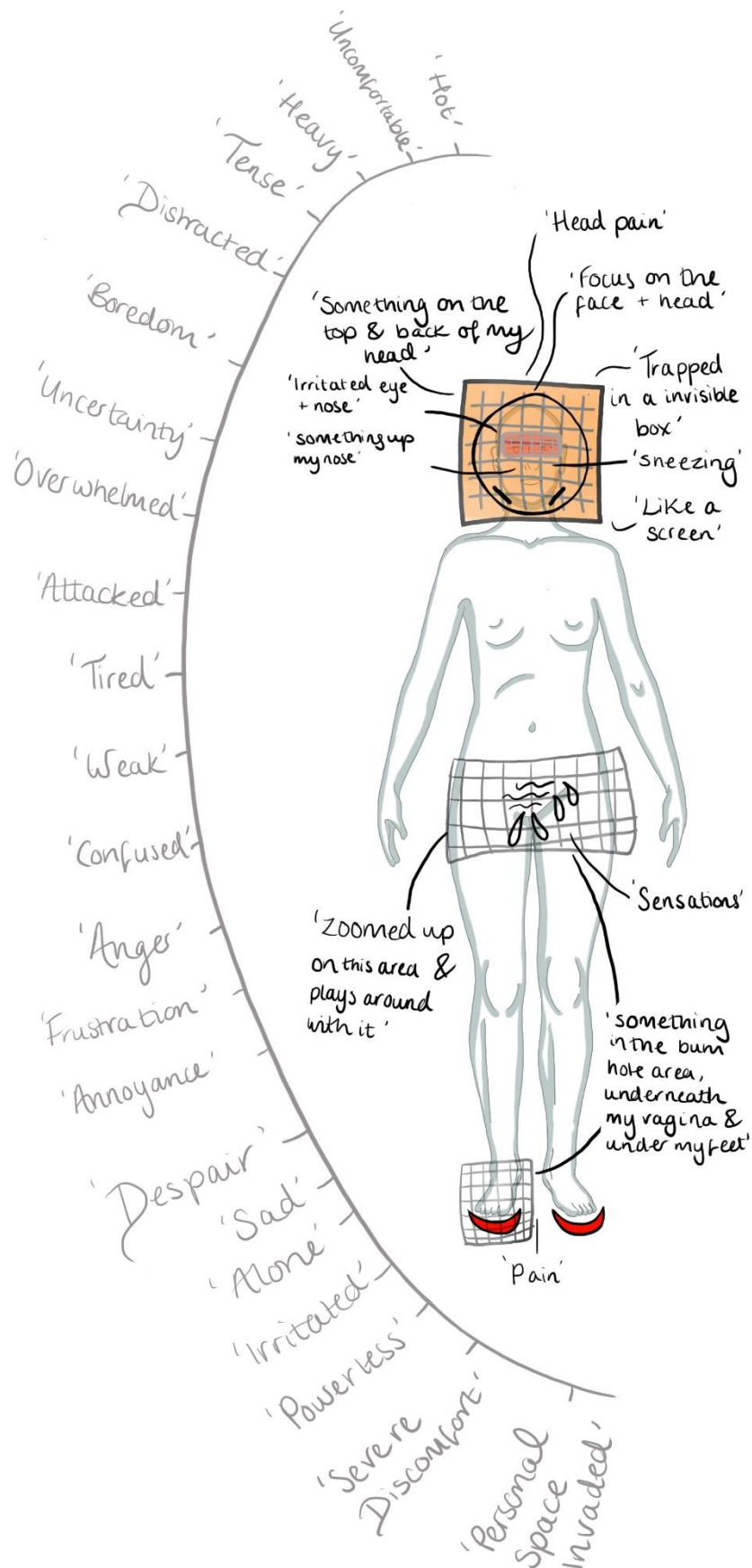


Figure 7.21 Collation of the immediate feeling of two AVH+BH+VH+TH.

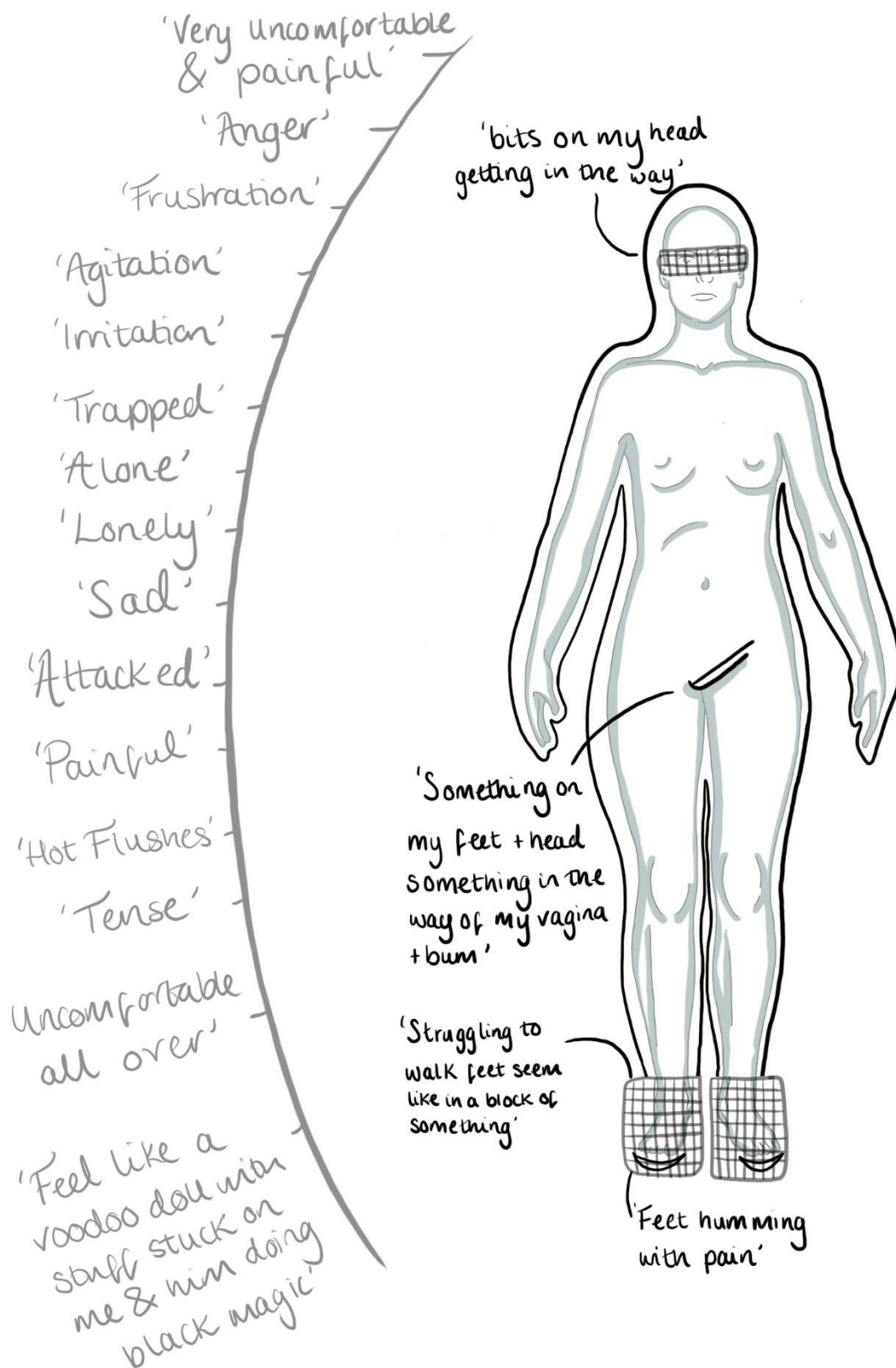


Figure 7.22 Digital illustration of immediate feeling of AVH+BH+VH+TH+GH.

The data presented in this final body-map series illustrates participants' consistent reports that the immediate experience of hallucinations was characterised by numerous co-occurring feelings. Feelings co-occurred within and across the explored analytic feeling categories explored. These body-maps provide visual examples of the immediate felt complexity of the hallucination experiences reported in the study.

These body-maps were presented as this participant's bodily and tactile sensory experiences were the most subjectively dominant, although simultaneous sensations of seeing, hearing and tasting were also reported. These sensations were experienced as generated by a person watching and abusing her through digital technology (further explored in chapter-8). The visual diary with micro body-map were particularly beneficial in understanding her experiences (and other MMH) as:

- The methods were built to generate data in the primary modalities in which her experiences arose;
 - The diary and body-map could document feelings as co-occurring;
 - The researcher-participant dynamics of visual and ABRM, seemed to facilitate the participant in sharing the sensitive features of her experiences;
 - With digital technology as an ongoing trigger and source of difficult past experiences, the availability of analogue data generation methods were ideal.
- This participant's experiences (as well as the remaining MMH) were unlikely to have been studied comprehensively (if at all) using the conceptual approaches or methods of existing research. Hallucinations across the dataset were characterised by features such as multimodality and the centrality of the body, sensitive and difficult content. As such, the novel data generation tools were both appropriate and helpful.

The combination of the visual diary, body-map and interview data together facilitated understanding what participants' hallucinations felt like. The immediate experience of dairy-documented hallucinations were characterised by simultaneously experiencing numerous feelings, many of which seemed closely bound to the circumstances they arose within. Future research studying the feeling of hallucinations should be designed to account for the features outlined in this chapter; regarding which analogue visual and ABRM seem ideally suited.

7.03.4 Immediate Feeling of Hallucinations: Key Outcomes.

Table 7.11 summarises key analytic outcomes regarding the immediate feeling of hallucinations. There were many novel research outcomes, particularly regarding what feelings may be experienced during hallucinations and where they may be felt. Hallucinations appeared characterised by feelings which may be described as emotional, extra-emotional, of knowing, of reality, localised to body areas or generalised across the body. Within Upthegrove et al.'s (2016) research of EIP service-users, they proposed AVH seemed more than simply auditory. The sensory data of this study built upon this outcome to indicate hallucinations were often more than simply unimodal and appeared more than simply sensory. The contribution of sensory feelings seemed to be one of many varied kinds of feelings which composed hallucination experiences, in much the same way that the sound from a single violin, is one of many instruments which contributes to the sound which emerges from an orchestra. The final analysis section of this chapter explores the remaining prospective data; of change over time.

Table 7.11

Summary of Key Analytic Outcomes from Diary-Documented Hallucinations.

<u>Analytic Area</u>	<u>Analytic Outcome</u>
Senses	Participants overall experiences of hallucinations were typically multimodal, with 83% (n=10) reporting MMH.
Senses	Hallucinations were reported as involving between one and five simultaneous modalities.
Senses	The modal types involved in hallucinations from highest to lowest number of reporting participants were AVH, BH (including sexual hallucinations), VH, TH, GH, OH and Te.
Senses	All simultaneous MMH were congruent.
Feelings	All participants reported feelings during experiences of hallucinations, this included feelings within analytic categories of: emotional feelings, feelings of knowing, feelings of reality and extra-emotional feelings.
Feelings	Participants reported feelings as bodily in general and as localised to certain body parts. Two further analytic categories of 'localised' and 'generalised' feelings were used to interpret the body-map data.
Feelings	Varied feelings often co-occurred simultaneously; this involved feelings reported within and across different analytic categories.
Feelings	The immediate experience of hallucinations was typically characterised by numerous feelings; hallucinations may not be a simply sensory experience.

7.04 Change During the Study: Longitudinal Data

The four-stage research design provided the opportunity to prospectively generate data on the feeling and circumstances of hallucinations. To ease the participant burden of the study, there was flexibility regarding data-generation including: study time-scale, optional ABRM tools, and semi-structured interview schedules. The data generated over time was guided by: what was salient for participants, whether participants attended the final interview (13 of 16 did) and when they attended the final interview (between 4 and 8 weeks after starting the study). Further to the novel use of a post-diary interview, the use of a second follow-up interview was novel in relation to the existing systematically reviewed research. This section explores the kinds of changes participants reported and what these changes were.

Most participants (77%, $n=10$) reported change over the four to eight weeks. The most commonly reported change was the frequency of a particular sensory kind of hallucination ($n=6$) including: more OH and GH ($n=1$), more AVH ($n=2$), more BH ($n=1$), as well as less AVH ($n=1$) and less VH ($n=1$). Many participants reported change in terms of their experience of hallucinations worsening and/or improving during the study ($n=7$). These changes, alongside participant quotes can be reviewed in Table 7.12.

Experiences of improvement during the study ($n=4$) included hallucinations stopping ($n=1$) improved feelings (emotional $n=3$, extra-emotional $n=1$, reality $n=1$) and feeling more able to cope ($n=1$). Improvements were often discussed in terms of one's current circumstances; a participant explained "my situation is getting better, so I have felt a whole lot calmer in myself". Improved emotional feelings were described as having a knock-on positive effect of feeling more able to "brush it off as probably false" or "you can let go of those things and they just don't get to you". These interrelating potentials generated by positive feelings and circumstances point to chapter-9's later analysis of feeling-traps.

Table 7.12

Quotes on the Ways in Which Hallucinations Improved and/or Worsened.

<u>Aspect of Change</u>	<u>Detailed Participant Report</u>	<u>N</u>
Improvement: Insight (Less Real, Less Fearful)	"I'm starting to realise it's a hallucination which has given me a little bit of hope...I feel in a better place now to when I did when the last time I saw you. I feel like I've gained better insight into it." "I'm not so fearful of them anymore...What's changed is my ability to brush it off as probably false."	1
Improvement: Reported Hallucinations Stopped	"Nothing where it's complete hallucination where there's something that's not real in front of me and it's like I can say that I saw visions or something. There's nothing like that that's happened recently, but definitely things darting across the road or just like a feeling of being watched"	1
Improvement: AVH Volume, Frequency, Emotional Feelings, Co-occurring Bodily Feelings	"I've been getting much better in myself; so the voices for me they've kind of been petering out a bit more" "It feels like things are kind of going in the right direction, they've been quieter" "I used to feel quite tense and ... a burning sensation, sort of in your forehead; not had those issues for quite a while now, so as they've been going as well, it just feels like I'm relaxing more and more."	1
Worsened: Emotional Feelings and Hallucinations	"There's been a lot of frustration and anger and stuff like that that I've dealt with in the past few days and I've not like felt as happy" "Been really stressed and stuff, it's been a bit hard. So, they've been a bit intense, really bad."	4
Worsened: Concentration Due to Hallucinations	"They've been distracting me". "During the meetings, it's just really hard to concentrate...you've got all these voices...really stressful".	2
Worse and Better: Frequency, Timing and Coping	"I'm getting the voices more throughout the day, which is a new thing, but I've also become better at handling it during the day, and at night."	1
Worse and Better: Over Time	"I've been doing better now, this week. I've been back to doing normal things"	1

In contrast to positive improvements over time, some participants also described their experiences as worsening (n=4); this included difficult emotional feelings (n=4) and difficulties concentrating (n=2). Worsened emotional feelings were described as either due to hallucination content being more intense and “heavy on me” (n=1) or difficult social-material circumstances (work-redundancy n=1 and familial relationship difficulties n=2). For two participants the change they experienced was both better and worse. For one participant, their hallucinations became more intense due to a difficult interpersonal situation and lack of appropriate available care; when this resolved their experience of hallucinations improved, with reduced difficult emotional feelings and hallucinations. For another, the timing and frequency of AVH changed but they had been “able to cope with it better”. This illustrates the varied potential ways hallucinations may change over time.

Participants often initially provided more concrete pictures experiences improving or worsening. During the remainder of the final interview, more nuanced descriptions often became apparent. For example, the participant who described increased insight, seemed to move between positions of experiences feeling concretely real and not real throughout the interview. A lens of hermeneutics of suspicion may propose participant’s initial descriptions of felt general changes, were experienced within a broader plethora of ongoing feelings and circumstances. By using a semi-structured interview and ABRM format, thick data could be generated to appreciate the nuances of potential change over time. A research format with a fixed series of questions or responses (e.g. questionnaire or structured interview), may have struggled to generate comprehensive and internally valid data on change over-time.

Overall, the longitudinal analysis pointed to hallucination experiences as generally feeling as though they changed over 4-8 weeks (77%, n=10 of participants). Still, in contrast to these reported changes, three participants (23%) reported no subjective changes in their hallucination experiences over the course of the study. This points to the often enduring, repetitive and ever-present feelings of hallucinations. Chapter-8 further explores such feelings in terms of presence and reality. For those who reported changes, these were felt in numerous different ways including:

- The frequency of sensory kinds of hallucinations can increase or decrease,
- Hallucinations can stop,
- Change in one's felt ability to cope,
- Change in the time of day hallucinations arise,
- Hallucinations, their feeling and their impact can worsen, improve or both worsen and improve.

Consistent with the broader approach to feelings within the thesis, felt changes should be understood as nuanced, multifaceted, fluctuating, differentially felt within co-constituting circumstances, and subject to continuous emergence themselves. The novel analytic outcomes reflect the value of generating data on hallucinations experiences over time and provide numerous areas regarding which further research could study.

7.05 In Summary: The Immediate Feelings and Circumstances of Hallucinations

The experiences of hallucinations prospectively reported by participants were characterised by unique and emergent combinations of feelings and circumstances. The circumstances of hallucinations held varied temporal, social and material features. Hallucinations were reported to last between 1 minute and 14 hours, with simultaneous MMH lasting substantially longer than unimodal hallucinations. It appeared the more modalities involved in a hallucination, the longer they seemed to last (up to a peak of 4 simultaneous modalities). Overall, the timing of hallucinations seemed to peak soon after waking and before sleep, with the highest peak around 2pm; though time-trends varied with different hallucination modal-types. Hallucinations happened most often when at home and when alone, although the social and material circumstances varied across the sample. Overall, hallucinations arose within a variety of situations which mirrored the features of their ongoing daily lives.

Akin to the varied circumstances of hallucinations, the immediate feeling of hallucinations varied too. Participants' reported hallucinations as arising in many modalities including: AH, BH, VH, TH, GH, OH and Te (ordered from highest to lowest report-rate). Participants' described hallucinations which involved between one and five simultaneous modalities; overall, hallucinations

typically involved multiple modalities either simultaneously or at separate time points. Hallucinations of all modal types, were characterised by numerous co-occurring feelings, including feelings which may be described as: emotional, extra-emotional, of knowing, of reality, and localised or generalised within the body. Experiences of hallucinations were described as changing over time in terms of their frequency, one's felt ability to cope, the time of day they arise, and both their feeling and impact potentially improving or worsening. Overall, hallucinations seemed to be emergent and fluxing experiences, characterised by the co-occurrence of numerous feelings, which were co-constituted by unique situated circumstances.

Reflecting upon this complex web of co-constituting features seemed to suggest hallucinations may represent variations in the same kinds of processes by which people experience and apprehend consensual -so called 'objective'-reality. Akin with sense-experiences consistent with consensual reality, participants reported navigating and coping with hallucinations including their: feeling, impact and potential for continuous emergence. Within a world of unforgiving social-material circumstances which flow on unaware, participants described the extra "burden" of life involving hallucinations.

As chapter-1 described, contemporary mental health research and care practices are dominated by individualist, biomedical and diagnostic approaches (Cromby, Harper & Reavey, 2013). Within such approaches, the feeling and context of distress are often neglected. In contrast, this chapter has demonstrated experiences described as hallucinations seem characterised by feeling, embodiment and situated social-material-temporal circumstances. Future research should continue to study each of these characteristic features of these lived experiences. The current study's prospective research design was novel in its methods and in the breadth of its scope. The many novel analytic outcomes of this study provide both an insight into the immediate experience of hallucinations, and an evidence base upon which future research and interventions could build.

8. Empirical Analysis:

A Picture of Madness in Modern Britain: The Broader Feeling and Circumstances of Hallucinations



Figure 8. Participant expression of the feeling of STI's after rape.

8.01 Introduction to Analysis

The systematic review outcomes suggested existing research could be developed by studying the feeling of hallucinations across modalities and the complexities of the circumstances they arise in. The thesis research questions reflected this, and the content of this chapter speaks to Table 8.01's questions.

Table 8.01

Thesis Research Questions Explored in Chapter-8.

<u>Question Number</u>	<u>Question</u>
1	What do participants express their hallucinations feel like?
2	What circumstances do participants express their felt experiences of hallucinations are situated in?
2a	What material circumstances do participants express their felt experiences of hallucinations are situated in?
2b	What social circumstances do participants express their felt experiences of hallucinations are situated in?
2c	From participants' expressed perspective, what does it feel like to experience a hallucination within these circumstances?
3	What autobiographical experiences are associated with hallucinations?

This chapter presents analysis of all sixteen participants' data to consider the broader feeling of hallucinations, before examining the multifaceted aspects of life in Britain salient to the participants' lives. This included (in order of their exploration in the chapter):

- Activities of Coping,
- Spirituality,
- Digital Technology (and it's Intimate Proliferation),
- Growing up and Adverse Childhood Experiences,
- Education,
- Work and Employment,
- Material (In)Security and Welfare,
- Drugs and Alcohol,
- Inequality, Discrimination, Harassment, Authority, and Police,
- Formal and Informal Mental Health Care.

Reflected in these focus areas and the data analysis which follows were that although experiences and circumstances were necessarily already nuanced by intersecting oppressions (i.e. gendered, raced, classed), these enduring circumstances were often not topicalised in the dataset; they were most overt within the digital and inequality streams. Building upon Chapter-7's exploration of the immediate feelings and circumstances of hallucinations, this chapter's analysis provides numerous novel insights into the ongoing lived experiences of people living in Britain who experience hallucinations and access services. This analysis opens by considering some broader ongoing feelings.

8.02 Broader Ongoing Feelings

This section foregrounds the analysis by exploring ongoing feelings of salience, presence and reality which seemed to characterise living in a world which included hallucinations. The use of salience here does not refer to aberrant salience theory; Appendix F1 holds an explanation for further reference. Hallucinations were described as salient. Whilst likening voices to lightening, a participant described "you're in a normal day to day situation. And then you...get a dark cloud come over you and then the voices are just like electrifying...they're striking. They're the thing which stands out more than anything else". Figure 8.01 shares an illustration wherein another participant likened voices to lightening. This feeling of salience chimed with "the pull" of AVH reported in Upthegrove et al.'s (2016) AVH research; within the current analyses salience appeared relevant to hallucinations beyond the auditory modality too.



Figure 8.01 Diary illustration of feeling of AVH.

The entities of hallucinations were often described as manipulative, of "trying to trick" or "play on your mind". Consistently, participants explained entities could be "annoyed when I ignore them" and "try and scare me to get attention". These features were prominent for hallucinations involving AVH (unimodal or MMH). Hallucinations were often described as generating content and feelings which would likely capture attention, with entities focusing on what "they think are things

that will get to me”. Hallucinations’ personalisation from the situated circumstances and ongoing lived histories in which they arose, seemed to generate this salience.

As indicated by the entity qualities of hallucinations and their interrelationship with salience, across the dataset a further broader feeling was of presence in terms of one or more of the following:

- Hallucinations feeling located within an ongoing experience of time and space,
- Hallucinations feeling a part of the broader flow of sense-experience,
- Hallucinations feeling as though they are arising from an animate entity.

Feeling of entity seemed to vary by modality, as it was reported in AVH, VH, BH and TH; but not for OH, GH or Te (unless they were part of MMH involving AVH, VH, BH or TH).

The characterising features of the feeling of presence are illustrated by participant quotes in Appendix F2 (Table F.1), and can be summarised as presences being: unwanted (presence and connection), wanted (presence), omnipresent, watchful (entity, digital, humanoid, supernatural, real), inescapable, in/visible, abusive, occupying mental space, invading bodily space, intruding upon mental space and life, and something to get rid of. The Digital Britain section further explores the watchful feeling of hallucinations. One participant shared a visualisation of the omnipresence of threatening entities and malicious voices (Figure 8.02). This expressed the often inescapable and distressing presence characterising the broader feeling of hallucinations. Overall, presence was commonplace, multifaceted, varied, and most-often difficult. These outcomes build further examples of presence and entity feelings were proposed as core parts of AVH phenomenology among EIP service-users (Upthegrove et al., 2016). Perhaps feelings of presence may be characteristic of hallucinations among EIP service-users.



Figure 8.02 A participant artistic expression of the distressing and confusing omnipresence of malicious voices.

Further to salience and presence, ongoing feelings of reality were also documented (summarised in Table 8.02), with detailed participant quotes presented in Appendix F2. Feelings of reality often seemed highly variable, with capacity to flux and change and the possibility to experience hallucinations feeling real and unreal at once. These feelings of un/reality seemed to arise from dual planes of sense-experience, where some sense-experiences corresponded to a consensual reality, whilst others did not; differentiating un/real experiences was often difficult. Consistent with existing research, differentiating un/reality was particularly difficult whilst hallucinations were happening, and often became more possible with time (Gauntlett-Gilbert & Kuipers, 2003; Lowe, 1973).

Navigating the onslaught of hallucinations alongside one's immediate circumstances (in consensual reality), was often challenging, distressing and had negative consequences. Chiming with Cromby and Harper's (2009) work on feeling-traps in paranoia, these experiences of un/reality seemed to shake the given security of one's lived experience. As Table 8.02 indicates, the broader feeling of reality seemed to entwine with experiences of hallucinations, the rest

of sense-experience, and existential feelings (of the world/reality/existence and one's place within it).

Table 8.02

Summary of the Feeling of Reality Among People who Experience Hallucinations.

<u>Realness of Hallucinations</u>	<u>Broader Feeling of Un/Reality</u>	<u>Impact of Feelings of Un/Reality And Navigating Dual Plans of Sense-Experience</u>
Sensory Realness: Sound and Feel Real in the Moment	Becoming Unreal	Experiencing Dual Planes of Sense-experience/Reality
Sensory Realness: Sound is Different yet Real	Uncertain Reality	Difficulty Navigating Dual Planes of Sense-experience/Reality
Sensory Realness: Most Real When it's Seen	Untrue Reality	Shame In Unreality
Sensory Realness: Mismatched Sensations	Traumatic Un/Reality	Consequences of Acting on Un/Reality
Hyper-Reality	Abusive Un/Reality	Embarrassment from Un/Reality
Fluxing Un/Reality	Confirmation of More Than Material Reality	Void (When Hallucinations Stop)
Concretely Real	Testing Unreality	Unresolved Trauma: Will Never Really Know
Not Knowing Where Consensual Reality Stopped and Hallucinations Started		Accepting Not Knowing Processing Un/Reality

To summarise, hallucinations felt salient, present, and un/real in varied ways. The broader reality of experiencing hallucinations included the feelings they generated, and the circumstances they disrupted. The combination of hallucinations' feelings of salience, presence and reality, often led to unanticipated outcomes, such as: struggling to focus on one's immediate circumstances, getting "wrapped up", and responding to hallucinations (in ways that may or may not be visible or acceptable to others). A participant described

“sometimes when you’ve been listening to them all day...I start shouting at them back and then you find yourself in a room on your own shouting at a wall and then just thinking, what the fuck am I doing?” With dual planes of sense experience, participants reported having to navigate an influx of un/real streams of sensory information, whilst also tackling the “what the fuck?” feelings, and the impact one’s reactions may have had on their circumstances. In trying to manage, participants activities of daily living included activities of coping. Examining these activities begins the exploration of the feeling and circumstances of living in Britain among people who experience hallucinations.

8.03 Activities of Daily Coping

All participants described many activities which comprised their daily lives, these could be broadly divided into overlapping categories of activities of daily living and of coping. These have been overviewed in the Figure 8.03 This section briefly examines activities of daily living before exploring activities of coping.

Consistent with Upthegrove et al.’s (2016) AVH research, both unimodal and MMH had a negative and at times detrimental impact on activities of daily living. This seemed to be due to the consequences of managing both the multifaceted aspects of consensual reality and the sense-experience of one’s hallucinations (including their relational qualities and their emotional, bodily and reality feelings). As one participant explained: other “humans don’t deal with extra layers...I’ve got this issue so I deal with it in an extra layer”. This reflects Upthegrove et al.’s (2016) participants’ reports of daily living becoming a battle. Activities of coping examined in the remainder of this section, arose within a context where participant’s capability and opportunity to engage in them varied.

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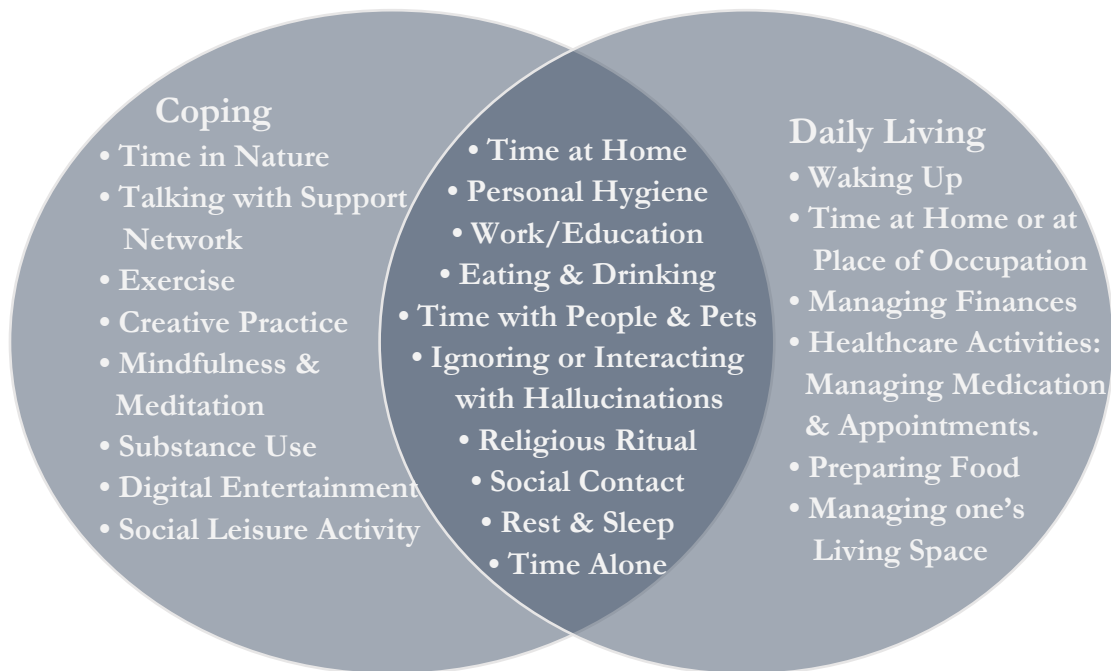


Figure 8.03 Activities of Living and Coping Among People Experiencing Hallucinations.

8.03.1 Activities of Coping.

All participants described engaging in activities to manage hallucinations and make the most of life. Most participants described seeking helpful activities “for something to do and get out”. These have been summarised in Figure 8.03 and Table 8.03. The activities described by participants reflect a much broader range of activities than has been documented in previous research (Nayani and David, 1996).

Going into natural spaces was beneficial for the largest number of participants, although this varied in terms of the kind of spaces including; one’s own garden, public gardens, and woodlands. A participant described “it’s about getting out and sort of taking in the environment...that’s really helped me”, explaining “when you’re out in nature” it encourages “just kind of looking around more, not being so caught up internally, just looking at, you know, the trees and the sounds...and stuff, so it’s kind of getting out of your head”. This also points to moments of mindfulness which was also described as beneficial for many participants. The value ascribed to mindfulness may reflect the zeitgeist of

mindful self-care and health-care practices, as well as the ease of access of mindfulness, including advice online and smartphone apps.

Table 8.03

Activities which managed experiences of hallucinations or improved one's.

<u>Coping Strategy</u>	<u>N</u>	<u>Coping Strategy</u>	<u>N</u>
Going into Natural Spaces	6	Meditation	3
Exercise (Boxing, park-gym, swim, team-sports, walk, yoga)	5	Art or Craft-making	2
Talking to Someone in Personal Support-network (Via Phone-call or In person)	5	Engaging One's Senses	2
Ignoring Hallucinations	5	Video Games	2
Time with Animals	5	Watching TV	2
Mindfulness	5	Visiting Another City	2
Talking to Someone in Health-care Support-network (Therapist, Care-Coordinator, Counsellor, Via Phone-call or In person)	4	Talking to someone via Instant-messaging Platforms (Text or Online Chatrooms)	2
Dog Walking	4	Being in Bed	2
Prayer and Religious Ritual	4	Time in Quietness to Reflect on Experiences	2
Spending Time in Religious Spaces	4	Smoking Cannabis	2
Writing (Diary, Creative)	3	Having a Cup of Tea	1
Being in Bedroom	3	Visiting the Cinema	1
Working	3	Being with Family	1
Listening to Music	3	Visiting the Library	1
Spending Time with Children	3	Cooking	1
Charity Shopping/2 nd Hand	3		

Interestingly, watching TV and going to the cinema were reported as coping mechanisms. The research considered in SR2 suggested the impact of TV was negative for hallucinations with the news especially holding potentially hallucinogenic impacts. For it to be used as an activity to help hallucinations could seem paradoxical however, although TV was described as exacerbating hallucinations for some (to be further explored in Digital Britain section), both watching TV and cinema films were reported as helpful in managing hallucinations. The participant who found this strategy most beneficial and used it daily, was a participant who's simultaneous MMH most strongly involved bodily sensations. Historical research of the negative impacts of TV were predominantly with AH (Nayani & David, 1996). Perhaps the interrelationship between television and hallucinations may vary by their modality.

The activities summarised in Table 8.03 served a range of potential beneficial purposes including:

- Decreasing the frequency of hallucinations;
- Reducing the negative emotional feeling or impact of hallucinations;
- Distracting one's attention from hallucinations;
- Improving one's mood for a time: this would either improve the hallucinations or, improve one's quality of life and level of distress despite hallucinations;
- Providing a fuller sense of life through experiences beyond hallucinations.

A participant explained "making memories and stuff, they're important...memories are the valuable things...you remember them tomorrow; even if you're going through something, you've done something at least".

The varied interrelationship between activities and their benefits suggests there is not a one fits all approach for best ways to cope. Upon being asked what advice they would give to another person experiencing hallucinations, one participant recognised "everyone has different things that'd set them off" and so recommended a combination of:

- Trying to "gain more insight" into one's own experiences of hallucinations;
- "Try and discover ways to help yourself";
- Try "to be more active";
- If possible "have more of a balance, work/life balance as well";

- “Don’t be afraid to talk to people about it either...because there’s help out there”.

The same participant clarified “you still have to be a bit careful, because not everyone understands”. This reflects the varied experiences of coping and help-seeking. Overall, this advice chimed with the broader value shared by participants of finding and using coping strategies and seeking help.

The feeling of coping was often one of perseverance, with many participants advising others experiencing hallucinations to: “keep going”, “don’t give up” and “don’t lose faith”. The feeling of coping was also characterised by adapting to changes and challenges of one’s circumstances and feelings over time and the interwoven experiences of hallucinations. Hallucinations themselves were often described in terms of their adaptation to have the greatest negative impact, including hallucinations which “seem to adapt to my coping strategies that I adapt”. The relational and entity-like qualities of hallucinations further nuanced experiences of activities.

Overall, the data suggested a complex interrelationship between activities, hallucinations and one’s broader feelings and circumstances, as they emerged over time. Although the research did indicate clusters of activities which may be beneficial including going into natural spaces, talking to someone (in one’s support-network), time with animals, mindfulness, and (where relevant) engaging in one’s religion. Although, a given activity’s benefits varied both between participants and over time, within participants. For example, engaging in online and digital-media was sometimes helpful, sometimes unhelpful, and for many participants were not readily available resources. The analytic outcomes are consistent with SR2’s arguments, that future research should account for potential change over time and variation in capacity and opportunity to engage in potentially beneficial activities. The analysis now considers experiences of growing up and living in Britain.

8.04 What is it like to Grow up, Live, and Experience Hallucinations in Modern Britain?

All sixteen participants were born, raised, educated and living in England, Britain; this shaped and contextualised their feelings, ongoing circumstances and lived experience of hallucinations. In 2017, the UN special rapporteur on health described a necessary revolution to address the environmental preconditions of distress (UNHRC, 2017). To generate a picture of madness in Modern Britain, this section maps the social and material circumstances of participants' ongoing daily lives and autobiographical histories here; this explores streams of:

- Spirituality,
- Digital Technology,
- Growing up and Adverse Childhood Experiences,
- Education,
- Work and Employment,
- Material (In)Security and Welfare,
- Drugs and Alcohol,
- Inequality, Discrimination, and Police,
- Mental Health Care.

These streams pulled together the most comprehensive picture of all participants lived circumstances; although some streams (especially spirituality and drugs and alcohol), were more relevant to some participants' lived experiences than others. The relevance of the stream to the overall sample will be indicated in each section. This analysis sheds light on aspects of Modern Britain in need of care.

8.04.1 Spiritual Britain.

Some participants' lives involved spiritual beliefs, practices, and experiences; this points to the spiritual aspects of life in Britain. Systematically reviewed research seldom considered spirituality. Where it was studied, it was in terms of culture; that for example AVH of religious or superstitious content were reported more often in Saudi Arabia than the UK (Kent and Wahass, 1996) and in India paranormal phenomena such as an evil eye were understood as culturally 'true' perceptions (Andrade et al., 1988). Within the current study, it was interesting to document hallucination experiences from a multi-cultural and multi-

faith population. Of the 38% (n=6) participants that reported religious-faith two were Hindu, one Catholic, one Multi-faith, one Muslim, and one Sikh; the remaining 62% (n=10) reported not holding a religious faith. Spirituality interrelated with hallucinations in terms of:

- Coping through ritual, prayer and visiting spiritual spaces,
- Feeling supported or protected through faith,
- Encountering spiritual entities,
- Hallucinations disrupting or confirming one's faith.

This section discusses each of these features of participants' lives in Britain today and consider what this may mean in terms of their care needs.

8.04.1.1 Support from Faith: Spaces, Practices and Feelings.

Four participants described the benefits of visiting spiritual spaces or engaging in ritual in managing their experiences. Hindu and Sikh participants reported benefits of regularly attending spiritual spaces. Hindu participants reported visiting temple was "good": "meeting people" and partaking in rituals and prayer "is very special...very therapeutic and it feels nice". The Sikh participant reported similar positive experiences including "socialising, getting food and doing mindfulness and relaxation", partaking in and "listening to prayers"; that "it's nice and peaceful" and "it's a good way of meeting your own culture". One multi-faith participant reported benefits of visiting a Church when in spiritual crisis they explained "it was really good actually. These voices that were bothering me they had to stand back and I was just sat there listening to nice voices". For these participants, routinely attending temple or church when in crisis was a helpful part of life in Britain.

Further to visiting religious spaces, some participants used religious reading and prayer to manage their wellbeing. Relief from malevolent voices was reported by the multi-faith participant who explained "I just counteract them with things I've learned from the bible". Support may also be experienced through prayer, as one Hindu participant explained "how good...praying is": "I've felt stronger and I've felt in a better mood as well...it's helped me get through like the day...praying...to God and stuff like that and believing in God...helps you...in your bad situation". Support through prayer may be sought routinely in daily life,

or in moments of distress or crisis. One participant expressed an experience using Figure 8.04 where during a visit from three malevolent visual figures “I was asked to sell my soul to make things better...easier” and “felt protected by my faith”. Prayer was often used to manage or seek freedom from difficult sensory experiences.

Overall, spiritual spaces and ritual seemed to offer benefits for people experiencing hallucinations in terms of social connections, easing distress, and generating peaceful or hopeful feelings. These benefits were reported across different faiths and as an un-researched area (in the systematic reviews), may warrant further study.



Figure 8.04 Painting of feeling protected through faith and prayer from negative dark presences.

8.04.1.2 Encountering Spiritual Entities.

Five participants (31% of sample) reported encountering spiritual entities; two were religious (multi-faith and catholic) and three were not. This prevalence was similar, if slightly lower than Daalman et al. (2011) where 37% of their clinical sample reported spiritual sources (including devils/demons). Table 8.04 summarises participant descriptions of spiritual encounters. Two of these participants also reported “shadows”, “presences”, “apparitions” and “ghosts”, although in much less detail.

Table 8.04
Participant Reports of Encounters with Spiritual Entities.

Entity Summary	Real	Detailed Participant Report
“Devil” (Negative)	X	“It’s weird because when I see the devil, it comes in different forms, like a shapeshifter...it’s intense very intense, it’s crazy”.

<p>“Demon” (Negative)</p>	<p>X</p>	<p>“It’s really really dark, got horns, that’s the demon, he’s got a tail, he’s got wings, it’s a dark colour, it’s really scary, big teeth, red eyes. Just like, crazy...it’s a big thing”.</p>
<p>“Genie” (Negative)</p>	<p>⊙</p>	<p>“Like smokeless flames. It’s a purple guy with his hair goes up like that, and smoke legs” “It’s trying to trick me and that’s annoying” “rhyming things ...challenging me to games...making me bargain...stereotypical genie stuff, doing wishes and stuff”. “Now, it’s more charismatic...even though it’s doing light hearted things, it’s still terrifying when it does something new”. “Even though I know it’s not there, it can convince me every single time and it can go on for 45 minutes, an hour, maybe longer and that’s really bad”.</p>
<p>Three “black ...shadow” presences (Negative)</p>	<p>●</p>	<p>“It was very much nothing, no details, very sort of plain hardly actually any outline there but just more of a presence. So that’s the colour for that really because it didn’t really have a colour...I caught this out of the corner of my eye, I could see just the bottom half of a figure, then I went towards it to challenge it and then it disappeared into the next room... there was 3 of them and they were standing in the tv...standing in the corner of the room were the TV was but exactly in it”.</p>
<p>“Spiritual being” (Positive)</p>	<p>●</p>	<p>“It was like someone painted a really beautiful eye, and I was looking at this eye thinking “oh god, that is beautiful”, and then it opened and when it opened it went (crashing sound) this full on person was in front of me and they were just like purple. And the only thing I said to them was ‘oh my god you’re beautiful’ and they smiled even more, and I just I felt this incredible love...recently it’s popped back this same purple being. You know protecting me and guiding me ...when I fret about stuff it tells me to ‘be peaceful, be peaceful’...’I’ve been with you from birth, so you are always going to be protected’ “.</p>
<p>“Guardian angel” (Positive)</p>	<p>●</p>	<p>“My guardian angel came in and he "duh duh" [divine sound] so to speak and pushed the scary ones away, that’s when I had the glowing crucifix and basically confirmation of faith, ‘don’t worry, you are protected’ which sort of resembles the yellow glow around, so it’s all good.”</p>

“Concentrated ball of consciousness” (Positive)	●	“It was basically moving around the room and basically I was training with it...I could feel it and I could see it. It was probably about...7 inches sort of ball. And it was about this far away from me and when I put my hand in it, I could feel it tingle and it was...not hot but warm. But it kept moving but it would also let me physically sort of hold it...I mean it stayed there when I moved my hand to get away. I could actually touch it”.
Deceased Grandmother (Positive)	●	“I do see ... and I hear her as well. I...think that’s her because it’s her voice and everything...I’m like yay she’s here. But sometimes, she doesn’t scare me but I don’t know; when she’s saying my name, I actually hear it and then I see her smile in my face and I say ‘I don’t like it!’...then she just goes. She’s not haunting me or anything...when I feel like I feel someone’s there. I feel like she’s cuddling me or something”.

⊙ In the moment the entity can feel concretely real and is experienced as existent; these feelings of reality deplete after the experience.
● The entity had an ongoing feeling of being concretely real and existent.
X Experience of entity not described in terms of feeling real or existent.

As the participant reports demonstrate, the entities encountered varied although there were some similarities. Two participants experienced warning signs of a coloured mist, which had a smell and taste for one participant. Spiritual entities were experienced visually; although for some participants this co-occurred with other senses including AH, BH, TH, OH or GH. Interestingly, consistent with chapter-7, spiritual entities were predominantly encountered whilst alone at home. The demon, angel, shadow presences, genie, and ball of consciousness were experienced at night, the remaining entities arose at different times. Further to these patterns, the analysis also documented the feeling of entities in terms of being positive, negative or real.

Although entity identity varied, spiritual encounters could be collectively streamed into positive or negative. Table 8.05 summarises these comparative features; positive encounters were enjoyable or helpful, whereas negative encounters had the opposite outcomes. Interestingly, where spiritual entities were reported which were felt as corresponding to a real and existent entity, they

were typically either being positive, or experienced by someone who had a religious faith.

Table 8.05
Reported Feeling of Positive and Negative Spiritual Entities.

