

THE UNIVERSITY OF HULL

Contributions to individual distress and personal growth following the  
experience of hallucinations

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by

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## **Overview**

Research suggests hearing and seeing things that others do not is universally experienced by many humans; yet, there is a dominant discourse that hallucinations are a negative and debilitating phenomenon. This portfolio examines the differences between those who seek help for their hallucinatory experiences and those who do not, and explores a more positive narrative of experiencing hallucinations as a medium in which a person can develop and personally grow. The portfolio is comprised of three parts.

Part one is a systematic literature review, in which existing empirical literature relating to mental health service-use and distress for individuals experiencing hallucinations is reviewed. A total of sixteen studies are first critically evaluated and assessed for quality, then the findings are collated and synthesised to examine the psychological and social factors which may contribute to a rise in hallucinatory distress and/or help-seeking.

Part two is an empirical paper, which explores experiences of personal growth with auditory and visual hallucinations. The qualitative study interviewed seven individuals to better understand the experience of personal growth, individuals' expectations of positive change, and highlight any facilitating or hindering factors in the development of personal growth.

Part three comprises the appendices. The supporting information for the systematic literature review and the empirical study are presented, in addition to epistemological and reflective statements to provide further context for the undertaken research.

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## **Part One: Systematic literature review**

This paper is written in the format ready for submission to the journal

*Clinical Psychology Review.*

Please see Appendix A for the submission guidelines.

**Hallucinatory distress and service use:  
A systematic literature review considering the contributory factors.**

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## **Abstract**

It has been increasingly acknowledged that hallucinations are experienced across a continuum, with some individuals needing to seek help from mental health services, whereas others do not. The present review aimed to synthesise the literature regarding psychological and social factors which may contribute to a rise in distress and/or help-seeking, and further considers the relationship between service-use and hallucinatory distress. A systematic search of the literature was conducted. The findings from sixteen articles were included in the narrative synthesis and thematically analysed, following comprehensive quality assessments. Evidence for a relationship between service-use status and hallucinatory distress was found; although, this relationship did not occur in isolation. Various other contributory factors were identified, including: characteristics of hallucinations; beliefs about the experience; coping responses; trauma and stress; perceived social context; and spirituality and religious belief. Strong evidence emerged for individual's appraisals of their experiences influencing distress and help-seeking. An understanding of the contributory factors identified within this review is presented, exploring their inter-relations. Inconsistencies within the literature are examined, alongside limitations of the overall body of literature, and implications for clinical practice and research are discussed.

## ***Keywords***

Hallucinations, service-use, help-seeking, distress, beliefs, review

## ***Highlights***

- This is the first systematic review available on service-use and hallucinatory distress
- Comparisons between help-seekers and non-help-seekers with hallucinations are made
- The experience of hallucinations is not always distressing
- Distress and service-use is related to individual's perceptions of the experience



## **Introduction**

Hallucinations are defined as the perception of an object or event in the absence of any sensory stimulus (National Institute for Health and Care Excellence, NICE, 2014); often described as hearing, seeing or feeling things that other people do not (British Psychological Society, BPS, 2000). Hallucinations have been found to be commonly interpreted as omnipotent and powerful, producing negative attributions, trauma and great distress (Peters, Williams, Cooke & Kuipers, 2012). However, a body of literature regarding hallucinations in the general population (those not involved with mental health services) has been emerging over the last 30 years (e.g. Posey & Losch, 1983; Tien, 1991) which raises some interesting implications for our previous clinical understanding of the experience. The concept of hallucinations has often been understood in biomedical terms, referring solely to hallucinations as the manifestation of genetic predispositions and neurological irregularities. However, literature revealing the commonality of such experiences has brought a shift in perspectives, recognising hallucinations as understandable reactions to social and psychological influences (Read, Mosher & Bentall, 2004).

The continuum model for auditory and visual hallucinations has gained recent popularity. The Division of Clinical Psychology of the BPS emphasised that the experience of hallucinations can lie on a continuum of mental health and 'illness', a continuous gradation from an absence of any detectable experiences through to persistent and disruptive events, with many individuals experiencing hallucinations without needing to access help from services (BPS, 2000). Hallucinatory experiences have consistently been found to be prevalent among non-clinical community populations, with studies reporting a range of 0.6% to 84% of the general population identifying personal hallucinatory experiences (Beavan, Read & Cartwright, 2011; Bentall, 2004; Ohayon, 2000). It has been proposed that these estimates vary so greatly due to fluctuations in definitions, methodologies, and social contexts (Beavan, Read & Cartwright, 2011).

With this acknowledgement of the general population broadly experiencing hallucinations there is a challenge to understand how the rather dichotomous categorisation of service involvement is made; at what point does a person seek help for their hallucinatory experiences, and when do

services provide such mental health support for individuals? Spitzer (1998) identified that mental health services are generally operated on assessments of distress and disability to allocate clinical status, as opposed to a system of clinical need. Additionally, the extent of distress and perceived normality of the hallucinatory experience has been identified as differentiating those who seek help in services from those that do not (Romme & Escher, 1993). This acknowledges that current mental health systems are often managed by categorisation of distress and diagnosis, as seen in the UK for example by the introduction of the NHS ‘clustering’ scheme (Self, Rigby, Leggett & Paxton, 2008; Wing et al., 1998), but also often relies on the individual seeking help which is often considered to be dependent on their perceived distress and social attitudes. It is worth noting that the present review is largely focussed on the UK system as the majority of studies included in the review are UK-based; however, it is acknowledged that systems of mental health services are likely to vary in differing areas.

Suggestions have been made that the descriptive characteristics of hallucinations (e.g. frequency, duration, loudness) are experientially similar across individuals using services and the general population, thus service-use status is not contingent upon the quality of hallucinatory experiences, but findings are varied (for a review see Larøi et al., 2012). This methodological approach of including a help-seeking and a non-help-seeking group in research is still novel; despite being inspired by Romme and Escher’s (1989; 1993) earlier work, studies accessing help-seekers and non-help-seekers are still limited.

Of the literature available, research has begun to compare the experiences of those seeking and not seeking help for hallucinations. For instance, Jones, Guy and Ormrod (2003) compared individuals’ understanding of their voice hearing, and found non-service-users were more likely to hold positive beliefs about their voices. Similarly, non-help-seekers reported significantly higher beliefs that their voices were benevolent, with lower beliefs of malevolence and omnipotence, and rather than resisting the experiences they instead engaged with their voices (Lawrence, Jones & Cooper, 2010). The vulnerabilities of experiencing hallucinations have also been assessed (Goldstone, Farhall & Ong, 2012), whereby predictors of hallucinations in both help-seekers and non-help-seekers were similar, with slight disparities, including the role of

childhood trauma and unhelpful cognitive strategies. Romme, Honig, Noorthoorn and Escher (1992) identified that non-help-seekers and people considered able to cope generally appraised their voices as positive, felt stronger than their hallucinations, adopted more active coping strategies rather than mainly distraction, and were more likely to perceive support from others. Previous literature reviews have compared factors related to help-seeking and non-help-seeking (e.g. Badcock & Hugdahl, 2012; Badcock & Chhabra, 2013; Daalman & Diederer, 2013; Johns et al., 2014; Larøi et al., 2012) or hallucinatory distress (e.g. Mawson, Cohen & Berry, 2010); however, unlike the present research, many of these are focussed solely on cognitive influences, were not conducted systematically, and fail to consider both factors of hallucinatory distress and service use.

The acknowledgement of a non-help-seeking population with hallucinatory experiences raises the question as to whether some individuals feel better able to manage the experience of hallucinations than others. Romme and Escher (1989) first termed this ‘copers’ and ‘non-copers’. Previously, research has used service-use status and this idea of ‘coping’ synonymously with individuals having a ‘healthy’ level of distress (e.g. de Leede-Smith & Barkus, 2013; Palmier-Claus, Dunn & Lewis, 2012), but as alluded to above there are many components to a person’s service-use status, of which distress appears to be one. It is worth noting that distress is not necessarily an undesirable experience, yet in our society we often take this approach and consider distress as something which must be resolved. Instead, as positive psychology highlights, positive and negative states co-occur (Aspinwall & Tedeschi, 2010) in the familiar notion of ‘experiencing the bad to recognise the good’. An emerging body of literature has begun evidencing that people can personally grow from distressing experiences of adversity (Hefferon, Greal & Mutrie, 2009; Tedeschi & Calhoun, 2004); resultantly the present article adopts a critical appraisal of the notion ‘healthy’ distress.

There are issues with the aforementioned literature only adopting a dichotomous perspective and categorising groups by service-use status, as the reasons why an individual may, or may not, be under the care of mental health services are extensive and complex, and those with no service contact may be more distressed than those in services. This contradiction occurs as those in

services are receiving care which intends to reduce distress (NICE, 2014), and those in the community may be facing barriers to accessing services (Bradford et al., 2008; Gulliver, Griffiths & Christensen, 2010).

It therefore, would be valuable to consider further the relationship between service use and distress, and what factors may contribute to a rise in hallucinatory distress and/or help-seeking. With this, services (and individuals) can be responsive to the precipitating factors rather than a heightening of distress; this would allow for services to better facilitate personal growth and ascertain treatment targets, improving their recovery prospects (Onken, Dumont, Ridgway, Dornan & Ralph, 2002).