<u>Positive</u>	<u>Negative</u>
"Felt good, happy...concentrated but confirmed" "Loose sort of, felt flowing...it made me relax"	"Numbness, it can be in my hands...my legs will seize up on me, you can't move"
"I just feel a loving energy a peaceful energy"	"It's scary, just feel scared and drained...makes me tired"
"Really vivid, it's undeniable kind of vivid"	"Really intimidating"
"It's there to help me" or "There to assist"	"Freaks you out"
"It was okay to be alone because I was physically but not unphysically"	"I was really vexed...really angry, I was so peeved of with all of this going on. I just felt like it was so unfair"

Overall, experiences of spiritual entities varied by their felt identity, feeling, their interrelationship with one's personal history and spiritual faith. The experience of multi-modal encounters with spiritual entities among EIP service-users does not appear to have been studied in existing research. The outcomes of the current study demonstrate that further to Grimby's (1993) research on grief reactions among widowers, grandchildren may also experience their grandparents after their death; such experiences may be relevant to EIP service-users and may generate positive feelings. The remaining novel outcomes suggest varied kinds of spiritual encounters may be experienced among EIP service-users and generate a range of feelings. This section of the analysis closes by considering spiritual experiences and healthcare.

8.04.1.3 Spiritual Feelings, Circumstances and Distress.

Encountering spiritual entities was reported by both religious and non-religious participants. Although their feeling was often similar, for participants who held a religious faith such encounters and hallucinations more broadly, seemed to have the potential to impact on faith. Encounters with spiritual entities

could provide “confirmation of more than a physical world” for religious participants; a confirmation of faith that “there’s more to the world...I feel like I’ve peered beyond the veil”. Unfortunately, sensory experiences could also disrupt faith. The multi-faith participant reported visiting a cathedral after their voices “turned all biblical”, saying he had “angered god”, was “unredeemable” and that “I’d given myself over to evil, I was gonna go to hell”. This generated “hopelessness epitomised; abandonment from god”. The experiences of these participants suggest people with spiritual faith accessing EIP services may have experiences and needs related to their faith.

To manage the malevolent voices, the multi-faith participant reported visiting a cathedral and speaking with a clergy person. They described:

He was really good actually because obviously I was going through some kind of spiritual kind of thing and he just brought me back. He said...‘remember god is love’. So whenever it [voice] used to try and say anything to me, I used to say ‘I’ve had it from the church, that God is Love’.

This supported in managing their distress in a way which was relevant and fitting with their lived experience. This participant’s experiences illustrate one’s circumstances can be characterised by:

- Spiritual faith and phenomena,
- The feeling and stability of one’s faith,
- The role of religious spaces and relationships,
- Available support from religious members.

In seeking to understand the experiences of people with spiritual faiths, one may wish to enquire and adapt to each of these bullet-pointed features of spiritual circumstances.

Consistent with the lack of research on spirituality in the phenomenology or circumstances of hallucinations, secular healthcare systems may struggle to account for spiritual diversity. For people who have spiritual experiences or beliefs, their experience of the world may already differ from some people around them. Importantly, consistent with Andrade et al. (1988), experiences considered as paranormal, supernatural or hallucinatory, could be ‘real’ perceptions when

consistent with a culturally shared consensus of reality. This may be relevant within multi-faith context of Modern Britain; seeking to understand another's spirituality/reality, may support in understanding their experiences. The secular features of healthcare provision may generate layers of complexity in healthcare interactions with service-users presenting with unusual sensory experiences whilst holding spiritual beliefs.

Many participants lived in a “more than...physical world”; a Spiritual Britain, where spiritual practices and beliefs could support in managing distress. One participant expressed their feeling of the world through Figure 8.05 and explained “God is everything, the universe itself” and a spiritual existence made:

More sense, as opposed to: there's nothing out there, other than millions and billions of miles away, you hear voices in your head and you're a paranoid schizophrenic or whatever...It doesn't have to be that way but for my understanding, comfort, it is.

This quote seemed to exemplify the held value of freedom of one's reality and the value of Spiritual Britain for many people here. A reflective commentary on the ethical quandaries surrounding studying spirituality and reality has been included in Appendix F3. As discussed earlier, within existing research, participant's religion or spirituality was not typically explored and none of the SR2 (circumstances) studies had documented the religion of their participants. Perhaps future research should integrate considerations of faith into research designs and data generation tools. As pointed to earlier, as service-users with spiritual beliefs are seeking support from secular-healthcare services, information related to faith and spiritual practice may not be readily provided. Clinical implications from these outcomes suggest practitioners should ask about service-users' spiritual beliefs and practices, and whether these can be used to enhance coping.



Figure 8.05 Painting of the spiritual and created feeling of the world.

8.04.2 Digital Britain.

The digital circumstances of Britain described by participants included technological objects of: TVs, radios, computers/laptops, cameras and CCTV, games consoles, smartphones, tablets, and digital screens. This section explores ways in which digital technology interrelated with hallucinations and the ongoing lives of people who experience them. A case of digital harassment and online abuse is presented, before further exploring experiences of hallucinations in terms of technology. This section closes by examining surveillance in Britain.

8.04.2.1 The Feeling of Digital Harassment: Becoming Subject to Omnipresent Abuse.

Concerns surrounding technology and social-media's potentials for harassment were described by female participants only; who identified the capacity for "anonymity" and not being "accountable...for the things you say" online. This section presents an in-depth case example to shine a light on the gendered experience of Digital Britain, and a trajectory of lived experience which chapter 9's analysis of feeling-traps explores further. This section explores a case of the experience and impact of becoming subject to online harassment by a group of men

After befriending the group, the participant described “I never expected it...it [harassment] just escalates”. It did so over two-to-three-years whilst completing a distance learning course. She described:

I was really literally stuck to the computer...friends were far away...I was happy just being alone...I used to stay in the house most of the time...always on the computer, I was always on social-media, so that was really my downfall.

She explained interactions “turned into something vicious” as “they saw me as an easy target” due to being isolated.

The harassment began with gendered written abuse via private instant-messaging on one social-media platform, she explained they “wanted...a target...a girl that they could call a slag and take the piss out of”. She explained the abuse escalated onto public posts on multiple social-media platforms of written posts “that she’ll do anything with this person, etcetera” and edited-images of “other people’s bodies and...your face on it”. These experiences generated distress, she described it being “really bad...the way I’ve been treated. It’s all built up...It’s all men...I’m the only girl and the target”, this was upsetting as “the bullying and everything was all sexual as well”. She reported during this time “I don’t know why, but I could feel them as well. Like I felt that psychically I felt them...I could feel like what they were doing...like being horrible and stuff like that”. This was the beginning of feeling presence and malevolence extending beyond the digital objects which would sustain and become ever-more intimate with time.

These feelings and the harassment continued. Further escalations included “hacking my laptop and mobile phone”; “I didn’t know anything about it until things started appearing on social-media about like personal stuff on my phone”. She described a feeling after “my laptop was hacked” that “they watched me write essays and I was really panicked...I’d take so long writing it and they’d take the piss out of that as well, like I feel all that basically”. Her reports indicated a feeling of watchful presence from digital objects (laptop, and mobile phone). This escalated further when “this device came into my life”, she explained “I felt all of them behind it, when they were doing things to me...I started to like get

scared because I felt like it [the device] came into my life then and I had the goosebumps and etcetera". "The device" was technology to visually monitor and act upon bodies by those given access to it. She explained "the same boys...doing the bullying also got given the device", the harassment thereby continued offline and beyond digital objects. Capacities of "the device" have been summarised in Table 8.06 and the Figure 8.06 body-map illustrates the reported feelings generated by the device. The information suggests many varied distressing feelings arise, alongside a strong sense of presence and concrete reality.

Table 8.06
Participant Reports of the Capacities of the Device.

<u>Device Capacity</u>	<u>Participant Quote</u>
Shareable Technology	"The one that had the device ...the satellite and stuff and he gave it out to all these people."
Monitoring and Stalking	"They all know about me...basically they were in my house."
Device Captures Live Images of Bodies	"He is connected with his eyes to the screen and it connects over to me...the device is watching me...I feel like it's surrounding me, my body, so I'm on his screen as well."
Closeness of the Device to Body Parts is Felt Through Heat	"It's just like heat...my heat reflected against me...It doesn't feel free. Like skin feels nice and tingly, but mine don't; mine feels all clammy all the time."
Device Can Zoom and Focus Onto Body Parts	"My face has been tracked. Like my eyes sometimes, like it feels like he zooms out my eyes or something and my eyes feel nice and cold and tingly at the same time. Or my feet have – like he's zoomed out of my feet and my feet have felt nice and tingly and I've felt really nice, like just in bed and stuff like that."
Device Shares Images of Bodies	"Like he was showing off my sister's body and my mum's body to all these people."
Using the Device to Act upon Bodies	"He's watching me, he's doing all these things to me." "If I feel like there's something really close to my vagina area and it feels really uncomfortable and I just keep pulling at it to take it away from me. That's when I get really angry and frustrated".

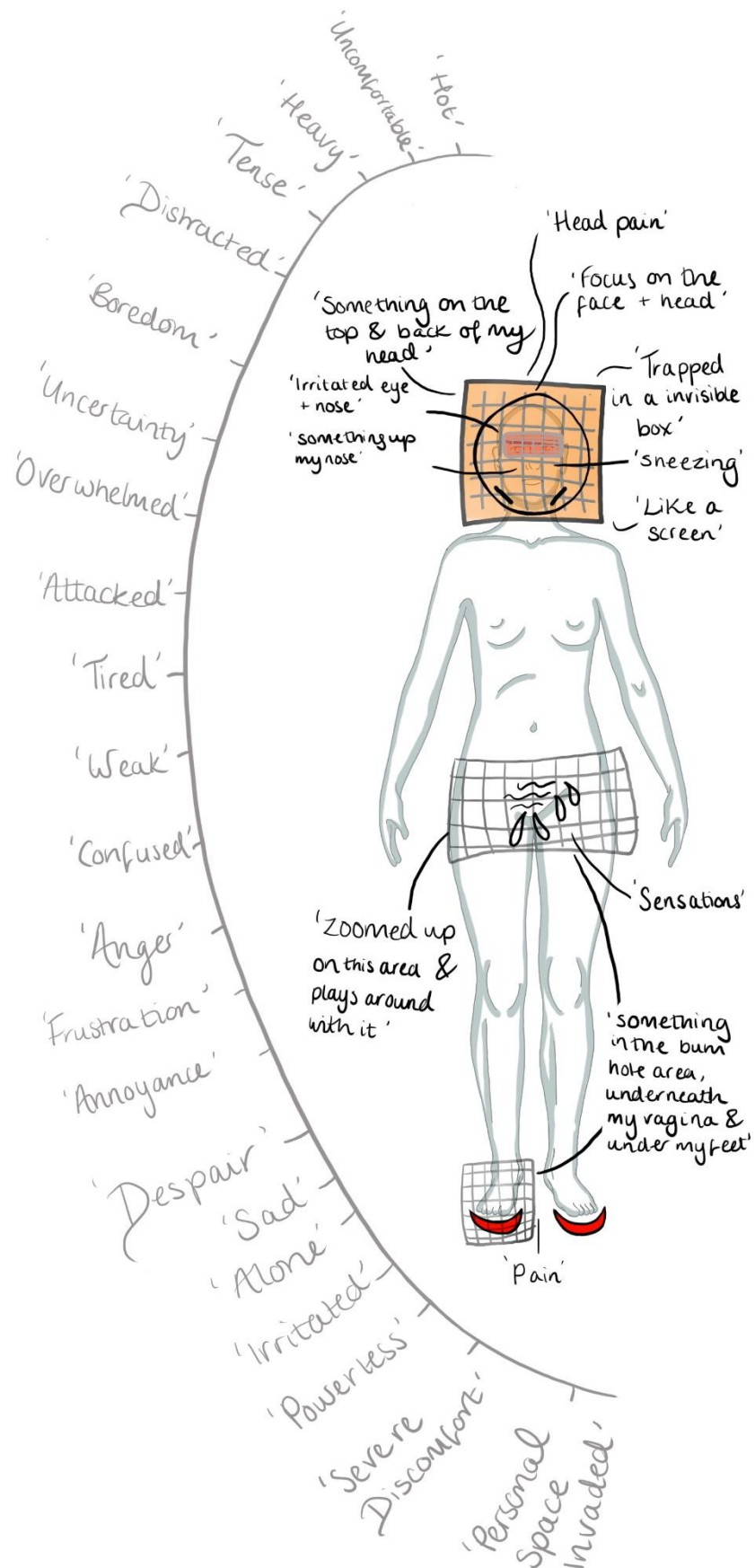


Figure 8.06 The feeling of "the device": body-map data analysed in C7.

Parities between “the device” experiences and prior harassment included gendered abuse from men, with sexual content focused upon women’s bodies. Figure 8.07 holds the participant’s expression of her experiences, of a long trajectory of feeling harassed and abused. She explained in the past “it was all done like via the social-media and then this device came into my life and the way they acted and followed me, stalked me, and then did things” it has felt “really horrible, like my mind is really horrible at that time...frustration and anger and mind’s racing constantly. And I just feel really panicked and like there’s no-one to help me”. She felt the harassment she had been subject to online was the source of the series of difficult events that followed, explaining “if I had deleted them back then, I think none of this would have like carried on and...happened to me”, “that [online harassment] happened six-seven-years-ago. I’m still dealing with all the impact of it”.



Figure 8.07 Participant drawing of the feeling of ongoing omnipresent digital harassment.

This case demonstrates Britain's digital circumstances hold emergent platforms for harassment against women, with distressing and novel impacts. Systematic review research had not explored the impact 21st century technologies such as smartphones, social-media, instant-messaging. This seems due to both rapid technological advances and neglect of circumstances within hallucination research.

8.04.2.2 Digital Technology and Hallucinations.

Digital technology related to hallucinations in varied ways such as: an ongoing hallucination trigger, a part of daily life's circumstances, and a source past difficult feelings or experiences. For some people digital objects were mediums through which hallucinations were experienced. With their illustration (Figure 8.08) a participant explained they "come through these devices. The TV, the radio, the computer...they also influence and contribute to my hallucinations". Consistent with Nayani and David's (1996) research of TV exacerbating AH, participants described TV's providing commentary, presenter's voices addressing the hearer, and the news as a potent trigger; such that a participant explained stopping "listening to the news because I just found it too distressing with the voices spinning off in my head".

Due to their embeddedness in material environments, where technological devices were triggers or sources of hallucinations, they seemed difficult to escape. A participant explained "he follows me around everywhere. Especially where there's technology...away from the technology I don't really hear [voices]...at all"; unfortunately, their workplace and home had many technological

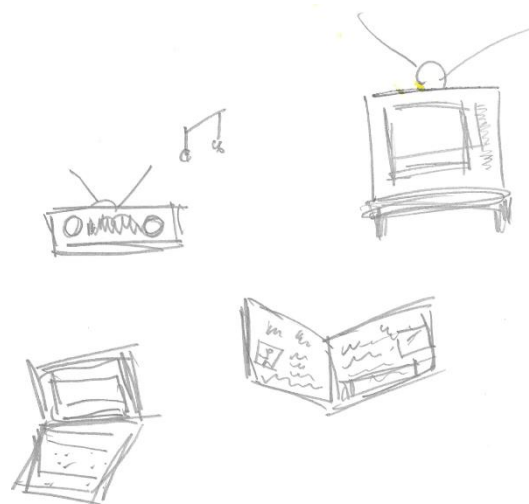


Figure 8.08 Illustration of the media and devices hallucinations come through.

devices. A participant explained "when I'm having a worse day" they sought and stayed in certain spaces to feel "more safe because there's no screens". This

may be relevant to designing clinical or support spaces, for people struggling with hallucinations

Digital-media such as films, youtube-videos, games, and chatrooms were also used to navigate and ease daily life. Video media (films and youtube-videos) were reportedly used for entertainment, or to make sense of unusual sensory experiences. For people spending most of their daily lives at home, digital-media such as games and chatrooms were used to connect with people “you make friends and you've got people to talk to...just benefit each other, which is quite helpful”. With a lens of hermeneutics of suspicion, although digital social spaces may be beneficial and accessible, they may also inadvertently maintain physical isolation from face-to-face social relationships. In the case study, ongoing isolation and social-media were described as the “downfall” which precipitated their distress.

Overall, experiences of hallucinations in terms of technology indicate technological devices and digital-media (e.g. TV, radios, computers, social-media-use, internet-use) may often have a negative impact upon one’s wellbeing and hallucinations. However, digital-media such as films, youtube, games and chatrooms may also be beneficial. Given the varied and novel outcomes, further research should study the advantages and disadvantages of digital technology and social-media use among people experiencing hallucinations. This section closes by considering watchful feelings and surveillance in Britain.

8.04.2.3 “One Nation Under CCTV”.

This subtitle references Banksy’s (2007) mural where a child painting the phrase is filmed by a policeman. Participants often reported feelings of being watched co-occurred with hallucinations; these were often described in relation to digital recording devices (overt and covert cameras) as Table 8.07 presents. Some participants reported consequences such as inspecting and adjusting their living environment. One participant reported negative health outcomes. They required hospital treatment as “my bladder was about to burst because I couldn’t go to the toilet...I thought cameras were everywhere and people were watching me...I was hallucinating really badly then”. This feeling of being watched through

technology reflects the earlier case-example, whilst pointing to the reality of being watched through ever-more intimate technology and surveillance.

Table 8.07

Participant Reports on the Feeling of Being Watched with Recording Devices.

<u>Report Summary</u>	<u>Detailed Participant Report</u>
Feeling Watched and Checking	"I feel like I'm constantly being watch and monitored...I feel like there are covert cameras and sound recording devices in my flat. Sometimes I go around with my flashlight on my phone and be like 'is that glass?' I'll go around to all the different places where I think there's a camera in my flat".
Cameras in Flat Livestreamed Online	"I could hear things going on outside. That there's a secret website that only certain people know about and they go to that website and there all the cameras in my flat. So they only have to go to that website and they can only go to that website and see what I was doing. It felt like that for a long time".
Checking and Covering Cameras	"I think there's cameras in my flat as well...I'm hunting for cameras and I find anomalies. I think that's weird like plugs that are different colours or slightly wonky; it just throws me off. So some days I've just covered them all up, cause I'm sure people were watching me through these cameras...As soon as I cover them up, they go. I hear them say 'Oh we'll go to his brother's then'".
Filmed At Home: Potential Test Subject	"I'll be washing up something and the TV's commentating on me washing up and I'm like "that's not possible" do you know what I mean? I mean I haven't got the curtains closed but there's no way, why would there be that kind of resource?...I don't know if it is someone in the room with loads of cameras. Just doing this strange thing on someone to see if we can handle it or to see if we're getting used to it. Or big brother. Everyone's going to have cameras in their houses one day and we're just the test people to try it on or I dunno. It could be anything...Definitely confused and question myself, my sanity but then I just ignore it and I just think I'm just going to do what I'm doing".

Given widespread reports of feeling watched, it seemed interesting to consider the extent of CCTV surveillance in Leicester, (where data-generation was based). Big Brother Watch (2012) relevantly reported Leicester had the highest number of CCTV cameras (2,083) of any British local authority; more-than-double the number in Leeds, Manchester and Liverpool combined. Perhaps

ongoing feelings of being monitored and watched (as participants reported), are understandable given the lived reality of this in Leicester. Although participants' locations varied, these outcomes point to the experience and potential outcomes of surveillance in Britain.

Alongside proliferation of CCTV and surveillance monitoring, recent years have seen rising personal data sharing through social-media. A participant explained "people are on social-media all the time", due to this, refraining from engaging with it could be difficult. Concerns regarding social-media and personal information sharing included being cyberstalked ("people will look on...profiles to find things out about people...I don't like that") or of being harassed or bullied online ("I did get bullied at school and I just could see it for what it could be used for"). A participant explained "I'd protect myself by trying to limit the amount of photos with my face on it, from going online". As exemplified in the case-example, such concerns surrounding stalking and harassment represented the lived realities of online-life. Further to formalised schemes of surveillance (e.g. CCTV), social-media seemed to form an inter-citizen and intra-citizen form of surveillance, in which people "kind of put a version of their life" and "other people can put photos up of you as well and tag you in things online", to be seen, monitored and potentially harassed by others.

For some participants the feeling of technology was of being "aware that I have...paranoid feelings of being watched or listened to" but of continuing to use technological devices as "there's not really any way you can't live in this day and age without technology is there?" A life intimately fused with technology seemed somewhat unavoidable, both technology and hallucinations seemingly shared an omnipresence. The analysis raises interesting questions of how one can stay and feel safe in a Digital Britain, what the mental-health impacts of technology are, and the reality of being monitored and watched. Given the parallel rise of digital healthcare interventions, it seems important for further research to consider the interrelationship between digital technology and unusual sensory experiences.

8.04.3 Childhood and Adolescence in Modern Britain.

Thirteen participants (81% of sample) attended interview two which explored life history; this sub-section considers their data. All participants' childhood's involved education, many also involved drugs and alcohol; later sections focus upon these. Adverse Childhood Experiences (ACE) are established risk factors for experiences described as psychosis (Bentall, 2003); Read et al.'s (2003) research evidenced CSA, and CPA were predictive of hallucinations. As such, the semi-structured and ABRM design aimed to accommodate for the likelihood participants may have been subject to abuse and trauma. This section documents what growing up in Britain was like for participants with a focus on ACE, and what this meant for their hallucination experiences.

8.04.3.1 Growing Up in Britain is ACE.

Experiences of growing up varied, some participants reported "a really happy upbringing", some described a positive childhood whilst also experiencing adversities, whilst some childhoods held numerous and longstanding hardships. Two participants did not report ACE and felt their experiences of hallucinations were elicited solely by events in adulthood, (online harassment and poor working conditions). This section focuses on ACE and their interrelationship with hallucinations. Experiences considered as ACE were those arising under-age eighteen, which were described as salient and negatively impactful upon one's wellbeing.

85% of participants (n=11) attending interview two reported twenty-five types of ACE shared in Table 8.08. ACE varied in terms of the: number experienced (between one and ten), length of time they endured, and consequences they had upon one's feelings and circumstances. Many of these experiences included being subject to harm from others, ongoing hardship, and witnessing distressing events, harm to others, or disaster. Reports surrounding being subject to harm through CPA or CSA, were consistent with Read et al.'s (2003) research. Many reported ACE were described as altering one's life course, or as the starting point or cause of hallucinations. Such ACE included murder of a loved one (one's sibling or friends), a parent becoming terminally

unwell, being raped, being subject to recurrent physical abuse from family members and witnessing domestic violence.

Table 8.08
Participant Reports of Adverse Experiences During Childhood.

<u>Experience</u>	<u>N</u>	<u>Experience</u>	<u>N</u>	<u>Experience</u>	<u>N</u>
Becoming Dependent on Substances (Illicit Drugs &/or Alcohol)	6	Friends Murdered	1	Recurrently Witnessing Domestic Violence: Grandmother Beaten by Boyfriend	1
Caring for a Chronically Unwell Parent	3	Sibling Murdered	1	Recurrently Witnessing Domestic Violence: Parents Physically Fighting One Another	1
Parents Separating	2	Terminally Unwell Parent	1	Teachers not Acting to Stop Physical Abuse from Peers	1
Parent Having Inpatient Psychiatric Care	2	Physically Assaulted by Teacher	1	Witnessing a Step-Parent have Sexual Intercourse with A Neighbour	1
Parent with Alcohol or Substance Abuse Problems	2	Threatened of Being Shot By Father	1	Recurrently Physically Assaulted by Cousins and Physically Assaulting Cousins	1
Recurrently Physically Assaulted by Father	2	Physical Abuse from Peers	1	Chased and Physically Threatened by Unknown Man	1
Being Left Out of Social Groups	2	Witnessing Dead Bodies Wash Up on Shore	1	Recurrently Physically Assaulted by Grandfather	1
Verbal Abuse from Peers	2	Accidentally Setting Self on Fire	1	Witnessing Riots	1
Sexual Assault (Rape)	1	Gendered Harassment (From boys to girls)	1		

The remaining ACE were described as contributing parts within a milieu of circumstantial features which precipitated hallucinations. Existing EIP

research considering childhood experiences, often focuses upon trauma, an umbrella under which some but not all the reported ACE fall. For example, ACE of an unwell parent appeared to profoundly impact wellbeing and education, but may not be conceptualised as trauma. Furthermore, difficult childhood friendships (recurrent verbal insults or being left out) reportedly had an ongoing negative impact. A participant described they had “no trust at all” in relationships as “childhood friendships” had been “awful for me” and another described feeling “self-conscious, very low self-esteem, just very socially awkward as a consequence. Just had it in my head people didn’t like me”. Using participant’s reports to define those examined as ACE, accounted for the variation in events which may be experienced as adverse or contributors to later hallucinations.

A varied interrelationship between experiences and wellbeing was exemplified by “Parental Separation” which for some participants was described as having a long-term negative impact on their wellbeing, whereas for others it was not. This nuance is consistent with Langer’s (1967) and Cromby’s (2015) approach to feeling. Ongoing feelings seemed to be interrelated with the unique circumstances and life histories within which they emerged. There did however appear to be consistent patterns wherein being subject to abuse (physical or sexual), and witnessing harm and death, and illness of a parent, generated ongoing distressing feelings and were felt to contribute to hallucinations. The analytic outcomes consolidate the importance of trauma-informed approaches to hallucinations and EIP, whilst indicating the relevance of further ACE.

Consistent with the previous paragraph’s discussions, the reported impact was as varied as the ACE were. Consistent with chapter-7, the reported feelings arising from ACE ranged across all analytic feeling categories; they were also often difficult and common feelings included fear, sadness, confusion and anger. To provide an example of feelings generated by ACE, a case of rape is now presented.

8.04.3.1.1 ACE Case-example of Rape.

Figure 8.09 holds a participant’s artistic expression of the feeling: after rape in adolescence, of contracting “loads of diseases”, and the trauma “ringing on” thereafter. The participant explained going “into a phase of such confusion”

after being raped, “where I wasn’t quite sure what had happened to me and that just lasted for years”. They described the difficult feelings and thoughts during this time, which began with wondering:

‘What, did that just actually happen to me? Did I consent to it?’ I really didn’t want to accuse him of something he might have not have done. But as I got older I realised that’s really wrong what he did...then it started to manifest in other ways, I would think I had scabies, I was worrisome and if anyone showed any kind of interest in me.

I avoided sex because I thought I would have to endure something like that again.

I was really over sensitive like if someone said something to me it really had a big effect on me. I’m always really worried what people think...I didn’t feel like other people, other people could socialise whereas...I’d get it wrong and end up feeling really stupid...I just didn’t feel the same as everyone else. I just felt really different and something wasn’t right.

Trying to brush it off as if nothing had happened but really I couldn’t actually, I wasn’t coping properly. It just kind of went like a haze a haze a haze a haze a haze a haze, like I said I was getting scabies, I kept going to the hospital, just confusion.

The report of this participant illustrates, the difficult feelings after rape, which interrelated, sustained and gained complexity with time. This points to feeling-traps, which chapter-9 explores further.

This case-example illustrates the complex distressing feelings which can arise after ACE, as well as the indirect ways their aftermath may present to health services (“feel like things are crawling on me. Just really itchy”). The participant reported recurrently attending sexual health clinics and healthcare services due to what was thought to be scabies; this was not found to be the case and the unidentified feeling persisted. These ongoing sensations reflect a similarity between the phenomenology of their trauma and hallucinations thereafter. This subsection continues by exploring further examples of such interrelationships.



Figure 8.09 An artistic expression created by a participant when the feeling after rape continues for years after.

8.04.3.1.2 ACE and Hallucination Phenomenology.

This section suggests past adverse circumstances may interrelate with hallucinations arising at a later time-point. Examples of phenomenological similarities between ACE and hallucinations have been documented in Table 8.09; including the case-example of rape. For two of these examples, the theme of hallucinations was the same as the ACE (Gendered Harassment, Rape), for the other three the sensory content was the same as part of the ACE (STI After Rape, Physical Assault by Father, Accidentally Setting Self on Fire). These outcomes are consistent with existing research on the potential interrelationships between the phenomenological qualities of trauma and hallucinations (Hardy et al., 2005). It builds on this research by providing qualitative data on the reports from participants; perhaps such examples may support disseminating research on the interrelationships between adversity and hallucinations. The next section explores reports of positive parts of childhood.

Table 8.09
Similarities Between ACE and Hallucination Phenomenology.

<u>ACE</u>	<u>Similar Phenomenological Report in Hallucination</u>
Gendered Harassment	Voice “threatens to rape, he threatens to kill, and it’s, yeah, it’s like to try and control your life, and to try and make your life a misery”.
Accidentally Setting Self on Fire	“I see or smell things, like gas and smoke, when I’m not even around it at that point”.
Rape	Voices of “Threat of rape and stuff, to me and my brother, that I can only connect that to what happened to me then [points to sexual assault point on timeline]...he would speak to me through the floors saying ‘there’s nothing you can do about it, it’s all been put in place, you’re just gonna have to go through it endure it’ “.
STI After Rape	“I feel like things are crawling on me. Just really itchy”.
Recurrently Physically Assaulted by Father	“I think it might be my dad’s voice” “telling me he wants to beat me up and stuff like that.”

8.04.3.1.3 Positive Parts of Childhood.

Importantly, alongside ACE difficult impacts, participants also described the benefits from positive childhood experiences. A participant whose hallucinations reportedly stopped during the study described:

I’ve had a pretty terrible time of it and then I guess that was the knock-on effect, was going into psychosis...my life has been majority good, so I think what helped me recover faster, was I have a lot of good memories.

They also consistently reported the support of female elder family-members, most notably their mother and grandmother throughout these times. The value of such networks of support, are discussed at the end of this chapter. This data suggests there is value in positive childhood experiences, and potential benefits in the outcomes of participants who have them. As well as seeking to prevent ACE, research and interventions should seek to generate positive childhood experiences.

Overall, a series of nine propositions (summarised in Table 8.10), can be made regarding hallucinations and ACE based on the evidence presented here.

To continue building data on the variable ACE which may precipitate hallucinations, further research may benefit from using life-timeline methods with EIP and child and adolescent samples. This may help in generating an understanding of the breadth of experiences hallucinations may arise from and support in developing interventions which could seek to prevent ACE. Reflective commentaries on the experience of researching and writing about ACE and the value of visual methods regarding this are shared in Appendix F4 and F5. This chapter will now continue to explore a feature of growing up in Britain: education.

Table 8.10
Propositions on the Interrelationship of ACE and Hallucinations on the basis of the Analysed Data.

<u>Proposition Number</u>	<u>Proposition</u>
1.	ACE were common among people experiencing hallucinations in adulthood.
2.	Many different kinds of ACE may feature in a life-course of someone who experiences hallucinations.
3.	People experiencing hallucinations can identify adverse experiences that have impacted negatively on their wellbeing.
4.	The impact of some events (e.g. parental separation) may be adverse and enduring within one person's situated circumstances but not necessarily another's.
5.	Many varied and difficult feelings can be generated by ACE and these may sustain over years.
6.	ACE were reported as both the sole cause and a contributing factor in starting to experience hallucinations.
7.	ACE and hallucinations in adulthood can share phenomenological properties.
8.	The outcomes of ACE may present to healthcare services in indirect ways.
9.	Positive childhood experiences may support the later reduction of distress.
10.	Future research may seek to understand how ACE can be prevented and how positive childhood experiences can be generated.

8.04.4 Education.

In SR2, some studies had demographic information regarding level of education (Bless et al., 2018; Janaki et al., 2017; Ma et al., 2016; Varese et al., 2011) but experiences of hallucinations did not appear to have been studied within the context of education. Within the current study, all participants were educated in England until at-least age sixteen. Education was discussed in terms of a:

- Social and material setting where one's formative years were spent;
- A source of pressure, stress, or isolation which precipitated hallucinations starting;
- An umbrella of social-material circumstances and necessary activities which were difficult to navigate or succeed within whilst experiencing hallucinations;
- A place of trauma through bullying from students (physical assault and verbal abuse) or for one participant physical assault from a teacher.

This section will briefly report and present the nuanced picture of participant's experiences of education.

Many participants were in education when they went through adverse or traumatic life events; events which many felt contributed to their experience of hallucinations. Participants also reported the features of navigating education itself (stress, pressure, isolation to study), contributed to their hallucinations starting. Consideration of this is also highlighted in a later sub-section of overworking in relation to cannabis use and hallucinations. Overall, most participants reported hallucinations starting whilst in education (63%,n=10): 19% in secondary education (age 11-16,n=3), 25% in further education (age 16+,n=4) and 19% in higher education (age 18+). Such participants reported experiencing hallucinations whilst in educational settings and during educational activities (both in and outside of the home). Experiencing hallucinations negatively impacted upon education in terms of engagement, attainment and attendance. Experiences of education seemed nuanced by pressures upon schools which were "just concerned about grades" such that "people that weren't doing well, people having trouble in their family lives and stuff, had been kicked out". The insecurity of education was reflected in some of participants' experiences of losing their place at school or university.

Difficulty navigating education seemed to arise within a context of limited or complete lack of support staff, such that “you don’t have anyone to help you”. Things which supported in staying in secondary education were a “time out pass...to go out for ten minutes” and in higher education, support where “most of the department helped me out” to return to university after being kicked out. Overall, the data suggested experiencing hallucinations whilst in education was:

- Common,
- Challenging,
- Negatively impacted on wellbeing and attainment, and
- Could be improved or worsened by features of educational practice.

With most participants experiencing hallucinations whilst in education, studying these experiences and potential interventions of support may be a key future research area. The next section considers work and employment.

8.04.5 Work and Employment.

As Table 8.11 summarises, this stream was constituted of many elements which this section explores. Among participants, 31% were employed (n=5), 6% in full-time education (n=1) and the remaining 63% were not in work or education (n=10). The unemployment-rate was lower than most SR2 studies of whom 74-81% were unemployed (Janaki et al., 2017, Ma et al., 2016; Varese et al., 2011). In Bless et al.’s (2018), Norway-based study however, a much higher 46-66% were employed; this may reflect differences in location and their sample being drawn from the general population.

Table 8.11

Streams Composing Work and Employment in Modern Britain.

<u>Characteristics of Work</u>	<u>Experience of Working</u>	<u>Hallucinations at Work</u>	<u>Gaining, Retaining and Losing Work</u>
Type of Employment	Difficulties	Triggers	Returning to Work
Good Work	Benefits	Feeling	Losing Work
Bad Work	Balance	Impact	Being Made Redundant
		Struggling	Unemployment
		Managing	Career Loss
		Declaring to Employer	Wanting to Return to Work
			Still

Experiences of work and employment varied; participants described both good and bad working conditions. 56% (n=9) of participants described bad working conditions as Table 8.12 summarises. Reported consequences included: stress and distress (n=9) and exacerbated hallucinations in terms of their frequency or emotional impact (n=6). Two participants reported hallucinations having been initially elicited by difficult working conditions; with a further third participant describing the unmanageable workload stress from employment and further-education elicited hallucinations.

Table 8.12

Features of Bad Working Conditions in Modern Britain.

<u>Feature Description</u>	<u>N</u>
Losing Work and Being Made Redundant Due to Hallucinations and Distress	3*
Being Treated Badly by Staff: "The managers and team leaders spoke to you badly, it was stressful"	3* **
Lack of Support from Employers Regarding Experiences of Hallucinations and Distress	2*
Insecurity of Employment	2*
Unmanageable Workloads "you can't be everywhere"	2* **
Change in Management: With a Decrease in Autonomy at Work	2* **
Emotional Labour: Contrived Social Interactions with Customers	2
Consequences of Time Pressured Mistakes or Incomplete Work (Overtime or Docked Wages)	2
Lack of Training and Personal Responsibility for Training	1
Time Pressure and being told "to act faster"	1
Repetitive Work Tasks "saying the same thing 400 times in a row"	1
Financial Stress of "cash flow" and Delayed Payment for Work	1
Colleagues Commenting on Appearance when Make-up is not Worn or Hair is not Styled: "My hair and that doesn't do anything to my job. ...I'm here to do my job, not to do my hair"	1
* Described as exacerbating hallucinations.	
** Described as a contributing cause to experiencing hallucinations.	

All employed participants reported bad working conditions made staying in work difficult. Some participants stayed in poor working conditions due to feeling "I'm a failure" whilst not working; this may reflect British cultures which may be argued to equate people's worth with their the employability and productivity. For 80% of employed participants (n=4), bad features of work were reportedly manageable due to:

- Being limited in total number experienced (≤ 4);
 - Occurring in limited time-periods;
 - Co-occurring good features of working conditions (summarised in Table 8.13).
- Their employment conditions had reported positive wellbeing outcomes through social connection, enjoyable work activities, and support from colleagues.

Table 8.13
Features of Good Working Conditions in Modern Britain.

<u>Features of Good Working Conditions</u>	<u>N</u>
Benefits of Completing Work Tasks: Having Activity, "Satisfaction", Relief from Hallucinations (engaged in work and "distracted")	4
Enjoying Work Tasks "It's a hard graft but I enjoy it" and "it's really helped me to get through what I've mentally been through"	3
Friendly Colleagues "I've made good friends through work" and "I enjoy the laugh with the lads"	3
Working in a Happy Team: "it's a nice atmosphere"	2
Able to Have a Work-Life Balance: Periods of Time with a Decreased Workload	2
Work Facilitating Autonomy or Creativity	2
Support to Manage Hallucinations and Wellbeing (Including time for breaks during the day, time off work, time to attend appointments and adjusted work schedules)	2
Colleagues Supportive and Understanding of one's Hallucinations and Distress "my work colleagues have stood by me and ... they've been very understanding"	2
In Control of Declaring Distress to Employer "they kind of let me share as much, or as little... as possible"	1

For the remaining employed participant, the negative features of their work environment were numerous, ongoing and without positive features. The

participant reported bad working conditions had a detrimental impact on his mental health and AVH had “all come from stress really...all to do with work”. They reported AVH were initially caused and continuously triggered by their working conditions. Overall, features of working conditions were described as contributing one’s experience of hallucinations and broader mental health. The data suggested an interrelationship between work and hallucinations beyond one’s employment status (the aspect of work studied in existing SR2 literature).

8.04.5.1 Losing Work.

Further to employment conditions impacting on one’s mental-health, some participants reported losing work due to hallucinations and distress (n=4) and one participant was being made redundant during the study. The analysis thereby documents prospective and retrospective data on the impact of losing work for people experiencing hallucinations. This was described as eliciting difficult feelings including:

- Uncertainty during redundancy unfolding of “not knowing what’s happening”;
- “Worry” and “really stressful” experience of the process;
- Worsened hallucinations: “I’ve got voices telling me that...I’m losing my house and everything like that and I can’t deal with it ... It’s all the things you don’t want to hear”;
- Incapable and hopelessness: “I kept crying...I can’t do a job. Any job I do I just lose it, so I can’t do it. I really just can’t do it”;
- Fear regarding the negative financial impact of losing work: “I’ve still got a mortgage to pay, a child to bring up, people to feed”.

Due to the insecurity of employment in the UK, upon finding or returning to work negative feelings continued, including feeling “really scared”, “lost confidence” and decreased “self-esteem”.

Two participants reported repeatedly losing work and their desired careers. They described missing their employment prior to hallucinations and mourning the loss of their careers and skills. Upon returning to employment by gaining a new job and relocating, one participant described two occasions where their hallucinations and distress worsened, resulting in job loss (twice), further relocation (twice) and hospitalisation (once). Their experiences exemplified the

complexities of modern work, which often includes changes and disruptions in one's social-material circumstances. Further to experiences of working conditions impacting upon one's mental health, this data demonstrates lived experiences of hallucinations often involves processes relating to losing, gaining and retaining work as well as changes in one's career trajectory.

8.04.5.2 Hallucinations at Work.

For employed participants, work environments and activities formed a central part of daily life. All employed participants reported experiencing hallucinations in work including VH (n=1), AVH (n=4) and simultaneous MMH (n=2; TH+BH+AVH or BH+AVH). All employed participants reported negative co-occurring feelings including fear, feeling upset ("it makes me wanna cry"), difficulty concentrating, feeling overwhelmed, stressed, feelings of being commented upon or talked about, and uncertain feelings of reality regarding one's sense-experiences. Two participants described interrelating work-related stress, and AVH volume such that they could "hardly even hear what they [colleagues] are saying, I can hardly even concentrate ". This will be further examined with regards to feeling-traps in chapter-9.

Overall, although participants consistently reported experiencing hallucinations "intensifies" in work their feeling, content and impact varied. Hallucinations at work seemed to vary in terms of one's job role (including its interpersonal demands), working conditions, and the experience of hallucinations themselves (including content and feelings). Experiences of hallucinations in work were further nuanced whether participants had opportunity to use their own coping strategies (summarised in Table 8.14). These helped to manage hallucinations whilst in work. The extent to which participants could use these strategies was mediated by features of their job role, support of their employer, and the quality of their working conditions.

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Table 8.14

Coping strategies to manage hallucinations whilst in work or employment.

<u>Coping Strategy</u>	<u>N</u>
Having time off work (Days, Weeks or Months): “catch up on sleep and try and get back to normality as much as I could, so I could carry on working”.	4
Having a break from work tasks: (“Just have time out”, go for a walk, talk with someone from one’s support-network on the phone).	3
Distracting oneself from hallucinations by engaging in work tasks.	3
Leaving work early “when it’s really intense, nothing works and I just want to go home where I’m comfortable and just go to bed”.	2
Boundaries with work: Having time for work-life balance.	1
Whilst working “music was quite a big one...just listen to it”.	1

Overall, the interrelationship between hallucinations and work and employment was nuanced by numerous processes for employed participants (summarised in Table 8.15). This analysis stream discussed issues surrounding career trajectory and gaining employment, indicating concerns surrounding employment can be relevant to unemployed people. For some participants, concerns surrounding work and employment did not arise during the study (n=3) however, due to the semi-structured design further participants may have had undocumented experiences or concerns. Work and employment were a relevant and nuanced circumstance of many participants’ experience of hallucinations. The novel analytic outcomes seemed important, as most SR2 studies did not mention participants’ employment. The chapter continues by exploring material (in)security and welfare.

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Table 8.15

Eight features of work and hallucinations which nuanced employed participants' experiences of hallucinations at work.

<u>No.</u>	<u>Features of Work and Hallucinations Which Nuanced Experiences</u>
1.	The kinds of activities work involved.
2.	The interpersonal demands of work.
3.	The broader quality of work and employment conditions (as summarised in Table 8.13 and 8.14).
4.	The sensory content of hallucinations.
5.	The feeling of hallucinations.
6.	The extent to which participants were able to use their own coping strategies to manage their experience of hallucinations (including time off work, leaving work early, and extra breaks).
7.	The extent to which employers and colleagues were supportive and understanding.
8.	The security of employment.

8.04.6 Material (In)security and Welfare.

Participant's material security varied greatly within the sample and seemed stratified by:

- Access to secure employment,
- Access to housing,
- Family support or resources (e.g. living in a family home, familial wealth), and
- Access to welfare-support systems (e.g. financial support and social housing).
- Extent of the impact of ongoing difficult life events or hallucinations,
- Financial circumstances and resources prior to hallucinations starting (e.g. secure employment, housing, financial savings, education and historical familial financial circumstances).

Experiences of hallucinations appeared interrelated with material security and many participants needed welfare-support to survive.

56% of participants (n=9) reported currently receiving financial welfare-support. The remaining participants maintained material security through employment (n=3), student loan funding (n=1) and support from family (n=3). Three participants (19% of sample) reported having been homeless for up to

four-years. Experiences of abuse during homelessness included: physical assault, labour exploitation and being robbed. All three participants experienced hallucinations whilst homeless; one participant reported first experiencing hallucinations whilst homeless. Such data suggests homelessness is a vulnerable state and issues surrounding homelessness may be pertinent to people experiencing hallucinations. These and three other participants (38% of sample) were living in council housing; which was consistently spoken of positively. A participant described being “properly looked after by the council, they’ve given me a really nice flat. I love my flat and...where it is”. These homes were described as places to take care of and feel pride; they were safe, quiet and predictable spaces to return to when the world or hallucinations were difficult. Despite their value, these resources have been under threat due to ongoing funding cuts to councils and welfare-support from government economic policies (Hastings, Bailey, Bramley, Gannon & Watkins, 2015).

The interrelationship between material security and hallucinations was exemplified by one participant who reported their AVH were elicited by the stressful process of purchasing and moving into their first house, whilst overworking and receiving verbal abuse from new neighbours. This generated a vulnerable situation for their material security and wellbeing, they explained: “I live on my own so I need to pay my bills...do my work...to carry on regardless”. This reflected the difficulties surrounding employment and financial welfare-support in Britain (summarised in Table 8.16). Financial welfare-support was described as a need one had to justify to access material “basics” and reduce worry: although due to its limitations and insecurity it could become a source of worry, anxiety and worsened voice hearing too. The insecurity of welfare-support further reflects the austerity policies and welfare spending cuts that contextualise Britain today.

The cultural impact of government economic policies of austerity seemed to be that the ideology behind the policies has been internalised, as a moral wrongdoing within individuals in need, that it’s “bad being on benefits” or receiving support. A brief reflection on working-class wellbeing has been shared in Appendix F6. Overall, the circumstances of experiencing hallucinations in modern Britain, seemed to be characterised by a need for material welfare-

support (financial support and housing) and a challenge and difficulty in maintaining one's material security without pre-existing wealth or ongoing family support.

Table 8.16
Features of Financial Welfare-Support.

<u>Feature Summary</u>	<u>Participant Report</u>
Less Desirable Than Work: Need to Justify Support	"I didn't want to for a long time because I thought, I wanna go back to work. I tried to go back to work twice. Both times I wasn't ready for work."
Need to Justify Support	"I'm trying to explain to the Jobcentre that day to day things is hard...everything is so much harder...and eventually you avoid doing things."
Access to Welfare-support Reduces Worry	"I get my benefits, so I don't worry too much."
Access to Basics	"It affects my life because I can't go and buy what I want, but I can afford just the basics of what I need. I've got a TV...I haven't got internet."
Limitations of Welfare-support a Source of Worry and Upset	"I used to worry... because I was used to an income of a job, so I used to get depressed over it. So I've learnt to manage not to get upset, that this is my money now... I just need to budget it; I've got to be stricter."
Reassessment of Welfare-support: Insecurity, Judgement and Worsened Mental Health	"My benefits are being reassessed at the moment, so that's like stressing me out ... it's very stressful cause it's like your whole character is being judged. It's like you're not effing worthy, am I not ill enough to receive these? It's like ugh, it's chaos... going through it all, definitely my anxiety has been worse and my voice hearing. It all correlates it does. Yeah it's been tough...it can take months."

8.04.7 Drugs and Alcohol.

This section explores eight participants' (50% of sample) reports of having used illicit drugs (n=6) or alcohol (n=5) in a problematic way; including their interrelationship with hallucinations and why they were used. Some participants mentioned taking illicit drugs around the time when hallucinations were first arising. As Table 8.17 illustrates, this was consistently reported alongside

precipitating features such as: overworking (n=2), conscience after causing accidental injury (n=1), coping after rape (n=1) and fear of criminal sanction due to drug criminalisation (n=1). Consistently, a participant described in the precipitation of hallucinations, illicit drugs seemed to be “bundled up into a big mess” with further features one’s broader lived experience and circumstances.

Table 8.17

Social-Material Circumstances of Hallucinations Starting, and Illicit Drug Use.

<u>Precipitating Situations</u>	<u>Participant Report</u>
Overworking	“It was like a candle burning at both ends.”
Overworking	Working 2 jobs and doing “a lot of hours in the week and then also trying to go to college as well, and trying to see my friends as well, and smoking [cannabis] at the same time. It all bundled up into a big mess kind of thing... I wasn’t going to enough classes and stuff and I was behind. All the stress and stuff built and then eventually I had the psychotic episode.”
Causing Accidental Injury	“I was on the drugs badly, the whizz. It fucked my head up to be honest” “I done something to her by accident and that’s what I hear. It’s conscience...that’s why I am how I am.”
Fear of Sanction	“It’s probably made me a little bit better because I shouldn’t have been doing it, so anything you shouldn’t be doing is always going to be making you a bit edgy, a bit paranoid, a bit afraid of something that may or may not because you know you’re doing something you shouldn’t.”
Coping After Rape	“My life just went like a haze... I got into drugs around this time aswell, yeah and just a haze really, I feel like that bloke stole my life from me.”

Of the six participants who reported prior drug use, during the study three reported abstaining and three described continued but reduced use. Continued drug use was due to:

- Pleasure “I just enjoy it too much” although AVH “gets louder, I can’t deal with it [AVH] as well” (methamphetamine [n=1]), and
 - Coping with hallucinations (“I have to smoke cannabis to block it out” [n=2]).
- The two participants smoking cannabis to manage hallucinations were currently

receiving ‘antipsychotic’ drugs via depot injection. This sheds interesting light on the research explored in chapter-1 regarding the inconsistent evidence surrounding the supposed benefits of ‘antipsychotic’ drugs and the lack of study regarding QOL (Moncrieff, 2015; Moncrieff, Cohen & Mason, 2009).

Like illicit drugs, drinking alcohol was described by five participants as a coping strategy to cope with hallucinations (summarised in Table 8.18), as well as trauma, and ongoing difficult circumstances. Overall alcohol seemed an accessible but ineffective coping strategy as one participant described; “you think you’re getting somewhere and you’re not, you’re still in the same place drinking.” During the study 80% (n=4) of these participants, were abstaining from alcohol. One participant described they found “it hardest not to drink these days”, this may be due to the legal status of alcohol increasing its availability, accessibility and its commonplace consumption within British culture.

Table 8.18

Experience of Using Alcohol to Cope with Hallucinations.

<u>Drug</u>	<u>Function +/-</u>	<u>Participant Quote</u>
Alcohol	+	Calms Hallucinations “I was hearing so much of everything, all of this and more. It was too much. And to calm it down is to drink alcohol”
Alcohol	+	Option When Other Strategies Don’t Work “If I’m at home, and you’re hearing the voices and you’ve turned the music up and you’re still hearing them and you’re pissed off ... you have a beer.”
Alcohol	-	Worsens Hallucinations “It normally gets worse.”
Alcohol	-	Begin Talking Out Loud to AVH “I’m speaking out to myself and saying things...when I had the alcohol it comes out loud.”
Alcohol	-	Vicious Cycle “If I feel like it’s that bad that I can’t go out of the house, because I feel like I’m walking down the road and everyone’s talking about you, and no one’s even at the window or anything, you tend to stay in. And you go through that vicious circle of thinking, oh, I’ll have a couple of drinks.”

Alcohol -	Unachievable Satisfaction and Illness “I don’t drink because it goes to another, I end up going for another bottle. That’s why I quit. I get a taste.” “It makes you ill.”
Alcohol -	Unsustainable Coping Strategy “I need to get drunk and not have to deal with all these things going on with me but...you can’t be drinking every night.”

Abstaining from illicit drugs or alcohol was reported as a difficult and ongoing process. Many participants reported seeking support regarding drug and alcohol use from their EIP practitioners, drug and alcohol services and their loved ones. Difficulty abstaining seemed to arise from both the “constant urge to use it” and that drug and alcohol use had been embedded into people’s daily-lives, experiences and social relationships. A participant described “I was using a crutch of cannabis for half my life. I feel like that’s left me a lot more unprepared for sober life and I need...new coping strategies.” Further to unpreparedness, successful abstinence often came at a cost of increased social isolation “I don’t hang around with no one now but I’m healthier”. This enmeshing of substances into one’s life and relationships, reflected the young age substance use often started.

All but one of the participants who described reliant drug or alcohol use, reported habitual use started during childhood (under age 18); the youngest of whom reported starting “smoking [weed] when I were 9” and “when I were 13 I used to drink a litre a day [vodka]”. Illicit drugs and alcohol seemed to be material phenomena embedded into the ongoing social fabric of many participants’ lives, and often from an early age. Drugs and alcohol seemed to be relevant features of life and hallucinations in Britain for many participants. Further research may benefit from studying:

- Experiences of using and abstaining from illicit drugs and alcohol among people experiencing hallucinations;
 - What coping strategies people turn to when ‘antipsychotic’ medications do not resolve distress;
 - Experiences of people using cannabis as a coping strategy for hallucinations.
- Such research could develop information, training and potential interventions

both for service-users, service providers (EIP and drug and alcohol services), and supporting loved ones.

8.04.8 Society of Inequality: Discrimination, Harassment, Authority, and Police.

Many aspects of the dataset pointed to a sense of a society of inequality, this included oppression and discrimination reported from female participants, BAME participants and working-class participants. As described at the beginning of this Modern Britain section, although experiences were already nuanced by intersecting oppressions, these were not often explicitly topicalised in the dataset. Analytic streams where inequalities were most overt regarded the gendered experience of Digital Britain, and the content of this current stream. Participants experiences of hallucinations arose within a context of mixed experiences of police, authority, harassment and discrimination. Further to previously documented difficult feelings in association with the criminalisation of drugs, participants reported varied experiences of police as Table 8.19 summarises. Two primary streams of police experiences include:

- Access to help and threat of police,
- Experiences of racial profiling (including stop and search) and managing discrimination.

With regards to accessing support from the police, the needs of people experiencing hallucinations may be complex as their experiences may not be felt as real by others. This may generate unique vulnerabilities and difficult feelings as one participant reported “I’ve tried the police, that got me nowhere. In those situations, I feel powerless”. To support both people experiencing hallucinations and the police, further research may benefit from studying their experiences of one another with aims to facilitate effective provision and service use.

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Table 8.19
Experiences of Police Among People Experiencing Hallucinations.

<u>Experience</u>	<u>Participant Quote</u>
Fear of Wrongful Prosecution	"I've been shouting and stuff because I felt like the police were assessing me as if I've done something wrong that I hadn't and do you know it infuriated me actually. I ended up defending myself and sticking up for myself."
Confusion Due to Lack of Help from Police	"I thought the police weren't helping me because they were involved in it. But really they weren't helping me because it was a hallucination."
A Source of Contact and Help	"I was contacting the police loads. I think I was doing their heads in but they were really nice really. They sent me to a few different places to get some help and stuff "
Wanting Support From Police	"I keep thinking about like tomorrow it's going to come out and the police will find out...like the police need to be involved, take him away from the computer and then I can be free."
Difficulty Accessing Police Support	"They were able to get away with it because every time I reported it was going down as psychosis when a lot of the time they were doing it."
Racial Profiling and Police Harassment	"You've got to worry about the police who constantly harass you because they assume you're the same as them but you're not...it's really inconvenient."
Racial Profiling and Disruption of Stop and Search	"It's 15 minutes of them stopping and searching and asking you questions. Then they offer you a little pink slip, so if you want to make a complaint – but by the time you've wasted 15 minutes, you just want to go at that point. If it happens too often ... at least once a month" "It's really irritating because I've got to take everything out my bag, my laptop and my journal and all this stuff and they look in the bag, then they go 'what are these pills?', 'that's my medication. There's the legal medication and box for it and everything, there's the receipt'."
Managing	"Just one bad move and the police are called on me or security is called on me. I don't know how I'm making people feel uncomfortable, but I have to make sure I'm making people feel relaxed and comfortable at all times so I don't have an encounter with the police or if I do have an encounter with the police I have to make sure I am extremely nice to them. I know they're just doing their job, but it is annoying if it happens twice a week sometimes."

Experiences of police also involved managing racial profiling and discrimination; this section will consider a case example of a participant of African Caribbean ethnicity. This case is important to share as the systematic reviews suggested, samples of research studying the feeling of hallucinations have been biased towards participants of white ethnicity, and the circumstances of hallucinations have seldom been studied. This participant described a constant emotional load involving dedicating “a big chunk of my energy into not making people feel uncomfortable, even though I’m constantly uncomfortable. It’s hard to deal with. It’s hard to...make the perfect balance that won’t get me in trouble or other people upset”. Managing this balance was a matter of safety as “you can get arrested just for walking. You can be arrested for being black on a Friday night” with the threat of “beaten up by the police or even killed by the police”. This threat was recurrently experienced through being stopped and searched by police. This reflects government figures of police discrimination in Britain, where in 2017/18 black people were 9.5 times more likely (than white people) to be stop and searched (Home Office, 2019). The hypervigilance, discomfort, and continuous emotional load of safely navigating daily life seemed to both generate and exacerbate distress and hallucinations.

The challenges of Modern Britain may be difficult to navigate among BME peoples who experience hallucinations; due to being subject to discrimination for their ethnicity and stigma surrounding distress. Further to police, interactions with security staff and people in authority were frequent and difficult, the same participant recalled:

I was stopped by security guards because they said I was looking weird and I was acting weird. That was because I was hearing things and I was trying to just get the thing I wanted and get home and get out of there as soon as possible. I’d already paid for it, got the receipt. I had to show them. They were saying I looked suspicious, that I stole something or looked like I was about to do something. Then it’s not really helping, me having a breakdown or meltdown, or me hallucinating. Sometimes it gives them more cause to stop me because they think I look suspicious.

Consistent with Crenshaw's works on intersectionality, BME peoples who experience hallucinations may be subject to the challenges of multiple oppressions (Cho, Crenshaw & McCall, 2013). Experience of or difficulty navigating interactions with people in authority (such as security staff or police), may put people experiencing hallucinations at risk of harm; as well as threaten their social-material security.

The opening chapters discussed concerns surrounding the neglect of circumstances in the study of experiences such as hallucinations; the data reported here illustrates why understanding the feeling and circumstances of hallucinations is so important. The experience of hallucination documented in this case example was nuanced by multiple features including (but not limited to):

- Where it happened (a shop) in contrast to where one felt able to manage their experience best (at home);
- One's ethnicity in relation to the where they were and the people present (e.g. shops and security staff as circumstances of racial profiling);
- One's ongoing personal history (of repeated difficult, distressing and unwarranted interactions with security staff and police).

Hallucination experiences (alongside one's capacity and opportunity to manage their wellbeing and safety) were enmeshed in these social-material-temporal features. Individualist or biomedical approaches which negate or obscure the relevance of circumstances to experiences, may be conceptualised as harmful to the wellbeing of communities who experience discrimination and inequality. To support in developing relevant understandings of experiences and interventions to manage them, the circumstantial nuance of hallucinations must be studied.

8.04.9 Mental Health Care in Britain.

All participants were current NHS EIP service-users, they each experienced and discussed care from NHS services. Whilst seeking and receiving mental health care for hallucinations, features of helpful and unhelpful encounters were reported. These features form the focus of the first sub-

section's analysis, after which spaces and chemicals of care are explored before closing the section by considering informal networks of care.

8.04.9.1 Reports of Positive and Negative Care.

The most common research base in both systematic reviews was the UK, despite this routine NHS care had not been studied. Negative and then positive experiences are documented in this section. Many participants described negative experiences of care for hallucinations. Where specified the healthcare practitioners included: GPs, accident and emergency (A&E) doctors and nurses, EIP psychiatrists and EIP nurses. Table 8.20 summarises the participant's negative reports of care for hallucinations with quotes in Appendix F7; these could be summarised into interrelated streams of problems with communication and problems with available care. The negative reports of care seemed related the current dominance of biomedical and individualist approaches to mental health care and the impacts of almost a decade of government cuts to healthcare funding.

Table 8.20
Summarised Negative Reports of Mental Health Care.

<u>Problems With</u>	<u>Negative Report Summary</u>
Communication	Not being believed (therefore no further care).
Communication	Feeling experiences are not adequately responded to or acknowledged
Communication	Distress not being recognised or validated
Communication	Lack of information regarding "what was going on" and "where I was" when forced to be admitted to an inpatient psychiatric ward and unable to leave.
Communication	Practitioner not understanding one's experiences.
Communication	Fear of not being supported due to not being understood.
Care	"Really scared" of diagnosis of psychosis or schizophrenia.
Care	Feeling uncomfortable due to the male gender of the practitioner.
Care	Fear of being sectioned.
Care	Being given ineffective drugs.
Care	Being given drugs without other support.

Care	Being diagnosed with drug induced psychosis when experiences preceded drug use.
Care	Struggle to find and access appropriate care (in general and when away from primary home).
Care	Assumptions from practitioners that experiences are hallucinations (when they may not be).

Positive care reportedly came from practitioners including: EIP Nurses, an EIP CBT Therapist, GP and a Clinical Psychologist. Good care seemed characterised by the value of safe relationships and attempts to understand and adapt to the experiences and needs of service-users. Positive participant reports of mental health care have been documented in Appendix F8. Summarised features of positive care included:

- Someone who visits to talk to,
- People to talk with when isolated,
- Support independent from one's personal life,
- Accessible, reliable and consistent ongoing care,
- Support to learn about experiences of hallucinations,
- Support and guidance to try coping strategies,
- Provision of future care planned.

EIP care seemed particularly valuable, as relationships of trust and support could be held and maintained over long-time-periods (up to three-years). Having a consistent support-network may be valuable to service-users such as those experiencing hallucinations, as stable relationships can hold trustworthy tethers to consensual reality. The provision of trusted long-standing support-networks seemed an invaluable resource for people experiencing hallucinations; a participant described “knowing that you’ve got someone there at the end of the phone is helpful...even just knowing that you’ve got someone there, you probably don’t ring them as much”. Although the positive features of care were discussed in terms of the value of talk and social connection, support for hallucinations also involved spaces and chemicals of care which the following sub-section considers.

8.04.9.2 Spaces and Chemicals of Mental Health Care.

Reported care often happened within clinical spaces and often through the provision of pharmacological drugs (chemical care). Appendix F9 summarises participant reports of chemical care through drugs which may be described as ‘antipsychotic’ and ‘antidepressant’. The features of chemical care with ‘antipsychotic’ drugs may be summarised as experiences of:

- Drugs not improving hallucinations,
- Drugs improving hallucinations,
- Time consuming health monitoring,
- Being forced to take drugs,
- Drugs being difficult to take,
- Despite benefits, drugs “cause more problems than what they solve”,
- Prescribed drugs replacing illicit drugs; becoming reliant,
- Something which people stop taking due to their effects,
- Not being supported to understand “horrible” effects before taking,
- A burden and often difficult to access form of care, and
- A way to make sense of experiences when other explanations haven’t been provided.

Given the infusion of chemicals into mental healthcare practices, the reported experiences were concerning. As chapter-1 discussed, drug-trials seldom consider QOL (Moncrieff, 2015), in the outcomes here, numerous and predominantly negative impacts on QOL can be seen including: lost time, burden of accessing medications, unpleasant to consume, unpleasant effects and feeling uninformed. The analysis generated concerns regarding the extent to which ‘antipsychotic’ drugs are helpful, and the extent to which service-users are supported to understand their risks and burdens.

Overall, the appropriateness of the primacy of chemical care for hallucinations seemed dubious. Although the medications were reported as helpful by some participants, the outcomes surrounding ‘antipsychotic’ drugs for hallucinations mirrored existing research for experiences described as psychosis, where they were often unhelpful, harmful and with inconsistent benefits (Moncrieff, Cohen & Mason, 2009). Based upon the analytic outcomes, clinicians providing chemical care must support service-users to understand the

drug effects (including those which are unpleasant) and inform them of the likelihood the drugs *will not* resolve their experiences. Further research should study the experience of ‘antipsychotic’ drugs for people experiencing hallucinations with a focus on: their felt effect on hallucinations, daily life and QOL; the extent to which they were informed about the drug; the extent to which they felt compelled to take them; and participants feelings about their distress and hallucinations when ‘antipsychotic’ drugs do not resolve them. To identify areas for necessary training, further research may need to also consider the understanding of ‘antipsychotic’ drug outcomes among clinicians overseeing chemical care.

The material circumstances of healthcare for hallucinations were infused with ‘antipsychotic’ drugs and clinical spaces. Spaces of care for hallucinations included GP surgeries, A&E departments, inpatient psychiatric wards, outpatient EIP clinics and one’s home during EIP visits. Experiences in A&E spaces and inpatient psychiatric wards seemed to be most problematic and as such, these are the spaces focused upon. A&E spaces were reportedly attended when:

- Experiences were not manageable with the available coping resources,
- When family members were concerned and unable to manage.

The experiences of one participant are focused upon as they attended A&E during the study. They reported struggling with simultaneous MMH at a time when they could not access the medication they needed (quote report in Appendix F10). They described “I was just lost there in a place I shouldn’t really be in (A&E). It was really loud, the smells, everything. It was really bad. It wasn’t good for me”. Their experience as expressed in Figure 8.10 illustrates the busy social-material features of A&E can be difficult to manage for people experiencing hallucinations. Furthermore, accessing the care was difficult; involving navigating the threat of being “sectioned”, and a wait of “six hours”. It seemed accessing urgent care for hallucinations was difficult, distressing and exacerbated hallucination experiences.



Figure 8.10 Visual expression of the distress and overload simultaneous MMH.

Hospital inpatient experiences for hallucinations also appeared characterised by difficult and distressing features. The experiences reported were often of being held in hospital spaces involuntarily and indefinitely (for days, weeks and months), and forcibly medicated. 31% (n=5) of participants reported prior inpatient psychiatric treatment due to their hallucinations and many participants reported concerns of being sectioned; this fear was shared by both participants who had and had not been sectioned before. The lived circumstances of hallucinations held an ongoing and fluxing threat of sectioning.

Whilst under section, the experiences of use of space and chemicals for care combined. A participant reported it being “really weird being in that hospital”, “I thought they were poisoning me or something”. This feeling of chemical malevolence seems understandable as they reported having been forced to consume psychoactive medicinal drugs whilst being made to stay in a unit without the freedom to leave. This participants’ reports reflected overarching difficult feelings and “weird”-ness of living in such circumstances and of retrospectively making sense of one’s care.

Overall, experiences of statutory care were mixed, although aspects of the EIP approach appeared beneficial. The positive features of current mental health care can serve as a present-guide for care providers; by focusing on understanding service-user's experiences and needs, whilst adapting available support to address these as best as possible. Given the difficult circumstances which hallucinations reportedly arose within, the primacy of chemical care and the difficult realities of inpatient treatment seemed ill-fitting. Despite reported experiences seeming tightly interwoven with one's circumstances, interventions such as chemical care do not address them. Fitting with the dominance of individualised and biomedical approaches, the individual body was often seen as the problem to be managed with regards to hallucinations. Despite chemical and inpatient care, lived circumstances would continue being toxic to mental health; securing housing stays difficult, poor working conditions would continue, and people are still overworked until they are unable to work. Consistent with UNHRC (2017), to have effective mental health care for experiences such as hallucinations in Britain, the conditions of the circumstances in which people live must be improved. This section closes by exploring informal care networks.

8.04.9.3 Informal Networks of Mental Health Care.

Beyond statutory care, many participants reported receiving support in navigating their experiences from people in their lives. Relationships with members of informal care networks were diverse and multifaceted; for some participants these relationships had been sources of (or related to) prior adversity or abuse. With this, the extent and quality of informal networks of care varied. To provide information and potential guidance for people providing informal care, this section will focus upon what was reported as helpful. Regarding family, one participant explained:

I guess it's just a safety net...there's always that security there for me if things go cray-cray there's people there for me. I've always got somewhere to stay and people to vent to essentially, they're my first port of call if it goes a bit wrong.

Where available, informal networks of care seemed to provide a social and material safety net and container for distress. Informal support included providing

material security (e.g. an ongoing place to stay), support to attend appointments, social contact, listening, and respecting lived experiences. One participant explained although her partner had different opinions on the source of her sensations, she felt supported by their listening and taking an interest each day so “he knows exactly what I’ve been through”. This process of listening and bearing witness to her lived experiences, provided a supportive connection during challenges she was otherwise facing alone. For some participants (n=3), their romantic partners provided ongoing valuable support for their experiences, however most support reported by participants came from friends, family, colleagues and people in their professional support-network (e.g. EIP nurses or psychologists).

Consistent with the example of care through listening, support of people being there was consistently described as beneficial. Contact with support-networks and spaces of safety such as long-term council housing provided moments of ease and positives to life as one participant explained: “I’ve got good friends, I’ve got a nice family, I’ve got a lovely flat that I’ve decorated...me and my brother go for a coffee...so other than the hallucinations and stuff I live a nice life”. This again points to the value of both social and material support. Further support through being there long-term was demonstrated best by the consistent positive reports of having pets (cats or dogs). As two participants explained “It’s like having a best buddy, isn’t it?” and “I love my dog loads, he’s been a massive help on the road to recovery for me”. Pets provided value through their ongoing companionship, alongside opportunities to provide care and share walks together.

Overall, although formalised care services had often provided a lifeline of care for participants, a lot of reported ongoing care was from informal support-networks (where these were available). Supporting a loved one with hallucinations often seemed to include providing emotional support (manage distress and often substance problems), material support (money, housing, food), and time (to listen, to meet healthcare needs). The care needs which informal support-networks are trying to meet may be complex, unfamiliar and beyond their existing coping strategies. Consistently, it was often family members who initiated support seeking to manage hallucinations; which they did

not appear to have support in facilitating. The reports of participants suggested their support-networks may benefit from support themselves.

One participant described their informal support-network was crucial to their wellbeing, that “where I’m blessed is that everyone around me is very loving and very caring and that’s what has ultimately enabled me to not go crazy”. Future research may benefit from studying what support is needed to facilitate care from informal support-networks. Based on the data, this could be anticipated to involve access to material resources (financial support to provide care, social housing close-by to support-network), support from employers to provide care (e.g. carers leave), and access to information on hallucinations and support from care services.

8.05 A Picture of Madness in Modern Britain

This chapter opened by describing that the lived experiences of hallucinations were characterised by their salience, presence and their part in reality. The exploration of the circumstances which compose life in Britain, provided evidence that ongoing circumstances were relevant to the characteristics of the hallucinations, how they felt, the impacts they had, and how they were navigated. The features which made hallucinations salient, seemed to reflect one’s lived experiences in Britain. This enmeshment was described by a participant who explained: “It’s not just all in my head. It’s actually the world I see and feel around me, in different ways, at different times”. Consistently, hallucinations form part of Modern Britain.

Consistent with the conceptual lens informed by Langer (1967) and Cromby (2015), participants’ experiences shared commonalities and differences nuanced through the fluxing interrelationships of feeling and socio-material circumstances. Upon asking a participant what they hoped had been learned from their experiences, they shared a sentiment which astutely captured the analytic outcomes that: “experiences vary, and they’re not the same across the board. Different upbringings and different things can manifest in different ways”. The social and material circumstances of hallucinations and a picture of madness in modern Britain was composed of many interwoven features including:

- Activities of Daily Coping,

- Spirituality,
- Digital Technology (and it's Intimate Proliferation),
- Growing up and Adverse Childhood Experiences,
- Education,
- Work and Employment,
- Material (In)Security and Welfare
- Drugs and Alcohol,
- Inequality, Discrimination, Harassment, Authority and Police,
- Formal and Informal Care.

The mental problems in Modern Britain seemed to be the social and material conditions people were navigating. The difficult conditions which characterise many people's ongoing realities here are reflected in the lyrics of midland's artist slowthai (2019) who wrote "I said there's nothing great about the place we live in, nothing great about Britain". Reflecting on the circumstances of hallucinations in Britain -of bad working conditions, discrimination, growing inequality, of chemical care and cuts to welfare- a picture of madness is Modern Britain.

9. Empirical Analysis: Feeling-Traps and Hallucinations



Figure 9. Participant artwork of the feelings of voices.

Figure 9 holds a participant expression of what hearing voices was like; her “own worst nightmare”. The experience was described as finding oneself in a labyrinth underneath a “toxic spotlight, and you’re trying to get out of that spotlight”; “the feelings...associated with the experience...flock to the light” from which there is no clear escape route.

You’re desperately trying to reach this exit, but it’s so difficult to find the way out, there’s so many twists and turns...you don’t really know how to get out of it. You’re...testing things as you go, to try and find the way out.

This expression seemed to chime with key pillars of feeling-trap theory, of feelings interrelating and sustaining over time, such that navigating life may become difficult (Scheff, 2012). In Cromby and Harper’s (2009) work on feeling-traps in paranoia, they explored how the stability of one’s landscapes of feeling may be disrupted by surges in interrelating feelings; such as the spotlight turning on in this participant’s expression. Feeling-trap theories would suggest as a feeling-trap sustains, one’s experiences may diverge from a consensual reality; of getting “sucked into this, it is a bit like another world and you’re trying to figure out how to get out of it”. This participant’s expressions point to the relevance of feeling-traps theory to understand hallucinations. As applying feeling-traps theory to hallucinations was theoretically and empirically novel, the theory has been broken down into principles (Appendix G1), which are examined in relation to the data in this chapter. The chapter concludes by discussing the extent to which the concept of feeling-traps was useful in understanding lived experiences of hallucinations.

9.01 Principle 1. Feelings seem core to experiences of hallucinations

Consistent with this principle, chapter-7’s prospective analysis illustrated hallucination experiences seemed characterised by feelings. This included emotional feelings, extra-emotional feelings (which were either localised within or generalised across body areas), feelings of knowing, and feelings of reality. The relevance of varied feelings builds upon existing feeling-trap theory which focused upon emotional feelings (namely of anger and shame). The outcomes of the analysis seemed consistent with Langer’s (1967) conceptualisation of mind, with hallucinations appearing to be an emergent organisation of varied

feelings. With a lens of feeling-trap theories, hallucinations could be conceptualised as feeling-traps themselves; as recurrent organisations of emergent feelings. Overall this principle of feeling-traps theory was nuanced as feelings did appear core to hallucinations, although the definition of feeling would be broader; consistent Langer (1967), Cromby (2015) and the theoretical developments provided within this thesis.

9.02 Principle 2. Hallucinations may be co-constituted and sustained by circumstances

Chapter-7 and 8's outcomes illustrated the relevance of both historical and immediate circumstances in precipitating and sustaining hallucinations. For example, prospective data indicated hallucinations most-often happened whilst alone or at home; this was consistent with Stevenson et al. (2011) where bothersome OH typically arose at home. The relevance of the historical circumstances was further demonstrated during analysis of Modern Britain. ACE were reported by 85% of participants who attended the final interview (which generated life-history data). The following ACE were reported as precipitating or the starting point of hallucinations: the murder of a loved one (one's sibling or friends), a parent becoming terminally unwell, being raped, being subject to recurrent physical abuse and witnessing domestic violence. ACE are further explored in principle 3. The relevance of circumstances in seemingly eliciting and sustaining hallucinations was further illustrated within the frequent relevance of technology to hallucinations and the analysis of work and employment conditions in chapter-8. Employed participants' hallucinations seemed nuanced by the quality of their working conditions and the extent to which they could use their own coping strategies whilst at work. With those participants who had better conditions (including support to use coping strategies) faring better than those with poorer working conditions (including less opportunity to use coping strategies).

Throughout the dataset, hallucinations appeared nuanced by one's ongoing circumstances in such a way that their feeling, form and presence seemed personalised to the person experiencing them. They did not appear to be random sensory fluctuations or material, they appeared mostly connected and

relevant to one's ongoing lived history. Analytic outcomes of chapter-7 and 8, including the material summarised here indicated that consistent with feeling-trap theory, experiences of hallucinations may be both co-constituted and sustained by one's circumstances.

9.03 Principle 3. Traumatic and adverse circumstances can be internalised through feelings and may relate to experiences of hallucinations

Analysis of both online harassment and ACE in chapter-8 suggested feelings co-constituted by adverse experiences generated precipitative grounds for hallucinations. The current principle is examined in relation to ACE. Chapter-8 demonstrated the feeling of hallucinations could share phenomenological parities with historical ACE such as gendered harassment, rape, STI after rape, accidentally setting oneself on fire and recurrent physical assault. This suggested the feeling of difficult experiences may be internalised and emerge as hallucinations. Chapter-8's case-example illustrated feelings after rape (including STI's) were "ringing on" years thereafter. The participant described recurrent experiences of feeling "like things are crawling on me" and would present to sexual health services in attempts to manage them. These reports appeared consistent with this theory principle. The close interrelationship between the feeling of difficult experiences (in childhood or adulthood) and the feeling of hallucinations, lead some participants to report sentiments that hallucinations were "like a continuation of the abuse from before". Consistent with Bebbington et al. (1993), many participants seemed to have an excess of adverse or stressful life events prior to hallucinations; although for some participants hallucinations arose years later. This is explored later in relation to potentially unresolved feelings.

The organisation of feelings and circumstances of traumatic experiences seemed to provide reference points or ways of understanding emerging experiences. One participant expressed their experience of hallucinations and episodes described as psychosis were akin to being stranded on a beach.

It's like, when you're on the edge of a big body of water. That's how I describe it. It [reality] seems so far away, you can see to the horizon; the

horizon line is reality. You're there, stuck on the other side of the water like, how do I get there?...It's very fearful and...you don't really want to think all that was fake because when you think that, it kind of feels like you have lost something, because it is so real in the moment. What if all those things are true?...When you realise 'wait, no no no no no, I'm just hallucinating', it's like. Wow. It dawns on you. You have to realise, 'oh no I have to go on with my life and be normal'...When you're on the beach, you're completely in it, and you have no comprehension of reality at all. Then you slowly paddle through the water; that's the scariest moment. When you're in the water you realise 'oh God, this wasn't real'.

The data points to looping feelings to be explored later, and moments of disruption of the security and stability of reality theorised by Cromby and Harper (2009). Most relevant to the principle under examination was the abstraction of phenomenal properties of a beach -with its power, mystery and fear- to describe experience of hallucinations. This abstraction became relevant in the final interview, when the same participant described an ACE whilst at a beach:

There were children diving in and they got washed out into the, because the tide was going out. All these men jumped in to try and save them and they just ended up dying. People were just washing up on the beach, dead. Me and my family were just there watching as it all happened. It was really bad...Really traumatic. A family member went out as well, to go and try and save the children. He was out in the water for hours and he got washed back in by the tide, and luckily he survived...that sticks with me. That stuck with me for a long time.

The ongoing feeling of hallucinations seemed to be composed of the same process-relations which generated their most traumatic experience. The participant described an understandable ongoing fear of bodies of water, and within their expression of the ongoing feeling of hallucinations, to see or return to consensual reality one had to "paddle through the water. That's the scariest moment" where "you realise 'oh God, this wasn't real' ". This seemed to bring a renewed understanding of the difficulty of facing feelings of un/reality. Furthermore, these extracts illustrated the feeling and experience of one's reality

in the present appeared to be shaped through the processes of lived histories. Here trauma seemed to be internalised through the organisations of feelings and experienced process-relations; these potentially provided precipitative grounds for hallucinations and ways of understanding them.

9.04 Principle 4. Feeling responses can be acquired and become habitual forming modes of embodied subjectivity

The case-report of online harassment provided an example of how experiences of digital harassment which persisted and escalated over years, generated many difficult feelings. Over time feeling responses were acquired of being: targeted, subject to gendered and sexual digital harassment, stalked, having one's body digitally acted upon and manipulated, and of one's privacy being digitally invaded. This persisted such that she reported "I could feel them as well. Like I felt that psychically I felt them...I could feel like what they were doing, like horrible – like being horrible and stuff like that". Modes of embodied subjectivity appeared to be experienced such that the participant reported although the original online harassment "happened six, seven years ago. I'm still dealing with all the impact of it". This chimed with the participant's report of the feelings after rape "ringing on" for years thereafter. Consistent with the previous principle, difficult experiences seemed to co-constitute organisations of feelings and process-relations such that the past continuously gnawed into the emergent present (Middleton & Brown, 2005). The current principle seemed exemplified through the feelings generated by difficult and ongoing experiences.

9.05 Principle 5. Feelings recursively loop over time in sustaining circumstances.

Consistent with the varied feelings and circumstances which characterised hallucinations, the patterns of co-occurring and potentially recursively looping feelings seemed somewhat infinite. This seems intuitively likely within a Langer (1967) informed approach to feeling, wherein feelings are finely attuned to unique situated positions within environmental process relations. However, such a picture of feelings is more varied than seems to have been proposed in existing feeling-trap theory; which is often focused upon interrelating

emotional feelings (mainly shame and anger). The contributing role of shame is examined further in principle 6.

Consistent with chapter-7 and feeling-trap theory, feelings did seem to co-occur with reports of recursive loops. The diary data analysis indicated the more modalities simultaneously involved in a hallucination, the longer the hallucination lasted (up to a peak of 4 simultaneous modalities). Although the analyses on the number of simultaneous modalities and duration was limited by the number of diary entries, further analysis suggested MMH may be sustained by their increasing felt complexity (i.e. simultaneously co-occurring sensory and other feelings). The experience of simultaneous MMH and enduring hallucinations was described as difficult due to navigating: negative content, the impact on one's immediate circumstances, loss of time, and of holding consensual reality. A participant provided an example of a confusing simultaneous MMH experience, they explained:

It's how different things can be at the same time. They [hallucination entities] can contradict each other, and I won't be able to spot it because I'm having too many experiences and too many things messing with my senses...just confusing me, so I don't know what's happening and at this point...my willpower to resist these things is not as strong.

Such evidence appeared consistent with feeling-traps, as hallucinations involving more simultaneous modalities (and co-occurring feelings), appeared to generate confusion, obscure reality and sustain longer. Further unimodal hallucinations were retrospectively reported to sustain over time typically when threats to one or another's safety were invoked.

As proposed earlier and in chapter-7, hallucinations themselves may be understood a recursive cluster of feelings as sensory feelings were part of an emergent tapestry of feelings which recurred and sustained. This may be consistent with Langer's (1967) conceptualisation of feeling as the basis of mind, and Cromby and Harper's (2009) propositions of recursive feelings as intersubjective modes. A further case-example of recursive feelings is presented next, with consideration of some feelings reported most often and the potential role of clinical spaces in sustaining hallucinations.

The principle of feelings recursively looping in sustaining circumstances was exemplified in the experiences of a participant whose poor working conditions reportedly caused, triggered and sustained hallucinations. They described whilst at work: “when your anxiety levels go up and you’ve got threats coming in from work, and then your anxiety levels go up...then they’ll [voices] pick up on that. If you let that wind you up then they’ll get louder”. This suggested recursively looping feelings of anxiety, and AVH volume were sustained by poor working conditions. Consistent with chapter-8’s analysis, these hallucinations felt salient, present, and un/real and maintained this through their interrelationship with the circumstances through which they were co-constituted.

As argued within chapter-8, these were recursive ongoing feelings of hallucinations. This pattern of recursive feelings may be further explored by revisiting the experiences, of the participant who generated this chapter’s opening image (Figure 9.01). The saliently personalised qualities of hallucinations enabled her to “get sucked into...another world”. Her experiences and the expression of difficult feelings swarming around the “toxic spotlight” of voices, appeared consistent with this principle of feeling-traps (of feelings recursively looping in sustaining circumstances).



Figure 9.01 Participant artwork of the feelings of voices.

Further to the data chiming with theorised notions of recurring feelings, chapter-8’s analysis suggested some situations or aspects of circumstances appeared to bind hallucinations. Such circumstances included ACE, poor working conditions, material (in)security and spaces and practices of clinical mental health care. Further exploration of spaces and chemicals of care closes this principle’s examination. There were often parities between health care practices and reported feelings of hallucinations such as “feeling cameras were

everywhere and people were watching me”, of people “trying to arrest me” or “poisoning me”. Furthermore, many aspects of clinical spaces and practices (particularly surrounding sectioning and inpatient care), appeared to exacerbate and sustain hallucinations and their interrelating clusters of feelings. These have been summarised in Table 9.01.

The process-relations which formed participant reports, seemed reminiscent of Seigal’s (1984) hostage-hallucination research. Siegal (1984) identified hallucinations could be elicited by the individual or combined impact of: visual deprivation, social isolation, physical abuse, restraint on movement and having one’s life threatened. Parallels may be drawn from inpatient practices, including the potential for: involuntary admission/incarceration, being held indefinitely, reduced sensory stimulation, forced biological treatments, physical restraint on movement, and the removal of freedom of movement. On the basis of the empirical literature, the thesis data and the analysis process, it seems reasonable to question whether features and practices of what is called inpatient psychiatric care may form socio-culturally sanctioned hostage situations; which could elicit or worsen hallucinations. Such a suggestion would be consistent with the sentiments Dillon (2010) of the capacity of supposed care to re-traumatise. The systematic reviews did not identify empirical studies of the potentially negative impact of clinical spaces or practices for people who experience hallucinations. This area warrants further study and could draw upon growing contemporary bodies of literature studying how the material features of psychiatric wards interrelate with the experiences of people admitted (Reavey et al., 2019).

Table 9.01
Features of Clinical Spaces and Sectioning Practices which seemed to Exacerbate Hallucinations or may Sustain Recursive Clusters of Feelings.

<u>Feature Summary</u>	<u>Detailed Participant Report</u>
Busy Sensory and Distressing Spaces	“When I was in the hospital, and I can hear all these machines going off and people in pain and crying”. “It was really loud, the smells, everything. It was really bad. It wasn’t good for me”.

Observation and Lack of Information Regarding Observation	"I didn't know who was watching me or why...that also is like a real thing as well because I had to have people with me at the time, following me around and stuff and I didn't understand why that was happening".
Inconsistent Contact With Loved Ones	"I would lose contact with them completely and not have any way of talking to them".
Unfamiliar Locations and Lack of Information	"At the time, I didn't understand where I was. No one really explained it to me...they wouldn't say anything to me...There was just massive confusion".
Changing Hospital Locations Whilst Medicated	"I'd just wake up in a hospital bed, and they'd be there, and then I'd fall asleep and then I'd wake up somewhere else and then I'd be strapped down or whatever".
Kept in an Unfamiliar Place (Not Aware of Where or Why) and Unable to Leave	"Confused and I was like is this part of a test or am I being held in custody?...because they have the locking doors and stuff, so I couldn't leave if I wanted to and I was trying to leave".
Forced to Take Medication to be Able to Leave	"They give you pills and are like, "Why aren't you taking your pills? What is the point in you being here if you don't take your pills?' And after a week or two...It was like, 'You can't leave if you don't take the pills.' So I took the pills".
Continuous Threat of Sectioning	"Even if it was really bad... I wouldn't even ring in because I feel— I don't like it, explaining again to people I don't know...if it's really bad, and then I'd feel scared...I get scared in case I say something wrong and they take me away".

Overall, the data seemed consistent with feelings recursively interrelating over time in sustaining circumstances. For some participants there was a gap between ACE and hallucinations starting, this will be examined further in principle eight (regarding prior unresolved feelings). This current principle was useful in attuning to what aspects of circumstances may mediate, sustain or intensify hallucinations; including circumstances described as care. Within individualist or biomedical approaches to mental health, problems are typically conceptualised and 'treated' in terms of the individual. This principle of feeling-traps theory was useful in considering problems in terms of circumstances which may sustain

them. A participant described, “I’ve found that if I’m in an uncomfortable situation, the voices can start, which just reinforces the feeling of trying to keep out of uncomfortable situations, which I suppose can help prevent you from growing. But I’ve found it...a safer and slower approach”. Such an approach recognises it may be both reasonable and helpful to “keep out of uncomfortable situations”; such as the many adverse circumstances reported in Modern Britain. Drawing upon theoretical concepts such as this feeling-traps principle, may support in holding the feelings of the individual in mind whilst identifying adverse circumstances, such that these may be addressed or prevented.

9.06 Principle 6. Shame is a primary emotion in binding feeling-traps and often co-occurs with anger

Feeling-traps as theorised by Scheff (2012) were predominantly described in terms of interrelating emotional feelings; with shame as the master emotion which binds together the feelings in a feeling-trap. A proposed difficulty of empirically studying shame, regards its tendency to go unspoken. Consistently, shame was not often explicitly described during the study, although shame did appear relevant to many participants’ ongoing experiences. Table 9.02 summarises participants experiences which seemed to chime with feelings of shame. There seemed to be an interrelationship between feelings of shame and feelings of un/reality (the extent to which hallucinations felt concretely real or consistent with a consensual reality). Consistent with the participant’s metaphor of the beach (in principle 3), “you don’t really want to think all that was fake because when you think that, it kind of feels like you have lost something, because it is so real in the moment”. Within process-relations where hallucinations correspond to reality, the feelings or responses generated by them feel reasonable (less shame). However, should feelings of un/reality flux, such that hallucinations do not feel unreal, and one’s feelings and responses generated by them feel unreasonable, shame may likely increase. Consistently, for many participants understanding or appreciating hallucinations as not corresponding to consensual reality, was the “the scariest moment”. Should one metaphorically stay on the beach however, feelings of unreality, shame and their negative implications can be avoided.

Table 9.02

Participant Reports of Ongoing Experiences of Hallucinations and Shame.

<u>Feature Summary</u>	<u>Detailed Participant Report</u>
Shame Due to Accessing EIP Services	"I don't want people knowing that I'm coming here because then they're going to ask why and stuff, and I don't like it."
Shame Due to Responding to Hallucinations; Realising Unreal Later	"They weren't being horrible to me at all...thought they were and I was adamant about it, I think I was really horrible to them so now I just feel embarrassed and horrible and they think I'm a dickhead and I was towards them because I thought they were to me".
Shame Due to Responding to Voices	"When you've been listening to them all day ... I start shouting at them back and then you find yourself in a room on your own shouting at a wall and then just thinking, what the fuck am I doing?".
Shame Due to Feelings Generated by Hallucinations (Unreal)	"I feel like I'm fighting against an evil...at the time, you're really in it, it's so real to you and then you come out of it and you go 'oh my god' I just feel stupid now -because that was clearly- It can just be horribly embarrassing actually, it can just make you feel embarrassed because you believed something which wasn't real...you can get really upset over something that it wasn't happening actually."
Shame During the Void of no Hallucinations	"When I'd be walking up to my flat, usually I'd be hearing things going on from all different directions but sometimes I'd hear nothing, it's just a void, an emptiness. It goes back to I've been worked up about something that I didn't need to get worked up about. So that's where the void sets in. Ugh yeah, it was all nothing, why did I get so emotional? Why did I shout so much about something that didn't happen? It's horrible, it's like that."
Shame Due to Experiencing Hallucinations	"I feel ashamed...Because not all people know what's going on with me...I don't just go like, 'well, this is what I experience'...I don't want people to think I'm weird and maybe judge me or something...It makes me feel sad, a bit, and stressed because I feel like I need someone to understand. But I don't dare share it in case they turn against me or think I'm weird and talk about me".