The present study aimed to synthesise research which assesses both distress and service-use status. To our knowledge the findings of such available research had not yet been compiled and compared; therefore, the present review provides a more cohesive foundation of literature, developing our understanding of these help-seeking and non-help-seeking populations and the factors that influence the experience of distress. Consequently, the fundamental questions underpinning this review were: i) is there evidence for the relationship between service-use status and distress; ii) what factors contribute to service-use status; and iii) what factors influence individual distress?

## **Method**

### ***Search strategy***

A systematic search of the literature was conducted through the electronic databases PsycINFO, CINAHL Complete, PsycARTICLES, and MEDLINE; these databases were selected to ensure a broad cover of the clinical specialities contributing to literature regarding hallucinatory experiences. The reference sections of the articles meeting criteria were also manually searched for further research pertinent to this literature review.

The search was conducted in October 2015 using Boolean operators and predetermined terms developed from existing key words in relevant literature and designed to approach the research

question. Three categories for searching were adopted, each with a comprehensive selection of terms to capture the applicable research articles; the categories were:

Terms regarding hallucinatory experiences: Psychosis OR hallucin\* OR voice\*

Terms regarding distress: Distress OR (psycholog\* N3 stress) OR emotion\*

Terms regarding service-use status: (clinical AND “non-clinical”) OR comparison OR (psychiatric AND “non-psychiatric”) OR (patient AND “non-patient”) OR (help N2 seek\*)

Two limiters were applied to the search findings: a date limiter and a source limiter. The date limiter included only research published after 1948 as it was considered that any conclusions drawn from research prior to this time was unlikely to be relevant to present day services due to the age of the literature and the structure of services being strongly founded in changeable societal perceptions of mental health as discussed above. None of the papers pre-dated 1998. The source limiter excluded dissertations, magazines and books and ensured all articles were peer-reviewed empirical studies.

### ***Inclusion and exclusion criteria***

Articles were included if they met the following set of criteria: i) included at least two study populations of differing service-use status, including a sample involved in services (and thus deemed to be help-seeking), and another that were not involved in any form of mental health service (and thus deemed to be non-help-seeking); ii) both a help-seeking and a non-help-seeking population reported experiencing hallucinations which were assessed; iii) an assessment of distress was present and comparisons of distress between groups were possible; iv) data were presented quantitatively to allow for measurable comparisons between groups’ reported distress and other identified variables, thus permitting the analysis of significant differences to infer contributory factors to group variances; v) available in the English language, vi) the article was an empirical study (i.e. not a literature review or commentary article). A total of 16 articles were ultimately selected to be included in the review (see Figure 1).

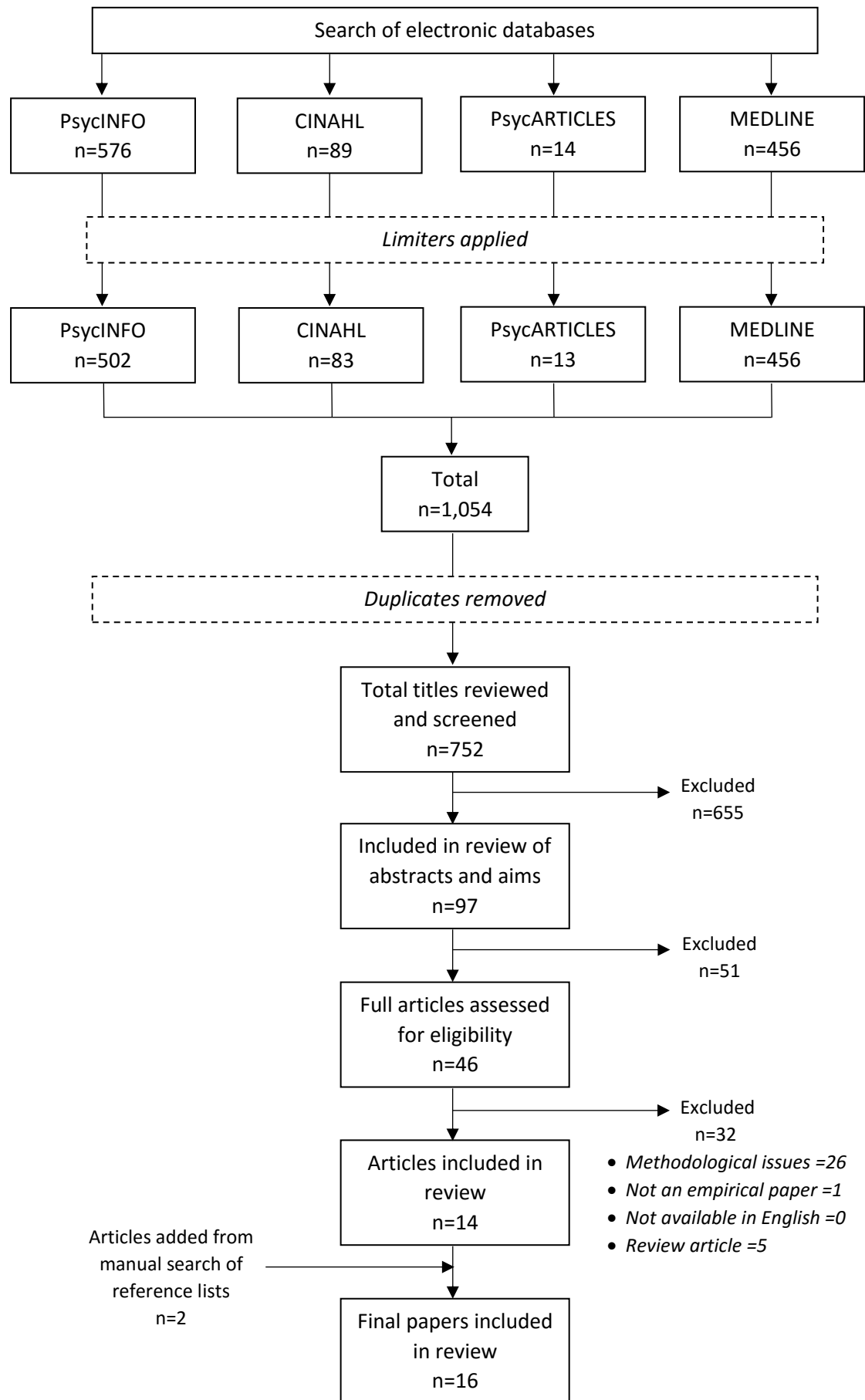


Figure 1. Flowchart detailing the article selection process (in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses; Liberati et al., 2009).

### ***Definitions***

As previously noted, the terms help-seeking and non-help-seeking are used for the purpose of the present literature review to refer to individuals involved and not involved in mental health services (respectively). It is acknowledged that individuals included in the help-seeking category may not have originally actively sought help (for instance, by making initial contact with their G.P.), and instead may have inadvertently become involved in services (e.g. as a condition of a community treatment order or for the protection of themselves or others). Nonetheless, all of the individuals categorised as help-seekers in the included articles maintained a degree of contact with services and thus were considered to be wanting to engage in the support available.

Five of the included studies utilised an 'At Risk Mental State' (ARMS) population; individuals who were involved in services but were not deemed to meet criteria for a psychotic disorder. In most articles they were assessed as meeting ARMS criteria using the Comprehensive Assessment of ARMS (CAARMS; Phillips, Yung & McGorry, 2000), but one article (Barkus et al., 2010) adopted the Positive and Negative Syndrome Scale (Kay, Fiszbein & Opler, 1987) for an assessment of ARMS criteria. Both assessments reviewed the presence of the individuals'

transient and attenuated symptoms. Three studies also adopted a 'Control' sample; these are individuals who had no involvement in mental health services and reported no hallucinatory experiences.

### ***Quality assessment***

The quality of each article was assessed using a 20-item quality assessment checklist devised by the lead author (see Appendix B). This checklist was adapted from pre-existing quality assessments, specifically: STROBE (von Elm et al., 2008), Downs & Black (1998), Mixed Methods Appraisal Tool (MMAT; Pluye, Gagnon, Griffiths & Johnson-Lafleur, 2009) and NICE (2012). Items were taken from each of these assessments to create a quality checklist suitably tailored to the literature examined in the present review, ensuring the importance of

methodological issues related to quantitative, cross-sectional studies with independent sampling were reflected. All aspects of the quality assessment were treated equally, with no weight given to certain criteria over others. This quality assessment was not employed as criteria for study inclusion, but instead to critically examine the methodological quality of the included articles, contextualising their findings, to inform the conclusions of the present review. When determining quality ratings, the lead author reviewed the articles and decided, based on the available evidence, whether each of the 20 criteria in the quality checklist had been completely/partially/or not met and recorded. To assess the reliability of these ratings, a random sample of five articles were also assessed by an independent researcher; inter-rater reliability was high (mean = 86%, range = 75%-90%), and thus the ratings of the lead author were determined dependable. In the case of any discrepancies in researchers' scores, the item was discussed and the final rating decision was made by the lead author.

### ***Data synthesis***

Given the diversity of the body of literature, and the broad range of assessment measures adopted, a meta-analysis was considered inappropriate. Instead, the present literature review aimed to create new understanding of issues related to hallucinatory distress and service-use status, by combining the existing literature and reflecting on its quality. Therefore, data analysis of the included articles was guided by narrative synthesis approaches (Popay et al., 2006; Baumeister & Leary, 1997), selecting, reporting and ordering evidence to tell the 'story' of the present literature (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005).