This principle of shame's primacy in fusing feelings to recur was useful in understanding the difficulty and scariness of experiencing the unreal. However, as much as the feeling of shame seemed important, so too did feelings of

un/reality. These seemed important to hallucination's both as unreality is core to hallucinations' definition and due to un/reality's fluxing potential. Cromby and Harper (2009) pointed to the importance of the stability and security of reality to experiences to paranoia; with hallucinations also being under the shared conceptual umbrella of psychosis, these propositions may have been both theoretically and empirically built upon here.

This principle's proposition of the common combination of shame and anger was less useful for the dataset. However, there were some relevant instances. As summarised in Table 9.02, hallucinations could at times be responded to with expressions of anger; when hallucinations later felt unreal, feelings of shame seemed to arise, and the cycle recurred. Such a feeling-trap would be of sensory feelings, reality, anger, unreality and shame. There was also one participant whose feelings over their life-course chimed with the traditional shame-anger feeling-trap. After experiencing a trauma during childhood of finding their sister murdered (a traumatic experience which caused substantial ongoing impacts for themselves and their family), they described "I were just angry all the time", "I had a little temper on me, I used to hit out all the time...either pick something up or throw something". After this they explained feeling "horrible, it's like I've flipped out" and feeling "disappointed in myself". Their experiences seemed to exemplify recurrent cycles of anger and shame. Later principles further explore parallels with feeling-trap theory.

To summarise, attuning to the role of shame was helpful in understanding experiences of hallucinations, but most often due to its interrelationship with fluxing feelings of un/reality and at times associated feelings of anger. The role of both anger and shame was useful in understanding the experiences of one participant, for which this feeling cycle seemed to characterise their ongoing feeling experiences from an ACE, until hallucinations started in adulthood. Overall, this principle regarding the primacy of shame and its co-occurrence with anger was somewhat useful. This contrasts with the other principles which were more applicable and conceptually useful.

9.07 Principle 7. Disavowed or unacknowledged feelings contribute to feeling-traps

This principle is examined in terms of the circumstances which seemed to contribute to the disavowal of feelings, with exploration of a case-example and consideration of the acknowledgement of feelings in care practices. Table 9.03 summarises numerous circumstances which contributed to feelings being disavowed or unacknowledged. Consistent with the principle, as chapter-8 explored these features also seemed to contribute to the recursive feelings which characterised ongoing experience of hallucinations. This principle is explored in terms of the potential that hallucinations themselves may contribute to the disavowal of feelings. Although substance and alcohol use was also very relevant, this is explored in principle 8.

Table 9.03

Situations which seemed to Contribute to the Disavowal or Un-acknowledgement of Feelings.

<u>Situation Summary</u>	<u>Participant Report</u>
Racial Profiling, Discrimination and Navigating Excessive Encounters with Authority (Police, Security)	"I have to be self-aware all the time. I have to make sure I don't look suspicious, I have to make sure I'm exceedingly polite to everyone...I'm also making sure I've got to really control my breathing and make sure I don't panic or get stressed out. Just one bad move and the police are called on me or security is called on me...big chunk of my energy into not making people feel uncomfortable, even though I'm constantly uncomfortable".
Distress of Poor Working Conditions	"Just have to try to cool things down and just plod on with it." "Just crack on with it".
Continuing with Employment Whilst Experiencing Hallucinations	"Just keep like getting on with my tasks, because I live in this world and like the other world that's following me basically".
Substance or Alcohol Use	"I have to smoke cannabis to block it out".
Hallucinations	"You can get so wrapped up...you don't have your own headspace...there's just so much going on in there, there's no space for you".

Consistent with the last quote in Table 9.03 on hallucinations, the swarms of feelings which characterised hallucinations that “there’s just so much going on in there, there’s no space for you”, often appeared to implicitly disavow one’s immediate ongoing feelings and circumstances. A case-example includes hallucinations after rape. A participant described a “first block” of disavowed feelings and hallucinations involving “confusion...I just kept it totally to myself” and “it started to manifest...where I think I got scabies”. They explained that before starting “counselling and finally face my sexual assault (that I’d never told anyone about for years)...this bloke comes in and starts harassing me”. This “second block” involved hearing many persecutory voices and threats of sexual violence. He explained “this second block has stopped me facing the first block. That’s what this second block was intending to do”. In this way, the voices contributed to the dual-disavowal of feelings after rape and the hallucinations he was seeking to manage. Existing research has demonstrated the interrelationship between CSA and hallucinations (Read et al., 2003). Perhaps this current analysis may shed light on the potential contribution of disavowed feelings within this interrelationship and the difficulties people may face upon trying to acknowledge traumatic experiences.

The data examined seemed to be consistent with the contributory role of disavowed feelings in some participants’ experiences, and of features of life in Modern Britain facilitating this. Chiming with chapter-8’s concerns surrounding mental health care in Modern Britain, the primacy of biomedical and individualised mental health approaches seemed relevant to this principle. As discussed in chapter-1, by conceptualising feelings and hallucinations as meaningless symptoms of illnesses, their lack of acknowledgement may be implicitly or explicitly encouraged. Furthermore, with circumstances placed separate from or unmentioned within such approaches, acknowledging circumstantially co-constituted feelings may become difficult. This seemed reminiscent of Waddingham’s (2017) writing shared in chapter-1, which described seeking care as entwined with a process of relegating the context of distress to an illness trigger. This provided an example of the processes by which feelings and contexts may be increasingly disavowed whilst seeking care. With the case-example of distress after rape, the facilitation of the disavowal of

feelings and circumstances during care seems ethically reckless and damaging. The realities of this however echo the writings of Dillon's (2010) re-traumatising experiences of seeking psychiatric care with a history of CSA. In contrast to the un-acknowledgement of feelings, participants often described understanding hallucinations in terms of their ongoing feelings and circumstances (of "why you're hearing stuff in your head"), as an important step in one's situation improving.

Regarding the un-acknowledgement of feelings, a participant explained by "bottling it up (which is what I've done a lot in the past) you hold onto it". They explained support from EIP practitioners lead to "being quite open with it [hallucinations]", this enabled being able to "just to get it out of the way and then you can move on, that's really quite a big, well massive help...it's not such a big deal...it's not such a...taboo". Perhaps acknowledging and sharing experiences helps to navigate ongoing feelings such as fear, shame and un/reality. The value of long-term support from EIP practitioners was "mainly having someone to speak to and talk about it and help you with it". Although such support was available through informal networks of care for some participants, EIP services held a valuable role as a place to share, acknowledge, understand and access support for feelings. Given the potential for individualised and biomedical approaches to contribute to the disavowal of feelings, EIP practices such as allocated ongoing practitioners, provision of care (up to three-years), and access to talking about experiences with mental health professionals (both during allocated appointments and ad hoc), may provide examples of how people who experience hallucinations may be supported.

To summarise, this principle was useful in noticing that numerous aspects of circumstances may impinge on acknowledging feelings (care practices and hallucinations themselves). A sentiment shared among many participants was a desire to make sense of their experiences, and the value of this in improving their ongoing situations. The support of people (often EIP practitioners) in facilitating the sharing of experiences, of bearing witness to and acknowledging feelings (whilst offering ongoing support), seemed beneficial in navigating hallucinations.

9.08 Principle 8. Prior unresolved feelings may be elicited by similar experiences later-on

This principle seemed relevant to hallucinations in two primary ways. Firstly of how clusters of feelings (including hallucinations) may be triggered through similar experiences, and secondly of how ACE could gain a renewed felt relevance through a similar event in adulthood (which precipitated hallucinations). Two case-examples evidence each of these notions, before closing the principle by considering the difficulty of resolving feelings whilst hallucinations are ongoing.

Ongoing adverse experiences and traumatic experiences often seemed to generate conditions in which difficult feelings may be disavowed or remain unresolved. As discussed in principle 5, distress arising from poor working conditions was often disavowed due to needing to “crack on” to maintain employment. Within a case-example, the participant explained “it’s all work-related stress that has led to this [hallucinations] for me”. With this they explained hallucinations and feelings of anxiety were exacerbated by going to work, being in the work building, being in work situations (e.g. meetings) and receiving correspondence from their employer. This participant’s hallucinations had been ongoing for between “two...three-years” since the poor working conditions started. With this, the prior difficult and unresolved clusters of feelings (including hallucinations), seemed to have no space to be resolved, as they were continuously subject to poor conditions to maintain material security. This principle seemed highlight the potential role and contexts of unresolved feelings, and how this may be relevant to people experiencing ongoing adversities.

The second case-example to illustrate the relevance of this principle, further explores the experiences of the participant whose experiences were consistent with a shame-anger feeling-trap. These recursive feelings were initially generated after finding their murdered sibling, after-which they were subject to CPA by their father and grandfather. These patterns of feelings where coped with through strategies of “sleep” and “drinking, smoking, taking drugs” to “try and forget it”, with advice to “lift your head up and that’s it”. Such experiences point to the disavowal and un-acknowledgement of feelings through using

available resources and coping strategies. They described further traumas and hardships throughout their adolescent and adult life and reported drinking upwards of “a litre a day [vodka]” from “when I were 13” as the primary ongoing coping strategy. To cope with traumas and ongoing adversities, feelings seemed to be disavowed and unresolved through ongoing drinking.

However, upon ceasing to drink alcohol, prior unresolved feelings were elicited after accidentally injuring a love interest. They described the same “disappointed in myself” feelings, they had in childhood. They explained that in the past whilst drinking: “I tend to forget about it. Helps, a lot” but due to no longer drinking “It didn’t help this time with that girl...The voices brought it back...probably that’s their way of getting me back, rather than beating me up”. With this, recursive feelings re-emerged, without drinking to cope (strategy to disavow feelings), after-which hallucinations started. This participant felt “its conscience, that sort of thing, that’s why I hear the voices”. He reported hearing her voice, and “a bloke’s voice and all, telling me he wants to beat me up and stuff like that...I think it might be my dad’s voice“. This participants’ experiences suggested that consistent with this principle, past unresolved feelings may be elicited by similar events, and also perhaps hallucinations may be generated.

Consistent with the potential role in hallucinations in disavowing feelings, hallucinations also seemed to generate difficulties regarding resolving feelings. Navigating the onslaught of dual planes of sense-experience appeared to generate difficulties in acknowledging feelings, or understanding how to resolve them; particularly given uncertainty surrounding their un/reality. A participant explained:

What’s difficult about it is, it’s so hard to know where to resolve it. Did it happen or did it not happen? Did that take place or did I imagine it? That’s what’s really difficult about it as I don’t know where to resolve it, so a lot of the time it’s just left unresolved. ‘Cause I’m not really sure what it was.

This difficulty in understanding or resolving experiences, seemed to further perpetuate feelings of un/reality and isolation which characterised the ongoing experience of hallucinations. Perhaps hallucinations could self-sustain through the difficult feelings they generate without resolution. Overall, this principle of

feeling-trap theory was useful in conceptualising how difficult past experiences ('real' or unreal), may contribute to emergent hallucinations and distress.

9.09 Principle 9. Feeling-traps generalise beyond their initial circumstance and sustain over time with increasing complexity

With hallucinations seeming to be characterised by the recurrence of interrelating feelings (i.e. feeling-traps), this principle examines how hallucinations seemed to generalise, sustain and gain complexity. This principle seemed to chime chapter-8's analysis of feelings of presence and un/reality within the ongoing experiences of hallucinations. The capacity for hallucinations increase in complexity and generalise across situations and time was recognised by many participants and exemplified by the following participant quote:

I still think it's snowballing. I don't think it's ended...bullying just came into my life a long time ago and it just got bigger and bigger and it's become so malicious and vicious that it's left me with this one person trapped in my own head and me constantly fighting like by myself. And it's still snowballing and I don't know what's going to happen tomorrow, like whether it'll end my life or whether I'll be broke free from it, or the police will interfere and catch this person, then tomorrow I'll be going to court, trying to give evidence...with all this that's gone on.

This participant's report exemplifies the continuing emergence and uncertainty of experiences as they sustain and gain complexity over-time. This feeling-trap principle helped to acknowledge the trajectory of their experiences over time, of online harassment becoming ever-more embodied and generalised throughout their circumstances.

Another participant explained how their hallucinations (which seemed to arise (in part) from verbal harassment from neighbours after moving into their first home), seemed to generalise over different material circumstances as time continued:

The abuse...what I'd hear from the neighbours...when it moved to winter, because I wasn't outside so much I could hear the abuse from them -their voices-...I could hear it inside my house, it felt as if it was coming from

their side; then the fear that the abuse from neighbours was coming from the technology too, so it wasn't just whilst I was at home, they could get to me anywhere, so I couldn't escape from it.

Hallucinations seemed to bind to aspects of material circumstances (or be co-constituted by them) and thereby generalise and gain complexity. This seemed to contribute to the omnipresent feeling of hallucinations described in chapter-8.

The same participant explained as hallucinations generalised and sustained, whilst they were struggling with the material insecurity of purchasing a home and overworking, they felt "really tired". They explained this "kind of escalated things...The voices got worse with death threats, and at times I was scared to leave my home...I was scared for my life". This exemplifies how the content, emotional feeling, and impact of hallucinations can gain complexity over time. Among participants who experienced MMH, the gaining of complexity over time seemed to be characterised by the accumulation of further sensory modalities as one participant explained: "the eye floaters turned to presence of feeling, turned to visual things, turned to audible things".

Further to hallucinations generalising across material circumstances and emerging in increasingly complex ways, hallucinations also seemed to generalise across social circumstances and relationships. As one participant explained: "It's like the longer I spend with someone the more they become a part of this conspiracy. I even thought that my friend (and...we're best mates)...was in on it about a month ago and she wasn't at all". Such experiences were described as "saddening disheartening" and reflect how hallucinations become increasingly enmeshed within one's circumstances, and may serve to disrupt the given security of reality (as pointed to in Cromby and Harper's [2009] theorisation of feeling-traps and paranoia).

The progress of hallucinations in generalising and complexity seemed to contribute to their reality. As hallucinations sustained and generalised, there was a sense of investment of time and energy, and of potentially unbearable implications should they be unreal. As a participant explained "sometimes I can think, that's just me hallucinating and sometimes I can't...I just cannot bring myself to think that's imaginary. It's been going on too long for it to be imaginary".

This reflects the sentiments shared in the metaphor of the beach that “it kind of feels like you have lost something” and the potential for recursive feelings of shame or un/reality. This participant quote points to the shared experience of the felt impact of hallucinations having sustained, generalised and gained complexity over time. Attuning to the relevance of this within the ongoing experience of hallucinations, was a useful feature of feeling-traps theory. To summarise, this principle was useful in studying the ways in which hallucinations may sustain over time and support in studying the feeling and impact of this.

Before continuing to the next principle, a lens of hermeneutics of suspicion is briefly drawn upon. Perhaps in the process of sharing one’s life narrative, this sense of thread of progression may reflect the narrative structures of how stories are told. The extent to which a trajectory in a retrospective narrative reflects the ways those experiences initially emerged is uncertain. In any case, there was a reported overarching feeling of increasing complexity and hallucinations generalising and sustaining across circumstances and time, with an ever-growing presence permeating throughout the lived experiences.

9.10 Principle 10. Feeling-traps can be broken

The circumstances which seemed to facilitate the depletion of hallucinations or the breaking/disruption of feeling-traps were:

- Opportunities to experience familiar people, places and activities,
- Ongoing support and contact with loved ones,
- Sharing one’s experiences of hallucinations (with a respectful listener),
- Reality testing hallucinations,
- Anti-psychotic drugs and coming off them,
- Understanding one’s hallucinations and identifying coping strategies which ease or disrupt them,
- Learning how to manage life whilst experiencing hallucinations,
- Learning to ignore or not respond to hallucinations,
- Cultivating feelings of calmness and patience to not respond to hallucinations,
- Continuing to partake in activities and gain interests beyond hallucinations.

Quotes have been provided for each of these in Appendix G2. Notably, further to

the beneficial situations listed, two participants described how humour and making a joke of their hallucinations (and associated experiences), supported them in managing them. These were two of the participants who reported the lowest current distress. Consistently, Scheff (1990, p.172) wrote of how shame could be dispelled when “one laughs good-naturedly”; with this, laughter could avoid entry into or end feeling-trap cycles.

Meaningful interactions with loved ones, in conversations and actions close to daily life as usual, were a strong feature in many participants discussions of what helped them to retune or reconnect with consensual reality. Such benefits were exemplified by the participant who shared the beach metaphor. Their beneficial experiences of support from family whilst at home and on the ward are shared in Table 9.04. These suggest the support of experiencing care and connection through meaningful relationships, were a way to face the fear of (un)reality and to travel from the beach across the water. He described visits, conversations, interactions and support from his family, helped to relocate complex feelings within relationships and processes which felt familiar. Through this he seemed able to reconnect with consensual reality and benefit from support for a time. In contrast to proposed way in which hospital environments may perpetuate distress, familiar experiences (where safe and supportive) seemed to help to disrupt the recurrence of feelings which perpetuated hallucinations.

The potential for feeling-traps to be broken within feeling-traps theory, supported in attuning to the situations which seemed to disrupt recurrent feelings which characterised hallucinations. It was interesting that the original propositions of Scheff (1990) of the value of laughter and humour, were evidenced in some participant’s experiences. This section provided numerous novel examples of situations which appeared to ease some participant’s ongoing experiences of hallucinations.

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Table 9.04
Participant Reports of the Value of Interactions with Loved Ones in Gently Re-Connecting with Consensual Reality.

<u>Situation</u>	<u>Participant Report</u>
At Home	“One day I thought I was training to be a special forces. I was out all day in the sun. Testing myself...I heard that this was real...I was just standing there at attention in the baking hot...Just staring at the wall and no one could get me to move. I was like “No, I have to do this”. Otherwise no one is going to notice me. I’m going to just fail at everything...Nurses would come and say “You need to get out of the sun, have some water or something”. And I was like, “No no no no no”. Then my mum came and she just grabbed my hand and was like “C’mon, just have a drink”. And I was like “wait”. That actually got me over the water, If you know what I mean. It got me back to where I needed to be.”
Visiting the Ward	“They would just act like nothing’s wrong you know like, ‘Hello is everything alright today?’ And it would kind of ground me... Some days when I was really bad and I was completely in a world of my own, you know, running away from aliens that weren’t there, they [family] would arrive at the visiting hours. I could be like ‘oh wait, maybe, everything’s alright, for now’ and I think that helped me recover...my family coming in to help me, coming in and playing games with me and stuff. That helped me a lot. To realise that I wasn’t...in this special story or anything.”

9.11 To what extent was feeling-trap theory useful in understanding empirical hallucination research?

This chapter examined the relevance and utility of feeling-trap theory principles in understanding hallucinations; summarised in Table 9.05. Feeling-trap theory was most useful in:

- Conceptualising feelings in terms of interrelationships and their potential to recur or sustain,
- Conceptually holding a continuous dynamic interrelationship between feelings and circumstances in sustaining hallucinations,
- Temporally conceptualising emergent experiences (including hallucinations) as both entwined with one’s immediate feelings and circumstances, and one’s past; this was relevant to ongoing adversities and ACE,

- Attending to ways in which hallucinations seemed to generalise across one's lived experience,
- Appreciating ways in which care practices may perpetuate or ease recurrent feelings (which seemed to characterise hallucinations),
- Appreciating the potential for hallucinations to be disrupted or eased, and attuning to the situations which facilitated this.

Overall, feeling-trap theory offered useful conceptual tools in understanding the generated data on the lived experience of hallucinations.

Table 9.05

Principles of Feeling-Trap Theory and their Examination within this Thesis.

<u>Principle No.</u>	<u>Details of Principle</u>	<u>Usefulness</u>
Principle 1:	Feelings seem core to experiences of hallucinations.	Very Useful
Principle 2:	Experiences of hallucinations may be co-constituted and sustained by circumstances.	Very Useful
Principle 3:	Traumatic and adverse circumstances can be internalised through feelings and may relate to experiences of hallucinations.	Very Useful
Principle 4:	Feeling responses can be acquired and become habitual forming modes of embodied subjectivity.	Very Useful
Principle 5:	Feelings recursively loop over time in sustaining circumstances (feeling-traps).	Very Useful
Principle 6:	Shame is a primary emotion in binding feeling-traps and often co-occurs with anger.	Somewhat Useful
Principle 7:	Disavowed or unacknowledged feelings contribute to feeling-traps.	Useful
Principle 8:	Emotional backlogs of prior unresolved feelings may be elicited through similar experiences.	Useful
Principle 9:	Feeling-traps generalise beyond their initial circumstance and sustain over time with increasing complexity.	Very Useful
Principle 10:	Feeling-traps can be broken.	Useful

Feeling-trap theory seemed most useful through use in conjunction with theories of feelings more broadly; namely Langer (1967) and Cromby's (2007;

2015) theoretical work. Such conceptual tools were useful as feelings inherently implied co-constituting circumstances; this seemed to fit with the situatedness of participants' experiences. Focusing on feelings supported in studying different modal kinds of hallucinations; they often shared co-constituting circumstances and properties such as co-occurring and recurring feelings. Focusing on these similarities, supported the comprehensive study of hallucinations within a clinical sample, in a research field historically focused on unimodal hallucinations and AVH.

The thesis' conceptual lens of feelings emergently arising through circumstances (Cromby, 2015; Langer, 1967; Scheff, 2012), supported in navigating the prominence of individualist and biomedical approaches which permeate throughout health research and care. Drawing upon feeling theories built an understanding of hallucinations which could acknowledge the complexity of participant's situated lived experiences. Nayani and David's (1996, p. 188) phenomenological research concluded AH "are repetitive, emotive utterances which are context dependent, spatio-temporally organized and appear to originate from stereotypical personifications...evolve by accretion and, increasingly, come to invade the patient's private life". This conclusion echoes this thesis' analysis of: the role of feelings and context dependence, recurrence, evolution and increasing generalisation across one's life. Theories of feeling-traps (Cromby & Harper, 2009; Scheff, 1990, 2012) and moreover theories of feelings (Cromby, 2007, 2015; Langer, 1967) provided the necessary conceptual tools to build on the systematically reviewed research (such as Nayani and David [1996]) and appreciate hallucinations as characterised by emergent, co-occurring, and circumstantially co-constituted feelings.

10. Conclusion



Figure 10. Participant artwork of the feeling of interconnection.

10.01 Reaching a Conclusion

The participant artwork of the ongoing feeling of interconnection (Figure 10) seemed to chime with both the analytic outcomes, and the process of interconnecting the thesis material to bring it to a close. Having explored the empirical, theoretical and methodological literature with which the novel study was designed, and having analysed the data generated, the thesis is reaching its conclusion. This final chapter overviews the context and the development of the empirical research, before discussing its ethics, potential limitations and analytic outcomes. The thesis will close with concluding remarks of the thesis' content and contribution.

10.02 Thesis Context and Development of Empirical Research

The thesis arose from a context where the feelings, circumstances and specific experiences of distress (including hallucinations) were seldom studied. The systematic reviews indicated further research was needed to provide a more comprehensive picture of the ongoing lived circumstances hallucinations arose within, and their feeling across modalities. Furthermore, given the lack of simultaneous study of both the feeling and circumstances of hallucinations, theoretical concepts and novel methods were needed. This thesis drew upon numerous feeling theories (Cromby, 2007; Cromby & Harper, 2009; Langer, 1967; Scheff, 2012) and qualitative research scholarship (Ellingson, 2017; Knowles & Cole, 2008; Reavey, 2011), to develop the conceptual and data-generation tools to address these areas for development. Theoretical developments were made through the application of feeling-traps theory to the study of hallucinations, and to Cromby's (2007) feeling taxonomy (through the feeling of reality category).

The novel data-generation tools included a visual diary with micro body-maps, an arts-based task, a life-timeline and two interview schedules. The design was approved through service-user review, HRA and NHS ethical review, and was tested through a novel application of self-practice and self-reflection, before piloting with participants. Consistent with existing successful research (Upthegrove et al., 2016), sixteen EIP service-users currently experiencing hallucinations were recruited at a single NHS site. Prospective and retrospective

data were generated with participants for up to eight weeks, with an 81% (n=13) completion-rate. The ethics of the thesis' methods will be discussed in light of existing literature.

10.03 Ethics of Mental Health Service-User Research

Chapter-6's brief ethics report explored the potentially undue difficulties to gain ethical approval for research with mental health service-users (Roberts & Kim, 2014). In Britain, the resource intensive ethics process for researching with NHS mental health service-users creates a further barrier for research (Keogh & Daly, 2009); which were challenging to navigate in the current study. Researching with EIP service-users was effective in generating novel and relevant data to the hallucination research field and potentially mental-health services too. A participant explained the value of lived experience research by explaining "people haven't really got it [psychosis] figured out yet. So, talking to people with the diagnosis, rather than keeping them locked away...is probably good". This speaks to the both the ethics of learning from service-users and bringing knowledge from lived experience into research.

The effectiveness of the research protocol speaks to three important notions:

- Researching with service-user samples is appropriate, relevant and useful for hallucination research,
- The methods facilitated participants in sharing their experiences of hallucinations (across modalities) and their life histories (including traumas) in a way which seemed comfortable for them,
- Retrospective and prospective visual and ABRM (including visual diaries, micro body-maps, arts-based tasks, interviews and life-timelines) were successful data generation tools with this population.

These reported benefits of visual and ABRM are consistent with existing literature (Knowles & Cole, 2008; Reavey, 2011), with the current study demonstrating these methods are suitable for studying EIP service-users experiences, and people currently experiencing hallucinations (in one or more modalities). The flexible research design alongside visual and ABRM tools, felt

crucial in building a comprehensive dataset; such methods may be effective and appropriate for future research with similar samples or objectives.

10.04 Limitations

Empirical limitations include the potential relevance of further diary components, and the sample's demographic bias. Within a field of predominantly retrospective methods, the prospective design was a strength. Although diary entries were supposed to be completed as close to when hallucinations arose as possible, data was not generated on how quickly this was done. Adding 'how long ago did this happen?' to each diary page, would allow data quality to be monitored or ranked. A further diary development mentioned in chapter-7, was a second body-map per-page as most participants used the body-map as front-facing. The two body-maps titled as "front" and "back" may generate further data which alongside the time-marker development, may enhance diary data quality.

Like sample biases encountered in existing studies (Upthegrove et al., 2016), the current sample was predominantly male (75%,n=12) or white British (69%,n=11). Initiatives seeking to improve sample diversity included:

- Sharing sample demographic bias updates at site meetings,
 - Encouraging care co-ordinators to consider recruiting BAME, female or non-binary service-users,
 - Asking care co-ordinators to screen their caseloads for potential participants.
- Although these strategies recruited more BAME and female participants, they also recruited an equal number of white and male participants; the overall sample diversity therefore did not improve. Upthegrove et al. (2016) also reported a white and male sample bias from their similar setting and sample. Despite being aware of this during recruitment, the same problem was encountered. Echoing Upthegrove et al. (2016), research is needed to document hallucination experiences among BAME and female service-users. Building upon these recommendations, future research should study how to facilitate BAME and female service-users to participate and fund service-user researchers who hold situated knowledge relevant to EIP research.

10.05 Discussing the Outcomes and Implications of the Research

This section discusses the theoretical and empirical outcomes and implications of the research. After exploring these, the thesis reaches its concluding remarks.

10.05.1 Theoretical Outcomes and Implications

The main theoretical developments from the thesis were:

- Extending Cromby's (2007, 2015) feeling categories through feelings of reality, and applying these to empirically analyse the feeling of hallucinations,
- Using feeling-trap theory to understand hallucination experiences, and doing so with a broader conceptualisation of feeling.
- Using theories of feelings consistent with process philosophy to study hallucinations.

This section explores these developments and their implications.

The feeling of reality analytic category supported in attuning to the defining un/real features of hallucinations. With this novel development, Cromby's (2007, 2015) taxonomy of feeling may provide a useful guide for future research and assessment of hallucinations. Consistent with chapter-3's theoretical proposal, this category may support future studies of experiences which disrupt or qualitatively alter the texture of reality. The final analysis chapter explored the extent to which feeling-trap theory was useful in understanding hallucination research. This chapter argued that based on the data, the feelings (by which hallucinations were composed) appeared to co-occur and recur in sustaining circumstances. With these circumstances seemingly being made salient by one's ongoing history, in a way which appeared consistent with principles of feeling-trap theory (Cromby & Harper, 2009; Scheff, 2012). Feeling-trap theory provided a conceptual basis to appreciate that feelings during adversities or traumas may be disavowed, and how these feelings may sustain or regain relevance at later time-points. Furthermore, feeling-traps theory was helpful in attuning to the disruption or depletion of recurring hallucinations. The principle of feeling-trap theory which appeared least relevant to the dataset, was the traditional shame-anger feeling-trap (Scheff, 2012), which chimed closely just one participant's experiences. Feelings of shame however, did appear relevant to the broader

dataset, particularly in terms of navigating the unreality of hallucinations. Overall, feeling-trap theory was useful in appreciating the reported experiences and trajectory of hallucinations. Principle-based examination may help future studies to provide a refined report on the extent of feeling-trap theory's utility.

Feeling-trap theory was most useful when applied in conjunction with Langer (1967) and Cromby's (2007; 2015) broader theories of feelings. For a potentially more comprehensive approach, future research seeking to empirically study feeling-traps may also benefit from their broader conceptualisation of feeling. Application of theories of feelings such as those used in this thesis, helped to navigate the dualisms which permeate through the understandings and studies of hallucinations and experiences described as psychosis. Drawing upon theories of feelings may support future hallucination research (and approaches to distress more broadly), in conceptually holding and appreciating interrelationships between feelings and circumstances.

10.05.2 Empirical Outcomes and Implications

The prospective analysis chimed with contemporary hallucination research, as most participants reported ongoing MMH (Lim et al., 2016). This contrasted with the reviewed research's unimodal and AVH focus. Further contrasts arose as the most common MMH was of AVH and BH; this contrasts with existing research which emphasised auditory and visual combinations (Gauntlett-Gilbert & Kuipers, 2003; Lim et al., 2016). It was proposed that as bodily feelings are often fleeting (Cromby, 2015), that perhaps the current prospective diary methods and broader conceptualisation of hallucinations supported in generating data on MMH, and AVH+BH in particular. Participants reported the ABRM options (visual diary with micro body-maps, arts-based task) alongside interviews supported in expressing the feeling of hallucinations. Perhaps semi-structured and ABRM can facilitate future study of the multimodality of hallucinations. Use of prospective diary methods with micro body-maps, may support clinical practice and self-practice in seeking to understand and communicate hallucination experiences.

Recent AVH research suggested emotional and bodily feelings were relevant to hallucinations (Woods et al., 2015; Upthegrove et al., 2016). The

current research was designed to explore this further. Participants reported a range of feelings during hallucinations including emotional, extra-emotional, of knowing, of reality, localised to body parts and generalised across the body. These outcomes illustrated a diverse dataset with novel similarities in feelings across modalities of hallucinations, and the first known body-maps of feelings during hallucinations. The empirical outcomes indicated hallucination experiences were characterised by feelings and as such, appear to represent core parts of their lived experience. Consideration of the feeling of hallucinations should therefore form central parts of its research and clinical assessment. The research outputs such as the feeling word-cloud and digital body-map illustrations may be useful in developing more relevant and empathetic understandings of hallucinations. This may help in providing training or information to people providing formal or informal care to someone experiencing hallucinations.

Further novel outcomes included simultaneous MMH seemingly lasting longer than unimodal hallucinations, and variations in their time of day; although soon-after-waking, mid-afternoon and soon-before-sleeping appeared overall peak times. These striking outcomes indicate that clinical assessments should consider hallucinations' temporal qualities, as they may be relevant to management strategies or reasonable adjustment plans. A key future research area should be to study the temporal and sensory qualities of hallucinations; the prospective diary with follow-up interview could be repeated with a larger mental health service-user sample. This could prompt further research on how hallucinations may be differentially felt and managed in terms of their sensory and temporal features.

The retrospective analysis examined the ongoing feeling of hallucinations and the broader circumstances and life histories they arose within. This analysis proposed the ongoing feeling of hallucinations was of their salience, presence and fluxing un/reality. These are further novel feeling outcomes which drew across different modal hallucination types to suggest potential shared properties. This analysis continued by examining the British circumstances hallucinations were unfolding within which included: activities of daily coping, spirituality, digital technology, childhood and ACE, education, work, employment, unemployment

and poor working conditions, material (in)security and welfare, drugs and alcohol, discrimination, harassment, authority and inequality, mental health care, chemical care and informal support-networks. This provided an examination of the multifaceted aspects of ongoing situated circumstances of hallucinations in a specific location, more comprehensive than seems to have been undertaken in the existing literature, particularly so for within Britain.

Reflecting on to the thesis' opening arguments, the feelings and circumstances of distress are often placed outside of the remit of study and consideration within mental health research and practice. It is concerning to consider that after experiences of abuse and adversity, that hallucinations are typically conceptualised in terms of mental illness, psychosis and associated with being given a schizophrenia or psychotic-spectrum diagnosis. Yet the same is unlikely to be the case for hallucinations from other life events such as bereavement. None of Grimby's (1993) bereaved participants experiencing hallucinations were referred for psychiatric care. These varying conceptualisations of the meaning of hallucinations illustrate that hallucinations are both co-constituted by circumstances in their initial instance and experienced through complex and unfolding circumstances over time; circumstances including complex systems of knowledge and values of what one's lived experiences signify.

The outcomes of the analysis had numerous relevant implications for the stakeholders involved in this research. This section will focus upon some of the main implications of the research for EIP service-users, practitioners and providers. Some of the main implications of the research for service-users have been summarised in Table 10.01. These have been written in terms of pieces of brief information and advice, guided by the dataset generated with participants. Outcomes to emphasise include the varied experiences of formal care and the reported benefits of discovering activities or circumstances which ease hallucinations. The varied experiences of formal care often pointed to the primacy of diagnostic, medicalised and pharmacological care for hallucinations; despite their primacy, they are not the only way (or necessarily the most-valid way) to understand or manage hallucinations. Some participants preferred the approaches and interventions provided by clinical psychologists,

psychotherapists, and mental health nurses which were accessed in EIP teams. Implications numbered 6 and 7 in Table 10.01, may support in navigating some of the outcomes of seeking formal care. A way of making the lived experience of hallucinations easier, was through a discovery orientated approach to self-care by trying different activities or accessing different circumstances some of which were helpful. The activities of coping listed in section 8.03.1 may provide some useful things to try to ease experiences of hallucinations.

Table 10.01
Implications of the Research for EIP Service-Users.

<u>N</u>	<u>Research Implication</u>
1	Hallucinations can arise in many sensory forms and can be associated with a broad variety of feelings and experiences.
2	Although hallucinations seem unique, similar experiences may be shared among people experiencing hallucinations in terms of the feelings they generate, the circumstances they arise from, and the impact they have upon one's life.
3	A range of formal care, informal care and self-care was used to try and manage hallucinations.
4	Self-care was advised by participants in terms of having a try to "discover ways to help yourself" (including the coping strategies suggested in section 8.03.1). Going into natural spaces, exercise, talking to someone, time with animals, and mindfulness were used by the highest number of participants.
5	If you have a spiritual faith, practicing this faith through attending spiritual spaces, engaging in rituals or prayer may be helpful.
6	Most participants had been prescribed pharmacological drugs for their hallucinations, which had varied outcomes and included unpleasant effects. Before taking a pharmacological drug, ask a medical doctor what the undesirable effects are, what the likelihood is that the drug will not resolve the experiences they are prescribed for, and the process of stopping taking the drug. These steps may help in making an informed decision about taking a new pharmacological drug; requesting to read or reading the information leaflet inside the drug box may also help.
7	If you are already taking a pharmacological drug which you feel is unhelpful or harmful, inform your medical doctor and ask whether and how you can be taken off this drug.
8	If you are struggling to remember or describe what your hallucinations feel like, using a visual diary, such as the one used in this study (Appendix D9) may help.

Further to the implications of the research for service-users, there were also numerous implications for EIP practitioners. Implications of the research for

EIP practitioners (Table 10.02) listed 1-9, regard numerous outcomes of the research which should be considered during information gathering with service-users; this may be most relevant during assessment or reviews. Understanding experiences in terms of these features, may help in attuning to relevant aspects of service-users ongoing lived experiences and needs. This may in turn improve the relevance of the support provided. Further implications listed 10-15 regard information giving which may be relevant at assessment and during ongoing care. These include the relevance of coping strategies, varied experiences of technology, out-of-hours care access and mitigating the primacy of pharmacological and diagnostic approaches of support.

Table 10.02

Implications of the Research for EIP Service Practitioners Supporting People Experiencing Hallucinations.

<u>N</u>	<u>Research Implication</u>
1	Keep an open mind regarding the modal feeling of hallucinations and be aware of biases towards unimodal and auditory experiences.
2	Assess the feelings and ongoing lived circumstances of hallucinations. Visual diary methods and life-timelines can help. Ask if there are any people or services which provide them with support and if so what sources of support these provide; this may enhance coping.
3	Ask about spiritual faith, including: religion, spiritual beliefs and practices, whether this helps, what spaces and support they may access through their faith, and how their faith is in light of their experiences.
4	Ask service-users about traumatic or adverse experiences; a life-timeline may support in this process. Be mindful that current hallucinations may interrelate with historical or ongoing adversities or trauma.
5	Enquire about service-users occupational status and how they feel about this, enquire whether their occupational status has changed due to their distress, and if they have goals or care needs related to their occupation. Where appropriate, provide employers or education-providers with information on reasonable adjustments for the service-users hallucinations (including support to use coping strategies).
6	Be aware of the distressing consequences of losing work, and the adverse and difficult circumstances that staying in work may involve.
7	Be mindful that where substance use was implicated at the time of hallucinations starting, there may have been further precipitating circumstances which warrant assessment and support. Enquire when hallucinations first began, as drug-use may have arisen later.
8	Ask service-users whether they consume drugs or alcohol, what purposes it is consumed for and whether they would like this to change.
9	Ask service-users about circumstances in which they feel unsafe and ask them what could help them to navigate these circumstances.
10	Inform service-users of coping strategies which may support in managing hallucinations (section 8.3.1). Where appropriate facilitate

- their use, and monitor whether they help and if so, in what way they help.
- 11 Be mindful that service-users may have limited access to technology and that they may be triggers of distress. Ask service-users about their experience of technology and how best to share information and contact them.
 - 12 Make service-users aware of the burdens of different routes of care such as availability to attend appointments and accessing pharmacological drugs. Provide service-users with interventions of care beyond pharmacological drugs.
 - 13 When providing information regarding available pharmacological drugs, ensure service-users are aware of their undesirable effects and the potential that the drugs may not alleviate their hallucinations or distress.
 - 14 Provide non-diagnostic options to understand experiences and before providing service-users with a diagnosis, ask if they would like one.
 - 15 Provide service-users and their family members information of what out-of-hours services they can access and what help they provide.
-

The research also holds implications for EIP service providers (Table 10.03). This includes markers of good-care provision, and potential adjustments to space and the gender of allocated practitioners. Implications also point to areas for staff training, funding allocations and staffing. Moreover, these outcomes point to the need for research to study both service-user and service provider perspectives of: how care for hallucinations could be improved, what resources are needed, and how this can be delivered.

Table 10.03
Implications of the Research for EIP Service Providers.

<u>N Research Implications</u>	
1	Create the availability of technology-free spaces and analogue (paper-based) versions of information and support.
2	Provide service-users with the option of male or female practitioners.
3	Ensure the following features of reported good care are available: <ul style="list-style-type: none">●Someone who visits to talk to;●People to talk with when isolated;●Support independent from one's personal life;●Accessible, reliable and consistent ongoing care;●Support to learn about experiences of hallucinations;●Support and guidance to try coping strategies;●Provision of future care planned.
4	Staffing and Funding: <ul style="list-style-type: none">●Employ staff trained in supporting the material security and welfare needs of service-users such as accessing housing and financial welfare.●To mitigate the primacy of chemical and diagnostic care approaches,

where possible hire more staff from non-medical caring professions (psychology, occupational therapy and social workers).

- Fund and facilitate co-working with drug and alcohol services.
- Fund long-term provision of EIP services (at least three years), with adequate staffing such that service-users can access regular appointments and ad-hoc support from familiar practitioners.

5 Provide Staff Training On:

- The feeling and circumstances of hallucinations; with a particular focus on their breadth of feeling, and the adversities (past or present) service-users may be navigating.
 - Supporting service-users with needs relating to substance dependency.
 - The undesirable effects of antipsychotic drugs.
 - Non-pharmacological care interventions, including coping strategies.
-

Varying routes for further study to build on the thesis outcomes have been pointed to over the analytic chapters, before concluding a broader need is described. Based upon the analytic outcomes, the mental health problem of hallucinations did not seem to be localised solely within the remit of one's body, but rather the broader ongoing interrelationships of a living body within circumstances. Circumstances should therefore be primary targets for future research and interventions. Prevention orientated research should seek to understand how the harmful and adverse features of circumstances can be reduced and mitigated, this may include: targeting reducing ACE, abuse, poor working conditions, harassment, racial discrimination and material insecurity. Research seeking to facilitate beneficial circumstances may include studying how to ensure the provision of housing, stable welfare support, good working conditions, support in education and ongoing statutory early intervention care with consistent practitioners. The outcomes of circumstance orientated research could support the improvement of environments and situations which generate distress and facilitate the development of resources and practices of care to support people in navigating distress as safely and gently as possible. Having considered the implications of the thesis, it concludes.

10.06 Conclusion

Based on the systematically reviewed empirical research, this thesis has generated the most comprehensive available picture of hallucinations among people living in Modern Britain; in terms of what hallucinations across modalities

feel like and what ongoing circumstances they arise within. This thesis opened with the suggestion that the term hallucination would be used in its historical sense as “semantically pregnant, i.e. their content was believed to carry a message for the individual or the world” (Berrios, 1996, p.35). The experiences of hallucinations explored within this thesis, appeared to carry numerous messages, and pointed to many aspects of lived circumstances in Britain in need of care. The feelings which composed hallucinations appeared dynamically contingent upon one’s ongoing circumstances (social, material and relationally situated in a life history), such that each term (feeling and circumstances) implies the other (consistent with the theoretical works of Langer [1967] and Cromby [2015]). With this the thesis concludes, that hallucinations may be understood as the complex co-constitution of emergent feelings and circumstances, and life in Modern Britain is mad.

Appendices

Appendix A

A1. Systematic Review Protocol

- Step 1.** Endnote software was used to search and identify journal articles. Each database was searched for articles with titles containing chosen key terms; wildcard functions maximised the search results. Stage 1 used the key term of “hallucinat*” and stage 2 used “hearing voic*” due to widespread use of this term and research arising from the hearing voices movement. Search date ranges were at the maximum range of between January 28th 2019 and 1971 for Web of Science, 1900 for PubMed and 1946 for Medline (OVID).
- Step 2.** Search results were collated into an Endnote group. The yield total from each search was recorded in a Microsoft Word document.
- Step 3.** The Endnote group dataset was exported into a Microsoft Excel spreadsheet to form a literature database; data included article year, author, title, journal, pages, DOI, abstract and language.
- Step 4.** Exclusion criteria were applied in their listed hierarchical order. Articles meeting any exclusion criteria were moved to a “Removed from Review” database. The reason for removal recorded for quantification to provide an overview of the available literature and transparency of the exclusion process.
- Step 4a.** Brief Screening: Article titles and abstracts were screened within the literature database; referring to full articles for clarification on a minority of occasions.
- Step 4b.** Full Screening: Remaining articles were downloaded and screened in full.
- Step 5.** Remaining articles are reviewed for quality.
- Step 6.** Consistent with the integrated design, a reporting style for data translation across studies was chosen. A qualitative approach, with quantitative descriptive values and phrasing used where appropriate to accurately represent the available data as well as possible.

•**Step 7.** Meta-aggregation was carried out. Microsoft Excel and Microsoft Word software were adequate collate and compare review information in SR2. In addition to these software, cross-article analysis in NVivo was used for in-depth synthesis for SR1, and close comparison of multiple articles in SR1b.

A.2 Systematic Review: Quality Review Framework

The framework summarised is composed of a series of principles which were written in the form of questions which reviewed the quality of the literature. The framework colour codes summarised in Table A.1 with reference to the summarised purposes of the framework questions. The framework as summarised in Figure A.1 was operationalised to hold quantitative values and functions; these are stated in brackets at the end of each question.

Table A.1

Summary of the Quality Framework Colour Codes and Mathematical Functions.

<u>Colour Code</u>	<u>Step</u>	<u>Function</u>	<u>Quality Under Review</u>
	Step 1	+	Basic Article Quality
	Step 1	+	Unique Contribution to Field
	Step 1	+	Research and Analysis Quality
	Step 2	-	Desirable Research Quality
	Step 5	+/-	Methodological Rigour Indicators

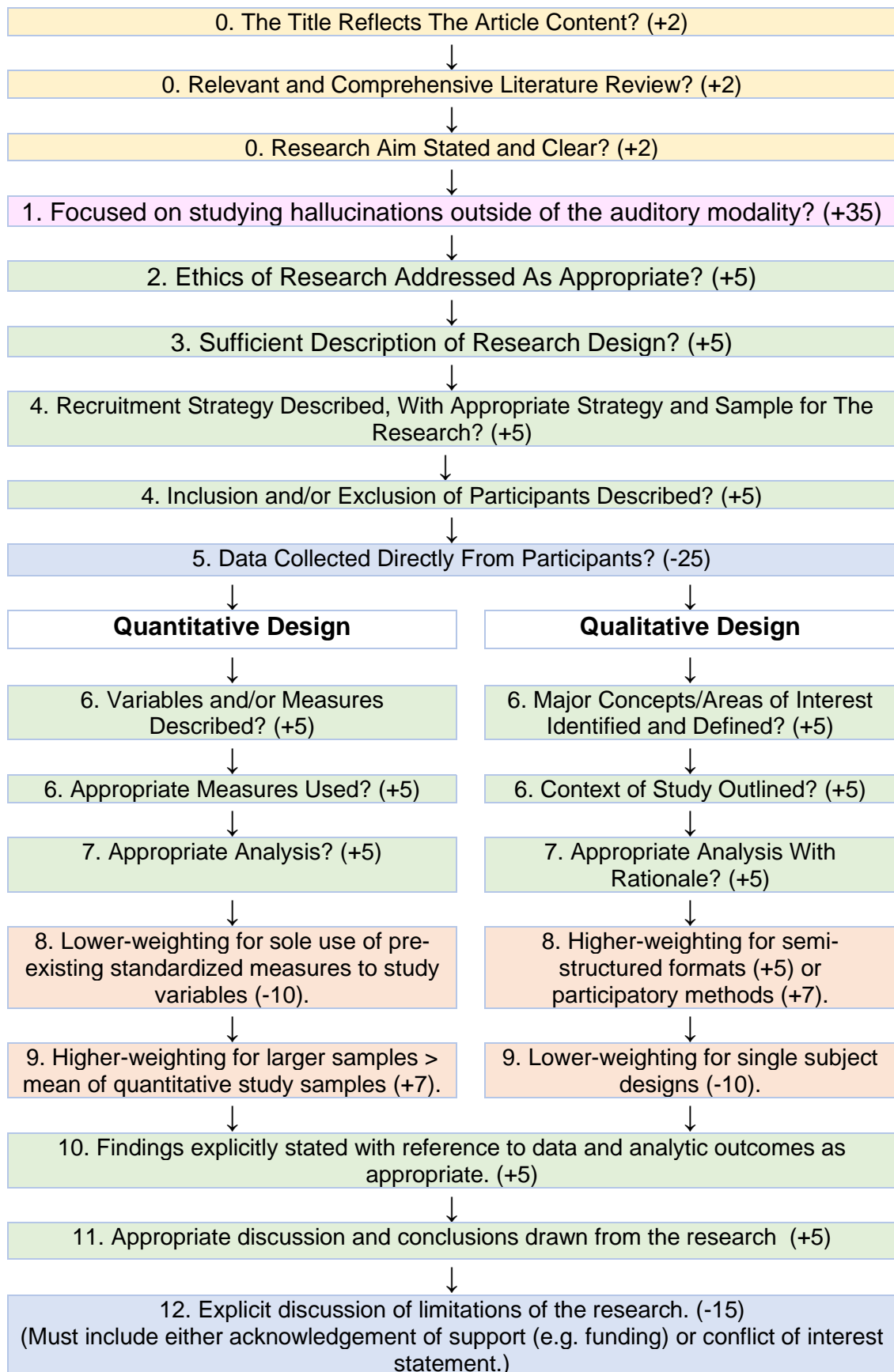


Figure A.1 Quality Review Framework Developed from Caldwell et al. (2011) Standards for Health Research.

A.2.1 Quality Review Process.

The quality review process was composed of 6 steps as follows:

- Step 1)** Remaining literature database articles were reviewed serially in reverse chronological order using the quality criteria summarised in Figure A.1. For mixed methods studies, the criteria which best assessed the study methods were used. Yellow, pink and green questions were applied first and scores were added to a scoring matrix (SR1, Appendix A5; SR2 Appendix B1).
- Step 2)** Blue questions were applied second. Where these criteria were not achieved, a negative score was applied in the scoring matrix.
- Step 3)** The total quality scores were calculated and ranked to indicate paper quality.
- Step 4)** The lowest quality papers in the bottom quartile were removed from the literature database.
- Step 5)** Orange questions were applied to the remaining papers, with values added to the scoring matrix to provide a methodological rigour weighting. Regarding the Quantitative Question-9 in the Framework (Figure A.1), study samples were calculated as the number of participants reporting hallucinations; where this was not clearly stated by the study, this criteria was not be applied.
- Step 6)** Weighted total scores were calculated and ranked.

A3. SR1 Stage 1 Literature Search Outputs.

Table A.2

Systematic Review 1. Hallucination Literature Search Outputs.

Web of Science Core Collection Literature Review 1, Stage 1	
<u>Search Term Applied</u>	<u>Number of Journal Articles</u>
"hallucinat*" AND "phenomen*"	99
"hallucinat*" AND "feel*"	1
"hallucinat*" AND "emot*"	50
"hallucinat*" AND "embodi*"	2
Total: 152 Articles with 3 Duplicates. Revised Total: 149 Articles	
PubMed (NLM) Literature Review 1, Stage 1	
<u>Search Term Applied</u>	<u>Number of Journal Articles</u>
"hallucinat*" AND "phenomen*"	0
"hallucinat*" AND "feel*"	0
"hallucinat*" AND "emot*"	0
"hallucinat*" AND "embodi*"	0
Total: 0 articles	
Medline Literature Review 1, Stage 1	
<u>Search Term Applied</u>	<u>Number of Journal Articles</u>
"hallucinat*" AND "phenomen*"	14
"hallucinat*" AND "feel*"	0
"hallucinat*" AND "emot*"	0
"hallucinat*" AND "embodi*"	0
Total: 14 Articles with 5 Duplicates. Revised Total: 9 Articles	
Total Yield from SR1 Stage 1 Search: 158 Articles	

A4. SR1 Stage 2 Literature Search Outputs.

Table A.3

Systematic Review 1, Stage 2 Hallucination Literature Search Outputs.

Web of Science Core Collection Literature Review 1, Stage 2	
Search Terms Applied	Number of Journal Articles
"hearing voic*" AND "phenomen*"	3
"hearing voic*" AND "feel*"	1
"hearing voic*" AND "emot*"	1
"hearing voic*" AND "embodi*"	1
Total: 6 Articles with 1 duplicate. Total = 5 Articles	
PubMed (NLM) Literature Review 1, Stage 1	
<u>Search Term Applied</u>	<u>Number of Journal Articles</u>
"hearing voic*" AND "phenomen*"	0
"hearing voic*" AND "feel*"	0
"hearing voic*" AND "emot*"	0
"hearing voic*" AND "embodi*"	0
Total: 0 Articles	
Medline Literature Review 1, Stage 1	
<u>Search Term Applied</u>	<u>Number of Journal Articles</u>
"hearing voic*" AND "phenomen*"	0
"hearing voic*" AND "feel*"	0
"hearing voic*" AND "emot*"	0
"hearing voic*" AND "embodi*"	0
Total: 0 Articles.	
Total Yield from SR1 Stage 2 Search: 5 Articles	
SR1 Final Total Yield: 163 Articles.	

A5. SR1 Quality Review Scoring Matrix

Final Rank	First Author (Year)	Question Number												Total	Rank	Weighted Total	
		0	1	2	3	4	5	6	7	8	9	10	11				12
1	Stevenson (2011)	4	35	5	5	10	0	10	5	0	0	5	5	0	84	1	84
2	Gauntlett-Gilbert (2003)	6	35	0	5	10	0	10	0	0	0	5	5	-15	61	2	61
3	Suryani (2013)	6	0	5	5	10	0	10	5	7	0	5	5	0	51	3	58
4	Upthegrove (2016)	6	0	5	5	5	0	10	5	7	0	5	5	0	46	5	53
5	Lowe (1973)	4	0	0	5	10	0	10	5	5	0	5	5	0	44	10	49
6	Jones (2016)	6	0	5	5	5	0	10	5	0	0	5	5	0	46	4	46
7	Moseley (2018)	6	0	0	5	10	0	10	5	0	0	5	5	0	46	6	46
8	McCarthy-Jones (2014)	6	0	0	5	5	0	10	5	5	0	5	5	0	41	12	46
9	Nayani (1996)	6	0	0	5	10	0	10	0	5	0	5	5	0	41	13	46
10	Woods (2015)	4	0	5	5	5	0	10	5	0	0	5	5	0	44	8	44
11	Daalman (2011)	4	0	5	5	10	0	5	5	-10	7	5	5	0	44	9	41
12	Smith (2006)	6	0	0	5	10	0	10	5	-10	0	5	5	0	46	7	36
13	Heveling (2004)	4	35	0	0	5	0	5	0	0	-10	5	5	-15	44	11	34
N/A	Badcock (2011)	4	0	5	5	10	0	5	5	---	---	5	0	0	39	14	---
N/A	Gecici (2010)	4	0	5	5	10	0	5	5	---	---	5	5	-15	29	15	---
N/A	Aggernaes (1972)	6	0	0	5	10	0	10	0	---	---	5	5	-15	26	16	---
N/A	Suhail (2002)	6	0	0	5	10	-25	5	5	---	---	5	5	-15	1	17	---

Appendix B

B1. SR2 Quality Review Scoring

Final Rank	First Author (Year)	Question Number												Total	Rank	Weighted Total
		0	1	2	3	4	5	6	7	8	9	10	11	12		
1	Siegal (1984)	6	35	0	5	10	0	10	5	0	0	5	5	-15	66	1
2	Grimby (1993)	6	0	5	5	10	0	10	5	5	0	5	5	0	51	4
3	Wickham (2014)	6	0	5	5	10	0	10	5	0	0	5	5	0	51	3
4	Andrade (1988)	4	35	0	5	10	0	10	0	0	-10	5	5	-15	59	2
5	Bless (2018)	6	0	5	5	10	0	5	5	0	0	5	5	0	46	5
6	Waite (2016)	6	0	5	5	0	0	10	5	5	0	5	5	0	41	7
7	Reynolds (2010)	6	0	5	5	10	0	10	5	5	0	5	5	-15	36	9
8	Bauer (2011)	6	0	0	5	10	0	10	5	7	0	5	5	-15	31	12
9	Janaki (2017)	2	0	5	5	10	0	5	5	-10	0	5	5	0	42	6
10	Ma (2016)	6	0	0	5	10	0	10	5	-10	0	5	0	0	41	8
11	Varese (2011)	6	0	0	5	10	0	10	5	0	0	5	5	-15	31	11
12	Delepaul (2002)	6	0	0	5	10	0	10	5	0	0	5	5	-15	31	13
13	Kent (1996)	6	0	0	5	10	0	10	2	0	0	5	5	-15	31	14
N/A	Fox (2004)	6	0	5	5	10	0	10	5	-10	0	5	5	-15	36	10
N/A	Thomas (2007)	6	0	5	5	0	0	10	5	---	---	5	5	-15	26	15
N/A	Luhrmann (2015)	6	0	0	5	10	0	5	0	---	---	5	5	-15	21	16
N/A	Goldstone (2012)	6	0	0	5	0	0	10	5	---	---	5	5	-15	21	17
N/A	Ndetei (1984)	6	0	5	5	5	-25	10	5	---	---	5	5	-15	6	18
N/A	Suhail (2002)	6	0	0	5	10	-25	5	5	---	---	5	5	-15	1	19
N/A	Kauffman (2016)	20	0	0	0	10	-25	10	0	---	---	5	0	-15	-13	20

B2. Demographics

Table B.1

SR2 Demographics of Nationality, Ethnicity and Religion

<u>Author (Year)</u>	<u>Female%</u>	<u>Male %</u>	<u>Nationality</u>	<u>Ethnicity</u>	<u>Religion</u>
Siegal (1984)	38%	62%	Not Stated	Not Stated	Not Stated
Grimby (1993)	80%	20%	Not Stated	Not Stated	Not Stated
Wickham (2014)	Not Stated	Not Stated	Not Stated	Not Stated	Not Stated
Andrade (1988)	0%	100%	Indian	Not Stated	Not Stated
Bless (2018)	51% [Adverse] 63% [No- adverse]	49% [Adverse] 37% [No- adverse]	Norwegian	Not Stated	Not Stated
Waite (2016)	70%	30%	Not Stated	80% White 10% Black 10% Chinese	Not Stated
Reynolds (2010)	0%	100%	Not Stated	41% White 38% Black-British 9% Caribbean 9% African 3% Asian	Not Stated
Bauer (2011)	37%	63%	Not Stated	Not Stated	Not Stated
Janaki (2017)	45%	55%	Not Stated	37% Malay 53% Chinese 0% Indian	Not Stated
Ma (2016)	42%	28%	Not Stated	Not Stated	Not Stated
Varese (2011)	Not Stated	62%	Not Stated	Not Stated	Not Stated
Delespaul (2002)	Not Stated	Not Stated	Not Stated	Not Stated	Not Stated
Kent (1996)	24%	76%	Not Stated	Not Stated	Not Stated

FEELING, CIRCUMSTANCES, AND HALLUCINATIONS

Table B.2
SR2 Demographics of Diagnosis and Medication

<u>Author (Year)</u>	<u>Mental Health Diagnosis</u>	<u>Psychiatric Medication</u>
Siegal (1984)	13% Paranoid Psychosis	Not Stated
Grimby (1993)	Not Stated	Not Stated
Wickham (2014)	Not Stated	Not Stated
Andrade (1988)	Prolonged Depressive Reaction and Asthenic Personality Disorder.	Not Stated
Bless (2018)	Not Stated	Not Stated
Waite (2016)	60% Schizophrenia 20% Schizoaffective Disorder 20% First Episode Psychosis	Not Stated
Reynolds (2010)	44% Paranoid Schizophrenia 41% Schizophrenia 9% Borderline Personality Disorder 3% Schizoaffective Disorder	Not Stated
Bauer (2011)	100% Schizophrenia	100% Antipsychotic
Janaki (2017)	65% Schizophrenia 35% Treatment Resistant Schizophrenia	100% Antipsychotic
Ma (2016)	100% Schizophrenia	Antipsychotic (% Not Stated)
Varese (2011)	95% Schizophrenia 5% Schizoaffective Disorder	90% Antipsychotic
Delespaul (2002)	Not Stated	Not Stated
Kent (1996)	100% Schizophrenia	100% Antipsychotic

Table B.3
SR2 Demographics of Education and Employment

<u>Author (Year)</u>	<u>Education</u>	<u>Employment</u>
Siegal (1984)	Not Stated	Not Stated
Grimby (1993)	Not Stated	Not Stated
Wickham (2014)	Not Stated	Not Stated
Andrade (1988)	Not Stated	Employed
Bless (2018)	Highest educational level	[Adverse Trigger Group]
	[Adverse Trigger Group]	46% Employed
	12% Primary School	4% Unemployed
	17% Vocational School	29% Social Welfare
	18% Secondary School	12% Student/Military Service
	40% College	9% Other
	13% University (4+ years)	[No Adverse Trigger Group]
	[No Adverse Trigger Group]	66% Employed
	9% Primary School	3% Unemployed
	30% Vocational School	10% Social welfare
	17% Secondary School	12% Student/Military Service
	24% College	7% Other
	20% University (4+ years)	
Waite (2016)	Not Stated	Not Stated
Reynolds (2010)	Not Stated	Not Stated
Bauer (2011)	Not Stated	Not Stated
Janaki (2017)	67% Lower 33% Higher	23% Employed 77% Unemployed
Ma (2016)	Average 11 Years of Education	74% Unemployed 26% Part-Time Employed
Varese (2011)	Average of 12 Years of Education	81% Unemployed
Delespaul (2002)	Not Stated	Not Stated
Kent (1996)	Not Stated	Not Stated

Table B.4

SR2 Demographics of Marital Status and Living Situation

<u>Author (Year)</u>	<u>Marital Status</u>	<u>Living Situation</u>
Siegal (1984)	Not Stated	Not Stated
Grimby (1993)	100% Widow/er	100% Living Independently
Wickham (2014)	Not Stated	Not Stated
Andrade (1988)	Not Stated	Not Stated
Bless (2018)	[Adverse Trigger Group] 32% Unmarried/not Cohabitant 28% Married 24% Cohabitant 4% Widow/er 13% Separated/Divorced [No Adverse Trigger Group] 34% Unmarried/not Cohabitant 36% Married 20% Cohabitant 2% Widow/er 7% Separated/Divorced	[Adverse Trigger Group] 27% Alone 40% With Spouse/Partner/Other Adult 11% Alone with 1+ Child 13% With Spouse/Partner & 1+ Child 8% Other [No Adverse Trigger Group] 14% Alone 34% With Spouse/Partner/Other Adult 9% Alone with 1+ Child 27% With Spouse/Partner & 1+ Child 15% Other
Waite (2016)	Not Stated	Not Stated
Reynolds (2010)	Not Stated	100% Forensic Services
Bauer (2011)	Not Stated	Not Stated
Janaki (2017)	Not Stated	Not Stated
Ma (2016)	86% Single/Divorced 14% Married	100% Inpatients Psychiatric Rehabilitation Services
Varese (2011)	Not Stated	Not Stated
Delespaul (2002)	Not Stated	Not Stated
Kent (1996)	Not Stated [No Statistically Significant Difference Between Countries Reported, Actual Values Not Stated]	[Saudi Arabia Sample] 64% In-Patients [UK Sample] 86% In-Patients

Appendix C

C1. A Reflective Note on Feminism and Feminist Theory

The theories of feeling and feeling-traps and chapter-4's conceptual lens may be understood as a process-relational approach. To form such an understanding of body, embodiment and experience in this way, holds harmonious potentials in its compatibility and resonance with feminist theory. For example, exploration of the multifaceted impacts and dynamic intersecting process relations between aspects of embodiment, social circumstances and material circumstances has a longstanding history in black feminist scholarship by authors such as hooks and Crenshaw (hooks, 1982; Cho, Crenshaw & McCall, 2013). In contemporary feminist science studies, further examples of compatible approaches can be seen in Barad's work surrounding intra-action, the work of Haraway (2003, p. 6) where "beings do not preexist their relatings" and where "reality is an active verb", and Puig de la Bellacasa's (2012) conceptual work on thinking with care. The methodological approach of this thesis which continues to develop, illuminates further parallels with feminist approaches, of the value of knowledge arising from situated standpoints and the strong objectivity that can arise from working with experts by experience to understand experiences in knowledge production (Harding, 2004). Exploring the parallels with theoretical feminist works is beyond the scope of this thesis but it is important to pay due credit to the theoretical works of feminist writers, whose works form a harmonious foregrounding and surrounding interdisciplinary context to the approach and tone of this thesis.

Appendix D

D1. Service User Reference Group Evaluation of Research Proposal

1. Is this a topic that has relevance to service users?

YES it is relevant to service users who experience hallucinations within their psychosis and could be useful for any condition where hallucinations are experienced.

2. Is the research problem stated clearly?

YES, there are clear aims in the form of questions used to understand the experience of psychosis in service users from the PIER team. It will aim to understand how service users feel when they experience hallucinations, aiming to understand whether they are related to past experiences that may have contributed to their experiences in addition to seeing if any current issues contribute to their experiences.

3. Is the background to the research clearly stated?

YES, It is stated that there has been little research done into understanding the experience of hallucinations and this has not been tested for empirically. Because there is so little known on this area it would shed light in this respect and enable service users to be supported better based on their unique experiences of psychosis.

4. Is the proposal logically organised and clearly written?

YES, organised logically discussing background research, aims and then a clear methodology of how to study the predefined aims, with ethical considerations kept in mind.

5. Additional comments: I really like this study as it utilises an arts based understanding of experiences. The arts based diaries and work produced can help the participants in a therapeutic way whilst undertaking the task, but at the same time being useful to test for the aims of the study. The idea of showcasing participant's work is lovely and turns the experience of psychosis into something positive for the individuals and at the same time helps the wider population understand psychosis. In terms of suggestions for the study, which you don't have to take on board, is that the experience of hallucinations may

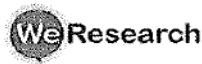
change over time. By this I mean that current experiences of hallucinations may be very vivid whereas participants in the PIER team who may be in remission may look back on their experiences of hallucinations differently and their art work may represent something different, although I realise the sample you are using is based on those currently experiencing hallucinations. It may be interesting to see if those experiencing psychosis in an organic way or because of past experiences produce artwork that has different themes identified within the analysis of the artwork. Also, some participants may be fond of their hallucinations and experience them in a positive way whereas others may have distressing experiences, it would be useful maybe to see how their experiences may change, which can reflect in their artwork as they gain more control over their psychosis. In terms of ethical considerations, I guess it should be emphasised that participants will be kept anonymous whilst showcasing their work, as it can be quite a personal thing exhibiting work that is based on current experiences and could be felt to be quite exposing. Also, participants should be recruited based on their likelihood to be less affected by exposure of their artwork as some participants may feel paranoid about their implications of showcasing their artwork or negatively affected by this. Overall, a really nice study, well done, hope the feedback is useful.

D2. Reflections on the Labour of NHS Research Access and Ethics

The documentation generated for this process and the time necessary to gain the permissions for the study required over 7 months of labour. Prior to submitting the study for ethical approval, the procedures were robustly developed and precisely planned. This provided a feeling of transparency and credibility to the research design alongside a sense of inflexibility. The body of procedural material developed to fulfil the ethical approval process was composed of over 45,000 words of original material, including a 36 page novel procedural protocol. Due to the quantity of supportive materials, only selected extracts have been provided within this Appendices section. The screenings and LoA were sought in parallel to developing the research design. This supported the study in commencing as soon as full ethical permissions were granted.

D3. Extract Copy from Letter of Access

Extract copy reduced in size to maintain original source formatting within printable boundaries.



A University Teaching Trust

Research & Development
Swithland House
352 London Road
Leicester
LE2 2PL

Wednesday 17th January 2018

Tel: 0116 295 3435
www.leicspart.nhs.uk

Private and Confidential

Miss Katie Melvin

Dear Miss Melvin

RE: Letter of Access for Research

This letter confirms your right of access to conduct research through Leicestershire Partnership NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on 17th January 2018 and ends on 1st October 2020 unless terminated earlier in accordance with the clauses below.

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

The information supplied about your role in research at Leicestershire Partnership NHS Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

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

While undertaking research through Leicestershire Partnership NHS Trust, you will remain accountable to your employer University of Leicester but you are required to follow the reasonable instructions of Dr Dave Clarke, Research and Development Operational Lead and to liaise Richard Holland with in this NHS organisation or those given delegated responsibility on his behalf in relation to the terms of this right of access.



Chair: Cathy Ellis Chief Executive: Dr Peter Miller
Trust Headquarters: Bridge Park Plaza, Bridge Park Rd, Thurmaston,
Leicester, LE4 8BL



D4. Extract Copy of HRA Approval

Extract copy reduced in size to maintain original source formatting within printable boundaries.



Dr John Cromby
Room 321, Ken Edwards Building
UNIVERSITY OF LEICESTER
UNIVERSITY ROAD
LE1 7RH



Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

23 April 2018

Dear Dr Cromby

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Feeling, Feeling-traps and Hallucinations in First Episode Psychosis: Using arts-based interview methods to study how hallucinations feel within their lived circumstances.
IRAS project ID:	238264
Protocol number:	0660
REC reference:	18/LO/0418
Sponsor	University of Leicester

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

D5. Participant Inclusion and Exclusion Criteria

D5.1 Inclusion Criteria

If all of the list below apply, the person is suitable to be recruited to the research.

- A. Currently accessing PIER service.
- B. No younger than 18 and no older than 64 (upper age limit of PIER service).
- C. Perceived by their care coordinators as having the capacity to consent to and participate in the research.
- D. Participants must be perceived by their care coordinators as able to safely engage with the data collection procedures.
- E. This includes but is not limited to, being able to safely manage any potential distress associated with discussing their hallucinations and personal histories and being safe to be in a PIER clinic room with the researcher (i.e. not being a risk to the researcher).
- F. Experiencing hallucinations at least every other day.
- G. Able to complete the interviews and diary in English comfortably.
- H. Hallucinations must not be known to be due to: another health condition, current medication use or current substance use.
- I. Participants can be of any gender identity.

D5.2 Exclusion Criteria

If any of the list below apply, the person is not suitable to be recruited to the research.

- A. Not currently accessing PIER service.
- B. Anyone under the age of 18 or over the age of 64 (upper age limit of PIER service).
- C. Not perceived by their care coordinator as having capacity to consent to or participate in the research.
- D. Not perceived by yourself (their care coordinator) as safely able to engage with the research or its data collection procedures: Not assessed as able to safely manage potential distress associated with discussing their hallucinations or personal histories or not assessed as safe to be in a PIER clinic room on a one to one basis with the researcher (i.e. being a risk to the researcher).
- E. Experiencing hallucinations at a less regular frequency than every other day.

FEELING, CIRCUMSTANCES, AND HALLUCINATIONS

F. Unable to complete the interviews or diary in English comfortably.

G. Hallucinations known to be due to: another health condition, current medication use or current substance use.

D6. Participant Information Sheet Summary

D6.1 Participant Information Sheet Summary.

Extract copy reduced in size to maintain original source formatting within printable boundaries.



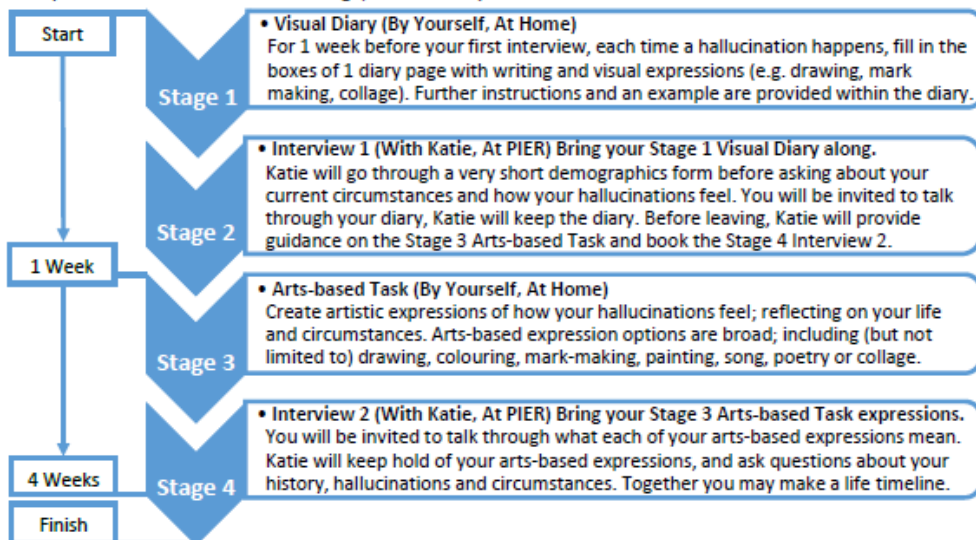
Document Title: Participant Information Sheet Summary

Participant Information Sheet Summary

Study Aim: To learn more about how hallucinations feel and what circumstances they happen in.

Who is this study being conducted by? Katie Melvin is conducting the study as part of a PhD at the University of Leicester. Katie's research is supervised by Dr Jon Crossley and Dr John Cromby.

What would taking part involve? The study involves 4 stages listed below. If you would like to take part, you will be provided with a consent form to sign, a Visual Diary to take home and Interview 1 will be booked in.



How long would this process take? Participation in the study should last around 4 weeks. If you would like to take more time, let Katie know. You may be invited to an extra interview if there are leftover interview questions.

What happens to the diary and arts-based task? These are donated to the research at interview, and subsequently owned by the researcher (including copyright). If you create something (e.g. a drawing) which you want to keep, please do. Create a much simpler artistic expression and bring this to interview instead.

After participation is finished, what happens to the information provided? Your information is confidential and will be securely stored at the University of Leicester. Information collected during the research stages will be anonymised and a pseudonym name given. Alongside the information of around 20-30 participants, your information will be analysed, and the findings from this analysis will be written into part of Katie's PhD thesis.

How will you share the research findings? Katie hopes to help improve understandings of hallucinations by sharing the study findings in academic, clinical and public settings. The write up and sharing of the research may include written interview quotes and pieces of material submitted for the research (e.g. a scanned arts-based task drawing). Participation is anonymous; your name will not be included in any write up or sharing of the research. We do not know yet what the results will be, or what opportunities for sharing the research will be. Potential examples could be clinical training, written publications, a website to summarise the research, conference presentations, public talks and displays. The consent form includes an option to opt out of having your art considered for display in public.

What happens if I do not want to carry on with the study? There is no obligation to continue if you do not want to; during an interview you can ask to stop at any time, you can also cancel beforehand by emailing Katie on km410@le.ac.uk. You can remove your information from the study until 1 week after your final interview.

Title of Project: Feeling and circumstance: Hallucinations in first episode psychosis.
Chief Investigator: John Cromby Researcher Name: Katie Melvin Sponsor ref: 0660
IRAS Number: 238264 Version Number: V1.0 Date: 05/04/2018

D6.2 Participant Information Sheet Full

Extract copy reduced in size to maintain original source formatting within printable boundaries

Participant Information Sheet



Feeling and circumstance: Hallucinations in first episode psychosis.

We invite you to take part in a research study.

- My name is Katie Melvin, I would like to invite you to take part in a research study I am running as part of a PhD at the University of Leicester.
- Before deciding take part, I would like you to understand what taking part would involve for you and why this research is being done.
- Please take time to understand this information sheet before deciding to take part and feel free to talk about the study with others if you wish.
- Participation is voluntary. If during the study you no longer wish to take part, you can stop. If you choose not to take part, or stop part way through the study, this will not affect your care.
- Ask for more information if anything is unclear or if you have questions.

Important things that you need to know.

- This study will research how hallucinations feel and what circumstances they arise in.
- We are looking for 25-30 NHS service users who experience hallucinations.
- Taking part will involve completing 1 diary, 1 arts-based task and 2 or 3 interviews; with opportunities for creative expression to share experiences such as drawing or poetry.
- This research is being conducted by a researcher from the University of Leicester. Participating in the research would be in addition your NHS care.

The Research Team

The researcher
Katie Melvin (PGCert, BSc)

Supervisors Dr Jon Crossley
Dr John Cromby

Contents

- Page 1 - Invitation
- Important Things
- Page 2 - Why are we doing this study?
- What would taking part involve for me?
- Page 3 - What are the potential benefits and disadvantages of taking part?
- Page 4 - Visual and arts based task guidance.
- Page 5 & 6 - More information about taking part.
- Page 6 - How to contact us

Contact Us?

If you have any questions about the research, please talk to the researcher Katie at km410@le.ac.uk.

Participant Information Sheet

Why are we doing this research?

- To learn about how hallucinations feel and what circumstances they happen in, this study wants to learn from people experiencing them first hand.
- Better understandings of what it's like to experience hallucinations may advance knowledge and support.

What would taking part involve for me?

- 1 diary, 1 arts-based task and 2 interviews.
- Interviews will be at PIER, lasting around 1 hour each and breaks can be taken if needed. In cases where questions left over, an extra 3rd interview may be taken to finish.
- Interviews will be audio recorded, before secure transfer onto a University Computer, for secure and anonymous storage.

Stage 1 – Visual Diary

- For 1 week before your 1st interview, each time a hallucination happens, as soon as you can, fill in the boxes of 1 diary page by writing and creating visual expressions.

Stage 2 – Interview

About 1 week later

- Fill in a very short form with some demographic details.
- Bring the visual diary and talk through it.
- The researcher (Katie) will keep the diary and ask questions about how your hallucinations feel and current circumstances. This may include starting a life timeline together.
- Katie will introduce Stage 3, discuss art-based expression options and provide a guidance sheet; you may be given some arts materials. 2nd interview will be booked.

Stage 3 – Arts-based Task

After 1st Interview

- In your own time, create arts-based expressions of how your hallucinations feel; reflecting on your life and circumstances.
- Options for arts-based expression are broad; including but not limited to painting, song, poetry or collage.

Stage 4 – Interview

About 3 weeks later

- Bring your Stage 3 arts-based expressions. Talk the through what they represent and mean to you.
- The researcher will keep the arts-based expressions and ask questions to understand your history, hallucinations and circumstances. Together you may make a life timeline.

Participant Research Timeline

- The study should take around 4 weeks.
- If you would like to take more time, just let the researcher know.



If interview time runs out you may be invited to an extra interview to finish.

More Visual & Arts-based Guidance

- On page 4.
- Please ask any further questions you may have.
- Specific short guides will be provided if you take part.

What will happen if I become distressed during an interview?

It's not anticipated that this will happen but discussing experiences can be upsetting. Should you feel distressed during an interview, the researcher Katie will support you to manage this. Together deciding how best to continue and respecting what feels right to you. This may include taking time for a break, or stopping the interview for the day.

Participant Information Sheet

What are the possible benefits of taking part in this research study?

- Opportunity to document, share and express your experiences and feelings.
- You will share your experiences with someone new and independent from your life, whose role in the interview is to listen and try their best to understand what it's like for you.
- The study encourages creative communication through visual and arts-based options. It's an opportunity to try a new way to express yourself or practice a familiar technique or skill.
- The process may be enjoyable and may provide useful personal insights.
- Opportunity to use your insights to contribute to research which may inform advances in academic, clinical and public knowledge and practice.
- Your insights may directly or indirectly support developments which help other people experiencing hallucinations.
- The research study is a confidential and anonymous platform to pass on your first-hand knowledge and donate creative pieces to research.
- Opportunity to have a researcher to sensitively yet actively share your insights anonymously; potentially reaching a range of audiences who you may not have had opportunity or felt comfortable to share them with.
- You can be kept in touch with the research findings and outcomes, by providing contact details on the informed consent sheet.

What are the possible disadvantages of taking part in this research study?

- Although you decide what you feel comfortable to share, discussing experiences and circumstances (past and present) may be distressing.
- The visual diary and arts-based expressions would be donated to research at interview and subsequently owned by the researcher.
- Written interview quotes, and pieces from the visual diary and arts-based task may be included in the write up and sharing of the study. If for example a quote or drawing was included in a talk, training, publication or display by Katie, for a clinical, public or academic audience, you would not be named or recognised for your quote, or creative work. Participant anonymity will be maintained and you would not be named or identified as having taken part in the study. This can be seen as advantage or disadvantage.

Before deciding to take part please consider:

- Would you feel comfortable sharing your experiences and expressions with the researcher, and the researcher then anonymously sharing these findings?
- If you take part: What you share is up to you. There's no obligation to share something you don't want to. The consent form also provides an option to opt out of having your art or creative expressions considered for display in public.

Advantages

- + Opportunity for expression
- + Someone to listen
- + Creative practice
- + Share your insights
- + Contribute to research
- + Researcher shares on your behalf
- + Anonymity maintained
- + Research Update

Disadvantages

- Potential Distress
- Expressions Donated
- Unnamed Quotes and Creative Work

Visual Diary and Arts-Based Task: Extra Information

DISCLAIMER: All art skill levels welcome!

There is no requirement to be skilled or experienced in visual or creative arts to take part.

Though highly skilled participants and submissions are welcome, it makes no difference to the research whether an expression comes from 0 days or 10 years of practice or time.

We hope diary and task will (1) Help you express or capture feelings, experiences and insights. (2) Help the researcher to understand your experiences. (3) Help in sharing the research findings with others.

Stage 1- Visual Diary Guidance

(1) For 1 week before interview 1, document hallucinations you have in the diary. The diary is structured into boxes to add information.

(2) Written sections: Are guided to write information in the boxes such as the time of the hallucination.

(3) Visual sections: Are guided to add visual expressions to express and document your experiences.

What options are there for visual expression?

- Visual expressions are often created by drawing, colouring, mark-making painting or collage.

Stage 3 Arts-Based Task Guidance

(1) For around 3 weeks between interview 1 and 2, in your own time reflect and create.

(a) Reflect on: How hallucinations feel; What the hallucinations are like, and how this may relate to your life: in the present and your personal history; How it feels to have hallucinations within the context of your life.

(b) Create arts-based expressions based on your reflections. This could include • drawing • painting • collage • mark-making AND • poetry • craft • song • music • textiles • small sculpture

(2) Depending on the type of arts-based take participants want to make, participants may be provided with materials to take home.

The visual and arts-based tasks are... a chance to express, document and communicate your insights. To share feelings and experiences through creative expression.

Be kind to yourself... The visual and arts-based expressions are not about creating masterpieces or beautiful things. They don't need to display some level of skill or quality; it's not like art in school or design. It's about expression!

Visual and arts-based expressions can be: A literal representation of what happened: A painting of a place or item related to the experience, a sketch of a vision or scene, a poem of words heard.

An abstract representation of how it felt: What colour, shape, texture or sound would an experience be?

How would it look as a landscape or how would it structure the pace of a poem?

Anything I should be Aware of?

- Please Remember: Visual and arts-based expressions are being made for research purposes. They will be given away to the researcher at the interview, like a donation to research and subsequently owned by the researcher (including copyright). Please bear this in mind and don't create anything too precious. If you create something but want to keep it, please do. Create another piece (it can be much simpler) to represent the same thing and give this to the researcher instead.

Any rules to follow?

- Be careful: With any creative tools or practice you use, make sure not to put yourself or anyone else at risk of harm.
- Visual and arts-based expressions must be original creations of your own ideas and making, not copies of existing works.
- Expressions must be capable of being brought into interview. E.g. Is textile work small enough to carry?

Participant Information Sheet

More Information About Taking Part (Question & Answers)

Q: Who has reviewed this study?

A: All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London Camden Kings Cross Research Ethics Committee.

Q: What will happen to the information I provide to this study?

A: The interviews will be recorded on a secure audio-device and then typed up by Katie (the researcher). Demographic form details will be anonymously added to a spreadsheet. The diary and arts-based submissions from stage 1 and 3 will be kept by the researcher; along with the interviews and demographics form, these will be confidentially and anonymously stored. In the current study, the transcription and other materials will be analysed; looking at individual's experiences, before considering similarities or differences with other participants. The study will be written up as part of Katie's PhD thesis. The write up and sharing of the research will include: interview quotes and pieces from the arts-based task and the diary. Participant names will not be included in any write up or sharing of the study and its results. Katie hopes to help improve understandings of hallucinations by sharing the study findings in clinical, academic, and public settings. We don't know what the results or the opportunities for sharing the research will be yet, examples could include research journal articles, written publications, a website to summarise the research, academic presentations, talks or displays about the research in clinical or public settings and clinical training. There is an opportunity on the consent form to opt out of having your art considered for publicly display. You can receive a summary of the research findings via email or post, it is possible that anyone who may have access to your post or e-mail would become aware of your participation in this study.

Q: What if I don't want to carry on with the study?

A: You are under no obligation to continue the study if you don't want to, so please let the researcher know. Before an interview: Cancel via email at km410@le.ac.uk During interview: It can be stopped immediately. You can also decide whether you want to withdraw information provided to the study. Participation and information can be withdrawn until 1 week after your final interview. If you lose capacity during the study, you will be withdrawn from the study but previously collected data may still be used.

Q: How do I consent to take part?

A: Before beginning the research, you will be given a consent form by the researcher or your care coordinator. This will have a series of questions, to confirm that you agree to take part and are aware of what the study will involve.

Q: Are there any situations where my information may be passed on?

A: If you provide information suggesting you or someone else may be at serious risk of harm, the researcher may ask if your care coordinator is aware; risk-related information may be passed onto relevant professionals, most likely your care coordinator or the PIER duty practitioner.

Q: Who is organising and funding this study?

A: Organised and funded as part of Katie Melvin's PhD research, at the University of Leicester.

Q: How will my information be kept anonymous?

A: To protect anonymity, participants will be given a pseudonym name and identification number for digital storage. Personal identifiers (e.g. names) will not be included in publication or presentation of the results; participants will not be named as the creators of arts-based or visual diary submissions. Participation is anonymous but your care coordinator will be aware you are a participant. Unless a serious risk arises, what you say within the interview will remain confidential; only the research team will have access to the participant's personal data during the study.

Q: What if I am harmed by the study?

A: It is very unlikely that you would be harmed by taking part in this type of research study. However, if you wish to complain or have any concerns about the way you have been approached or treated in connection with the study, you should ask to speak to Katie the researcher (contact details on Page 6), or you can speak with Research Supervisors, Jon or John (contact details are also on Page 6) and we will do our best to answer your questions. If you remain unhappy and wish to address your concerns or complaints on a formal basis, you should contact Patient Advice and Liaison Service (PALS) by Email: PALS@leicspart.nhs.uk or Telephone: 0116 295 0830. In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against the University of Leicester but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Participant Information Sheet

More Information About Taking Part (Question & Answers)

Q: How will my information be kept confidential?

A: Research Data Includes: Interview Audio Files, Transcripts and Demographics Forms, Visual Diaries and Arts-Based Diaries. Personal Data Includes: Your personal details on the consent form. Anonymised Research Data will be stored at the University of Leicester. Demographics details, interview audio files, anonymised transcripts, and life timelines will be stored in the researcher Katie's password protected account, where possible, files will also be password protected; only Katie will know the passwords. Visual diaries and arts-based task submissions will be stored in a university building and room, for which an approved security access card is needed, in a metal locker for which the researcher will have the key; providing 3 layers of security. Personal Data on written consent forms will be stored in a locked cupboard in the Academic Supervisor's locked office at the University of Leicester, only accessible to the Research Team. As this research is being completed as part of Katie Melvin's PhD research at the University of Leicester, research and personal data may be accessed by authorised individuals from the Sponsor, regulatory authorities or host NHS organisation for monitoring and audit purposes. Research Data and Personal Data will be kept for a maximum period of 5 years, after which it will be destroyed.

Q: Will I be provided expenses?

A: Participants will be given £15 in expenses for completing the study. Participants can also claim up to £15 for travel expenses within Leicestershire and Rutland to attend the interviews by bus or train; receipts must be provided. Maximum total expenses is £30.

Q: How have service users been involved? in this study?

A: Reviewing information from service user group websites and forums. Research design reviewed and approved through service user reference group.

Q: How can I help to protect my anonymity?

A: During interviews, diaries and artworks, try to keep information that could identify you at a minimum, particularly so for detailed artistic creations. Rather than sharing something identifiable to you, describe what it means to you or how it relates to you. Example: Say my brother lives nearby, rather than my brother Alex lives next door on George Street. Consider: Rather than a detailed painting of your family home, you could do a rough sketch instead or draw something less identifiable to represent the place or what it means to you?

Contact Details for Further Information

For information or advice about the research study, please contact the researcher:

- Katie Melvin at km410@le.ac.uk

The contact details of the supervisors of this PhD are:

- Dr Jon Crossley at jpc18@leicester.ac.uk
- Dr John Cromby at john.cromby@leicester.ac.uk

Please note emails to these accounts are outside of the NHS and are held by the University of Leicester; emails sent by potential participants, participants or the research team, will be deleted within 6 months of the end of the study.

A Big Thank you for Considering the Invitation & Participant Information Sheet!

Want to Take Part?

- If you're with the researcher: Get started by signing an informed consent form.
- If you're with your care coordinator: Let them know you want to take part; they will guide you on the next steps to take to get started.
- If you're at home: Contact the researcher regarding next steps via email at km410@le.ac.uk

If you have any further questions, please do not hesitate to ask the researcher.

Document Name: Participant Information Sheet Version Control: V1.1 Date: 05/04/2018
IRAS Project ID: 238264 Sponsor Ref: 0660 Project Title: Feeling and circumstance: Hallucinations in first episode psychosis.

D7. Consent Form

Extract copy reduced in size to maintain original source formatting within printable boundaries.



Document Title: Consent Form

Participant Identification Number for this study:

Title of Project: Feeling and circumstance: Hallucinations in first episode psychosis.

Chief Investigator: John Cromby Researcher Name: Katie Melvin Sponsor ref: 0660

IRAS Number: 238264 Version Number: V1.1 Date: 04/04/2018

Please initial box

1. I confirm that I have read the information sheet dated 05.04.2018 (version V1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. 1
2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason, without my medical care or legal rights being affected. 2
3. I understand that if I withdraw from the study, or lose capacity during the study, any data already collected will be retained for use in the study. 3
4. I agree to my interview being audio recorded and then transcribed by researcher Katie Melvin. I am aware interview data will be given a participant ID code (e.g. Interview A01) and a unique name to protect my identity. 4
5. I understand that materials I provide for the purposes of this study (such as diaries and artworks) are for research purposes and will subsequently be owned by the researcher. 5
6. I understand that the information and materials I provide for the purposes of this study, may be used anonymously as examples to share the results in multiple formats; including but not limited to Katie Melvin's Doctoral Thesis and potential publications, presentations and displays. 6
7. At this stage we do not know what the outcome of the research will be, or what the opportunities for sharing the research will be. It may be the case that, there is an opportunity to anonymously display art submitted to this study in public settings such as a gallery to help share the research. Would you like your art to be considered to be displayed in public? Please initial one box

7
Yes

7
No
8. I understand that data collected as part of this study may be looked at by authorised individuals from: the NHS; the University of Leicester (Sponsor) or from regulatory authorities, for monitoring and audit purposes. 8
9. I understand that personal data and data collected as part of this study will be transferred to the University of Leicester, where it will be stored on a secure computer network. 9
10. I understand that whilst my interview and information I provide to the research will be treated with confidentiality, Katie (the researcher) may have to share my information with relevant professionals if there is a serious concern about my safety or the safety of others. It is only under exceptional circumstances that breaking confidentiality would not be discussed with me. 10

FEELING, CIRCUMSTANCES, AND HALLUCINATIONS



Please initial box

11. I am aware that if I decide to receive a written summary of the research findings through the post or via e-mail, then it is possible that anyone who may have access to reading this letter or e-mail would become aware that I had participated in the study.