Data from each article was extracted (see Appendix C) and categorised following principles of thematic analysis (Braun & Clarke, 2006). Initially, vote counting was used for a preliminary examination of factors identified in the articles (Popay et al., 2006). Then, themes were continually developed, collating evidence of these categories, and comparing findings between service-use groups and, more widely, other articles, until a coherent story of the data was formed. The present review offers opportunity for findings to be collated, providing a more extensive pool of completed data to compare the results of literature from a wide range of sources; by assimilating the literature in this way the overall comparable findings are thought to be more reliable.



## **Results**

### *Overview of the literature*

A summary of the included articles can be found in Table 1. Of the 16 studies included most help-seeking participants were recruited from the mental health services they were attending for support; however, in Hill et al. (2012) two help-seeking participants (out of 20) were no longer involved in services, and Robson & Mason (2015) recruited online and later asked participants to define their service-use status. The included studies recruited non-help-seeking participants through a range of sources including: student populations (n=4); churches (n=3); groups identified as endorsing hallucinatory experiences (e.g. psychism/witchcraft/spiritualism; n=6); and local media and events promoting the ordinariness of voice hearing (n=3). The research was largely conducted in the UK (n=13), but also the Netherlands (n=2) and Spain (n=1).

### *Quality of literature*

The included articles were largely appraised as respectable in quality, with quality ratings ranging from 55% - 87.5% (mean = 72.5), see Appendix D for a full overview of the quality assessments. Generally the assessment criteria were well covered. The included studies routinely provided details regarding research rationale, objectives, participant recruitment and eligibility. The studies used valid sources for assessment data and appropriate statistical analysis, and drew tentative interpretations of their findings. Although, some criteria scored markedly poorly; particularly of note were the low ratings for participant representativeness of the source population (criterion 6). It was found that evidence for this criterion was often not reported to a great enough extent to be adequately assessed, with key demographic details of participants being omitted. In turn, this had substantial implications on the ability to assess the generalisability of the findings (criterion 19) which then also scored poorly. There was also an issue of data completion (criterion 9), with some articles not meeting a minimum level of 80% outcome measure completion, but again this criterion was skewed by the lack of reporting completion rates meaning quality could not be easily assessed;

Table 1. Summary of included articles

Article Country	Design	Participants service-use status	Measures Used	Groups' distress level different?	Key Findings	Hallucinatory Characteristics Similar?	Quality Rating
<b>Andrew, Gray &amp; Snowden (2008)</b> UK	Independent samples Quantitative	Help-seekers (n=22) Non-help-seekers (n=21)	PSYRATS-AH BAVQ-R PDS IES BAI BDI-II	Yes. Help-seekers rated more frequent occasions of distress and more severe degree of distress (PSYRATS-AH)*** Help-seekers reported higher depression and anxiety (BDI-II & BAI).***	Help-seekers had less control and more malevolent and omnipotent voices with more negative content, and reported more resistant coping behaviours.*** Non-help-seekers reported voices as more benevolent and engaged with them more.*** No difference in the number of people who had a past traumatic event, but help-seekers experienced more types of trauma. Beliefs about malevolence & total IES score predicted distress.	Auditory hallucinations located similarly. Help-seekers typically heard voices more frequently, more loudly, and for longer durations.*	80%
<b>Barkus, et al. (2010)</b> UK	Independent samples Quantitative	Help-seekers At-Risk Mental States (ARMS; n=58) Non-help-seekers (n=95); split into 3 subgroups: high, medium, low schizotypal experiences.	SPQ & LSHS ( <i>to healthy volunteers only</i> ) GHQ MCQ	Yes. ARMS scored higher on GHQ total than all subgroups of non-help-seekers.*** High schizotypal non-help-seekers scored higher than the low schizotypal participants.**	ARMS scored significantly higher than all non-help-seeking subgroups on MCQ subscales (Uncontrollability & Danger; Cognitive Confidence; and Superstition, Punishment, and Responsibility).*** High schizotypal non-help-seekers also differed from the low on some subscales. No difference between groups for Positive Beliefs and Cognitive Self-Consciousness.	Not reported	70%
<b>Brett, Johns, Peters &amp; McGuire (2009)</b> UK	Independent samples Quantitative and Structured Interview	Help-seekers (n=27) ARMS Help-seekers (n=32) Non-help-seekers (n=24) Control (n=32)	MCQ SCL-90-R AANEX	Partially. Significant group effects on anxiety & depression (SCL-90-R)*; help-seekers scored higher than control group. Non-help-seekers did not differ from help-seekers or control group.	Overall significant effect of group on MCQ score*** and for each MCQ subscale.*-*** The Undiagnosed group did not differ significantly from the control group on any MCQ subscales. The ARMS group could not be reliably distinguished from Diagnosed group by any MCQ subscale.	Not reported	85%

Higher negative beliefs about thoughts was associated with greater distress.

Article Country	Design	Participants service-use status	Measures Used	Groups' distress level different?	Key Findings	Hallucinatory Characteristics Similar?	Quality Rating
<b>Brett, Heriot-Maitland, McGuire &amp; Peters (2014)</b> UK	Independent samples Structured Interview	Help-seekers (n=35) ARMS Help-seekers ( n=20) Non-help-seekers (n=36)	AANEX (Inventory and CAR: Content, Appraisals, Responses)	Yes. Significant effect of group; help-seekers and ARMS group reported higher negative emotional responses and lower positive emotional responses than the Non-help-seekers group (ANNEX).***	Predictors of greater distress were: experiences perceived to alter awareness and cognitive processes**; external appraisals of experiences***; and attempting to control the experiences.*** Significant predictors of lower distress were: appraising the experiences as 'spiritual'***, identifying greater social support/understanding**, perceiving to have more controllability**, and reacting with neutrality***.	Not reported	70%
<b>Cottam et al. (2011)</b> UK	Independent samples Quantitative and Qualitative	Nonreligious help-seekers (n=14), Christian help-seekers (n=15), Non-help-seeking Christians (n=20)	LSHS TVRS (Modified) AEQ Hour-long semi-structured interview	Yes. Significant differences in distress (measured by TVRS), both help-seeking groups experienced more distress when hearing voices than the non-help-seeking Christians.***	Both help-seeking groups responded most commonly with negative emotions, whereas no non-help-seeking Christians reported negative responses, and instead identified positive/mixed responses to the voices.*** The groups experienced the power and the meaning of their voices differently, with non-help-seekers reporting more positive power and meaning***. Help-seekers reported voices had more negative content**. All three groups reported life-event related distress preceded hearing voices for the first time.	The identity of the voices differed, with Christian participants reporting more religious identities. Non-help-seeking Christians heard voices less frequently***, more clearly* and quietly*. Voices located similarly.	67.5%
<b>Daalman et al. (2011)</b> Netherlands	Independent samples Quantitative	Help-seekers (n=118) Non-help-seekers (n=111)	PSYRATS-AH 5 additional questions written by authors	Yes. Help-seekers had higher ratings of total distress (the sum of intensity of distress and disruption to life on the PSYRATS-AH).***	Help-seekers experienced less control, and reported more negative emotional valence of voice content than non-help-seekers.*** Control was not a predictive factor of help-seeking, the strongest predictor was emotional valence.	Help-seekers were older when they first heard a voice, heard voices more frequently and for longer durations.*** The perceived location of voices, the number of	87.5%

<b>Article</b> <i>Country</i>	<b>Design</b>	<b>Participants</b> <b>service-use</b> <b>status</b>	<b>Measures</b> <b>Used</b>	<b>Groups' distress level</b> <b>different?</b>	<b>Key Findings</b>	<b>Hallucinatory</b> <b>Characteristics</b> <b>Similar?</b>	<b>Quality</b> <b>Rating</b>
<b>Davies, Griffin &amp; Vice (2001)</b> <i>UK</i>	Independent samples Quantitative	Help-seekers (n=18), Non-help-seeking Christians (n=29), Controls (n=55)	LSHS 2 scales created by authors: AEQ PVQ	Yes. Non-help-seeking Christians were significantly more positive than the control group*, which were more positive than the Help-seekers* (measured by AEQ).	Most recent experiences of voice hearing were rated more positively than their first experience.** Non-help-seeking Christians perceived the voices more positively than the control group*, which in turn perceived them more positively than the Help-seeking group.*	voices, loudness, and personification did not differ between groups. The help-seekers heard voices more frequently than the non-help-seeking Christians*, who in turn heard voices more frequently than the control group**.	62.5%
<b>Gaynor, Ward, Garety &amp; Peters (2013)</b> <i>UK</i>	Independent samples Quantitative and Structured Interview	Help-seekers (n=28) Non-help-seekers (n=39)	AANEX (Inventory and CAR: Content, Appraisals, Responses) SBQ BDI-II BAI	Yes. Significantly higher anomaly-related distress*** and lower positive emotional response** concerning anomalies in the help-seeking group (measured by AANEX). Also higher anxiety and depression (BAI & BDI-II) in help-seeking group.***	Help-seekers made significantly more negative interpretations of their unusual experiences than the non-help-seekers, and made more threat appraisals.*** Non-help-seekers reported using safety behaviours, but the help-seekers had greater frequency usage.* Threat appraisals mediated the relationship between safety behaviours and distress.	Groups had similar ratings of anomalous experiences (AANEX Current total and AANEX Past total). Help-seekers were older at the onset of anomalous experiences.*	80%
<b>Hill, Varese, Jackson &amp; Linden (2012)</b> <i>UK</i>	Independent samples Quantitative Cross-sectional Questionnaire and	Help-seekers (n=20) Non-help-seekers (n=20) Controls (n=20)	PANSS PSYRATS-AH MCQ-30	Yes. Help-seekers experienced more distress and to a higher intensity *** (measured by PSYRATS-AH).	Groups differed significantly on MCQ-30 ratings. The help-seekers identified more negative beliefs about worry** (concerning uncontrollability and danger) and negative beliefs about need for control***, and reported more negative content for voices***.	Help-seekers and non-help-seekers hallucinations did not experientially differ (measured by PANSS). On the PSYRATS-AH the physical	82.5%

Semi-structured Interview

There were no significant differences in MCQ-30 ratings between the non-help-seeking and control group.  
The help-seekers reported more extreme disruption to their lives due to the voices\*\*\*.

characteristics of the voices were similar.