11

Please initial one box

12

12

12. I would like to receive a summary of the research findings.

Yes

No

If you have indicated that you would like to receive a summary copy of the research results and are happy to be sent this via email or post by the research team, please provide your details on the line below.

Email: _____

Postal Address (If Unable to Receive Emails): _____

Please initial box

12

12. I agree to take part in this study.

Name of Participant
(WRITE IN BLOCK CAPITALS)

Date

Signature

Name of Person Taking Consent
(WRITE IN BLOCK CAPITALS)

Date

Signature

D8. Demographics Form

Extract copy reduced in size to maintain original source formatting within printable boundaries.

Document Title: Demographics Form

Project Title: Feeling and circumstance: Hallucinations in first episode psychosis. IRAS Number: 238264

Version Number: V1.0

Sponsor ref: 0660

Date: 14/02/2018

To be Completed by The Participant

Date of Birth:	Gender:	Ethnicity:	Nationality:
Religion:	Marital Status:	Occupation Status:	Accommodation Type:
Psychiatric Diagnosis (if known):		Any other health conditions:	
Current Medications (if known):		Care Co-ordinator Name:	

To be Completed by the Researcher

Participant ID Number:	Interview Date:	Researcher Signature:	Date Submitted:

D9. Extracts from Visual Diary

Extract copy reduced in size to maintain original source formatting within printable boundaries.

D9.1 Visual Diary Instruction Page

What do I do & When do I do it? Each time you have a hallucination, as soon as you can, fill in the boxes of 1 diary page by writing and creating visual expressions. Do this for 1 week before the first interview. The entire diary does not need to be filled, just enough to document your experiences of hallucinations for 1 week.

Visual Expression Guidance

How Can I Create the Visual Expressions? It's up to you, whatever feels most appropriate and that you are most confident/comfortable with. Options could include expressive styles such as: Drawing, Painting, Collage or Mark-making.

What's the Aim of the Visual Expressions? To document, capture or express some aspects of an experience or feeling.

Visual Expressions can: • **Be simple or complex.**

- **Be a Literal representation of what happened:** A sketch of a vision, scene, or object related to the experience.
- **Be an abstract representation of how it felt:** What colour, shape, landscape, or texture suit your experience?
- **Messy or neat, colourful or black and white.** Use the diary to have a try at putting something on paper. Experiment and express!


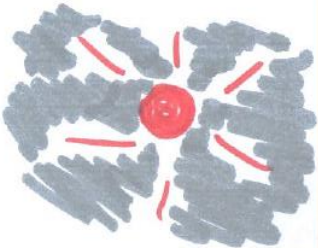

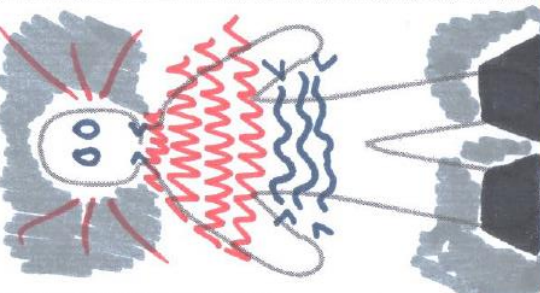
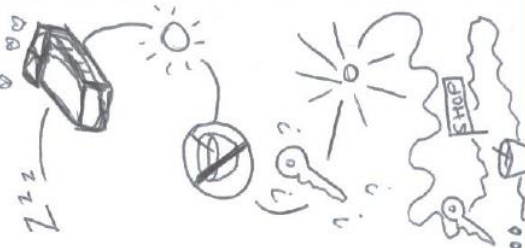

Are there any rules to follow when completing this activity?

- **Be careful:** With any creative tools or practice you use, make sure not to put yourself or anyone else at risk of harm.
- **Be kind to yourself:** Visual expressions do not need to be masterpieces, beautiful or pleasing to the eye.
- **Expressions should be original creations not copies:** If any copies of artwork or photos are used, write (COPY) below the image.
- **Anonymity Advice:** Try to ensure submitted photos or drawings of people & places will not be identifiable to you. Strategies to manage this: blur or cover parts of photos, do rough sketches of something, rather than a precise sketch or photo.
- **Make sure diary contents** can be brought into the interview and shared. E.g. Can photos be printed before the interview or emailed during the interview?

Remember: The diary will be given away to the researcher. Please bear this in mind and don't create anything too precious.

Document Title: Visual Diary IRAS Number: 238264 Version Number: V1.0 Date: 14/02/2018
 Project Title: Feeling and circumstance: Hallucinations in first episode psychosis. Sponsor ref: 0660
 For further information: Please refer to the participant information sheet.

D9.2 Visual Diary Example Page

<h1>EXAMPLE PAGE</h1> <p>For written guidance and tips, please see the back page.</p>		What happened? (Write Below)				What Senses? (Cross X All That Apply)			Room For More: Expression OR Information
		It Lasted	Time of Day	Where	Who With	Hearing	Seeing	Bodily Feeling	
→→→→→ Written	→→→→→ Description	<p>The sensory experience was:</p> <p>VOICE TOO QUIET TO HEAR. FEELING OF A PRESENCE. (BODY)</p>	<p>During this time I also felt:</p> <p>ALERT. TIRED. CONCERNED. ON EDGE. DISTRACTED.</p>	<p>During this time my body felt:</p> <p>TIRED. HEAVY. TENSE (NECK, BACK, JAW). EYES LOOKING AROUND BUT NOT FOCUSING. ON EDGE STOMACH.</p>	<p>The circumstances of the hallucination were:</p> <p>GETTING READY TO GO TO SHOP. COULDN'T FIND KEYS. NOT WANTING TO GO OUT.</p>	<p>Room For More:</p> <p>COMMON FREQUENT EXPERIENCE</p> <p>DISTRACTS ME AT THE TIME.</p>			
→→→→→ Visual	→→→→→ Expression	 				<p>LIKE A PRESENCE I SHOULD BE ATTENDING TO. IN MOMENT I CAN'T SEE PAST IT. BUT PASSES VERY QUICKLY.</p> 			

D9.3 Visual Diary Empty Page

VISUAL DIARY GUIDANCE		What happened? (Write Below)		What Senses? (Cross X All That Apply)				Room For More: Expression OR Information		
		It Lasted	Time of Day	Where	Who With	Hearing	Seeing		Feeling Touched	Bodily Feeling
In the shaded boxes: Respond with writing.										
In the white boxes: Respond with a visual expression.										
	The sensory experience was:	During this time I also felt:		During this time my body felt:		The circumstances of the hallucination were:				
→→→→→ Written Description →→→→→										
→→→→→ Visual Expression →→→→→ (E.g. Draw, Make Marks, Colour, Collage,)										

Part One: Interview Questions

TOPIC	Interview Schedule Questions	FUNNEL Questions (potential)
Daily Living, Material Circumstances	Can you talk me through an average day for you, what happens from when you wake up until you go to bed?	Where do you spend your time? What do you do with your time?
	What is the area like where you live?	
	What are your housing circumstances like?	
	What is your financial situation like?	
Social Circumstances	What else can you describe about your current circumstances?	
	What people do you have in your life at the moment?	
	What else can you describe about your current social circumstances?	What is your social life like? What is your family life like? What is your romantic life like?
	Who can you lean on for support?	
Feelings and Circumstances	You have described that your current circumstances involve X, Y, can you tell me a bit more about what your day to day life is like at the moment?	Feeling Prompts
	"During our interviews, I'll be using a technical term of Hallucination, to describe sensations and perceptions, which we may experience but those around us don't. Is hallucination a term you are familiar with? (If no, explain further). I'm going to ask you a few questions about these sort of experiences."	
	How often do hallucinations happen for you?	
	How long do the hallucinations last?	
	Looking broadly at how your circumstances are at the moment, how does it feel to experience hallucinations within these circumstances?	
	How do you think these circumstances may relate to your experiences of hallucinations?	

"Thank you for talking me through your current circumstances, it helps to give me an idea of what day to day life is like for you. Now I'm going to ask you some questions about some of the experiences you have been having."

TOPIC	Interview Schedule Questions	Funnel Questions(potential)
Experiences	<p>From start to finish, describe an experience of a hallucination; try to go into as much detail as possible.</p> <p>Have you had an experience of hallucinations that you would describe as positive?</p> <p>From start to finish, describe a positive experience of a hallucination.</p> <p>Have you had an experience of hallucinations that you would describe as negative?</p> <p>From start to finish describe a negative experience of a hallucination.</p>	<p>Circumstance Prompts</p> <p>Feeling Prompts Life Experience Prompts</p> <p>What things lend themselves to a positive experiences of hallucinations?</p> <p>What things lend themselves to negative experiences of hallucinations?</p>

Part Two: Visual Diary

"Thank you for answering those questions and talking me through some of your experiences. In this next part of the interview, we will have a look at the visual diary you were invited to complete. I'll ask you to talk me through it page by page. In your descriptions, please go into as much detail as possible to describe what your experiences of hallucinations were like and what circumstances you were in."

Researcher Action: Use prompt sheet as needed to funnel questions.

"Thank you for talking me through your visual diary and sharing your experiences. Your descriptions were very helpful. I'll keep hold of the visual diary and ask some more questions. I'm interested to hear about your experiences of hallucinations, so please feel free to go into as much detail as possible."

Part Three: Interview Questions

	TOPIC	Interview Schedule Questions	(potential) FUNNEL Questions	
			Feeling Prompts	Hallucination Features + Content Prompt
Circumstances	Compare	How did your experiences of hallucinations this week, compare to how they are in general?		
		How did the situations when hallucinations happened, compare to how they are in general?		
		When you think of situations when hallucinations happen, what comes to mind?		
		What's happening at the time?		
		What time of day?		
Hallucination Features		Who are you with?		
		Remembering that situation, how did you feel there?		
		What did you do when the hallucination happened?		
		What is it like to interact with your surrounding circumstances when hallucinations happen?		
		During hallucinations, how do you feel around people you know? (i) people you don't know		
Feelings		When hallucinations aren't happening, how does it feel to interact with your surrounding circumstances?		
		How do you think these circumstances may relate to your experiences of hallucinations?		
		How do hallucinations compare to other things you (see/hear/think)?		
		Where does it feel like the hallucination is coming from?		
		Is the content of the hallucination familiar ?		
Feelings & Time		What identity do your hallucinations have?		
		Have you been able to interact with your hallucinations?		
		Have hallucinations interacted with each other?		
		Have you been able to influence your experiences of hallucinations?		
		Just before the hallucination happens, how do you feel?		
Feelings		What differences do you notice just before a hallucination happens?		
		During a hallucination, how does your body feel?		
		How did your emotions feel?		
		How do hallucinations effect your sense of:		
		(i) Vision (ii) Hearing (iii) Touch (iv) Taste (v) Smell (vi) body (vii) Time		
Feelings & Time		From start to finish, how do these feelings change during the course of the hallucination?		
		How do you feel after the hallucination?		
		Around the time when you have hallucinations, how do you feel about yourself?		
		How do you think the feelings you've been describing may relate to the experiences of hallucinations themselves?		

Part Three: Interview Questions (Continued)

<i>TOPIC</i>	<i>Interview Schedule Questions</i>	<i>(potential) FUNNEL Questions</i>
<i>Feelings & Circumstances</i>	When did your experiences of hallucinations start?	
	What was going on in your life at that time?	
	What was it like to start experiencing hallucinations?	
	How do you feel your hallucinations relate to your life at that time?	
	What were your hallucinations like at the start?	
	How does that compare to what your hallucinations are like now?	
<i>Closing Check</i>	*What happened in your life between that time and attending PIER?	* If running out of time, ask these questions in Stage 4, Interview 2.
	*How do you think the changes in your life between then and now, relate to the changes in your hallucinations?	
	That brings us towards the end of the questions I'm intending to ask today. We've been exploring how your hallucinations feel and what circumstances happen in. Is there anything else on this topic, which you think I should know about?	
<i>Visual Diary Experience</i>	Thank you for talking me through some of your experiences today, you have provided me with a really helpful insight into some of the things that have gone on for you recently. As part of the research process, you completed a visual diary.	
	What was it like to visually express your experiences?	What were the advantages?
	How did you find the process of completing the visual diary?	What were the disadvantages?

Closing Statements

“That brings us to the end of the interview today, thank you so much.
What we’ll do now is I will talk you through what happens next and then before you leave, we will arrange your expenses.
The next steps in the study involves an arts-based task to complete at home before our next interview.
I’ll talk you through what to do now but here is an arts-based guidance sheet to take and keep at home (provide Arts-based Guidance Document).
The aim of the arts-based task is to reflect and then create arts-based expressions based on your reflections.
(1) Reflect and think about: How hallucinations feel. What the hallucinations are like, and how this may relate to your life: in the present and your personal history. How it feels to have hallucinations within the context of your life. (2) Create arts-based expressions based on your reflections.

Do you have any questions so far?

“Arts-based” means that the options for creative expression are broader than with the visual diary. So, if you have strengths in other creative art forms you can use them.
Creative options for the arts-based task include drawing, painting, poetry, craft, song, sound, music, small sculpture or small textiles are welcome.
So long as the pieces can brought into the next interview to show and discuss with me.
So for example, short poems, drawings, or short songs would be easy to bring in and show me. A two hour theatre play or a dance routine wouldn’t be suitable.

How do you think you will create the arts based expressions?
(Supply materials if appropriate.)
Do you have any questions so far?

The plan would be that once you make some creative pieces in your own time at home for around 3 weeks, then you would bring them into an interview appointment with me. 3 weeks from now would be meeting again the week of the _____.
How does that plan sound for you?
The interview will be in this building again, what date and time would suit you?

Sort expenses if participant opted to have expenses today.

Do you have any questions before we finish today?
Thank you for coming today, I look forward to seeing you on the _____.

TOPIC	<p>(potential) FUNNEL Questions</p> <p>Use funnel questions if needed and modify wording as appropriate, to identify feeling and circumstances of hallucinations based on prompts in the visual diary.</p>		
<p>Diary Prompts</p>	<p>Can you tell me a bit more about _____?</p> <p>How does this _____ relates to your experiences?</p>		
<p>Feeling Prompts</p>	<p>How did your emotions feel?</p> <p>How did your body feel at that time? (prompt: from head to toe)</p> <p>How did it feel to experience _____ when you're feeling _____?</p>	<p>How do hallucinations effect your sense of:</p> <p>(i) Vision (ii) Hearing (iii) Touch (iv) Taste (v) Smell (vi) body (vii) Time</p>	<p>Page 7 of 7</p>
<p>Circumstance Prompts</p>	<p>Where were you?</p> <p>What was happening at the time?</p> <p>What time of day was it?</p> <p>Who were you with?</p> <p>When you remember that situation, how did you feel there?</p>	<p>How did you feel around people you know?</p> <p>How did you feel around people don't know?</p> <p>What did you do when the hallucination happened?</p> <p>What happened next?</p> <p>What effects does _____ have on your life?</p>	
<p>Hallucination Features Prompts</p>	<p>How long did this hallucination last?</p> <p>How clear was the hallucination?</p> <p>Where did it feel like the hallucination is coming from?</p> <p>Was the content of the hallucination familiar?</p> <p>What identity do your hallucinations have? i.e. gender, age</p> <p>How does the hallucination compare to other things you (see/hear/think)?</p>	<p>Have you been able to influence your experiences of hallucinations?</p> <p>What are your experiences of interactions with hallucinations (voices, vision, touch)?</p> <p>(i) Have your hallucinations interacted with you?</p> <p>(ii) Have your hallucinations interacted with each other?</p>	
<p>Life Experience Prompts</p>	<p>What sense did you make of this experience?</p> <p>How does _____ relate to your experiences at the time?</p> <p>_____ "at the moment?"</p> <p>_____ "experiences in the past?"</p> <p>_____ "circumstances in the past?"</p>		

D10.2 Stage 4 – Interview 2

Document Title: Stage 4 Interview Schedule Project Title: Feeling and circumstance: Hallucinations in first episode psychosis. IRAS Number: 238264 Version Number: V1.0
Date Last Amended: 14/02/2018 Sponsor Ref: 0660

Please Note: The following interview schedule is a flexible tool and topic guide which is open to revision if new areas of interest arise during the process of data collection. In order to adapt to any logistical factors (e.g. limited time for an interview) it is not essential that each interview should include every line of questioning as detailed below.

Question Prompts: Listed on "Question Prompts" Page.

If questions are all finished please end the interview with the "Closing Statements (Final Interview) section.

If questions are not all finished such that a 3rd interview is seen to be needed, please finish with the "Closing Statements (If interview questions are not finished before ending and 3rd interview will be needed)" section. During the 3rd interview please use the "Part One" section of this schedule, and complete any remaining interview schedule questions, finishing with the "Closing Statements (Final Interview)" section.

Part One: Introduction, Confidentiality, Write to Withdraw, Agenda

" Hi, good to see you again.

Just to introduce myself again though I am sure you are aware, my name is Katie and I'm a Doctoral Researcher at the University of Leicester.

I'm working with PIER to do some research to learn about how hallucinations feel and what circumstances they happen in. We will not be trialling any treatments as part of the research and the research appointments are in addition to your NHS care. As you may be aware, we do intend to reimburse participants for their travel expenses by bus or train. Do you have any receipts to be reimbursed for your travel today? Great, we will sort that out _____.

You will also be given £15 for taking part at the end of your last interview. So your expenses will be sorted at the end of the interview today. "

If you have any questions at any stage, please do feel free to ask. Just a reminder of some formalities.

Before we get started, I just need to talk through some information regarding confidentiality and some formalities regarding the research.

(1) The research interviews will be audio recorded and I may also keep some notes, alongside any other information submitted for the research, these will be stored separately from your medical notes at the University of Leicester.

(2) The information you provide to the study will be treated as confidential and your participation is anonymous.

(3) The only time where any information could be passed on, is if you provide information which suggests you or someone else may be at serious risk of harm, this risk-related information may be passed onto your care co-ordinator or a relevant professional.

(4) The hope is that today we will create a safe space for you to discuss some of your experiences. Whatever you decide to share is up to you, you are under no obligation to answer any questions you don't want to, or share anything you don't want to.

(5) You can take a break at any point if you want to, just let me know.

(6) If during the interview you decide that you want to stop for today, or want to stop being in the study altogether, please just let me know. This will not affect your NHS care.

(7) You have the right to withdraw your information from the research until 1 week after the final interview.

Does that all sound okay?

The plan for our conversation today is that:

(a) I'll ask you a few questions, before talking me through the arts-based expressions that you have created.

(b) After this we will further discuss, your experiences of hallucinations and your current circumstances. Today in particular we will be considering your previous history.

This may include continuing to make a timeline together. (c) At the end of the interview, I will talk you through what the research does next..

(d) If we run out of time for all the questions today, we may follow up with these in an additional interview.

Today's interview should take around 1 hour to complete and around 10 minutes to arrange your expenses and talk through what's next for the research.

Is that time frame okay for you today?
Before we get started, do you have any questions you would like to ask? "

Part One: Interview Questions

TOPIC Interview Schedule Questions		(potential) FUNNEL Questions
Compare Circumstances	What's happened since we last met?	Life History Prompts
	How have you been since we last met?	
	What (if any) changes have there been in your circumstances since we last met?	Feeling Prompts
	How are things at the moment?	Hallucination Features
	How have your hallucinations been since we last met?	Content Prompts
Compare Hallucinations	What (if any) changes have there been in your hallucinations?	
	What (if any) changes have there been in how your hallucinations feel?	
	How often have your hallucinations been happening?	
	How long do they last?	
	What circumstances have you been in when they happen?	
	What senses are involved when they happen?	
	How does your body feel when they happen?	
	How have your emotions felt when they happen?	

Part Two: Arts-Based Task: “Thank you for answering those questions and talking me through some of your experiences. In this next part of the interview, we will have a look at the arts-based task you were invited to complete between the last interview and today. I’ll ask you to talk me through what you have brought along and ask you to go into as much detail as possible, in terms of what they represent and mean to you.”

Use prompt sheet as needed to funnel questions for more information.

“Thank you for talking me through your arts-based expressions and sharing your experiences. Your descriptions were very helpful.

I’ll keep hold of the artworks and we can talk through some questions I’ve brought with me. Before we move onto those, is there anything else regarding the artworks that you think it may be useful for me to know?”

Part Three: Timeline: During the interview today, I’m interested in learning what your past experiences were like and how they may relate to some of the experiences you have been having. So we will start by creating a timeline together where we will map out some of your personal history on a page of A3 paper. We will start from when you were born, working through each year until the present. Thinking about how you were at the time, what life was like and anything that happened to you. As we will be drawing this out as well as talking, would you prefer for me to write or would you like to write?”

Use prompt sheet as needed to funnel questions for more information.

Part Four: Interview Questions

TOPIC Interview Schedule Questions		(potential) FUNNEL Questions
Life Circumstances & Feelings	Looking over your life span, is there anything which stands out in particular for you?	Life History Prompts
	How do you think the experiences on the time line may relate to what your circumstances are like for you at the moment?	Feeling Prompts
	How do you think these experiences on the time line may relate to how you feel now?	Circumstance Prompts
	How do you think these experiences on the time line may relate to how your hallucinations feel?	Hallucination Features Prompts
	How do you think these experiences on the time line may relate to how your emotions feel?	
	How do you think these experiences on the time line may relate to how your body feels?	
Review & Bringing Interview to a Close	How do you think these experiences on the time line may relate to the content of what happens in your hallucinations?	
	What (if any) are the difficult things about experiencing hallucinations?	
	What (if any) are the positive things about experiencing hallucinations?	
	What do you hope I've learned from your experiences?	
	During the research, we've been exploring how your hallucinations feel and what circumstances happen in. Is there anything else on this topic, which you think I should know about?	
	As part of the research process, you completed a visual diary.	
	How did you find the process of completing the arts-based task?	
	What was it like to express your experiences through art?	
	How do you think this compared to just answering research questions alone?	What were the advantages? What were the disadvantages?
	What are your thoughts on creating the timeline together?	
	What do you wish members of the public knew about hallucinations?	
	What do you wish clinicians knew about hallucinations?	
	If you could give advice to someone who is experiencing hallucinations, what would you say?	

Closing Statements (Final Interview)

“That brings us to the end of the interview today and the end of your participation in the study, thank you so much.

What we’ll do now is I will talk you through what happens next and then before you leave, we will arrange your expenses.

So again thank you for taking part in the research and talking me through your experiences. As you’re aware this research hopes to improve understandings of what it’s like for people who experience hallucinations, I’m really grateful for your support in helping the research. From now, I’ll be collecting the things you’ve shared with me together with things shared with the other participants in the study. Looking at the similarities and differences across the group. I’ll be writing up a thesis, which is a very big research document. I hope to write some shorter papers and do some presentations, to support in sharing the results to researchers, clinicians and other members of the public as best I can.

As you may be aware, in a year or so, when the research is finished, we can send out a short summary of the results to any research participant who wants them.”

Check whether or not the participant would like the results summary, if details not formerly documented write down (store with informed consent sheet).

Arrange expenses.

Thank participant again for taking part.

Closing Statements (If interview questions are not finished before ending and 3rd interview will be needed.)

“Thank you for your time today, your insights are really helpful in supporting the research to better understand some of the experiences people have.

What we’ll do now is I will talk you through what happens next and then before you leave, we will arrange your expenses.

As you’re aware we haven’t been able to complete all the interview questions today.

I would like to invite you to meet again, just to finish the remaining questions, would you like to?

If yes, arrange a date and time for meeting.

If no, thank the participant for taking part.

Check if the participant also wants to withdraw the information they have submitted to the research.

Highlight that all participants are welcome to receive a summary of the results once the study is finished. Check whether or not the participant would like the results summary, if details not formerly documented write down (store with informed consent sheet).

If they still want to be included:

Inform participants that as they haven’t completed the full research process, their contributions may not be able to be included in the research.

Let them know if they change their mind about finishing the study, that they can get in touch via the contact details are on the participant information sheet (check if they still have a copy, provide one if not).

Describe that once interviews with the remaining participants are complete, the study will come to a close and they won’t be able to participate after this time (provide a rough time estimate of when this will be).

Prompt Page

<i>TOPIC</i>		<i>(potential) FUNNEL Questions</i> <i>Use funnel questions if needed and modify wording as appropriate, to identify feeling and circumstances of hallucinations based on prompts in the visual diary.</i>	
<i>Arts-Based Prompts</i>		Can you tell me a bit more about _____?	
		How does this _____ relate to your experiences?	
<i>Feeling Prompts</i>		How did your emotions feel ?	How do hallucinations effect your sense of:
		How did your body feel at that time? (prompt: from head to toe) How did it feel to experience _____ when you're feeling _____?	(i) Vision (ii) Hearing (iii) Touch (iv) Taste (v) Smell (vi) body (vii) Time
<i>Circumstance Prompts</i>		Where were you?	How did you feel around people you know?
		What was happening at the time? What time of day was it? Who were you with ? When you remember that situation , how did you feel there?	How did you feel around people don't know? What did you do when the hallucination happened? What happened next ? What effects does _____ have on your life?
<i>Hallucination Features Prompts</i>		How long did this hallucination last?	Have you been able to influence your experiences of hallucinations?
		How clear was the hallucination? Where did it feel like the hallucination is coming from? Was the content of the hallucination familiar ? What identity do your hallucinations have? i.e. gender, age How does the hallucination compare to other things you (see/hear/think)?	What are your experiences of interactions with hallucinations (voices, vision, touch)? (i) Have your hallucinations interacted with you ? (ii) Have your hallucinations interacted with each other ?
<i>Life Experience Prompts</i>		What sense did you make of this experience?	
		How does _____ relate to your experiences at the time ? "_____ at the moment?" "_____ experiences in the past?" "_____ circumstances in the past?"	
<i>Life History Prompts</i>		What happened to you?	
		How did it affect you? What sense did you make of it? What did you do to manage?	

D11. Life Timeline

Extract copy reduced in size to maintain original source formatting within printable boundaries.

Document Title: Life Timeline IRAS Number: 238264 Version Number: V1.0 Date Last Amended: 14/02/2018 Project Title: Feeling and circumstance: Hallucinations in first episode psychosis. Sponsor Ref: D660



D12. Arts-Based Task Guidance

Extract copy reduced in size to maintain original source formatting within printable boundaries.

Document Title: Arts-based Task Guidance IRAS Number: 238264 Version Number: V1.0 Date: 14.02.2018
 Project Title: Feeling and circumstance: Hallucinations in first episode psychosis. Sponsor ref: 0660
 For Further Information: Please refer to the Participant Information Sheet.

Arts-Based Task Guidance

What's the Aim of the Arts-Based Task?

To document, capture and express some of your insights, aspects of your experiences and feelings.

What do I need to do?

(1) Reflect and think about: • How hallucinations feel.

• What the hallucinations are like, and how this may relate to your life: in the present and your personal history.

• How it feels to have hallucinations within the context of your life.

(2) Create arts-based expressions based on your reflections.

Arts-based expression could include • drawing • painting • collage • mark-making

AND broader options such as • poetry • craft • song • music • textiles • small sculpture

Arts-Based Expressions Can Be....

• Simple or complex.

• Messy or neat.

• Colourful or black and white.

• A Literal representation of what happened:

A sketch of a vision or scene. A poem of words heard. A sketch of a relevant object or place.

• An abstract representation of how it felt:

What type of colours, shapes, forms, textures or landscapes suit your experience?

So long as it can be brought into the interview and shared with the researcher, expressive style is up to you. Have a try with whatever feels most appropriate or what you are most confident/comfortable with.

Use the arts-based task to have a go at expressing and documenting some of your experiences and insights. Practice a familiar creative style, or try something new.

Are there any rules to follow?

Similar to the visual diary...

- **Be careful:** With any creative tools or practice you use, make sure not to put yourself or anyone else at risk of harm.
- **Be kind to yourself:** The arts-based expressions do not need to be masterpieces, beautiful or pleasing to the eye/ear. Creativity and expression come in many forms.
- **Expressions should be original creations not copies.** Please let the researcher know if any expressions are copies. Due to copyright issues copies can't be included in research publications.
- **Anonymity Advice:** Try to ensure submitted creations will not be identifiable to you. Strategies to manage this: Do rough sketches of something, rather than a precise sketch. Don't submit copies or originals of your own previously created artworks.
- **Make sure the arts-based task** can be brought into interview and shared. E.g. Is textile work or a painting of a small and manageable size?

Remember: The arts-based task and expressions are being made for research purposes. They will be given to the researcher at the interview. Like a donation to research. The pieces may be displayed in formats such as written publications of the research or a public display at a research presentation. Please bear this in mind and don't create anything too precious. If you create something but want to keep it, please do. Create another piece (it can be much simpler) to represent the same thing and give this to the researcher instead.

D13. EPA Extract: Under “Spiritual Britain” Stream.

Codes indicate the participant and interview: “(1.1)” indicates notes and quotes arise from the first participant’s first interview, (15.2) indicates the 15th participant’s second interview.

Protection from Spiritual Beings

(1.1) Encountering the purple being:

Calmer feeling of pace of talk, softer voice when retelling the experience of communication with purple being and feeling protected, feeling calm myself and as though I was learning about something precious, divine and special. Highly powerful and valued experience of connection and access to a loving higher being. Points to anchor question response regarding the potential for wonderful as well as difficult experiences. However, majority of reported experiences were difficult.

“They were filled with such love, that’s all I remember. Then they kind of disappeared and came back recently and one of the things they said to me was “don’t worry you’ll be protected, this has been planned from birth and you were always gonna be protected, I’ve been with you from birth, so you are always going to be protected”, so the first time I actually witnessed it, I think it was about this time, I remember being at college...it was the most amazing experience I’ll never forget it.”

Recent visitations happened whilst alone at home.

(15.2) Encountering their guardian angel:

Introduction of guardian angel felt like a saviour, a protective being and experience of safety in an otherwise unsafe situation. Feeling relief, hope, light. It felt as though the guardian angel is very much his, existent and with a strong protective connection. Symbolism is consistent with participant’s Catholic faith. SR1 and 2 had neglected exploration of religious faith on feeling and content of hallucinations.

“That’s when my guardian angel came in and he “duh duh” [divine sound] so to speak and pushed the scary ones away, that’s when I had the glowing crucifix and basically confirmation of faith, ‘don’t worry, you are protected’ which sort of resembles the yellow glow around, so it’s all good. It was okay to be alone because I was physically but not unphysically.”

(Line 345, 15.2)

Visitation whilst alone at home at night.

Protection through Prayer:

(15.2) One participant expressed an experience using Figure X where during a visit from three malevolent visual figures “I was asked to sell my soul to make things better...easier” and “felt protected by my faith”.



D.14 Evaluation of Research Methods

Table D.1

Reported benefits of taking part in the research.

<u>Benefit Summary</u> (Method If Specified)	<u>Participant Report of Benefits</u>
Supported Reflection	"Really good actually I think it's made me reflect really well".
Opportunity to Help Others	"I guess as long as it's helping people understand what people like me go through, I'm up for any way to help for people in the future to be understood".
Cool To Share (Interviews)	"Being able to talk about it has definitely been a good thing...being able to speak about things and it not be sort of like, weird, you know it's cool".
Express and Offload (Visual Diary)	"I thought it was a really good tool like just to express myself. I think I was able to communicate exactly what I go through so – and it felt like a relief as well, just very therapeutic getting it down on paper...It's like sharing it with people rather than having it just in my head and stuff like that".
Document Experiences (Visual Diary)	"I'm like screaming out for help so this is like helping to kind of like put it on paper, so there it's portrayed for you, kind of in front of you".
Communicate to Presence (Visual Diary)	"I think it was like a strategy basically because like it made him aware, the presence of that he shouldn't be doing all these things. And every time I wrote it down, it's just like it acted as evidence on paper so it was quite good".
Enjoyable, Relieving, Felt Understood (Visual Diary, ABRM & Interviews)	"I just find it fun. Like it's just like – for me it's just like relief basically, just being able to talk about myself and just like someone to listen to everything that I go through and understand it. It's just what I want and that's what I used to get from therapy as well...just feels a relief and understanding and like that's what I want from someone, so I've got that".
Felt Good (ABRM Drawing)	"It felt good to try and draw my experiences. I didn't think I would be able to really. Yeah it felt good to do it".
Expressing Feelings (ABRM Story-	"I liked it because I feel like I'm expressing my emotions and feelings".

Telling, Visual &
Written)

**Opportunity to
Express
Experiences**
(ABRM Painting)

"I got the paintbrush set out that you gave me and I just let it go".

**Evidence of
Recovery**
(ABRM, Rap)

"To be able to make a bit of a joke about it and sort of make fun of it is definitely a good road to recovery bit of evidence for me. I've enjoyed it."

**Achievement Of
Creating**
(ABRM Rap)

"I'll be happy when it's finished and then sort of like be a little bit of a nice achievement".

**Organising Life
History and
Feeling Better
About it**
(Life Timeline)

"This way set it up so you know from A to B, birth up to today...I feel a lot better now because I can see how my life has gone as well. I had it in my head jumbled up, but now it's all in order."

**Art Resources To
Keep and Use
Beyond Study**

"I love my stuff so much! I kept looking at it on my table and I thought I love the paints. Do you know what I painted a few things in my flat. My flat has a colour theme so I painted a wooden box, plant pots and stuff, so I've really put them to good use. Thank you."

D.15 Reports Regarding Features Which Impacted on Sharing

Table D.2

Reports of features of circumstances or design which impacted on being able to share experiences.

<u>Feature Summary</u> <u>(Design)</u>	<u>Impact</u>	<u>Participant Report</u>
Omnipresence of Hallucinations	Negative	"I'm sure someone's over there out there, watching our meeting listening to our meeting I know they're not but I can hear it going on do you know what I mean?"
Personal Content Under Study	Negative	"It's complicated because some things are personal and as much as I know it's confidential, you're a nice person and I trust my environment, the environment and everything else. It's still personal to me".
Hard Sharing Due to Past Reactions From Others	Negative	"I can't just open up about that straight away because I've tried not to talk about that kind of stuff for a year and a half now, after trying to tell everybody I knew about it ... It scares people. I know it probably won't scare you, but it's just not great".
Toughness Documenting Life History (Life Timeline)	Negative	"I found that a bit tougher just to talk about experiences and stuff and try to be like 'this is my life' and getting it on paper. It's a bit like writing a CV, isn't it?"
Worried About Drawing Skills: Could Write Instead (ABRM)	Negative/ Positive	"It was a bit hard because I couldn't draw very well. So it was a bit stressful, to be fair, because I was worrying; I can't draw...I preferred writing this bit."
Helpful to Explain (Body-Map & Visual Diary)	Positive	"Especially this [body map], this was perfect because it was drawn out a figure of a person because everything is to do with my body...I've heard other people with mental issues they have other kinds of sensations, not on their body as much. This really helped, what I was feeling about how my body feels attacked and targeting. It was really good drawing it out on my body. That really helped. Drawing out the different little pictures to go with it...everything fit, every description that I wanted to write down. It was really helpful, I

		want a diary of these when I'm on my own and do it every day."
Sharing (ABRM Drawing)	Positive	"That helped. I showed how it is".
Visual Sense-Making, Using Skills (ABRM Drawing)	Positive	"It's kind of like, that's how I work anyway and it's interesting... creatively you can visualise, quite a horrible experience and to visualise it in a different way that, you can sort of apply those thoughts or feelings or the experiences to different sort of objects or characters, or to try and make sense of it...it does help to sort of draw it for me, because that is my background as well, that's how I can make sense of things".
Becoming Relatable (Visual Diary & ABRM Drawing)	Positive	"Writing it and putting it on paper, drawing something is so much better than just like trying to explain something and they don't have a visual understanding of it, so you've got like that visual thing there...you can relate to it basically and become relatable".
Explaining Feelings & Becoming Relatable (ABRM Painting & Drawing)	Positive	"They can't really relate to it because you can't see it...I think that helps explaining to people what's happening, so you can see what I'm seeing or what it would feel like to see. You've got the ears and the nose so you can picture what it might be like or what I'm feeling when I'm hearing or seeing these things."
Share Hallucinations Experiences With Someone Unknown (Visual Diary & ABRM Drawing)	Positive	"Somebody who's not been through it, to try and allow them to see how it kind of feels, or how it could be portrayed in a different way, that's maybe more understandable than just what you're hearing in your head."
Share Psychosis with Someone Unknown (Visual Diary & ABRM Drawing & Painting)	Positive	"I think the visual aspect really helps explain to people who don't suffer from psychosis".
Share Situated Positions	Positive	"A representation of how it was when I was in this position".

(ABRM Painting)

Flexibility of Mode of Linguistic Communication (Open ABRM Leaflet)	Positive	"I'm really good at writing...I can explain and express more, by typing or writing, than speaking".
One-To-One Interviews and Opportunity to Meet Researcher Multiple Times (Interviews)	Positive	"You should feel good as well because usually I don't come in by myself... I feel comfortable with you now. So that's why I came by myself...I wouldn't tell you everything if someone was in the room".
Sharing Life Events and Chronology (Life Timeline)	Positive	"I thought it'd just be go to school, go to work...it come out with quite a lot of information, dates and times and events."
Communicate Temporality of Stressful Life Events (Life Timeline)	Positive	"I suppose when you see it written down, visually, it's visual isn't it, you can see that there's really nothing there, then there's a little bit, and then it's really jam-packed, towards the end I was struggling to find space to write it all in, so yeah, it really came to a head."

Appendix E

E1. Temporal Data: Duration of Hallucinations

Table E.1

Duration Data by Hallucination Type.

<u>Reported Length of Time</u>	<u>U-N</u>	<u>SiMMH-N</u>	<u>H-N</u>
1 minute	6		6
1.5 minutes	1		1
2 minutes		2	2
4 minutes		1	1
5 minutes	2		2
10 minutes		1	1
15 minutes"	2		2
20 minutes	2	2	4
30 minutes	2		2
40 minutes		2	2
1 hour		1	1
7 hours		1	1
9 hours		1	1
12 hours		1	1
14 hours		1	1
"Minutes"		1	1
"Short Time"		1	1
"All night"		1	1
"All Day"		2	2
"All Morning"	1		1
"A While"	1		1
"Most of the Day"		1	1
	<u>U-N</u>	<u>SiMMH-N</u>	<u>H-N</u>
	<u>Missing</u>	<u>Missing</u>	<u>Missing</u>
	4	2	6

U-N: Number of documented hallucinations involving one modality.
SiMMH-N: Number of documented simultaneous MMH hallucinations.
H-N: Total number of documented hallucinations

E2. Temporal Data Transformations: Time of Day

Table E.2

Key of Transformed Temporal Data: Linguistic to Numerical Temporal

<u>Temporal Qualitative Descriptor</u>	<u>Numerical</u>	<u>Number of Diary Entries</u>
	<u>Coding</u>	
“All Day”	08:00 – 23:59	1
“Night”	23:00	3
“Mid Afternoon”	15:00	1
“Morning”	09:00	1
“All Morning”	09:00 – 12:00	1
“Evening”	20:00	1
“Day Time”	08:00 – 20:00	2

E3. Temporal Data: Time of Day Combination Graph

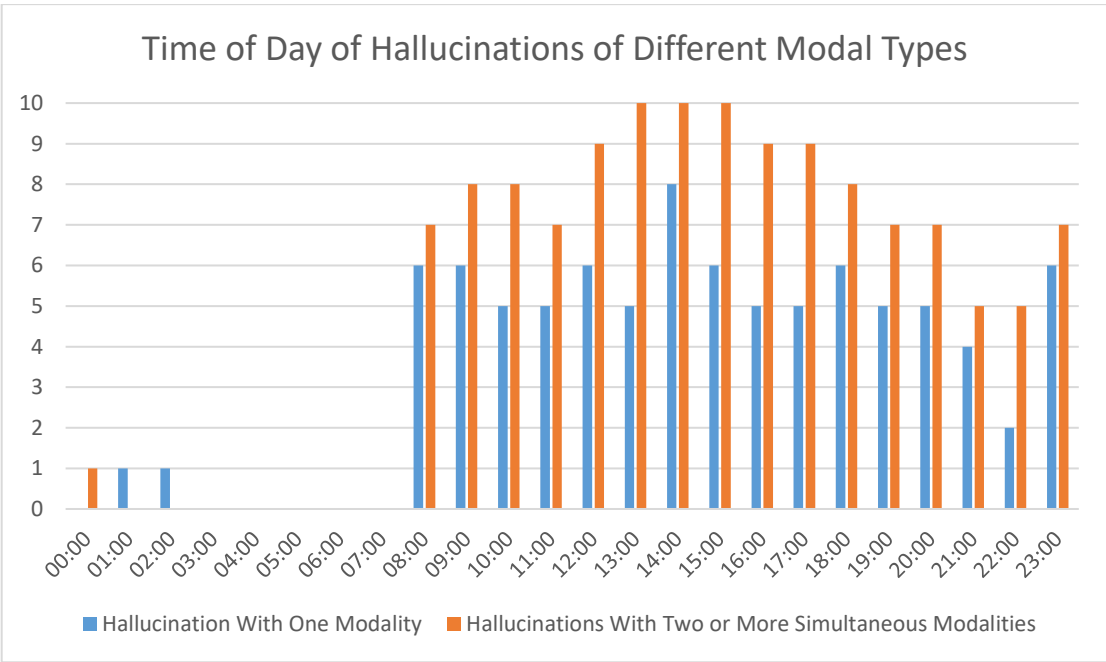


Figure E.1 Time Visualisation for Diary-Documented Hallucinations involving One Modality Compared to Multiple Modalities.

E4. Circumstances of Hallucinations Exemplar Data Table

Table E.3

Circumstances and modalities of hallucinations.

<u>Circumstances</u>	<u>H-N</u>	<u>P-N</u>	<u>Hallucination Types</u>
<u>Social and Leisure Activities</u>			
"Walking" Outside	4	4	AVH + BH
"Walking past the houses"			
"As I'm walking off"			AVH
"Walking...through woods"			AVH
"Long walk"			TH + GH + OH
"Walking through a crowd of people"			
Social Interaction	2	2	
Family Meal			AVH
"Bonfire Display with Friends"			AVH + BH + GH
With a dog	2	2	
"Walking...through woods"			AVH + BH
"In the garden"			AVH + VH
Reading	2	2	
"Trying to read"			AVH
"Reading the newspaper...couldn't read newspaper because of voices"			AVH
Managing Content of Voices	2	2	AVH
"Covering the covert cameras"			AVH
"Checking all doors and windows"			
At an Exercise Class			
"Difficulty in yoga pose"	1	1	AVH
"At Home...Writing"	1	1	AVH
"Talking on skype"	1	1	AVH + BH + VH + TH
<u>Circumstances</u>	<u>H-N</u>	<u>P-N</u>	<u>Hallucination Types</u>
<u>Material Circumstances</u>			
"Watching the tele"	2	2	AVH
"Watching a children's film on TV"			VH
Relaxing	2	2	
"I'd just laid down"			AVH + BH
"Just sit down and relax"			AVH

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Being Around Technology

"At my computer"	2	1	AVH
Radio "decided to switch off"			AVH

<u>Circumstances</u>	<u>H-N</u>	<u>P-N</u>	<u>Hallucination Types</u>
<u>Difficult Social-Material Circumstances</u>			
Isolation	3	2	AVH VH
"Being alone feeling low"			AVH + BH + VH
Relational Problems	2	2	
"Having an argument with my mum"			AVH + BH + VH
"Being around mum"			AVH + BH + TH
Wanting to Rest at Home	2	1	
"Desperate to get home"			AVH + BH + VH + TH
"Felt like lying down & resting my feet"			

<u>Circumstances</u>	<u>H-N</u>	<u>P-N</u>	<u>Hallucination Types</u>
<u>Activities of Daily Living</u>			
Preparing to and Leaving the House	5	4	
"Going out to meet a friend"			AVH + BH + VH + TH
"Getting ready to go to town"			BH BH
"Going out to see friends"			AVH
"Trying to get ready for work"			AVH + VH + BH + Te
For a "seminar"			
Sleep	4	4	
"Lack of sleep"			AVH + BH + TH
"Stressed about falling asleep"			AVH AVH
"Trying to sleep"			VH + BH
Waking "with sleep paralysis"			
Work	4	3	
"Working Being On My Feet" "Getting Sad + Fed Up With Customers"			AVH + BH + VH + TH + GH
"Trying to meet deadlines at work...at my desk at my			AVH

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computer"			
"Hearing voices of the people around me talking about me"			AVH + BH
Interacting with Colleagues			AVH + BH + VH
"Looking at each other and talking, a few of us were in between a task, how we were gonna do it, deciding who does what and that happened."			
In a "Hurry" "Rush"	2	2	AVH + BH AVH
To Leave			
To "Get all the food warm"			
"Eating"	1	1	AVH + BH + VH +TH
Bathroom	1	1	AVH +BH
"Having a shower. Time in Bathroom"			
"Drying my hair"	1	1	AVH + BH + VH +TH
"Sitting on a bus"	1	1	AVH
"Collecting my delivery" at home	1	1	AVH
In a "Shop"	1	1	AVH + BH
"Going to GP's"	1	1	AVH + BH +TH
"In my head planning the next day"	2	1	AVH + BH
"Revising...theory test"	1	1	AVH

<u>Circumstances</u>	<u>H-N</u>	<u>P-N</u>	<u>Hallucination Types</u>
<u>Managing Hallucinations</u>			
Interacting With Entity			
Via Touch			
"Kept on touching the areas I felt attacked with my hand to soothe it"	2	1	AVH + BH + VH +TH + GH AVH + BH + VH +TH
Via Talk			
"Kept on speaking out"	3	3	AVH + BH + VH +TH + GH
"I heard voices and wanted to reply"			AVH + BH AVH
"I'm fighting my cause. I've said wat I've needed to say, I say it in a calm manner but I say, I make sure I get my			

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point across...to make sure I'm heard"			
Managing Content of Voices	2	2	
"Covering the covert cameras"			AVH
"Checking all doors and windows"			AVH
Shouting Out to Others	1	1	AVH + BH + TH
"I thought somebody shouted out of a car, I did get really mad and I screamed "just leave me alone"... crazy like scream"			
Data Missing	2	1	AVH + BH AVH

H-N: Number of times a feeling within a cluster was used to describe a hallucination.

P-N: Number of participants who diary documented a feeling.

F-N: Number of feeling terms.

E5. Feeling of Hallucinations: Modalities in MMH

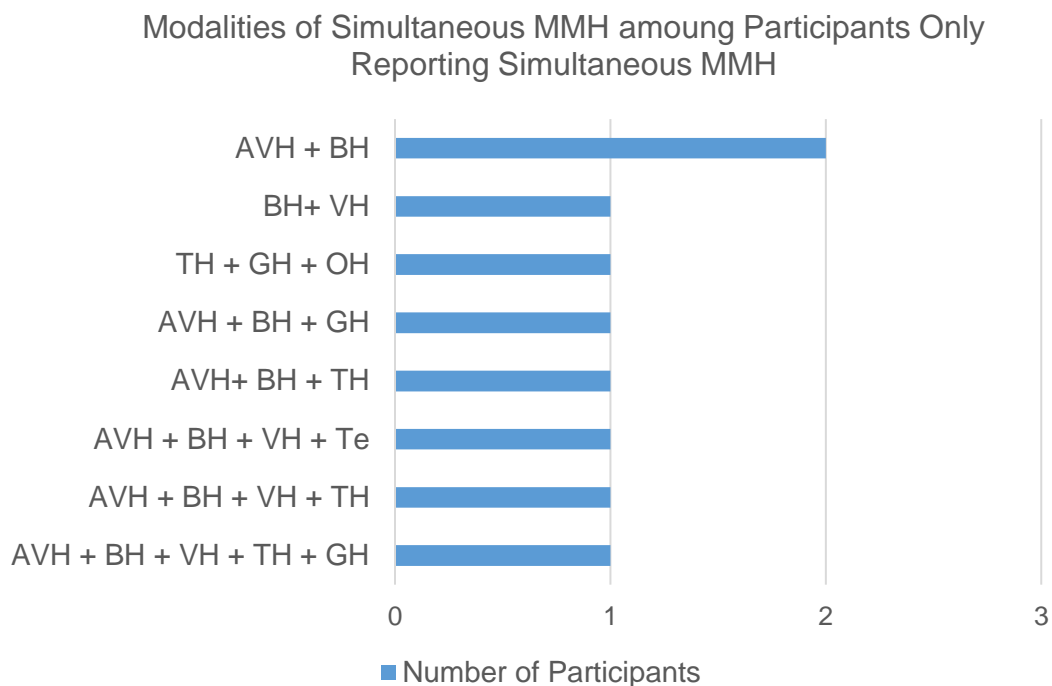


Figure E.2 Modal combinations of Simultaneous MMH.

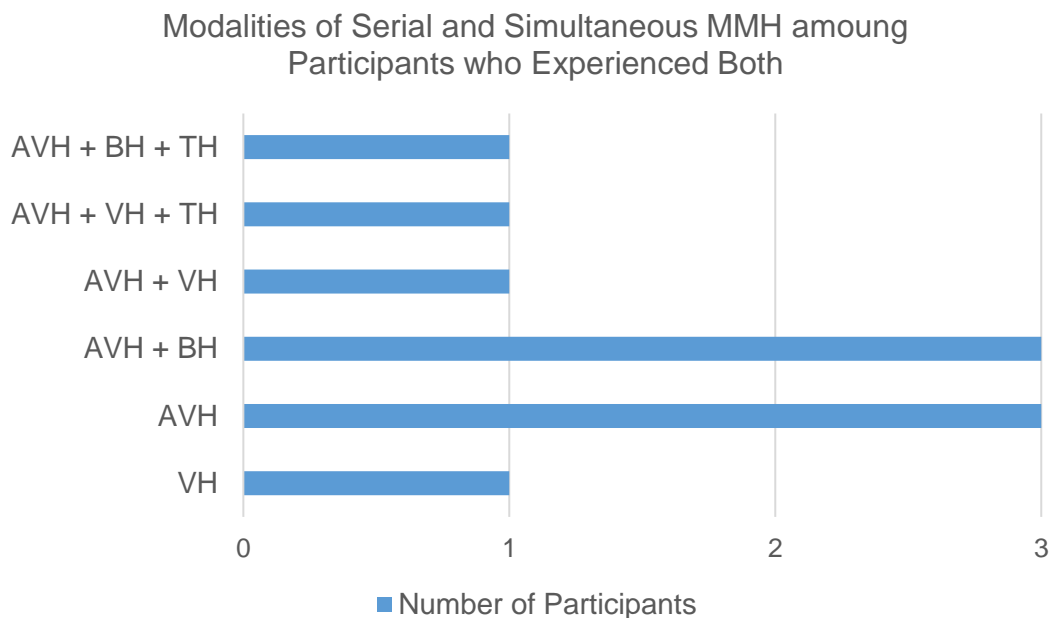


Figure E.3 Modal Combinations of Simultaneous and Serial MMH.

E6. Feeling of Hallucinations: Words and Counts

Table E.4

The Frequency of Diary Documented Feelings which Reportedly Co-occurred with Hallucinations.

<u>Word</u>	<u>Count</u>	<u>Word</u>	<u>Count</u>	<u>Word</u>	<u>Count</u>
confused	10	weak	2	manipulated	1
scared	10	annoyance	1	melancholy	1
frustration	8	apprehensive	1	monitored	1
worried	8	assessment	1	nagging	1
anxious	7	boredom	1	nasty	1
tired	7	boring	1	occupied	1
anxiety	5	busy	1	organised	1
distressed	5	concentration	1	overwhelmed	1
frightened	5	concerned	1	overwhelming	1
happy	5	confirmed	1	pensive	1
irritated	5	crazy	1	powerless	1
sad	5	critical	1	questioning	1
alone	4	curious	1	real	1
excited	4	curse	1	rush	1
fed-up	4	deflated	1	scary	1
paranoia	4	derogatory	1	severe	1
watched	4	desperation	1	smiling	1
alert	3	disoriented	1	spacey	1
anger	3	dizzy	1	stuck	1
distracted	3	dream	1	sucked	1
on-edge	3	edgy	1	talked	1
lonely	3	evil	1	threatened	1
abuse	2	excited	1	touched	1
agitated	2	floaty	1	trapped	1
angry	2	free	1	turmoil	1
attacked	2	funny	1	uncertainty	1
despair	2	gloomy	1	uncomfortable	1
interested	2	harm	1	unpleasant	1
nervous	2	haunted	1	unsure	1
pressure	2	heavy	1	vulnerable	1
repetitive	2	heightened	1	wind-up	1
stressed	2	intense	1	worse	1
over-thinking	2	invaded	1	wrong	1
time	2	judged	1	zone-out	1
unhappy	2	lost	1		
upset	2	making	1		

Appendix F

F1. Differences between Proposed Salience of Hallucinations in Analysis, and the Aberrant Salience Theory of Psychosis

Theories of salience in psychosis have existed for some time, most notably the aberrant salience theory of schizophrenia (Kapur, 2003). The relevance of salience proposed here conceptually differs from such theories in ways which will be discussed here. Aberrant salience theory holds its basis in dopamine dysregulation models of schizophrenia and uses the prominence of dopaminergic antagonist ‘anti-psychotic’ medications as core evidence to support its claims (Kapur, 2003). Consistent with the literature which opened this thesis and the arguments which followed, such models and medications may not be empirically sound grounds upon which to base theory. Although ‘anti-psychotic’ medications may reduce dopamine transmission and dampen salience, for many people (including participants of this study) antipsychotics do not reduce or stop hallucinations, and can leave people feeling worse. Within research focused on salience and neural matter alone, both the contribution of further interrelating feelings and circumstances may go unaddressed. In contrast, the outcomes of this thesis have indicated that these seem very much relevant to the lived experience of hallucinations. A final note of difference between this thesis and *aberrant* salience theory, is the thesis does not invoke the notion of normal and non-normal ways of feeling-in-the-world. As experience is composed of the emergent unique interrelationships of bodies situated in circumstances, the boundaries of ‘normal’ shifts. From a process perspective, the conceptualisation of an aberrant level of salience does not seem to make sense.

F.2 Reported Features of Feelings of Presence

Table F.1

Participant reports of the feeling of presence of hallucinations.

<u>Feeling</u>	<u>Detailed Participant Report</u>
<u>Summary</u>	
Unwanted	"It is like someone else being in the room, maybe at times when you really don't want them there for stuff".
Wanted	"If I'm really anxious, they come and try and calm me down...I know them so it's calm...It's okay that they've come and they've gone."
Omnipresent	"Wherever I go, it goes with me".
Watchful (Entity Digital)	"It's almost like you're on a reality TV programme, each and every move you make is watched and commented on, and insinuations are made about you from the voices, and they try and figure you out all the time, sometimes they get it right, sometimes they get it wrong. So it's like this spotlight's always on you".
Watchful (Entity, Humanoid, Supernatural Real)	"I feel like things are watching me. So, if I hallucinate a person or someone who is not there and it's in the corner of my eye and I get really paranoid because I think something is there and the eyes aren't always people eyes...a goat's eye...a genie's eye. Things are watching me that are supernatural almost, that aren't normal things to see. But I'm witnessing them, and they're really convincing me that they are there and it's really troubling".
Inescapable	"You can't get away from it, there's no respite, there's no safe haven to kind of retreat to and feel like you're safe and you can just get some rest. My only rest was when I went to sleep; when I was at my worst that was my time out".
In/visible	"The black is sort of a shadow, that's how they were in the physical. They weren't there physically as much as this table it was more sort of spiritually or of a different vibration, or frequency, or energy or dimension or whatever; and it was very much nothing, no details, very sort of plain hardly actually any outline there but just more of a presence. So that's the colour for that really because it didn't really have a colour." "Being in a very dark room when there's actually nothing else to be seen, I actually noticed darker things in the dark and they were the shadows that I have spoken of."
Connected (Unwanted) Abusive	"This bond needs to be broken really quick and really fast".
	"I still feel like there's someone there with me all the time, sitting there watching me, with me, so like it does get me down. Like say having someone extra with you, on your body, like taking – doing stuff on your body to you and then share that, looking at everything you're looking at and like there's no privacy or there's a lot of intrusion and stuff."
Occupying Mental Space	"I was scared to think, because I didn't want anyone to hear it...all this stuff would be going on and on in my head and

	there wouldn't be a response from me, I wouldn't hear my voice, my internal voice".
Embodied Space Invaded	"It never leaves me. I never get to get on with my life and I want to experience fresh air on my face, with my eyes feeling nice and tingly and stuff again and my body feeling nice and clear and clean again."
Intrusive	"These voices, I just feel like its intrusive and my life isn't my own anymore. I haven't got my space that I used to have...I get no space from it. It intrudes on my life and I haven't got a life anymore, they've got my life".
Something to Get Rid of	"It's trial and error to see if anything you could do would make them go away. It's just this constant sort of, well you're desperate, you're desperate to get rid of them, so you try anything that you can think of to get rid of them".

Table F.2

The feeling of realness of hallucinations.

<u>Feeling Summary</u>	<u>Detailed Participant Report</u>
Sensory Realness: Sound and Feel Real in the Moment	"They seem quite real to me, like their voices are as real as you're talking to me now, probably a bit quieter, but it, yeah, it's a very odd experience to go through".
Sensory Realness: Sound is Different yet Real	"It's different, it's quite different because you're here, I know you're there. I know that they're there. It's scary".
Sensory Realness: Most Real When it's Seen	"It goes to something more real that you can see. Then the other things come in separately. So, it's easier to convince me to listen to the commands when they turn up, because I've been seeing something before for a longer time before".
Sensory Realness: Mismatched Sensations	"If I'm having a psychotic breakdown and I have to eat...textures of food don't match what they usually are. So, if I'm eating something soft like mashed potatoes, it will taste crunchy somehow. I don't know how to explain that, but it just is, or soup will not feel right. I can't do soup when I'm having a psychotic breakdown, it just doesn't work...it feels too weird. I'll just spit it out."
Hyper-Reality	"It feels more real than something when you actually experience it. If I was seeing the people on the road or walking next to the road and stuff, it was more real than real life, if you know what I mean? ... I couldn't tell at the time, if they were or weren't real. I don't even know now if there were people on the road or not, so I can't tell you if there were actual real people there or they were just visions... They were coming to make me feel like they were reporting on me or talking about me or something."
Fluxing Un/Reality	"I'll think someone shouts after me. That can make me really irrational. Sometimes when I'm in a bit of a better state of mind, I think 'no that can't be real', because I

	find it hard to distinguish. Sometimes it could be, there is times where it could be real, ...I can't always differentiate. Like I said sometimes I think somebody's shouting after me, maybe even neighbours but then when I'm not too distressed, I'll challenge it, I'll maybe listen out again and really think about it though, try and get out of my own mind, heighten my senses a little bit and then there's like nothing. A lot of the time I just get wound up".
Reality: Concretely Real	"These are real people, they actually are harassing me. I've struggled for years to get people to believe me because I've struggled to get evidence for it. They actually do have cameras in my flat and every time I go down, they speed off when they see me. That's why I've struggled to get evidence."
Not Knowing Where Consensual Reality Stopped and Hallucinations Started	"I don't know when the abuse turned into voices...it was very difficult for me to pinpoint, because it did start as abuse and then it kind of, I think my mind went into overdrive. So for me to say when, what I'd heard, or what I'd made up, I don't know"

Table F.3

The feeling of un/reality among people who experience hallucinations.

<u>Feeling Summary</u>	<u>Detailed Participant Report</u>
Becoming Unreal	"You can get so wrapped up...it was really difficult because you don't have your own headspace, you know, I don't know, there's just so much going on in there, there's no space for you...it's completely distorted, it's not reality at all."
Uncertain Reality	"Very careful...if I literally don't see the person in front of me speaking, I can't see their mouth move, I won't respond back because it's, you have to be so careful".
Untrue Reality	"It's horrific ...They were saying I was the morning star...I've realised I'm not the morning star...Sometimes the voices lie to me, sometimes they tell me the truth and its learning which ones I can listen to and learning I can't really trust any of them really. I've got to trust my own judgement a bit more."
Traumatic Unreality	"I was sat in lectures and I walked out crying, out of the lecture...I came back home panicking about what was happening." "I didn't know what was happening. I just couldn't concentrate. That was traumatic."
Abusive Un/Reality	"It's like abuse, and people sort of getting involved and picking you apart, and if people saw that in reality they'd think, my god, that is absolutely awful. But it's all in your head and they can't quite see sort of the effect it's having on you." "It's an experience in itself. It's like if you were on your own with this, and it was happening in

Confirmation of More Than Material Reality	reality, the horror, people would be horrified at how you're being treated."
Testing Unreality	"I would probably say it's confirmation of more than a physical world for me. I think, something at the times when it's happened, negative, not really negative feelings or emotions more just confirmation of what is already there."
	"It wasn't until I bought a thermal imaging camera and tried to find them that I then actually realised that they are in my head. Yeah. So that was a turning point."

Table F.4

The impact of feelings of un/reality and navigating dual planes of sense-experience.

<u>Feeling Summary</u>	<u>Detailed Participant Report</u>
Experiencing Dual Planes of Sense-experience/Reality	"Because humans don't deal with extra layers like your usual normal, you know, fully functioning humans. But like obviously I've got this issue so I deal with it in an extra layer, like a person being there and doing my own thing as well at the same time, all the time, constantly."
Difficulty Navigating Dual Planes of Sense-experience/Reality	"You'd have this internal battle that you're trying to fight, and then you're trying to have a conversation with someone and concentrate on what they're saying too...it's like you're there, but you're not quite there. And sometimes the internal would take over, so you'd hear more of that than the actual conversation and it's, there's too much noise, so you'd miss bits of the actual conversation...like one of the voices would say something and it would just completely distract you from the actual conversation and so you'd slow down."
Consequences of Acting on Un/Reality	"They weren't being horrible to me at all. It's just in my head I thought they were and I was adamant about it, I think I was really horrible to them so now I just feel embarrassed and horrible and they think I'm a dickhead and I was towards them because I thought they were to me."
Shame In Unreality	"I think if I asked someone directly, " do you feel that?" they would be like "what are you on about?" Then I'd feel stupid."
Embarrassment from Un/Reality	"I feel like I'm fighting against an evil...I've got good insight right now. I know it's a hallucination...But when I'm in it, it just feels like an evil conspiracy's taking place...Then I come out of it and at the time, you're really in it, it's so real to you and then you come out of it and you go 'oh my god' I just feel stupid now because that was clearly, It can just be horrible-y embarrassing actually, it can just make you feel embarrassed because you believed something which wasn't real. I think I said to you last time you can get really upset over something that it wasn't happening actually".

Void (When Hallucinations Stop)	“Walking up to my flat, usually I’d be hearing things going on from all different directions but sometimes I’d here nothing, it’s just a void, an emptiness. It goes back to I’ve been worked up about something that I didn’t need to get worked up about. So that’s where the void sets in. ugh yeah, it was all nothing, why did I get so emotional? Why did I shout so much about something that didn’t happen? It’s horrible, it’s like that.”
Unresolved Trauma: Will Never Really Know	“It’s soul crushing it’s like an mmmmmmm. That just keeps me at that low kind of level of mmmmmmm ...it’s just horrible actually to come to terms with that I’m never gonna know what happened. Where as I like to know about lots of stuff...to not know is horrible and to know that I’m never going to know whether it was real or not or which parts were real or not is just a bit ugh. I just have to live with that for the rest of my life really. Not knowing what it really was. I’m just going to have to live with that now. That’s what it feels like, I’ve got something to carry now...It pre-occupies my life... this block [hallucinations] stops me from facing that block [rape].”
Accepting Not Knowing	““Accept you’re not going to find out what it actually is and then you’ll be a bit more peaceful and strong.” “I’m very observant, I’m inquisitive. I ultimately would like to know what’s going on but I have come to the realisation that that can’t be forced and I accept that. At first it was obviously a big “What’s going on!?” as time’s gone on it’s like okay. In time maybe but it might not.”
Processing Un/Reality	“It’s hard to process some of the stuff like I said, my technique is to sit in bed with a cup of tea. Stare at the wall and think about it, nice and gently do it bit by bit. Sometimes that’s really depressing”

F3. Reflective Commentary: Whose Reality is it anyway?

The extent to which participants’ experiences corresponded to a material stimulus or consensual reality was continuously under question; both from themselves and those around them. For all participants, experiences which felt real and were experienced as such, were reframed as hallucinations through interactions with others and had been cause for being given psychotic-spectrum psychiatric diagnoses. In this way, hallucinations and true reality were in the eye of the beholder; with the right to decide what constitutes a hallucination or reality often belonging to someone else. Issues surrounding who gets to define reality and the validity of sense-experiences were relevant to all experiences described and studied as hallucinations in the thesis. During data generation it felt apparent

that religion and spirituality often are characterised by numerous features comparable with hallucinations including the: felt reality and experience of immaterial existent entities, forces, and powers; entities with felt capacities to enact benevolent or malevolent actions and which can be engaged with through acts of ritual. This generated initial concerns surrounding as to whether firstly, spiritual experiences which fit a particular religious dogma should be conceptualised as different from those which do not, and secondly, whether experiences relating to religion/spirituality could be regarded as different from those described as 'hallucinations'.

Such concerns surrounding reality felt most relevant regarding data of spiritual and religious experiences and practices. Issues regarding what makes a hallucination or reality may be pertinent for people who:

- Have religious or spiritual sense-experiences,
- Who hold religious or spiritual beliefs and have experiences described as hallucinations,
- Engage with religious or spiritual practices to manage their experiences of hallucinations.

These reflections lead to further concerns relating to freedom of reality and spirituality, as well as concerns surrounding available support. The data generation and analysis brought ethical quandaries of defining another person's reality and of the value of people being free to experience and believe in a reality which feels personally right. Still, during analysis concerns remained regarding the extent to which people's spiritual experiences and needs may be respected, understood, accounted for and supported within contemporary secular society and health care practice; particularly among those experiencing hallucinations and accessing EIP services.

F4. Visual methods and the parts of life we don't talk about.

In the current study, whilst making the visual timeline, one participant did not feel able to share their life history prior to age 12. At this age, hallucinations began, and he started smoking cannabis “to block it out”. When asked what was going on at the time they explained “loads of stuff, loads of stuff...stuff that happened when I was younger that I don't really like talking about”. Existing research by Woods et al. (2015) suggested voices which start in childhood most often first appeared in negative or “explicitly traumatic” circumstances. A lens of hermeneutics of suspicion could propose this participant may have likely experienced childhood trauma but, in any case, they were not able to speak about their experiences prior to adolescence.

The emptiness of part of the participant's timeline provided a visual symbol of the difficult parts of life one may feel unable to share; the timeline seemed to achieve a delicate balance of both acknowledging and respecting that. Visual methods such as timelines may support in sensitively coming to know the histories of people who experience hallucinations, this seems important as the analytic outcomes here and in existing research suggest childhood often involves adverse and traumatic experiences (Read et al., 2003; Woods et al., 2015).

F5. Visual methods and the parts of life we don't write about.

Of all the parts of the thesis, the ACE data analysis was the most difficult to write. This difficulty mirrored the sensitivity felt during the corresponding moments in data generation where voices tremored, voices raised, voices quietened, eyes stayed forward, eyes looked down, tears fell and hands slammed upon the table as grammar. Sitting with the data, listening, re-listening and writing, re-writing, tears fell again. With the intensity of the feelings shared and felt, there was a parallel heightened feeling of needing to honour the participant's experiences and contributions. There was a continuous struggle of finding a right way to communicate this data. Figure F.1 holds an expression from the research visual-reflective journal of a feeling of concern that sharing snapshots within analytic prose may do a disservice to the experiences shared.



Figure F.1 Researcher visual journal entry, of the feeling of concern whilst writing about ACE and traumas.

As explored in the methods chapter with reference to Ellingson (2017), this sense of translation of experiences into research was inherent throughout the analysis

process but most challenging here. Studying experiences difficult to talk about or write about, reflects the value of arts-based research in orientating to experiences which are salient and, also the distress which can arise for researchers in their attempts to share them. This feeling of struggling with how best to share ACE and trauma was not resolved but felt poignant to share. Using the streaming approach of EPA, with a visual reflective journal and reflective discussion with a peer, supported in moving with these feelings to be able write and honour the participants contributions by sharing them.

F6. Working Class Wellbeing

There was an overwhelming sense of difficulty associated with maintaining one's wellbeing and material security whilst being working class. Participants reported experiences of negative impacts on one's mental health due to being "lower...class" including: less access to resources (e.g. education, money, leisure time, opportunities) and bad working conditions. Reflecting the experiences of others within the sample, one participant explained:

for people in the lower...class of society, if you are struggling with mental health or problems like that, you actually struggle to get a job, struggle to work to actually probably live a way of life which can take your mind off it a bit easier...If you have money, it can keep you calm and at peace and more accepting of what is. If you've got no money...you're stuck...you can't really go anywhere and do anything, you may have already had all those experiences and accuse people, and people got upset with you because...you're some strange mental person...you're stuck in that environment then. You can't get out of it.

Such circumstances suggest a perpetual negative spiral in which difficult social-material circumstances negatively impacted upon one's mental health, which served to worsen one's circumstances and so on.

F7. Negative Reports of Mental Health Care

Table F.5

Negative Reports of Mental Health Care.

<u>Feature Brief Summary</u>	<u>Detailed Participant Report</u>
Not Believed (GP)	"When I went to my first doctor, it made me feel like I was just saying it, like it's not really happening."
Experiences Not Recognised (A&E Doctor and Nurse)	"The doctors...they kicked me out because they said there was nothing wrong with me. This is one specific psych nurse who is in the Royal Infirmary... She makes me upset."
Uncomfortable and Not Understood (EIP Psychiatrist)	"I don't like men anyway...I'm scared. So, I felt really uncomfortable. Obviously I was trying to explain, because it's hard every time I explain things....I find it hard having to speak to someone that I don't know and I kept laughing, nervous laughing, because I don't know how else— He was like, 'What are you laughing for? You clearly aren't sad'. That's what got me mad. I literally had to say to my dad, 'I can't go and see him again'."
Not Understood (EIP Psychiatrist)	"I think, you're not understanding me, because of the things they say, I'm like, 'no, you're not getting me'. That's what I think and that really stresses me to hell... as soon as I get in the car, I cry my eyes out. ... Because I'm like, they're not understanding me, they're not going to help me. Then I get scared in case they don't help me." "I feel they're not understanding me properly, maybe because I come with makeup on or— I don't know"
Ineffective Drugs (EIP Psychiatrist)	"I wish they knew the truth...instead of like...giving me some medication which is not going to work."
Misdiagnosed & Ineffective Drugs	"Getting to the problem quicker, than throwing tablets and stuff. The tablets didn't work for me. Treating you for the right thing. I was getting treated for drug induced psychosis and...it weren't that."
Not Responded to	"This is actually happening to me, that I actually suffer sexual abuse and stuff like this at the hands of this person that's on me" "I want this person arrested or just taken, moved away from me and this device away from me as far as possible."
Assumed Any Adversities Are Hallucinations	"I wish sometimes they would realise that some of the things I'm saying to them aren't hallucinations, I am experiencing intimidation tactics from my neighbours...I wish it wouldn't always go in the hallucination direction, I wish it was that "ooh there could be some truth in what they're saying" but it always goes that way."

Struggling to Access Care Whilst Out of Area – Fear of Section	“It’s pretty difficult when you’re on the phone to a helpline and they’re saying...‘we can’t really help you because you’re not based in here right now’. So, they just assume they can’t help you and try and talk you down from doing anything, self-harm and stuff. But it’s really – it’s hard when they say they can’t help you because you’re staying here. Now, I’m worried ...when I go back for a week or two, if something happens, it would probably be section and I don’t want that to happen... they’ll say ‘you’re going to stay here’ and not going to let you go until they think you’re ready to go.”
Struggling to Access Care	“It took me about six tries to find a place that could help me really well and not just send me to A and E or try and section me and just take me out of commission altogether.”
Too Quick to Medicate	“I just wish they’d [clinicians] be a bit more patient, because sometimes they can get frustrated and offer you the medication straight away with nothing else with it, no support.”
Focus on Risk and Neglect of Needs (GP)	“When I finally did go to the GP and I was trying to talk about the delusions...they were more concerned about how I was cutting myself.”
Uninformed (Inpatient Psychiatric Ward)	“That’s probably the worst part...I didn’t know what was going on...no one told me what was going on and how I didn’t know where I was.”
Unreliable Care (EIP Nurse)	“I need to talk to my care coordinator ... she hasn’t seen me for a while. She was meant to come and see me but I’ve not heard anything for weeks...But I just thought it’d be nice if she’d pre-warned me because I was looking forward to seeing her.”
Difficulty Accessing Care	“When I do feel really down, really depressed, when my voice and my thoughts are really bad, I think I just need someone to talk to. But I can’t even ring the doctors myself, never mind someone here.” “I don’t like doing that because I feel like— I’m not very confident with new people and that ... I wouldn’t even ring in because I feel— I don’t like it, explaining again to people I don’t know, because it takes a lot of time.”
Fear of Section	“I get scared in case I say something wrong and they take me away.”
Fear of Diagnosis	“I always chose to speak of it as flashbacks...because I was really scared about my sort of, what I’d be labelled as. I didn’t know what it would be, whether it’d be schizophrenia, or if it would be psychosis or, I was scared as well. I knew I was okay in myself, it was just the burden of the voices, and then the fear of what other people would think of me. “
Lack of Acknowledge-	“I think the problem is the fact that you can’t prove anything with regard to hallucinations or mental health, as

ment of Struggles	opposed to a broken leg ...you can see that it is broken, and you can see how you need to fix it. You sort of lack, naturally, lack a little bit of acknowledgement and, care. Because of that perhaps it's easier to sort of just forget that person...a cloudy ball of mess and distress, that you've got no idea what's even going on. “
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F8. Positive Reports of Mental Health Care

Table F.6

Positive Reports of Mental Health Care.

<u>Feature</u>	<u>Detailed Participant Report</u>
<u>Summary</u>	
Someone Who Visits to Talk to (EIP Nurse)	“I do like seeing her when she comes to my house and stuff. I like having a chat because it makes me feel better.”
People to Talk With When Isolated (EIP Nurse)	“Needed like a counsellor, somebody to talk to, and it was somebody different. It was good. Because I didn’t have my wife there to talk to, so I had my community practice nurse, CPN, to talk to, which is good.”
Support Independent From Personal Life (EIP Nurse & CBT Therapist)	“They understand...you don’t go and speak to – you know, ring my mates and say, ‘I’m just hearing some voices’. You don’t, you keep it to yourself. And it’s having someone, it’s mainly having someone to speak to and talk about it and help you with it.”
Future Care Planned (GP)	“That lady, she was so lovely ... I was there [seen by EIP team] within a week and they just really helped me, and she was very understanding.”
Accessible Consistent Care (EIP Nurse)	“Having my care coordinator to speak to whenever, that’s really helpful ...I’ve rang him up on numerous occasions and been like ...‘this is happening’ and he can just talk you through it...and it’s normal that you think that, and then that kind of calms you down. Otherwise you can just get yourself more and more worked up and then they [AVH] start getting louder and louder and then you end up in a mess.”
Reliable Ongoing Care (EIP Nurse)	“Knowing that you’ve got someone there at the end of the phone is helpful... even just knowing that you’ve got someone there, you probably don’t ring them as much, but it’s just having someone.”
Support to Learn About Experiences	“Have that reading there, the support and to try and understand and try and gain insight into it, so you can try and overcome it, I think is quite important.”
Support and Guidance to Try	“Quickly distract your mind so you don’t have to hear it...I’m better at it now but it’s taken me a long time to get back to

Coping Strategies (Clinical Psychologist)	this point. Like sometimes it's good to have something that can distract you. Obviously with...the Psychologist I've gone through quite a few different distraction techniques as well which play to different senses. I find having a lot of noise (especially at home) completely sort of clears them away for me."
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F9. Participant Reports of Chemical ‘Care’

Table F.7

Features of chemical care among people who experience hallucinations.

<u>Feature</u>	<u>Detailed Participant Report</u>
<u>Summary</u> <u>(Drug</u> <u>Name)</u>	<u>‘Antipsychotic’ Drugs</u>
Time Consuming Health Monitoring (Clozapine)	“On clozapine and then I had to go to the hospital and stay the day there basically...then I used to go in for like blood tests...to see it’s not affecting me health-wise and stuff like that because I was on that specific medication...I did that for like six, seven weeks, then I just – like I would stay at home.”
Forced to Take Drugs	“They give you pills (laughs) and are like, ‘Why aren’t you taking your pills? What is the point in you being here if you don’t take your pills?’ And after a week or two, I started taking the pills... It was like, ‘You can’t leave if you don’t take the pills.’ So (laughs) I took the pills.”
Drugs Not Working	“I still took it, obviously...It doesn’t help with the voices though”
Drugs Not Working	“If there was a pill or medication to get rid of like this curse that I have on me, so then I wouldn’t be as sensitive to the device or whatever I’ve got...I take the antipsychotic medication. None of them work. So just anything to get rid of this, so just to kind of like get me free from it...and I’ll never be able to be touched and stuff.”
Drugs Unhelpful Overall	“I think the tablets take an edge off it when you’re really bad, but they don’t solve it. They cause more problems than what they solve.”
Prescribed Drugs Replace Illicit Drugs; Becoming Reliant (Risperidone Lorazepam)	“The other medicines that I have are kind of also a coping mechanism. In the evening, when I’ve got all these things going on, I will have my tablets and then that will calm me down, so that helps. ...Risperidone, and if I’m really anxious, then I’ll have a Lorazepam or something like – something that will make you drowsy. I think I rely on that a little bit too much, but that’s what it is. ...I think it’s like not enjoyable but it’s something that I can look forward to that isn’t illegal...It’s something that I can ... get away with it. It’s something that’s allowed and I don’t get much of that any more. It like ... replaces it [cannabis], almost.”
Drugs Working	“I think my meds have been working and stuff and I haven’t had any more weird experiences or weird thoughts.”

Drugs Helping	"The Quetiapine seems to help, make it more of those [voices] than the violent ones or something that would harm myself."
Drugs Helpful but Not Best Treatment	"Basically the tablets make me not give a shit, but then you just don't give a shit about anything. It wasn't nice. Just bland, just didn't care about anything. So they do help, they take the edge off things. But I think learning why you hear them and why they get louder is a lot better way round it."
Stopping Drugs Due to Effects	"Everything from erectile dysfunction to weight gain to – I was on one set of tablets and just wake up in the night – you just kind of do it in your sleep, went downstairs and made a crisp sandwich and just ate two of them. Just randomly make you hungry. ... Really hungry, starving... I've decided just to not have anything at the moment and just plod on."
Not Properly Informed of Drug Effects	"They just come with loads of different side effects. If I read them all I probably wouldn't have took them anyway, but yeah, they come with some – yeah, horrible side effects."
Burden of Drugs: Difficulty Accessing Unpleasant Drugs To Take and AVH	"I didn't know I had no medication with me, because the medication is pretty strong medication so you can't just go and pick them up from the pharmacy. You have to make sure you've got a script and it's really difficult." "Really bitter. Not nice. That's usually a way that the voices can convince me not to take my medication because it's like, if you take the medication, you're not going to be able to swallow properly, because we're not going to let you and it's going to dissolve in your mouth and you're going to have this awful taste that you can't get rid of."
Making Sense Via Prescribed Drugs	"They pointed out, my tablets are for treating bipolar or schizophrenia."

'Anti-depressants'

<u>Feature Summary (Drug Name)</u>	<u>Detailed Participant Report</u>
Increase in Prescribed Ineffective Drugs (Sertraline)	"It doesn't really do anything. I'm just taking it because the doctors say to take it...I don't think it's [sertraline] working because they keep upping the dose and they still don't – I just get the side effects and still feel bad."
Unpleasant Effects of	"Heart palpitations, no sleep, lower mood which is – supposed to be higher mood but for four weeks it makes

Sertraline Without Benefits (Sertraline)	your mood the lowest it can possibly be. Loss of appetite, gaining of appetite. It's really random. You just feel really bad or not sure of yourself for about four weeks. Then it will start to die down. Then every now and then some of the side effects come back. But it's not very good. ... The no sleep one and it makes me queasy. Your head hurts. It just gives you a really bad headache or migraine and it doesn't go away for two weeks. That one I always get because I get migraines already, so it's not really very good for me. I have to voluntarily feel bad in order for the pill to work, and at this point, I know it's not going to work. So, every time they up the dose, I just know I'm not going to feel well for four weeks."
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F10. Participant Report of Attending A&E

"I had a panic attack and sensory overload. So, I can smell things, I can hear things. I can taste things and that's all a bit too much, and then I feel like I'm being watched. I see eyes everywhere, and then the genie [VH] becomes larger than life. I get so scared of things. Basically, like commands, they start to worry me and I get confused about some things that I see, and it's so fleeting, I don't know what to do...when I was in the hospital, and I can hear all these machines going off and people in pain and crying and stuff...I almost got sectioned...They told me I couldn't leave and I had to stay there. I would have probably had to drop out of university...They could treat me but obviously they couldn't contact the [EIP] team on a Sunday. I was just lost there in a place I shouldn't really be in. It was really loud, the smells, everything. It was really bad. It wasn't good for me. I waited six hours for that [medication] and then they brought it and gave me to it and let me leave."

Appendix G

G1. Examined Principles of Feeling-Trap Theory

Table G.1

Principles of Feeling-Trap Theory and their Examination within this Thesis.

<u>Principle No.</u>	<u>Details of Principle</u>	<u>Analysis Chapter</u>
Principle 1:	Feelings seem core to experiences of hallucinations.	7
Principle 2:	Hallucinations may be co-constituted and sustained by circumstances.	8
Principle 3:	Traumatic and adverse circumstances can be internalised through feelings and may relate to experiences of hallucinations.	8 & 9
Principle 4:	Feeling responses can be acquired and become habitual forming modes of embodied subjectivity.	9
Principle 5:	Feelings recursively loop over time in sustaining circumstances (feeling-traps).	9
Principle 6:	Shame is a primary emotion in binding feeling-traps and often co-occurs with anger.	9
Principle 7:	Disavowed or unacknowledged feelings contribute to feeling-traps.	9
Principle 8:	Emotional backlogs of prior unresolved feelings may be elicited through similar experiences.	9
Principle 9:	Feeling-traps generalise beyond their initial circumstance and sustain over time with increasing complexity.	9
Principle 10:	Feeling-traps can be broken.	9

G2. Situations Which Eased Hallucinations

Table G.2

Participant Reports of Regarding the Situations which Eased Hallucinations in Some Way.

<u>Beneficial Situation</u>	<u>Participant Report of the Situation and Hallucinations</u>
Ongoing Support & Contact With Loved Ones	"Where I'm blessed is that everyone around me is very loving and very caring and that's what has ultimately enabled me to not go crazy."
Sharing Experiences & Reducing Shame	"To talk about the experience and to several different people, and kind of get rid of the shame of it and the fear of it, of talking to different people, and to not hold onto it, that really helps with your anxiety as well, because you're not so afraid... You're unburdening yourself basically... it's offloading and it's really, really hard to begin with and you're really sort of squirming and you really don't want to do it, but it's part of the healing process".
Sharing & Disrupting Feeling-Traps	"Having my care coordinator [EIP Nurse] to speak to whenever, that's really helpful...—I've rang him up on numerous occasions and been like ... this is happening" and he can just talk you through it of why...and it's normal that you think that, and then that kind of calms you down. Otherwise you can just get yourself more and more worked up and then they [the voices] start getting louder".
Reality Testing	"There were times when I could hear their voices, but I could see that they weren't coming from them [people nearby]. So that, helped me to sort of calm down more"
Benefit of Anti-psychotic Drugs, Learning About Hallucinations, & Coping Strategies	"They take the edge off things but the side effects...you need it [anti-psychotic drugs] to begin with, but then really...instead of being tried on all these different drugs you need to understand why you're hearing them, which has probably taken me about three years to get to really...and obviously what you can do to try and lower the tone of them and not let them wind you up. Because if they wind you up then they get louder...you get more distressed and then you end up in a mess."
Learning: Disrupting Feeling-Traps	"It helps if there's more background noise as well so you have something if the voices start up you can escape to somewhere else and quickly distract your mind so you don't have to hear it. Yeah, then you just don't get so sucked in, like I'm better at it now but it's taken me a long time to get back to this point".

Learning: Managing Hallucinations + Life	“Just to find those distraction techniques, just to give you that bit of respite, and to be kinder to yourself as well. Try and discover ways to help yourself and to be more active as well, have more of a work-life balance as well”.
Ignoring: Dispelling Salience	“Disconnected from them, they don’t mean anything to me, what they’re saying, it’s a load of rubbish. It doesn’t interest me. Sometimes you just feel like, oh I just really want to have a go back, but you just think, what’s the point? I’m only going to wind myself up...they’re going away more, it’s not as anywhere near as bad as it was before, so it’s easier to manage anyway...it doesn’t get to me...it’s more the past and I’m moving on”.
Cultivating Calmness	“They”ll be, doing their best to wind you up, so they get a reaction out of you, so it’s trying not to let it get to you and I feel like I’m getting there now...there’s just nothing more they can get at you from”.
Focusing on Calm; Gaining Patience	““now I’ve been through those things, now I’m in a position where it doesn’t upset me as much even if it’s something different. I can focus on calming down and giving it time as opposed to needing to know, right now, what’s going on and not being able to know what’s going on right now and then getting frustrated and acting irrationally so yeah. Definitely feel like I can react more calmly and patiently to those similar triggers. I think I would have gone crazy by now if I was going crazy”.
Building Life Beyond	“I’ve made a life for myself outside of that (voices) and I feel like I’m heading in the right direction, it’s not something I want to get messed up in again...I feel like I can let go of it”.

References

- Aggernaes, A. (1972). Experienced reality of hallucinations and other psychological phenomena: An empirical analysis. *Acta Psychiatrica Scandinavica*, 48(3), 220-238. doi:10.1111/j.1600-0447.1972.tb04364.x
- Anderson, M. L. (2003). Embodied cognition: A field guide. *Artificial Intelligence*, 149(1), 91-130. doi:10.1016/S0004-3702(03)00054-7
- Andrade, C., Srinath, S., & Andrade, A. C. (1988). True hallucinations as a culturally sanctioned experience. *British Journal of Psychiatry*, 152(6), 838-839. doi:10.1192/bjp.152.6.838
- Association, A. P. (2013). *Diagnostic and statistical manual of mental disorders* (5 ed.). Washington, DC: American Psychiatric Publishing.
- Attard, A., Larkin, M., Boden, Z., & Jackson, C. (2017). Understanding Adaptation to first episode psychosis through the creation of images. *Journal of Psychosocial Rehabilitation and Mental Health*, 4(1), 73-88. doi:10.1007/s40737-017-0079-8
- Banksy. (2007). *One Nation Under CCTV* [Removed Graffiti Art Mural]. London.
- Badcock, J. C., Paulik, G., & Maybery, M. T. (2011). The role of emotion regulation in auditory hallucinations. *Psychiatry Research*, 185(3), 303-308. doi:10.1016/j.psychres.2010.07.011
- Baerveldt, C., & Voestermans, P. (2005). Culture, emotion and the normative structure of reality. *Theory & Psychology*, 15(4), 449-473. doi:10.1177/0959354305054747
- Barrett, L. F., & Bar, M. (2009). See it with feeling: Affective predictions during object perception. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 364(1521), 1325-1334. doi:10.1098/rstb.2008.0312
- Bauer, S. M., Schanda, H., Karakula, H., Olajossy-Hilkesberger, L., Rudaleviciene, P., Okribelashvili, N., . . . Stompe, T. (2011). Culture and the prevalence of hallucinations in schizophrenia. *Comprehensive Psychiatry*, 52(3), 319-325. doi:10.1016/j.comppsy.2010.06.008
- Bebbington, P., Wilkins, S., Jones, P., Foerster, A., Murray, R., Toone, B., & Lewis, S. (1993). Life events and psychosis: Initial results from the

- Camberwell collaborative psychosis study. *British Journal of Psychiatry*, 162(1), 72-79. doi:10.1192/bjp.162.1.72
- Bentall, R. P. (2003). *Madness explained: Psychosis and human nature*. London: Allen Lane.
- Bentall, R. P. (2014). The search for elusive structure: A promiscuous realist case for researching specific psychotic experiences such as hallucinations. *Schizophrenia Bulletin*, 40 (4), S198-S201. doi:10.1093/schbul/sbu044
- Berrios, G. E. (1996). *The history of mental symptoms: descriptive psychopathology since the nineteenth century*. Cambridge: Cambridge University Press.
- Biondi-Zoccai, G., Lotrionte, M., Landoni, G., & Modena, M. G. (2011). The rough guide to systematic reviews and meta-analyses. *HSR Proceedings in Intensive Care and Cardiovascular Anesthesia*, 3(3), 161-173.
- Bless, J., Laroi, F., Laloyaux, J., Kompus, K., Krakvik, B., Vedul-Kjelsas, E., . . . Hugdahl, K. (2018). Do adverse life events at first onset of auditory verbal hallucinations influence subsequent voice-characteristics? Results from an epidemiological study. *Psychiatric Research*, 261, 232-236. doi:10.1016/j.psychres.2017.12.060
- Blom, J. D. (2015). Defining and measuring hallucinations and their consequences – what is really the difference between a veridical perception and a hallucination? Categories of hallucinatory experiences. In D. Collerton, U. P. Mosimann, E. Perry (Eds.), *The Neuroscience of Visual Hallucinations*, (pp.23-45). Chichester: John Wiley & Sons Ltd.
- Boden, Z. V. R., Gibson, S., Owen, G. J., & Benson, O. (2015). Feelings and intersubjectivity in qualitative suicide research. *Qualitative Health Research*, 26(8), 1078-1090. doi:10.1177/1049732315576709
- Boydell, K. M., Ball, J., Curtis, J., de Jager, A., Kalucy, M., Lappin, J., . . . Watkins, A. (2018). A novel landscape for understanding physical and mental health: Body mapping research with youth experiencing psychosis. *Art/Research International: A Transdisciplinary Journal*, 3(2), 236-261.