Article Country	Design	Participants service-use status	Measures Used	Groups' distress level different?	Key Findings	Hallucinatory Characteristics Similar?	Quality Rating
<b>Honig et al. (1998)</b> <i>Netherlands</i>	Independent samples Semi-structured Interview	Help-seekers diagnosed with Schizophrenia (n=18) Help-seekers diagnosed with Dissociative Disorder (n=15) Non-help-seekers (n=15)	Auditory Hallucination Interview	Yes. Help-seeking groups were significantly more afraid of their voices than non-help-seekers. ***	Help-seeking groups reported more negative voices*, whereas non-help-seekers reported predominantly positive voices. Although, a similar percentage of participants in the 3 groups reported positive voices. Schizophrenia group identified voices as more critical/restricting. ** Help-seekers reported feeling less in control. *** There were no differences regarding experiences of abuse across the 3 groups; more than 50% of participants experienced both emotional neglect and abuse.	The form of voices was similar in all 3 groups. Help-seekers reported hearing voices more frequently and continuously*, and that they commented on their thoughts/thoughts of others more. *	55%
<b>Langer et al. (2015)</b> <i>Spain</i>	Independent samples Matched Quantitative and Structured Interview	Help-seekers (n=60) Non-help-seekers (n=68)	RHS SIAPE (devised by authors)	Yes. On the RHS the help-seekers rated a higher degree of discomfort for 10/13 of the items***. Anxiety was also higher for the help-seeking group on 11 items*.	The help-seeking group more commonly defined the experiences as negative*, identified that the experience occurs in a stressful situation*, and reported that the experiences produce a greater degree of interference in daily life. *** For some items the non-help-seekers reported greater perceived control. ** Both groups reportedly sought to eliminate the experiences and could identify a precipitating factor.	The help-seeking group reported more frequent experiences for most items (8/13). ***	57.5%
<b>Robson &amp; Mason (2015)</b> <i>UK</i>	Independent samples Quantitative	Help-seekers (n=32) Non-help-seekers (n=12)	PAM BAVQ-R VAY PADS	Partially. Group's distress did not differ on the Distress scale; but the help-seeking group had	Help-seekers reported greater voice omnipotence*, but otherwise very few differences between groups. Both attachment avoidance and attachment anxiety were positively associated with distress.	Not reported	60%

	Cross-sectional Correlational		BDI-II Distress 5-point Likert scale	higher depression ratings** (BDI-II).	Distress was positively correlated with most subscales of the PAM, VAY and BAVQ-R (negatively correlated with BAVQ-R Benevolence and Engagement).		
<b>Article</b> <i>Country</i>	<b>Design</b>	<b>Participants service-use status</b>	<b>Measures Used</b>	<b>Groups' distress level different?</b>	<b>Key Findings</b>	<b>Hallucinatory Characteristics Similar?</b>	<b>Quality Rating</b>
<b>Sorrell, Hayward &amp; Meddings (2010)</b> <i>UK</i>	Independent samples Quantitative Cross-sectional Correlation	Help-seekers (n=32) Non-help-seekers (n=18)	PSYRATS-AH VAY BAVQ-R BDI-II	Yes. Help-seekers were more distressed than the non-help-seekers** (PYSRATS-AH 'intensity of distress') and were more depressed ** (BDI-II)	Non-help-seekers perceived their voices to be less dominant, intrusive, omnipotent, and malevolent, and instead perceived them as more benevolent.** No group differences in hearer dependence. Large correlations between distress and voice dominance, voice intrusiveness and hearer distance (independent of depression and beliefs about the voice's benevolence).	Group did not have an effect on characteristics of the voice(s), i.e. gender/identity. Non-help-seekers had heard voices for longer.**	77.5%
<b>Taylor et al. (2014a)</b> <i>UK</i>	Independent samples Quantitative Correlation	Help-seekers with First Episode Psychosis (FEP; n=20) ARMS Help-seekers (n=113) Help-seekers with no service contact (n=28) Non-help-seekers (n=30)	CAARMS BCSS	Yes. Means data of distress (measured by CAARMS) indicates group differences. Statistical analysis is reported in Taylor et al. (2014b).	All three help-seeking groups scored higher for negative-self and negative-other schemas than the non-help-seekers, who expressed higher positive-self schemas than the ARMS and HSC group. ***** There were no differences between the clinical help-seeking groups for any of the schemas. Negative-other schemas was correlated with perceptual abnormality distress** and severity*.	Not reported	75%
<b>Taylor et al. (2014b)</b> <i>UK</i>	Independent and dependent samples Quantitative Correlation	<i>Same sample as Taylor et al. (2014a)</i>	CAARMS BDI-PC SIAS	Yes. Help-seeking groups scored higher on perceptual abnormality distress than non-help-seekers (CAARMS). ** *** Also, all three help-	Group's social anxiety differed, with the FEP and ARMS group scoring higher than the help-seekers with no service contact and non-help-seekers. * Perceptual abnormality severity was positively correlated with social anxiety (at the uncorrected significance level), and depression.	Significant effect of group on perceptual abnormality severity, non-help-seekers scored lower than the FEP and ARMS groups*, and the	72.5%

seeking groups had higher depression levels than the non-help-seekers (BDI).\*\*\*

FEP group scoring higher than the ARMS and help-seekers with no service contact\*.

Article Country	Design	Participants service-use status	Measures Used	Groups' distress level different?	Key Findings	Hallucinatory Characteristics Similar?	Quality Rating
Ward et al. (2014) UK	Independent samples Quantitative	Help-seekers (n=28) Non-help- seekers (n=34)	UEQ-ST (devised by authors) AANEX QT BDI-II BAI Appraisal & Response Style ratings (devised by authors)	Yes. Depression and anxiety scores were higher in the help- seeking population (BDI- II & BAI)*** Also the help-seekers rated the experimental anomalous experience (Card Task) as more distressing. ***	Non-help-seekers reported the experimental anomalous experience of the Card Task to be less striking** and threatening* (no group differences for the Virtual Acoustic Space Paradigm). The help-seekers reported higher maladaptive appraisals*, and had higher maladaptive and lower adaptive response styles**. Help-seekers were more likely to identify the 'Active resistance/distraction' and 'Passive/giving up' response styles.	The group's hallucinatory experiences were comparable, with no differences on overall AANEX (past & present) scores. The non-help- seekers had been having these experiences for longer. ***	77.5%

**Note:** Significance levels: \* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$

*AANEX* (Appraisals of Anomalous Experiences Interview, Brett et al. 2007); *AEQ* (Affective Experiences Questionnaire; Davies et al., 2001); *BAI* (Beck Anxiety Inventory; Beck, Epstein, Brown & Steer, 1988); *BAVQ-R* (Belief About Voices Questionnaire – Revised; Chadwick, Lees & Birchwood, 2000); *BCSS* (Brief Core Schema Scales; Fowler et al., 2006); *BDI-II* (Beck Depression Inventory – II; Beck, Steer & Brown, 1996); *BDI-PC* (The Beck Depression Inventory for Primary Care Winter, Steer, Jones-Hicks & Beck, 1999); *CAARMS* (The Comprehensive Assessment for At Risk Mental States; Phillips, Yung & McGorry, 2000); *GHQ* (The General Health Questionnaire; Goldberg & Hillier, 1979); *HADS* (The Hospital Anxiety and Depression Scale; Zigmond and Snaith, 1983); *IES* (Impact of Events Scale; Horowitz et al. 1979); *LSHS* (The Launay-Slade Hallucinations Scale; 1981); *MCQ* (The Metacognitions Questionnaire; Cartwright-Hatton & Wells, 1997); *MCQ-30* (The Metacognitions Questionnaire – Short Form; Wells & Cartwright-Hatton, 2004); *PADS* (Persecution and Deservedness Scale; Melo, Corcoran, Shyrane & Bentall, 2009); *PAM* (Psychosis Attachment Measure; Berry et al., 2006); *PANSS* (The Positive and Negative Syndrome Scale; Kay et al., 1987); *PDS* (Post-traumatic Diagnostic Scale; Foa, 1995); *PSYRATS-AH* (Psychotic Symptom Rating Scales – Auditory Hallucinations Subscale; Haddock, McCarron, Tarrier & Faragher, 1999); *PVQ* (The Perception of Voices Questionnaire; Davies et al., 2001); *QT* (Quick Test of Intelligence; Ammons & Ammons, 1962); *RHS* (Revised Hallucination Scale; Morrison, Wells, & Nothard, 2000); *SBQ* (The Safety Behaviours Questionnaire; Freeman et al., 2001); *SCL-90-R* (Symptom Checklist 90 – Revised; Derogatis, 1986); *SIAP* (Structured Interview Assessment of Psychotic Experience; Langer et al., 2015); *SIAS* (Social Interaction Anxiety Scale; Mattick & Clarke, 1998); *SPQ* (The Schizotypal Personality Questionnaire; Raine, 1991); *TVRS* (Topography of Voices Rating Scale; Hustig & Hafner, 1990); *UEQ-ST* (Unusual Experiences Questionnaire–Screening Tool; Ward et al., 2014); *VAY* (Voice and You; Hayward et al., 2008).

this then also impacted on the generalisability of the findings. Identified criteria may have had an influence on the overall generalisability of the relevant research (and therefore this review), but did not substantively impact the credibility of their findings. The results obtained from participants were still highly pertinent, but it raises the issue that full research participation when adopting quantitative measures may be difficult.

### *Distress*

The vast majority found unambiguous evidence that distress levels differed between groups, with all but two studies (Brett, Johns, Peters & McGuire, 2009; Robson & Mason, 2015) finding that distress was significantly higher for help-seekers than non-help-seekers. In these exceptions, Brett et al. (2009) found non-help-seekers' self-reported anxiety and depression were no different than those of help-seekers and controls. Robson & Mason (2015) found partial evidence for this relationship; the groups' 'distress' ratings did not differ, but the help-seekers' depression ratings were significantly higher than those with hallucinatory experiences and no service contact. However, the 5-point distress ratings scale used here was devised by the authors and not validated, which may explain the variation in findings. This alludes to the complication of defining, and thus measuring, distress, which varied greatly across and within the studies. Many used a distress measure already included in hallucinatory assessments, and over half of the articles adopted a measure of depression and/or anxiety to assist the assessment of distress; this was typically the BDI-II (Beck, Steer & Brown, 1996) or BAI (Beck, Epstein, Brown & Steer, 1988). The only study to use the SCL-90-R (Derogatis, 1986) as an alternative was Brett et al. (2009). The SCL-90-R (Derogatis, 1986) does differ to these other measures, such as it asks raters to merely consider their last week and only has 13 items and 10 items to assess depression and anxiety (respectively), whereas the BDI-II and BAI (Beck, Steer & Brown, 1996; Beck et al., 1988; respectively) are much more comprehensive, proposing raters review the last two weeks and is comprised of 21 items each, which could explain why their results appeared to counter all other findings. Whilst many of the studies simply indicated elevated levels of distress in help-seeking populations, Hill et al. (2012) utilised regression analyses to conclude the most significant predictor of distress was individual help-seeking status. From reviewing this evidence, the



literature is contradictory at times, but largely the research confirms a positive relationship between service use and distress; individuals involved in services are more likely to have higher levels of distress, regardless of the experiential characteristics of their hallucinations or diagnosis. Since evidence is in support of this relationship, the present review now considers what influences may be contributing to this relationship, gaining insight into the factors that may cause greater distress and motivate an individual to seek support from services.

### *Characteristics of hallucinations*

Many articles directly compared the descriptive features of the hallucinations themselves, seeking to understand if the characteristics of the hallucinations differed between groups. Overall some studies concluded that features of the hallucinatory experiences in help-seeking and non-help-seeking groups were comparable (i.e. Andrew et al., 2008; Cottam et al., 2011; Daalman et al., 2011; Gaynor et al., 2013; Hill et al., 2012; Honig et al., 1998; Sorrell et al., 2010; Ward et al., 2014), whereas some also found significant differences between participant's hallucinations (i.e. Andrew et al., 2008; Cottam et al., 2011; Daalman et al., 2011; Davies et al., 2001; Langer et al., 2015; Taylor et al., 2014b; Ward et al., 2014).

The hallucinations of help-seeking participants' were generally more frequent and lasted longer (see Andrew et al., 2008; Cottam et al., 2011; Daalman et al., 2011; Davies et al., 2001; Honig et al., 1998). Hill et al. (2012) found no such differences despite using the same assessment tool as other studies. There was also contested evidence regarding the loudness of hallucinations, with two articles finding help-seekers and non-help-seekers experienced hallucinations at a similar volume (Daalman et al., 2011; Hill et al., 2012), but another two articles concluded a significant difference between groups, with help-seekers hearing voices louder (Andrew et al., 2008; Cottam et al., 2011). However, all of these articles agreed that the location of hallucinations (i.e. internal or external to the person) and the number of voices were similar and did not differ between groups (Andrew et al., 2008; Cottam et al., 2011; Daalman et al., 2011; Hill et al., 2012). It was found that the identity (e.g. religious identity) did significantly differ between help-seekers and non-help-seekers; Christian participants reported more religious identities (Cottam et al., 2011). Non-

help-seekers had clearer hallucinations (Cottam et al., 2011), but the reported origin of hallucinations did not differ, with groups reporting similar beliefs of whether the voices originated from within them or an external source (Hill et al., 2012). Finally, help-seeking participants were found to have been significantly older at onset when compared to non-help-seeking participants, and had therefore not been having hallucinatory experiences for as long when compared to non-help-seeking participants (Daalman et al., 2011; Gaynor et al., 2013; Honig et al., 1998; Sorrell et al., 2010; Ward et al., 2014).

A significant correlation was found between depression and ‘Perceptual Abnormality’ severity (Taylor et al., 2014b), indicating possible mediation between severity of hallucinations and distress. In this case, hallucinatory severity was measured by the CAARMS (Phillips, Yung & McGorry, 2000), whereby lower severity is defined by a mild heightening or dulling of perceptions forming distortions and illusions, with increasing severity with more vivid and intense sensations, through to more ‘true’ hallucinations that the individual consistently believes.

Despite this evidence, when reviewing types of experiences associated with psychosis, Brett et al. (2009) concluded that hallucinations themselves were not associated with current distress for the three groups experiencing them, but rather distress was associated with participants’ revelation and awareness – moments of sudden insights into their hallucinatory experiences and potential meaning behind them. This suggests hallucinatory distress is complex with various factors contributing to its development. While few findings regarding descriptive characteristics of hallucinations do appear to be agreed upon within the literature, overall, this data seems too inconclusive to be able to decisively report its contributions to the relationship between distress and service use.

### ***Beliefs about the experience***

#### *Appraisal of hallucinations*

Help-seeking participants were more likely to identify the content of their voices as negative (Andrew et al., 2008; Cottam et al., 2011; Hill et al., 2012; Honig et al., 1998); although, in Honig et al.’s (1998) study they noted no significant difference in the proportion of positive voices

experienced between groups, only non-help-seekers reported predominantly positive voices with significantly fewer negative voices. Additionally, these voices were described as significantly more critical and restricting than non-help-seekers' voices (Honig et al., 1998). Non-help-seekers perceived their voices as less malevolent, and instead believed them to be more benevolent (Andrew et al., 2008; Sorrell et al., 2010). This belief about voice malevolence was found to be a strong predictor of participant distress (Andrew et al., 2008). It is worth noting however, much of this evidence is based on literature of a lower quality, such as Honig et al. (1998) which was assessed as the lowest quality article included in the review. Much of the above data was collected via interview and thus, whilst producing rich information into the appraisal of hallucinatory voice content, the data is also vulnerable to observer bias and interpretation, and therefore conclusions must be drawn tentatively.

Help-seeking participants appraised their hallucinatory experiences as more negative than non-help-seeking individuals (Cottam et al., 2011; Daalman et al., 2011; Davies et al., 2001; Gaynor et al., 2013; Langer et al., 2015; Ward et al., 2014). This emotional valence, as measured by the PSYRATS-AH (Haddock, McCarron, Tarrier & Faragher, 1999), was found to be the strongest predictor of the service-using group (Daalman et al., 2011), and reacting to the experience with neutrality was a significant predictor of lower distress (Brett et al., 2014). Brett et al. (2009) concluded negative metacognitive beliefs about the experience, including punishment and superstition (e.g. *If I did not control a worrying thought, and then it happened, it would be my fault*), were associated with greater distress, and served as a predictive factor for help-seeking. They also cautioned that this response could feed into a self-perpetuating cycle with increased anxiety and presence of hallucinations (Brett et al., 2009). In Langer et al. (2015) both help-seekers and non-help-seekers sought to eliminate the experience of hallucinations, although it was also reported that recent hallucinatory experiences were rated more positively than earlier experiences (Davies et al., 2001). This therefore, suggests evidence for a progression towards habituation and distress reduction, linking to the finding that non-help-seekers have had the experiences for longer and from a younger age. This has implications for these and other findings

presented, as length of time since (and age at) onset of hallucinations may be a confounding variable for distress, and resultant service use, when considering the contributions of other factors (as in Honig et al., 1998). Overall, there appears to be strong evidence supporting the role of appraisals, of both experience and content of hallucinations, in determining individual distress and service use.