- Bracha, H. S., Wolkowitz, O. M., Lohr, J. B., Karson, C. N., & Bigelow, L. B. (1989). High prevalence of visual hallucinations in research subjects with chronic-schizophrenia. *American Journal of Psychiatry*, 146(4), 526-528.
- Bracken, P., Thomas, P., Timimi, S., Asen, E., Behr, G., Beuster, C., . . . Yeomans, D. (2012). Psychiatry beyond the current paradigm. *British Journal of Psychiatry*, 201(6), 430-434. doi:10.1192/bjp.bp.112.109447
- British Psychological Society. (2014). *Code of Human Research Ethics*. Retrieved from: <https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20%20Files/BPS%20Code%20of%20Human%20Research%20Ethics.pdf>
- Brooks, J., McCluskey, S., Turley, E., & King, N. (2015). The utility of template analysis in qualitative psychology research. *Qualitative Research in Psychology*, 12(2), 202-222. doi:10.1080/14780887.2014.955224
- Brown, S. D., & Reavey, P. (2015). *Vital Memory and Affect: Living with a difficult past*. Hove: Routledge.
- Brown, S. D., Reavey, P., Cromby, J., Harper, D., & Johnson, K. (2008). On psychology and embodiment: Some methodological experiments. *The Sociological Review*, 56(S2), 199-215. doi:10.1111/j.1467-954X.2009.00823.x
- Burkitt, I. (2012). Emotional reflexivity: Feeling, emotion and imagination in reflexive dialogues. *Sociology*, 46(3), 458-472. doi:10.1177/0038038511422587
- Burkitt, I. (2014). *Emotions and Social Relations*. London: SAGE Publications.
- Burr, V. (2015). *Social constructionism* (3 Ed.). Hove: Routledge.
- Caldwell, K., Henshaw, L., & Taylor, G. (2011). Developing a framework for critiquing health research: an early evaluation. *Nurse Education Today*, 31(8), e1-7. doi:10.1016/j.nedt.2010.11.025
- Cantor-Graae, E., & Selten, J.-P. (2005). Schizophrenia and migration: A meta-analysis and review. *American Journal of Psychiatry*, 162(1), 12-24. doi:10.1176/appi.ajp.162.1.12
- Castelnovo, A., Cavallotti, S., Gambini, O., & D'Agostino, A. (2015). Post-bereavement hallucinatory experiences: A critical overview of population and clinical studies. *Journal of Affective Disorders*, 186, 266-274. doi:10.1016/j.jad.2015.07.032

- Chadwick, R. (2017). Embodied methodologies: Challenges, reflections and strategies. *Qualitative Research*, 17(1), 54–74. doi:10.1177/1468794116656035
- Chamberlain, K. (2012). Do you really need a methodology? *QMIP Bulletin*, 13, 59-63.
- Chang, C. K., Hayes, R. D., Perera, G., Broadbent, M. T. M., Fernandes, A. C., Lee, W. E., . . . Stewart, R. (2011). Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental health care case register in London. *Plos One*, 6(5), e19590. doi:10.1371/journal.pone.0019590
- Charmaz, K. (2008). Grounded theory as an emergent method. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of Emergent Methods* (pp. 155-172). New York, NY: The Guilford Press.
- Charney, D. S., Barlow, D. H., Botteron, K., Cohen, J. D., Goldman, D., Gur, R. E., . . . Nestler, E. J. (2002). Neuroscience research agenda to guide pathophysiologically based classification system. In D. J. Kupfer, M. B. First, & D. A. Reiger (Eds.), *A research agenda for DSM-V* (pp. 31–83). Arlington, VA: American Psychiatric Association.
- Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and Society*, 38(4), 785-810. doi:10.1086/669608
- Clark, M. L., Waters, F., Vatskalis, T. M., & Jablensky, A. (2017). On the interconnectedness and prognostic value of visual and auditory hallucinations in first-episode psychosis. *European Psychiatry*, 41, 122-128. doi:10.1016/j.eurpsy.2016.10.011
- Coid, J. W., Kirkbride, J. B., Barker, D., Cowden, F., Stamps, R., Yang, M., & Jones, P. B. (2008). Raised incidence rates of all psychoses among migrant groups: Findings from the east London first episode psychosis study. *JAMA Psychiatry*, 65(11), 1250-1258. doi:10.1001/archpsyc.65.11.1250
- Cooper, C., Morgan, C., Byrne, M., Dazzan, P., Morgan, K., Hutchinson, G., ... P. Fearon. (2008). Perceptions of disadvantage, ethnicity and psychosis. *The British Journal of Psychiatry*, 192(3), 185-190. doi:10.1192/bjp.bp.107.042291

- Cooper, S., Crawford, M., Dicks, S., Etherington, A., Jayakumar, S., Lemmey, S., & Zalewska, K. (2014). *Report of the second round of the national audit of schizophrenia (NAS) 2012*. Retrieved from: <https://eput.nhs.uk/wp-content/uploads/2015/02/National-Audit-of-Schizophrenia-NAS2-Report.pdf>
- Corstens, D., Longden, E., McCarthy-Jones, S., Waddingham, R., & Thomas, N. (2014). Emerging perspectives from the hearing voices movement: implications for research and practice. *Schizophrenia Bulletin*, 40(S4), S285-S294. doi:10.1093/schbul/sbu007
- Cosgrove, L., & Krinsky, S. (2012). A comparison of DSM-IV and DSM-5 panel members' financial associations with industry: a pernicious problem persists. *PLoS Med*, 9(3), e1001190. doi:10.1371/journal.pmed.1001190
- Cromby, J. (2007). Towards a psychology of feeling. *International Journal of Critical Psychology*, 21, 94-118.
- Cromby, J., & Harper, D. J. (2009). Paranoia: A social account. *Theory & Psychology*, 19(3), 335-361. doi:10.1177/0959354309104158
- Cromby, J., Harper, D. J., & Reavey, P. (2013). *Psychology, mental health and distress*. Basingstoke: Palgrave Macmillan.
- Cromby, J. (2015). *Feeling Bodies: Embodying Psychology*. London: Palgrave Macmillan.
- Cromby, J., & Willis, M. E. H. (2016). Affect—or feeling (after Leys). *Theory & Psychology*, 26(4), 476-495. doi:10.1177/0959354316651344
- Csikszentmihalyi, M. R., R. E. (1990). *The Art of Seeing: An Interpretation of the Aesthetic Encounter*. Los Angeles, CA: Getty Publications.
- Cummins, I. (2018). The impact of austerity on mental health service provision: a UK perspective. *International Journal of Environmental Research and Public Health*, 15(6), E1145. doi:10.3390/ijerph15061145
- Daalman, K., Boks, M. P. M., Diederens, K. M. J., de Weijer, A. D., Blom, J. D., Kahn, R. S., & Sommer, I. E. C. (2011). The same or different? A phenomenological comparison of auditory verbal hallucinations in healthy and psychotic individuals. *Journal of Clinical Psychiatry*, 72(3), 320-325. doi:10.4088/JCP.09m05797yel
- Damasio, A. R. (1994). *Descartes' error*. New York, NY: Putnam.

- de Jager, A., Tewson, A., Ludlow, B., & Boydell, K. (2016). Embodied ways of storying the self: A Systematic review of body-mapping. *Forum: Qualitative Social Research*, 17(2). doi:10.17169/fqs-17.2.2526.
- de la Bellacasa, M. P. (2012). 'Nothing comes without its world': Thinking with care. *The Sociological Review*, 60(2), 197-216. doi:10.1111/j.1467-954X.2012.02070.x
- Deacon, B. J. (2013). The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review*, 33(7), 846-861. doi:10.1016/j.cpr.2012.09.007
- Delespaul, P., deVries, M., & van Os, J. (2002). Determinants of occurrence and recovery from hallucinations in daily life. *Social Psychiatry and Psychiatric Epidemiology*, 37(3), 97-104. doi:10.1007/s001270200000
- Delespaul, P., deVries, M., & van Os, J. (2002). Determinants of occurrence and recovery from hallucinations in daily life. *Social Psychiatry and Psychiatric Epidemiology*, 37(3), 97-104. doi:10.1007/s001270200000
- Dew, A., Smith, L., Collings, S., & Dillon Savage, I. (2018). Complexity embodied: Using body mapping to understand complex support needs. *Forum: Qualitative Social Research*, 19(2). doi:10.17169/fqs-19.2.2929.
- Dillon, J. (2010). The tale of an ordinary little girl. *Psychosis*, 2(1), 79-83. doi:10.1080/17522430903384305
- Dorling, D., Mitchell, R., Orford, S., Shaw, M., & Tunstall, H. (2009). Health Inequalities. In R. Kitchin (Ed.), *International Encyclopaedia of Human Geography* (pp. 46-50). Oxford: Elsevier.
- Droit-Volet, S., & Gil, S. (2009). The time–emotion paradox. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 364(1525), 1943-1953. doi:10.1098/rstb.2009.0013
- Ellingson, L. L. (2017). *Embodiment in Qualitative Research*. Oxon: Routledge.
- Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12(4), 531-545. doi:10.1177/104973202129120052
- Freeman, D., & Garety, P. A. (2003). Connecting neurosis and psychosis: The direct influence of emotion on delusions and hallucinations. *Behaviour*

- Research and Therapy*, 41(8), 923-947. doi:10.1016/S0005-7967(02)00104-3
- Frese, F. J., III, Knight, E. L., & Saks, E. (2009). Recovery from schizophrenia: With views of psychiatrists, psychologists, and others diagnosed with this disorder. *Schizophrenia Bulletin*, 35(2), 370-380. doi:10.1093/schbul/sbn175
- Frith, H., Riley, S., Archer, L., & Gleeson, K. (2005). Editorial: Imag(in)ing visual methodologies. *Qualitative Research in Psychology*, 2(3), 187-198. doi:10.1191/1478088705qp037ed
- Gale, C., & Schröder, T. (2014). Experiences of self-practice/self-reflection in cognitive behavioural therapy: A meta-synthesis of qualitative studies. *Psychology and Psychotherapy: Theory, Research and Practice*, 87(4), 373-392. doi:10.1111/papt.12026
- García-Ptacek, S., García Azorín, D., Sanchez Salmador, R., Cuadrado, M. L., & Porta-Etessam, J. (2013). Hallucinations and aberrant perceptions are prevalent among the young healthy adult population. *Neurología (English Edition)*, 28(1), 19-23. doi: 10.1016/j.nrleng.2012.02.002
- Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. E. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological Medicine*, 31(2), 189-195. doi: 10.1017/s0033291701003312
- Gauntlett-Gilbert, J., & Kuipers, E. (2003). Phenomenology of visual hallucinations in psychiatric conditions. *Journal of Nervous and Mental Disease*, 191(3), 203-205.
- Gecici, O., Kuloglu, M., Guler, O., Ozbulut, O., Kurt, E., Onen, S., . . . Albayrak, Y. (2010). Phenomenology of Delusions and Hallucinations in Patients with Schizophrenia. *Bulletin of Clinical Psychopharmacology*, 20(3), 204-212. doi:10.1080/10177833.2010.11790661
- Gillies, V., Harden, A., Johnson, K., Reavey, P., Strange, V., & Willig, C. (2005). Painting pictures of embodied experience: The use of nonverbal data production for the study of embodiment. *Qualitative Research in Psychology*, 2(3), 199-212. doi:10.1348/014466604322916006
- Gleeson, K. (2011). Polytextual Thematic Analysis for visual data – pinning down the analytic. In P. Reavey (Ed.), *Visual Methods in Psychology* (pp. 314-329). Oxon: Psychology Press.

- Glenberg, A. M. (2010). Embodiment as a unifying perspective for psychology. *Wiley Interdisciplinary Reviews: Cognitive Science*, 1(4), 586-596.
doi:10.1002/wcs.55
- Goddard, C., & Wierzbicka, A. (1994). *Semantic and Lexical Universals: Theory and Empirical Findings*. Amsterdam: John Benjamins Publishing Co.
- Goldstone, E., Farhall, J., & Ong, B. (2012). Modelling the emergence of hallucinations: early acquired vulnerabilities, proximal life stressors and maladaptive psychological processes. *Social Psychiatry and Psychiatric Epidemiology*, 47(9), 1367-1380. doi:10.1007/s00127-011-0446-9
- Goodwin, M. H. (2006). *The Hidden Life of Girls: Games of Stance, Status and Exclusion*. Malden, MA: Blackwell.
- Grimby, A. (1993). Bereavement among elderly people: Grief reactions, postbereavement hallucinations and quality-of-life. *Acta Psychiatrica Scandinavica*, 87(1), 72-80. doi:10.1111/j.1600-0447.1993.tb03332.x
- Guillemin, M., & Drew, S. (2010). Questions of process in participant-generated visual methodologies. *Visual Studies*, 25(2), 175-188. doi:10.1080/1472586X.2010.502676
- Halcomb, E. J., & Davidson, P. M. (2006). Is verbatim transcription of interview data always necessary? *Applied Nursing Research*, 19(1), 38-42.
doi:10.1016/j.apnr.2005.06.001
- Hall, S. (1997). *Representation: Cultural Representations and Signifying Practices*. Milton Keynes: The Open University.
- Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3), 575-599.
doi:10.2307/3178066
- Haraway, D. J. (2003). *The companion species manifesto: Dogs, people, and significant otherness*. Chicago, IL: Prickly Paradigm Press.
- Harding, S. G. (2004). *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. London: Routledge.
- Hardy, A., Fowler, D., Freeman, D., Smith, B., Steel, C., Evans, J., . . . Dunn, G. (2005). Trauma and hallucinatory experience in psychosis. *The Journal of Nervous and Mental Disease*, 193(8). doi:10.1097/01.nmd.0000172480.56308.21

- Harris, A., & Guillemin, M. (2011). Developing sensory awareness in qualitative interviewing: A portal into the otherwise unexplored. *Qualitative Health Research*, 22(5), 689-699. doi:10.1177/1049732311431899
- Harrison, G., Gunnell, D., Glazebrook, C., Page, K., & Kwiecinski, R. (2001). Association between schizophrenia and social inequality at birth: Case–control study. *British Journal of Psychiatry*, 179(4), 346-350. doi:10.1192/bjp.179.4.346
- Hasson-Ohayon, I., Kravetz, S., Roe, D., David, A. S., & Weiser, M. (2006). Insight into psychosis and quality of life. *Comprehensive Psychiatry*, 47(4), 265-269. doi:10.1016/j.comppsy.2005.08.006
- Hastings, A. B., N., Bramley, G., Gannon, M., & Watkins, D. (2015). *The Cost of the Cuts: The Impact on Local Government and Poorer Communities*. Retrieved from: <https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/CostofCuts-Full.pdf>
- Heveling, T., Emrich, H. M., & Dietrich, D. E. (2004). Treatment of a rare psychopathological phenomenon: Tactile hallucinations and the delusional other. *European Psychiatry*, 19(6), 387-388. doi:10.1016/j.eurpsy.2004.06.026
- Home Office. (2019). *Stop and Search*. Retrieved from: <https://www.ethnicity-facts-figures.service.gov.uk/crime-justice-and-the-law/policing/stop-and-search/latest>
- hooks, b. (1982). *Ain't I a Woman: Black Women and Feminism*: London: Pluto Press.
- Humpston, C. S., & Broome, M. R. (2016). The spectra of soundless voices and audible thoughts: Towards an integrative model of auditory verbal hallucinations and thought insertion. *Review of Philosophy and Psychology*, 7(3), 611-629. doi:10.1007/s13164-015-0232-9
- Jackson, S., Backett-Milburn, K., & Newall, E. (2013). Researching distressing topics: Emotional reflexivity and emotional labor in the secondary analysis of children and young people's narratives of abuse. *SAGE Open*, 3(2). doi:10.1177/2158244013490705
- Janaki, V., Suzaily, W., Hamid, A. R. A., Hazli, Z., & Azmawati, M. N. (2017). The dimensions of auditory hallucination in schizophrenia: Association

- with depressive symptoms and quality of life. *International Medical Journal Malaysia*, 16(2), 55-64.
- Johnson, M. (2008). *The meaning of the body: Aesthetics of human understanding*. London: University of Chicago Press.
- Jones, N., & Luhrmann, T. M. (2016). Beyond the sensory: Findings from an in-depth analysis of the phenomenology of "auditory hallucinations" in schizophrenia. *Psychosis-Psychological Social and Integrative Approaches*, 8(3), 191-202. doi:10.1080/17522439.2015.1100670
- Jones, S. R., Fernyhough, C., & Laroi, F. (2010). A phenomenological survey of auditory verbal hallucinations in the hypnagogic and hypnopompic states. *Phenomenology and the Cognitive Sciences*, 9(2), 213-224. doi:10.1007/s11097-010-9158-y
- Jorm, A. F., Kelly, C. M., & Morgan, A. J. (2007). Participant distress in psychiatric research: A systematic review. *Psychological Medicine*, 37(7), 917-926. doi:10.1017/S0033291706009779
- Joukamaa, M., Heliövaara, M., Knekt, P., Aromaa, A., Raitasalo, R., & Lehtinen, V. (2006). Schizophrenia, neuroleptic medication and mortality. *British Journal of Psychiatry*, 188(2), 122-127. doi:10.1192/bjp.188.2.122
- Kapur, S. (2003). Psychosis as a state of aberrant salience: A framework linking biology, phenomenology, and pharmacology in schizophrenia. *The American Journal of Psychiatry*, 160(1), 13-23. doi:10.1176/appi.ajp.160.1.13
- Kauffman, P. R. (2016). Might hallucinations have social utility? A proposal for scientific study. *Journal of Nervous and Mental Disease*, 204(9), 702-712. doi:10.1097/Nmd.0000000000000542
- Kearney, K. S., & Hyle, A. E. (2004). Drawing out emotions: The use of participant-produced drawings in qualitative inquiry. *Qualitative Research*, 4(3), 361-382. doi:10.1177/1468794104047234
- Kent, G., & Wahass, S. (1996). The content and characteristics of auditory hallucinations in Saudi Arabia and the UK: A cross-cultural comparison. *Acta Psychiatrica Scandinavica*, 94(6), 433-437. doi:10.1111/j.1600-0447.1996.tb09886.x

- Keogh, B., & Daly, L. (2009). The ethics of conducting research with mental health service users. *British Journal of Nursing*, 18(5), 277-281. doi:10.12968/bjon.2009.18.5.40539
- Keshavan, M. S., & Kaneko, Y. (2013). Secondary psychoses: An update. *World Psychiatry*, 12(1), 4-15. doi:10.1002/wps.20001
- Kinderman, P., Read, J., Moncrieff, J., & Bentall, R. P. (2013). Drop the language of disorder. *Evidence-Based Mental Health*, 16(1), 203. doi:10.1136/eb-2012-100987
- Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J., . . . Jones, P. B. (2012). Incidence of schizophrenia and other psychoses in England, 1950-2009: A systematic review and meta-analyses. *Plos One*, 7(3), e31660. doi:10.1371/journal.pone.0031660
- Kirkbride, J. B., Fearon, P., Morgan, C., Dazzan, P., Morgan, K., Murray, R. M., & Jones, P. B. (2007). Neighbourhood variation in the incidence of psychotic disorders in southeast London. *Social Psychiatry and Psychiatric Epidemiology* 42(6), 438-445. doi:10.1007/s00127-007-0193-0
- Knapp, M. (2012). Mental health in an age of austerity. *Evidence Based Mental Health*, 15(3), 54-55. doi:10.1136/ebmental-2012-100758
- Knowles, J. G., & Cole, A. L. (2008). *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*. London: Sage Publications.
- Kulhara, P., Shah, R., & Grover, S. (2009). Is the course and outcome of schizophrenia better in the 'developing' world? *Asian Journal of Psychiatry*, 2(2), 55-62. doi:10.1016/j.ajp.2009.04.003
- Langdridge, D. (2004). The hermeneutic phenomenology of Paul Ricoeur: Problems and possibilities for existential-phenomenological psychotherapy. *Journal of the Society for Existential Analysis*, 15(2), 243–255.
- Langer, S. K. (1967). *Mind: An essay on human feeling* (Vol. 1). Baltimore, MD: The John Hopkins Press.
- Larkin, M., & Thompson, A. (2012). Interpretative phenomenological analysis. In A. Thompson & D. Harper (Eds.), *Qualitative research methods in*

- mental health and psychotherapy: A guide for students and practitioners* (pp. 99-116). Oxford: John Wiley & Sons.
- Leavy, P. (2018). *Handbook of Arts-Based Research*. New York, NY: The Guilford Press.
- Ledgin, E. (Writer), & Biermann, T. (Director). (27 January 2016) Dee made a smut film [Television series episode] In T. Biermann (Producer), *It's always sunny in Philadelphia*. United States of America: FXX.
- Lewis, H. B. (1971). *Shame and Guilt in Neurosis*. New York, NY: International Universities Press.
- Leys, R. (2011). The turn to affect: A critique. *Critical Inquiry*, 37(3), 434-472. doi:10.1086/659353
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gotzsche, P. C., Ioannidis, J. P. A., . . . Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLoS Medicine*, 6(7). doi:10.1371/journal.pmed.1000100
- Lim, A., Hoek, H. W., Deen, M. L., & Blom, J. D. (2016). Prevalence and classification of hallucinations in multiple sensory modalities in schizophrenia spectrum disorders. *Schizophrenia Research*, 176(2-3), 493-499. doi:10.1016/j.schres.2016.06.010
- Livingstone, K., Harper, S., & Gillanders, D. (2009). An exploration of emotion regulation in psychosis. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice*, 16(5), 418-430. doi: 10.1002/cpp.635
- Lovata, T. R. (2008). Zines: Individual to community. In J. G. Knowles, A.L. Cole (Eds.), *Handbook of the arts in qualitative research* (pp. 323-335). London: Sage Publications Ltd.
- Lowe, G. R. (1973). Phenomenology of hallucinations as an aid to differential diagnosis. *British Journal of Psychiatry*, 123(577), 621-633. doi:10.1192/bjp.123.6.621
- Lugnegård, T., Hallerbäck, M. U., & Gillberg, C. (2011). Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome.

- Research in Developmental Disabilities*, 32(5), 1910-1917. doi:10.1016/j.ridd.2011.03.025
- Luhrmann, T. M., Padmavati, R., Tharoor, H., & Osei, A. (2015). Hearing voices in different cultures: A social kindling hypothesis. *Topics in Cognitive Science*, 7(4), 646-663. doi:10.1111/tops.12158
- Lutz, C. (1988). *Unnatural emotions: Everyday sentiments on a Micronesian Atoll*. Chicago, IL: University of Chicago Press.
- Ma, Y. C., Beckstead, J. W., Lo, S. C., & Yang, C. Y. (2016). Auditory hallucinatory beliefs in patients with schizophrenia: Association of auditory hallucinations with social interactions, characteristics and emotional behaviors over 3 months. *Archives of Psychiatric Nursing*, 30(3), 363-369. doi:10.1016/j.apnu.2015.12.010
- Maj, M. (2005). 'Psychiatric comorbidity': An artefact of current diagnostic systems? *British Journal of Psychiatry*, 186, 182-184. doi:10.1192/bjp.186.3.182
- Mannay, D. (2010). Making the familiar strange: Can visual research methods render the familiar setting more perceptible? *Qualitative Research*, 10(1), 91-111. doi:10.1177/1468794109348684
- Mannay, D. (2016). *Visual, narrative and creative research methods*. Oxon: Routledge.
- Marmot, M. (2010). *Fair society, healthy lives: The Marmot review*. Retrieved from <https://www.parliament.uk/documents/fair-society-healthy-lives-full-report.pdf>
- Massumi, B. (1995). The autonomy of affect. *Cultural Critique*, (31), 83-109. doi:10.2307/1354446
- Mattheys, K. (2015). The Coalition, austerity and mental health. *Disability & Society*, 30(3), 475-478. doi:10.1080/09687599.2014.1000513
- Mayaba, N. N., & Wood, L. (2015). Using drawings and collages as data generation methods with children: Definitely not child's play. *International Journal of Qualitative Methods*, 14(5). doi:10.1177/1609406915621407
- McCarthy-Jones, S., Trauer, T., Mackinnon, A., Sims, E., Thomas, N., & Copolov, D. L. (2014). A new phenomenological survey of auditory hallucinations: Evidence for subtypes and implications for theory and

- practice. *Schizophrenia Bulletin*, 40(1), 225-235. doi:10.1093/schbul/sbs156
- McDaid, D., Park, A.L., Iemmi, V., Adelaja, B., & Knapp, M. (2016). *Growth in the Use of Early Intervention for Psychosis Services: An Opportunity to Promote Recovery amid Concerns on Health Care Sustainability*. Retrieve from: http://eprints.lse.ac.uk/65630/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_PSSRU_Growth%20in%20the%20use%20of%20early%20intervention_2016.pdf
- McEntegart, C., Barnes-Holmes, Y., Dillon, J., Egger, J., & Oliver, J. E. (2017). Hearing voices, dissociation, and the self: A functional-analytic perspective. *Journal of Trauma & Dissociation*, 18(4), 575-594. doi:10.1080/15299732.2016.1241851
- Merleau-Ponty, M. (2002). *Phenomenology of perception* (C. Smith, Trans.). London: Routledge.
- Middleton, D., & Brown, S. D. (2005). *The social psychology of experience studies in remembering and forgetting*. London: SAGE.
- Mills, C. (2018). 'Dead people don't claim': A psychopolitical autopsy of UK austerity suicides. *Critical Social Policy*, 38(2), 302-322.
- Mills, C., & Fernando, S. (2014). Globalising mental health or pathologising the global south? Mapping the ethics, theory and practice of global mental health. *Disability and the Global South*, 1(2), 188-202.
- Misiak, B., Krefft, M., Bielawski, T., Moustafa, A. A., Sasiadek, M. M., & Frydecka, D. (2017). Toward a unified theory of childhood trauma and psychosis: A comprehensive review of epidemiological, clinical, neuropsychological and biological findings. *Neuroscience & Biobehavioral Reviews*, 75, 393-406. doi:10.1016/j.neubiorev.2017.02.015
- Mobbs, D., Garcia, A. & Melvin, K. (Photographers). (2018). *Still photographic exhibition images [photographs]*. Personal Collection.
- Moncrieff, J. (2013). *The bitterest pills: The troubling story of antipsychotic drugs*. London: Palgrave Macmillan.
- Moncrieff, J. (2015). Antipsychotic maintenance treatment: Time to rethink? *PLoS medicine*, 12(8), e1001861. doi:10.1371/journal.pmed.1001861

- Moncrieff, J., Cohen, D., & Mason, J. P. (2009). The subjective experience of taking antipsychotic medication: A content analysis of Internet data. *Acta Psychiatrica Scandinavica*, 120(2), 102-111. doi:10.1111/j.1600-0447.2009.01356.x
- Morrison, A. P., Frame, L., & Larkin, W. (2003). Relationships between trauma and psychosis: A review and integration. *British Journal of Clinical Psychology*, 42(4), 331-353. doi:10.1348/014466503322528892
- Moseley, P., Alderson-Day, B., Kumar, S., & Fernyhough, C. (2018). Musical hallucinations, musical imagery, and earworms: A new phenomenological survey. *Consciousness and Cognition*, 65, 83-94. doi:10.1016/j.concog.2018.07.009
- Murray-Thomas, T., Jones, M. E., Patel, D., Brunner, E., Shatapathy, C. C., Motsko, S., & Van Staa, T. P. (2013). Risk of mortality (including sudden cardiac death) and major cardiovascular events in atypical and typical antipsychotic users: A study with the general practice research database. *Cardiovascular psychiatry and neurology*, 2013. doi:10.1155/2013/247486
- Myin-Germeys, I., & van Os, J. (2007). Stress-reactivity in psychosis: Evidence for an affective pathway to psychosis. *Clinical Psychology Review*, 27(4), 409-424. doi:10.1016/j.cpr.2006.09.005
- National Institute for Health and Clinical Excellence. (2011). *Psychosis and schizophrenia in children and young people: Final scope*. Retrieved from <https://www.nice.org.uk/guidance/cg155/documents/psychosis-and-schizophrenia-in-children-and-young-people-final-scope2>
- Nayani, T. H., & David, A. S. (1996). The auditory hallucination: A phenomenological survey. *Psychological Medicine*, 26(1), 177-189.
- Ndeti, D. M., & Vadher, A. (1984). A comparative cross-cultural-study of the frequencies of hallucination in schizophrenia. *Acta Psychiatrica Scandinavica*, 70(6), 545-549. doi:10.1111/j.1600-0447.1984.tb01247.x
- Nielssen, O., Bourget, D., Laajasalo, T., Liem, M., Labelle, A., Hakkanen-Nyholm, H., . . . Large, M. M. (2011). Homicide of strangers by people with a psychotic illness. *Schizophrenia Bulletin*, 37(3), 572-579. doi:10.1093/schbul/sbp112

- Packard, J. (2008). 'I'm gonna show you what it's really like out here': The power and limitation of participatory visual methods. *Visual Studies*, 23(1), 63-77. doi:10.1080/14725860801908544
- Padma, T. V. (2014). Developing countries: The outcomes paradox. *Nature*, 508, S14. doi:10.1038/508S14a
- Palmer, B. A., Pankratz, V. S., & Bostwick, J. M. (2005). The lifetime risk of suicide in schizophrenia: A reexamination. *Archives of General Psychiatry*, 62(3), 247-253. doi:10.1001/archpsyc.62.3.247
- Parrett, N. S., & Mason, O. J. (2010). Refugees and psychosis: A review of the literature. *Psychosis*, 2(2), 111-121. doi:10.1080/17522430903219196
- Pashler, H., & Wagenmakers, E. J. (2012). Editors' introduction to the special section on replicability in psychological science: A crisis of confidence? *Perspectives on Psychological Science*, 7(6), 528-530. doi:10.1177/1745691612465253
- Pauwels, L. (2010). Visual sociology reframed: An analytical synthesis and discussion of visual methods in social and cultural research. *Sociological Methods & Research*, 38(4), 545-581. doi:10.1177/0049124110366233
- Prosser, J., & Loxley, A. (2008). *ESRC National Centre for Research Methods Review Paper: Introducing Visual Methods*. Retrieved from: <http://eprints.ncrm.ac.uk/420/1/MethodsReviewPaperNCRM-010.pdf>
- Rathod, S., Pinninti, N., Irfan, M., Gorczynski, P., Rathod, P., Gega, L., & Naeem, F. (2017). Mental health service provision in low and middle-income countries. *Health Services Insights*, 10, 1-7. doi:10.1177/1178632917694350
- Read, J. (2010). Can poverty drive you mad? 'Schizophrenia', socio-economic status and the case for primary prevention. *New Zealand Journal of Psychology*, 39(1), 7-19.
- Read, J., Agar, K., Argyle, N., & Aderhold, V. (2003). Sexual and physical abuse during childhood and adulthood as predictors of hallucinations, delusions and thought disorder. *Psychology and Psychotherapy: Theory, Research and Practice*, 76(1), 1-22. doi:10.1348/14760830260569210
- Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms.

- Epidemiology and Psychiatric Sciences*, 18(4), 299-310. doi:10.1017/S1121189X00000257
- Read, J., Haslam, N., & Magliano, L. (2013). Prejudice, stigma and 'schizophrenia': The role of bio-genetic ideology. In J. Read, & J. Dillon, *Models of madness: Psychological, social and biological approaches to psychosis* (2nd ed., pp. 157-177). New York, NY: Routledge.
- Read, J., van Os, J., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112(5), 330-350. doi:10.1111/j.1600-0447.2005.00634.x
- Reavey, P. (2011). *Visual Methods in Psychology*. Oxon: Psychology Press.
- Reavey, P., Brown, S. D., Kanyeredzi, A., McGrath, L., & Tucker, I. (2019). Agents and spectres: Life-space on a medium secure forensic psychiatric unit. *Social Science & Medicine*, 220, 273-282. doi:10.1016/j.socscimed.2018.11.012
- Regier, D. A., Narrow, W. E., Clarke, D. E., Kraemer, H. C., Kuramoto, S. J., Kuhl, E. A., & Kupfer, D. J. (2013). DSM-5 field trials in the United States and Canada, part II: Test-retest reliability of selected categorical diagnoses. *American Journal of Psychiatry*, 170(1), 59-70. doi:10.1176/appi.ajp.2012.12070999
- Reynolds, N., & Scragg, P. (2010). Compliance with command hallucinations: The role of power in relation to the voice, and social rank in relation to the voice and others. *Journal of Forensic Psychiatry & Psychology*, 21(1), 121-138. doi:10.1080/14789940903194111
- Roberts, L. W., & Kim, J. P. (2014). Giving voice to study volunteers: Comparing views of mentally ill, physically ill, and healthy protocol participants on ethical aspects of clinical research. *Journal of Psychiatric Research*, 56, 90-97. doi:10.1016/j.jpsychires.2014.05.007
- Romme, M. A. J., Honig, A., Noorthoorn, E. O., & Escher, A. D. M. A. C. (1992). Coping with hearing voices: An emancipatory approach. *The British Journal of Psychiatry*, 161(1), 99-103. doi:10.1192/bjp.161.1.99
- Rose, D., & Thornicroft, G. (2010). Service user perspectives on the impact of a mental illness diagnosis. *Epidemiology and Psychiatric Sciences*, 19(2), 140-147. doi:10.1017/S1121189X00000841

- Rummel-Kluge, C., Komossa, K., Schwarz, S., Hunger, H., Schmid, F., Lobos, C. A., . . . Leucht, S. (2010). Head-to-head comparisons of metabolic side effects of second generation antipsychotics in the treatment of schizophrenia: A systematic review and meta-analysis. *Schizophrenia Research, 123*(2), 225-233. doi:10.1016/j.schres.2010.07.012
- Rupert, S. L., Hollender, M. H., Mehrhof, E. G. (1961). Olfactory Hallucinations. *Archives of General Psychiatry, 5*(3), 313-318. doi:10.1001/archpsyc.1961.01710150095014
- Sandelowski, M., Voils, C. I., & Barroso, J. (2006). Defining and Designing Mixed Research Synthesis Studies. *Res Sch, 13*(1), 29.
- Sara, G., & Lappin, J. (2017). Childhood trauma: psychiatry's greatest public health challenge? *The Lancet Public Health, 2*(7), e300-e301. doi:10.1016/S2468-2667(17)30104-4
- Scheff, T. (1990). *Microsociology: Discourse, emotion, and social structure*. London: The University of Chicago Press.
- Scheff, T. (2012). A social/emotional theory of 'mental illness'. *International Journal of Social Psychology, 59*(1), 87-82. doi:10.1177/0020764012445004
- Shepherd, S., Depp, C. A., Harris, G., Halpain, M., Palinkas, L. A., & Jeste, D. V. (2012). Perspectives on schizophrenia over the lifespan: A qualitative study. *Schizophrenia Bulletin, 38*(2), 295-303. doi:10.1093/schbul/sbq075
- Shore, D. (2006). Ethical issues in schizophrenia research: A commentary on some current concerns. *Schizophrenia Bulletin, 32*(1), 26-29. doi:10.1093/schbul/sbj031
- Shotter, J. (1993). *Cultural politics of everyday life: Social constructionism, rhetoric and knowing of the third kind*. London: Open University Press.
- Shweder, R. A. (2004). Deconstructing the emotions for the sake of comparative research. In A. S. R. Manstead, N. Frijda, & A. Fischer. (Eds.), *Feelings and emotions: The Amsterdam symposium* (pp. 81-97). New York, NY: Cambridge University Press.
- Siegel, R. K. (1984). Hostage hallucinations- visual-imagery induced by isolation and life-threatening stress. *Journal of Nervous and Mental Disease, 172*(5), 264-272. doi:10.1097/00005053-198405000-00003

- Singh, S. P. (2010). Early intervention in psychosis. *British Journal of Psychiatry*, 196(5), 343-345. doi:10.1192/bjp.bp.109.075804
- slowthai. (2019). Nothing great about Britain [Recorded by slowthai]. On *Nothing great about Britain*. London: Method Records.
- Smith, B., Fowler, D. G., Freeman, D., Bebbington, P., Bashforth, H., Garety, P., . . . Kuipers, E. (2006). Emotion and psychosis: Links between depression, self-esteem, negative schematic beliefs and delusions and hallucinations. *Schizophrenia Research*, 86(1-3), 181-188. doi:10.1016/j.schres.2006.06.018
- Stevenson, R. J., Langdon, R., & McGuire, J. (2011). Olfactory hallucinations in schizophrenia and schizoaffective disorder: A phenomenological survey. *Psychiatry Research*, 185(3), 321-327. doi:10.1016/j.psychres.2010.07.032
- Stuckler, D., Reeves, A., Loopstra, R., Karanikolos, M., & McKee, M. (2017). Austerity and health: The impact in the UK and Europe. *European Journal of Public Health*, 27(S4), 18-21. doi:10.1093/eurpub/ckx167
- Suhail, K., & Cochrane, R. (2002). Effect of culture and environment on the phenomenology of delusions and hallucinations. *International Journal of Social Psychiatry*, 48(2), 126-138. doi: 10.1177/002076402128783181
- Sundquist, K., Frank, G., & Sundquist, J. (2004). Urbanisation and incidence of psychosis and depression: Follow-up study of 4.4 million women and men in Sweden. *British Journal of Psychiatry*, 184(4), 293-298. doi:10.1192/bjp.184.4.293
- Suryani, S., Welch, A., & Cox, L. (2013). The phenomena of auditory hallucination as described by Indonesian people living with schizophrenia. *Archives of Psychiatric Nursing*, 27(6), 312-318. doi:10.1016/j.apnu.2013.08.001
- Taylor, P. J., Awenat, Y., Gooding, P., Johnson, J., Pratt, D., Wood, A., & Tarrier, N. (2010). The subjective experience of participation in schizophrenia research: a practical and ethical issue. *Journal of Nervous and Mental Disease*, 198(5), 343-348. doi:10.1097/NMD.0b013e3181da8545

- Tew, J. (2017). A crisis of meaning: can 'schizophrenia' survive in the 21st century? *Medical Humanities*, 43(2), 111. doi:10.1136/medhum-2016-011077
- Thomas, P., Mathur, P., Gottesman, I. I., Nagpal, R., Nimgaonkar, V. L., & Deshpande, S. N. (2007). Correlates of hallucinations in schizophrenia: A cross-cultural evaluation. *Schizophrenia Research*, 92(1-3), 41-49. doi:10.1016/j.schres.2007.01.017
- Thornicroft, G., Tansella, M., Becker, T., Knapp, M., Leese, M., Schene, A., . . . Grp, E. S. (2004). The personal impact of schizophrenia in Europe. *Schizophrenia Research*, 69(2-3), 125-132. doi:10.1016/S0920-9964(03)00191-9
- Torregrossa, L. J., Snodgrass, M. A., Hong, S. J., Nichols, H. S., Glerean, E., Nummenmaa, L., & Park, S. (2018). Anomalous Bodily Maps of Emotions in Schizophrenia. *Schizophrenia Bulletin*. doi:10.1093/schbul/sby179
- United Nations Human Rights Council. (2017). *Report of the special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. Retrieved from: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/076/04/PDF/G1707604.pdf>
- Uptegrove, R., Ives, J., Broome, M. R., Caldwell, K., Wood, S. J., & Oyeboode, F. (2016). Auditory verbal hallucinations in first-episode psychosis: A phenomenological investigation. *BJPsych Open*, 2(1), 88-95. doi:10.1192/bjpo.bp.115.002303
- Vanheule, S., Desmet, M., Meganck, R., Inslegers, R., Willemsen, J., De Schryver, M., & Devisch, I. (2014). Reliability in psychiatric diagnosis with the DSM: Old wine in new barrels. *Psychotherapy and Psychosomatics*, 83(5), 313-314. doi:10.1159/000358809
- Varese, F., Barkus, E., & Bentall, R. P. (2012). Dissociation mediates the relationship between childhood trauma and hallucination-proneness. *Psychological Medicine*, 42(5), 1025-1036. doi:10.1017/S0033291711001826
- Varese, F., Udachina, A., Myin-Germeys, I., Oorschot, M., & Bentall, R. P. (2011). The relationship between dissociation and auditory verbal

- hallucinations in the flow of daily life of patients with psychosis.
Psychosis-Psychological Social and Integrative Approaches, 3(1), 14-28.
 doi:10.1080/17522439.2010.548564
- Waddingham, R. (2017). Why do we never talk about the harm that can be done by diagnosing someone with a mental illness? *The Independent*. Retrieved from: <https://www.independent.co.uk/voices/mental-health-illness-schizophrenia-depression-borderline-personality-disorder-ptsd-labels-diagnosis-a7993251.html>
- Wade, D. T., & Halligan, P. W. (2004). Do biomedical models of illness make for good healthcare systems? *British Medical Journal*, 329(7479), 1398-1401. doi:10.1136/bmj.329.7479.1398
- Waite, F., Evans, N., Myers, E., Startup, H., Lister, R., Harvey, A. G., & Freeman, D. (2016). The patient experience of sleep problems and their treatment in the context of current delusions and hallucinations. *Psychology and Psychotherapy-Theory Research and Practice*, 89(2), 181-193. doi:10.1111/papt.12073
- Warr, D. J. (2004). Stories in the flesh and voices in the head: Reflections on the context and impact of research with disadvantaged populations. *Qualitative Health Research*, 14(4), 578-587. doi:10.1177/1049732303260449
- Watch, B. B. (2012). *The Price of Privacy: How Local Authorities Spent £515m on CCTV in Four Years*. Retrieved from: https://www.bigbrotherwatch.org.uk/files/priceofprivacy/Price_of_privacy_2012.pdf
- Waters, F., Collerton, D., ffytche, D. H., Jardri, R., Pins, D., Dudley, R., . . . Larøi, F. (2014). Visual hallucinations in the psychosis spectrum and comparative information from neurodegenerative disorders and eye disease. *Schizophrenia Bulletin*, 40(S4), S233-S245. doi:10.1093/schbul/sbu036
- Wengraf, T. (2001). *Qualitative research interviewing: Biographic narrative and semi-structured methods*. London: SAGE.
- Wetherell, M. (2012). *Affect and emotion: A new social science understanding*. London: Sage Publications.

- Wetherell, M. (2013). Affect and discourse— What's the problem? From affect as excess to affective/discursive practice. *Subjectivity*, 6(4), 349-368. doi:10.1057/sub.2013.13
- Whitaker, R. (2005). Anatomy of an epidemic: Psychiatric drugs and the astonishing rise of mental illness in America. *Ethical Human Psychology and Psychiatry*, 7(1), 23-35.
- Wickham, S., Taylor, P., Shevlin, M., & Bentall, R. P. (2014). The impact of social deprivation on paranoia, hallucinations, mania and depression: The role of discrimination social support, stress and trust. *Plos One*, 9(8). doi:10.1371/journal.pone.0105140
- Wilson, A., & Golonka, S. (2013). Embodied cognition is not what you think it is. *Frontiers in Psychology*, 4, 58. doi:10.3389/fpsyg.2013.00058
- Wilson, M. (2002). Six views of embodied cognition. *Psychonomic Bulletin & Review*, 9(4), 625-636. doi:10.3758/BF03196322
- Woods, A., Jones, N., Alderson-Day, B., Callard, F., & Fernyhough, C. (2015). Experiences of hearing voices analysis of a novel phenomenological survey. *Lancet Psychiatry*, 2(5), 378-378. doi:10.1016/S2215-0366(15)00163-7
- Woods, A., Jones, N., Bernini, M., Callard, F., Alderson-Day, B., Badcock, J. C., . . . Fernyhough, C. (2014). Interdisciplinary approaches to the phenomenology of auditory verbal hallucinations. *Schizophrenia Bulletin*, 40, S246-S254. doi:10.1093/schbul/sbu003
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215-228. doi:10.1080/08870440008400302
- Yardley, L. (2015). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (3rd ed. pp. 257-266). Los Angeles, CA: SAGE.