#### *Control and hallucinatory omnipotence*

Findings regarding perceived control and omnipotence were unanimous across the 10 studies that examined group effects. Help-seeking participants consistently reported having less control over the experiences and believed their hallucinations were more omnipotent when compared to non-help-seekers (Andrew et al., 2008; Barkus et al., 2010; Brett et al., 2009; Cottam et al., 2011; Daalman et al., 2011; Hill et al., 2012; Honig et al., 1998; Langer et al., 2015; Robson & Mason, 2015; Sorrell et al., 2010). There was also an effect of group on metacognitive beliefs, including those related to control, with individuals in services or with greater hallucinatory qualities scoring higher on the MCQ (Barkus et al., 2010; Brett et al., 2009). Control was not found to be a predictive factor for service-use (Daalman et al., 2011), but Sorrell et al. (2010) reported control had a strong influential and predictive relationship with distress. There are strong correlations between distress and factors related to power and control, specifically voice dominance, intrusiveness, and hearer distance, even once levels of depression and beliefs about benevolence were controlled for (Sorrell et al., 2010). This relationship between control and distress still held after service-use group was controlled for (Brett et al., 2014), thus providing evidence for a moderating relationship between control and distress. However, as the analyses are largely correlational, interpretations regarding the direction of this interaction cannot be made.

#### *Coping responses*

Safety behaviours are coping responses, often unique to the individual, that help alleviate distress in the short-term but serve as a maintenance factor for difficulties in the long-term (Salkovskis, 1991). When exploring the role of coping responses, Gaynor et al. (2013) found that both help-

seekers and non-help-seekers commonly used safety behaviours, but those involved in services used them significantly more frequently. This suggests that it is not the presence of safety behaviours which is unhelpful, but their over-use. Gaynor et al. (2013) also reported that safety-seeking behaviour was a significant predictor of hallucinatory distress, a relationship which was mediated by participants' threat appraisals. From this evidence it seems safety-seeking behaviours are an important factor in distress and service use. However, the development of such excessive safety behaviours may not be contributory, rather a response to the other factors presented here that impact on the individual's appraisals.

Other studies have also found differences in groups' response styles. In Ward et al. (2014) help-seekers reported higher maladaptive and lower adaptive responses to hallucinatory experiences when compared to non-help-seekers (although the helpfulness of response styles were decided by the researchers, and these experiences were experimentally produced). The help-seeking participants responded to experiences with 'Active resistance/distraction' and 'Passive/giving up', which may be a functional reaction when voices are identified as omnipotent and malevolent. These findings were confirmed by Andrew et al. (2008), who found help-seekers reported more resistant coping behaviours and engaged with their voices less, thus taking on more of an avoidance response. This was assessed using the BAVQ-R (Chadwick, Lees & Birchwood, 2000) which was also used by two other articles included in this review (Robson & Mason, 2015; Sorrell et al., 2010), the first of which did not find a significant difference between help-seekers and non-help-seekers' resistance or engagement to hallucinations, and the latter did not report on such findings. This contradiction in findings may in part be due to sampling; Robson and Mason (2015) recruited online and later differentiated current service use status, therefore participants in the non-help-seeking group were not engaged in services only at the time of research. In fact, there is evidence suggesting that at least 6 people in Robson and Mason's (2015) sample had previous contact with services and received a mental health diagnosis. All other articles presenting findings on coping responses excluded participants from the non-help-seeking group if they were currently or have ever been involved with mental health services. Furthermore, the findings from Robson

and Mason (2015) are less reliable, with matters of poorly reporting methodological issues, giving little consideration to confounding variables and other limitations, and a limited sample with issues of representativeness to the population; this leaves overall assessment of quality as much lower than that of the other articles here. The literature seems to suggest a positive relationship between avoidant coping responses and help-seeking related to negatively appraising the experience (often as threatening), heightening hallucinatory distress. Although, there are some variations in research and the relationship with coping responses is considered responsive to other factors, and not solely contributory to distress and service-use.

### *Trauma and stress*

Both help-seekers and non-help-seekers could identify triggering events for their hallucinatory experiences, but the help-seeking group more commonly identified their experiences as occurring in a stressful context (Langer et al., 2015). In Cottam et al. (2011) both help-seekers and non-help-seekers reported that their hallucinatory experiences were precipitated by life-event related distress (e.g. assessment failure or bereavement). However, in Cottam et al. (2011) the recognition of a triggering event and the appraisal of stress were amalgamated, therefore making it difficult to ascertain whether participants equally appraised the precipitating event as stressful. The triggering events could have been similar for both help-seekers and non-help-seekers, but based on the findings above, help-seekers made more threat appraisals and more readily appraised these events as stressful, and accordingly used more safety behaviours.

The suggestion that groups' experiences of stress and trauma were comparable is further supported by findings that there were no significant differences in occurrence of traumatic events or childhood abuse between help-seekers and non-help-seekers (Andrew et al., 2008; Honig et al., 1998). Whilst Andrew et al. (2008) identified the number of participants experiencing abuse did not vary between groups, they did note help-seekers reported more types of trauma and childhood sexual abuse. These findings did not match those in Honig et al. (1998), but this conflict in reporting may be due to methodological differences; Honig et al. (1998) adopted an interview structure to obtain information regarding abuse which was then translated to quantitative data,

whereas Andrew et al. (2008) utilised self-report measures in the hope that this would promote more disclosure. Andrew et al. (2008) also reported predictive relationships between trauma variables and participants' beliefs about their hallucinatory experiences, whereby increased reports of current trauma symptoms were associated with increased thoughts of hallucinatory malevolence and omnipotence and reduced benevolence. Consequently impacting on participants' distress and help-seeking as identified above. In summary, there is little evidence in support of trauma and stress contributing to the differences in service-use status and distress, with groups experiencing comparable past trauma. However, reports of current trauma were found to influence the individual's appraisal of their hallucinatory experiences.

### *Perceived social context*

Brett et al. (2014) identified individual's perceptions of greater social support and understanding as a significant predictor of lower hallucinatory distress. Whilst they noted that advice and companionship may be sources of emotional benefit, they also suggested that this may bring experiences of normalisation and validation that enable the individual to feel accepted in social contexts (Brett et al., 2014). This perception of social acceptance (or lack thereof) has been associated with differences in help-seeking status whereby participants engaged in services reported higher social anxiety than those not in services (Taylor et al., 2014b). It is worth noting that some of these participants were seeking help and not yet involved in services, but their social anxiety was still significantly lower than those in services; this raises interesting considerations as to whether it is the involvement in services which raises the social anxiety, and not the social anxiety which raises the help-seeking behaviour. Attachment avoidance and attachment anxiety have been found to be positively associated with distress, and through mediation analysis a model was proposed whereby this relationship was mediated by beliefs about voices, interpersonal processes (the quality of the relationship with the voice), and feelings of persecution and deservedness (Robson & Mason, 2015).

Taylor et al. (2014a) found differences in core schemas between help-seekers and non-help-seekers, identifying that those who sought help had significantly higher negative-self and

negative-other schemas than those who did not seek help for their hallucinatory experiences; hallucinatory distress was also significantly correlated with negative-other schemas. Non-help-seekers instead reported higher positive-self schemas when compared to most help-seekers, with the exception of those diagnosed as First-Episode Psychosis which was explained by the authors that these participants may have been experiencing some grandiosity (Taylor et al., 2014a). This highlights a considerable shortcoming of the literature regarding social context as it is reliant on individuals' perceptions of their social circumstance which is open to bias and misrepresentation, and may objectively appear similar but be subjectively perceived as different. Yet, it appears to be these perceptions, the individual's subjective experience of their social context, which impacts their experienced distress.

### *Spirituality & religious belief*

Three studies specifically sought to examine the impact of spirituality on hallucinatory distress. Holding religious appraisals of the hallucinatory experiences was a significant predictor of lower distress (Brett et al., 2014). Spiritual non-help-seekers reported significantly higher (and thus more positive) affective reactions, and interpreted their hallucinations as more positive, than non-spiritual help-seekers and non-help-seeking individuals who were not spiritual (Davies et al., 2001).

This evidence might suggest that spirituality and religious belief supports individuals to experience lower distress and resultantly seek help less; but this conclusion is challenged by research that also considers spiritual help-seekers. In Cottam et al. (2011) the participants' religious belief alone did not predict their distress level or need for care; help-seeking Christians experienced significantly more distress and were less positive than non-help seeking Christians (in line with literature comparing help-seekers and non-help-seekers regardless of religious belief). Additionally, religious belief did not significantly influence affective response in clinical groups when comparing Christian help-seekers and non-Christian help-seekers (Cottam et al., 2011). In conclusion, non-help-seeking Christians were able to more positively make sense of



their hallucinatory experiences through their religious belief, which may help explain Davies et al.'s (2001) findings, but religious help-seekers seem less able to do this.

## **Discussion**

The present study aimed to synthesise literature which assessed both hallucinatory distress and service-use status; it sought to explore whether there is evidence for the often assumed relationship between service involvement and distress, and what factors may contribute to service-use status and increased individual distress.

Although some inconsistencies with the assessment of distress were acknowledged, there was still strong evidence for a relationship between hallucinatory distress and service use, with those involved in services reporting more distress than those not seeking any help from services. The variability with assessing distress, particularly in populations experiencing hallucinations, is also witnessed throughout mental health services and has been highlighted as an area to better develop, especially given the current culture of economic evaluation of services based on outcome measures (Kinderman & Tai, 2009; Papaioannou, Brazier & Parry, 2011).

The relationship between distress and help-seeking did not occur in isolation. The present review found confirmation for some of the research outlined earlier, regarding differences between help-seeking and non-help-seeking populations, identifying a range of other factors that influenced both service-use status and the experience of distress. There was widespread support for the role of perceived control over the hallucinatory experiences; the literature indicated that lower perceived control predicted higher distress and influenced individuals' help seeking from services, confirming conclusions drawn in Lawrence, Jones & Cooper (2010) and Romme, Honig, Noorthoorn and Escher (1992). There was also strong confirmatory support for the influence of appraisals, with people involved in services or who reported higher distress identifying more negative appraisals of the hallucinatory experience and content, thus endorsing findings noted above (e.g. Jones, Guy and Ormrod, 2003; Lawrence, Jones & Cooper, 2010; Romme, Honig, Noorthoorn & Escher, 1992).

No reliable conclusions could be drawn regarding the comparability of the hallucinatory characteristics between help-seekers and non-help-seekers. On the other hand, throughout the review findings of increased distress or help-seeking often related to the individuals' appraisals: the perceptions of their experiences, of the content of the hallucinations, of their support system, of threat, or of religious meaning. Help-seekers were significantly older when they first experienced hallucinations and had less time since their onset; these findings may go to explain some of the outcomes regarding this central role of appraisals. Hallucinatory experiences may come as more of a shock to an older person, first experiencing them later into adulthood, than if they had these experiences for most of their life, starting before adolescence, as was the case in Daalman et al. (2011), Gaynor et al. (2013), Honig et al. (1998) and Ward et al. (2014).

Romme and Escher (1989) theorised a three-part phasic model of voice hearing: 'Startling' (a confusing and often frightening time following the sudden onset of voice hearing); 'Organisation' (the coping stage, with voice selection and communication); and 'Stabilisation' (the development of suitable methods for dealing with the voice hearing). This process of learning to manage the experiences was reflected in the literature included in this review (Davies et al., 2001), but it is also thought that a later onset of hallucinatory experiences produces a stronger 'startling' response as the individual's world, which they previously perceived with understanding and certainty, becomes unpredictable. Whereas a younger person, who is still forming their sense of self and the world (Erikson, 1994), may find it easier to integrate the hallucinatory experiences as part of their identity, this has been noted as a key process in mental health recovery (Leamy, Bird, Le Boutillier, Williams & Slade, 2011). Identity integration may not be the only explanation for this strong 'startling' response, for instance an individual may find that later onset of hallucinations shatters their previous assumptions of the world, producing a trauma response (Janoff-Bulman, 2010; Morrison, Frame & Larkin, 2003), and may find the uncertainty of hallucinations less tolerable (Dudley et al., 2011). These understandings of the promotion of a startling response may also explain why help-seekers were found to have more avoidant and resistant forms of coping (Lawrence, Jones & Cooper, 2010; Romme, Honig, Noorthoorn & Escher, 1992; and then

confirmed in the present literature review), attempting to reject the hallucinatory experiences as opposed to engaging with them. Given the findings, the age at onset of hallucinations may confound other research findings, and therefore care should be taken to account for this in further research comparing help-seeking and non-help-seeking groups. Future research may be interested to explore these effects of age at (and length of time since) onset of hallucinations, particularly examining any predictive influences it may have on the appraisal of the experiences.

The present literature review also confirmed findings that there are inconsequential variations in help-seeker's and non-help-seeker's experiences of trauma (e.g. Goldstone, Farhall & Ong, 2012). Andrew et al. (2008) and Honig et al. (1998) were the only two articles included in the review that directly explored trauma variables in each service-use group, yet they reported contrasting findings on the extent of trauma incidence encountered between groups. As identified above, this conflict may be due to methodological variation whereby disclosure of past trauma and abuse may have been facilitated by the indirect nature of survey data collection utilised by Andrew et al. (2008).

There is very mixed evidence on whether self-report measures enhance disclosure of trauma; some research concludes that impersonal self-report assessments have supported individuals to reveal over 5 times more information than in interviews (Carr, Ghosh & Ancill, 1983), whereas other studies have found prevalence rates of abuse have more than trebled by using clinical interviews as opposed to self-report measures (McFarlane, Christoffel, Bateman, Miller & Bullock, 1991). Furthermore, the use of research protocols requiring simple yes/no responses has been advised against for studies comparing help-seeking and non-help-seeking populations experiencing hallucinations as the measures alone do not provide detailed data of rich enough quality (Stanghellini, Langer, Ambrosini & Cangas, 2012). One thing is clear, that in order to accurately assess and detect trauma in a clinical interview the questions need to be direct and clear, whilst demonstrating an appropriate degree of sensitivity and clinical empathy. It is difficult to know whether the information was reliably and sensitively obtained in Honig et al.'s (1998) study as there is no information provided on the interview schedule. That said, Andrew et al.

(2008) identified that the self-report measure adopted in their study (the PDS; Foa, 1995) was not standardised for use with individuals experiencing hallucinations, and thus the assessment may have been detecting issues related to experiencing hallucinations as opposed to trauma.

When Taylor et al. (2014b) found that social anxiety was significantly higher in groups involved in services, despite one group seeking help but not involved in services, it raised a question as to whether involvement in services elevated the individual's social anxiety, and not the social anxiety which elevated the help-seeking behaviour. Of importance is the finding that distress levels of the ARMS group and the help-seekers with no service contact did not differ, hence why both groups were help-seeking. It is considered that the ARMS group may experience a rise in social anxiety following the stigma that many involved in mental health services face, especially those with hallucinatory experiences (Dinos, Stevens, Serfaty, Weich & King, 2004; Gulliver, Griffiths & Christensen, 2010). However, treatment approaches have been developed that specifically address this, focused on normalisation of experiences to reduce stigmatisation (French & Morrison, 2004).

Whilst the groups experienced no variation in distress, the ARMS groups did demonstrate higher severity for some experiences assessed by the CAARMS (although interestingly not 'perceptual abnormalities'), thus meeting ARMS criteria and becoming involved in services. Therefore, the heightened social anxiety reported by those in services may be due to either the unassuming categorisation of being involved in services or the severity of other experiences besides hallucinations, such as unusual thoughts, disorganised speech, or non-bizarre thinking. Many variables on the CAARMS (Phillips, Yung & McGorry, 2000) assessment are likely to share diagnostic characteristics with social anxiety (such as "*Are you aware that you are talking about irrelevant things, or going off the track?*" / "*Does it ever make you want to stay silent and not say anything?*" from the disorganised speech subscale, and "*Do you feel like people have been talking about you, laughing at you, or watching you?*" from the non-bizarre ideas subscale); therefore, there may be issues of cross-contamination within the assessment. The answer to this quandary would lie in determining whether the ARMS group's experiences of social anxiety became raised

at the point of heightening severity of other experiences, or simply after they became involved in services. This highlights a wider issue faced by this body of literature – the emphasis on cross-sectional research with a lack of longitudinal assessment.

### *Methodological limitations*

The present review explores many relationships between service use, distress and other contributory factors, however the studies are largely cross-sectional and correlational, and therefore generalisations about cause and effect cannot be made. Many of the contributory factors outlined above are considered dynamic (i.e. distress, characteristics of hallucinations, beliefs about the experiences, coping responses, social context, spirituality) and therefore may be motivators for an individual to seek help, but might equally be a consequence of being involved in services.

Whilst strong evidence for interactions between these factors and help-seeking are provided, the review is unable to conclude whether the observed rise in distress, for example, precipitates the engagement with services, or if in fact it comes as a by-product of service engagement. Indication of the latter come from service interventions often targeted towards improving an individual's insight and awareness (Lincoln, Lüllmann & Rief, 2007; Perivoliotis et al., 2010), which Brett et al. (2009) identified as associated with increased distress. Although, further indication into the direction of this relationship may come from the current structure of services; as mentioned earlier, mental health services are presently organised to use individual distress as a gateway assessment for suitability for service use, thus suggesting the individual must first meet a certain degree of distress. Conclusions should be drawn tentatively, and it is suggested that future research may wish to further explore the relationships here in an attempt to understand and confirm their direction related to service-use. A considerable strength of this review is the sole inclusion of studies that directly compare help-seekers and non-help-seekers, thus allowing for clearer interpretations of the identified interactions whilst limited to the presently available literature.

The literature was found to be respectable in quality, although some common issues of sample representativeness and data completion were identified, which in turn influenced the extent to which such research could be generalised to wider populations. Firstly, all of the included studies were limited to Europe, and the majority were UK based, so it cannot be assumed that these findings would apply to other populations, particularly those which hold differing perspectives of hallucinatory experiences or mental health service use (Larøi et al., 2014; Wahass & Kent, 1997).

Secondly, recruitment procedures may have influenced the review findings. Romme and Escher (1992) excluded individuals that described themselves as clairaudient as they suggested these experiences may not be comparable to others' experiences, questioning whether these could be identified as 'true' hallucinations. We must therefore raise attention to the fact that many of the articles included in the present review utilised these populations for their non-help-seeking samples, actively engaging with spiritualist churches, psychics and medium networks. This may have influenced the findings, for instance highlighting the role of religion, but presents a wider understanding of hallucinatory experiences and such appraisals made in the general population.

Finally, the representativeness of the study populations may have been influenced by sample exclusion criteria. Whilst efforts were made to ensure help-seeking and non-help-seeking populations were well defined, some studies did not specify if the non-help-seeking sample had ever had contact with mental health services, or if they were just not currently seeking help (e.g. Robson & Mason, 2015; Taylor et al., 2014a; Taylor et al., 2014b). Additionally, some articles excluded help-seeking participants if they were identified as acutely distressed to the point where participation was not feasible or was deemed likely to exacerbate their mental health difficulties (e.g. Andrew et al., 2008). This evidently limits the representativeness of the help-seeking populations presented, although it is considered that the non-help-seeking population may also face this sampling discrepancy through their self-selection.

### *Clinical implications*

This review continues to provide evidence in support of the continuum model, identifying a non-help-seeking population of individuals experiencing hallucinations, who continue to manage the experience well with minimal distress. As recognised above, most of the contributory factors identified here are dynamic and liable to change. The only factor which is more generally considered to be static and unchanging is past trauma and stress, which interestingly had little, if no, evidence regarding any difference between help-seeking and non-help-seeking individuals' experiences, unlike the remaining factors. This indicates that differences in service-use status lie within dynamic factors, which commonly related back to the individuals' appraisals, holding a negative or unhelpful perception of their experiences and/or hallucinations. This is an encouraging finding, and has implications for the therapeutic interventions offered by services. It confirms the value of interventions targeting cognitive appraisals as previous clinical work has shown these to be changeable and the present review indicates such appraisals are central to the identified contributory factors for distress and consequential service use. Specifically, interventions challenging individuals' more negative beliefs about the hallucinatory experiences, which evidence in this review highlighted as particularly pertinent to reducing both the individuals' distress and need to seek help.

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## **Part Two: Empirical Paper**

This paper is written in the format ready for submission to the journal

*Psychology and Psychotherapy: Theory Research and Practice.*

Please see Appendix E for the submission guidelines.

Running head: Personal growth with hallucinations

**A weird but interesting journey: An exploration of personal growth for individuals with auditory and visual hallucinations.**

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## **Abstract**

**Purpose:** Research has suggested that hearing and seeing things that others do not is often a universal human phenomenon; yet, there is a dominant discourse around hallucinations as a negative and debilitating phenomenon. Limited literature considers the potential benefits of hallucinatory experiences, exploring the possibility of positive change in the individual. The present research aims to help define our understandings of personal growth as a result of experiencing auditory and visual hallucinations.

**Design:** A phenomenological qualitative approach was used to explore experiences of personal growth with auditory and visual hallucinations, adopting Interpretative Phenomenological Analysis methodology.

**Methods:** Semi-structured interviews were conducted with seven individuals regularly experiencing hallucinations. Participants were asked about experiences of personal growth, their expectations of individual transformation, and any facilitating and hindering factors in the attainment of personal growth. Qualitative data was then analysed using Interpretative Phenomenological Analysis.

**Results:** Six superordinate themes, each with a number of subordinate themes, were identified: A process of change; The developing self; Changing relationships; Holding onto hope; Difficult to talk about; and Finding the right help.

**Conclusions:** Evidence in support of personal growth occurring with auditory and visual hallucinations was found. Participants identified a meaningful process of gaining new perspectives and appreciation following their hallucinatory experiences. The importance of maintaining hope for change was highlighted, but on occasion participants struggled to engage in a positively orientated conversation. Services and the use of coping strategies were both identified as facilitative and hindering of personal growth at times.



## **Practitioner points**

- Previous literature supporting the development of personal growth with hallucinatory experiences is novel and empirically limited; the present research provides further information of the phenomenon in order to better inform service provisions.
- This research supplies a necessary alternative to the often negative literature; challenging societal perceptions and helping promote much needed hope in clinicians, the public, and individuals experiencing hallucinations.

## **Introduction**

Despite the acknowledgement that hallucinations are in fact a familiar human experience for many, there are widely held negative perceptions of hearing or seeing things that others do not, which are fed by limited public understanding (BPS, 2000). Much of the literature regarding hallucinations is deficit-driven, focused on reducing hallucinatory experiences, the functional deficiencies, or costs associated with the experience. This directive elicits a stance of ‘necessary clinical recovery’, focussing on symptom remission and a restoration of functioning, holding the discourse of ‘getting back to normal’ (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

In order to better understand the subjective perception of hallucinations we need to explore all aspects of the experience, both the positive and negative experiences, rather than assuming the two cannot concurrently occur (Aspinwall & Tedeschi, 2010). This understanding comes from the positive psychology movement – the science of mental health as opposed to mental illness, empirically acknowledging and supporting the positive features and qualities within experiences to foster wellbeing and improve overall quality of life (Seligman, 2002). This movement has been criticised for forming a ‘tyranny of the positive attitude’ (Held, 2004) whereby positive ideology and approach had become almost compulsory, forming a dichotomy between literature, and risked failing to acknowledge and validate individuals’ negative experiences when facing mental health difficulties. However, if literature solely operates in terms of symptom remission and deficits there is an equal risk to failing to acknowledge and validate the potential benefits and positives to experiencing hallucinations. We must therefore hold a balanced and open exploration of

experiences, constructing positive literature to compliment the wealth of deficit driven literature available.

There may be some clinical value in focusing on the concept of personal recovery – widely defined as a “unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles” (Anthony, 1993, p. 527), acknowledging that personal recovery is attainable even if the individual is still experiencing mental health complaints (Anthony, 1993). Typically, mental health services are organised towards achieving clinical recovery (Slade, 2013); however the present research considers individual development beyond mere restoration of the premorbid self and reduction of complaints (‘symptoms’ in the language of psychiatry), to consider personal recovery from a service user perspective.

It is acknowledged that the term ‘hallucinations’ comes with many connotations and suggestions of epidemiology, often biomedical. For the purpose of this report, ‘hallucinations’ refers to the experience of perceptual events, specifically hearing or seeing things, which are not shared by others. This may include a continuum of experience (BPS, 2000), from distortions or illusions of stimuli to clear disruptive events which are believed to be true.

### ***Personal growth***

The concept of personal growth refers to the often positive changes in self-awareness, acceptance and social integration that may result from shifting life-tasks and social roles (Sheldon, Kasser, Smith & Share, 2002). Literature has alluded to the attainment of personal growth with auditory or visual hallucinations (e.g. Roe & Chopra, 2003; Sass, 2007), yet only a few studies attempt to define the individual experience or consider how it may be identified and promoted.

Dunkley, Bates, Foulds and Fitzgerald (2007) presented two cases, specifying elements of personal growth following participants’ first episode of psychosis: a greater appreciation of life (e.g. reassessing values and feeling there is more to life), deeper understanding of others (e.g. the experience bringing people closer together and developing empathy), and enhanced perception of personal strength (e.g. overcoming previously unimaginable challenges, understanding personal

assets and developing self-reliance). Mapplebeck, Joseph and Sabin-Farrell (2015) concluded that personal growth in psychosis is a fluid process of the adapting self, defined by four common themes: finding meaning and purpose; support and understanding; inner strength and determination; and self-acceptance and awareness. In addition to this initial research, there are an increasing number of personal stories, such as Eleanor Longden, Ron Coleman, and Rufus May (see Longden, 2013; Coleman, 2011; May, n.d.; respectively), endorsing the attainment of personal growth and arguably personal recovery from hallucinatory experiences. Furthermore, mindfulness (Nixon, Hagen and Peters, 2010) and self-disclosure (Pietruch and Jobson, 2012) have been identified as factors which might facilitate personal growth with hallucinations.

These studies provide preliminary evidence for the existence of personal growth with hallucinations, and present some common concepts of what defines it. The current literature is very limited in its theoretical approach and study population, and is aimed solely at the identification of personal growth but does not consider influencing factors beyond this. To illustrate, Dunkley et al. (2007) and Mapplebeck et al. (2015) adopted broad diagnostic definitions, such as psychosis, as opposed to working with the current paradigm shift of complaint-specific approaches, such as hallucinations or delusions, as advocated by Bentall (2004; 2006). Both studies also selected very specific sample populations, individuals experiencing first-episode psychosis (Dunkley et al., 2007), and members of psychosis support groups (Mapplebeck et al., 2015). Whilst this supports sample homogeneity, it is valuable to explore whether their findings apply to other populations experiencing hallucinations, thus deepening our understanding of the phenomenon.

Furthermore, Mapplebeck et al.'s (2015) study is retrospective in nature, reliant upon participants recalling past experiential accounts. Instead, by involving individuals potentially experiencing this 'growth' process in the present, research would emphasise personal growth as a voyage; not a journey with a particular destination of recovery, but rather an expedition of experience through the lifetime (Deegan, 1997). It is arguably easier for growth to be perceived in retrospect, to notice the changes from before. However, by acknowledging this voyage and paying respect to the

changing nature of growth, the present research allows participants to notice and reflect on current change whilst exploring issues of future expectations. It also allows for a non-confabulated reflection of the facilitators and hindrances of the individual's personal growth. Although Nixon et al. (2010) and Pietruch and Jobson (2012) identified some facilitators of personal growth with hallucinations, such research could be further developed. Considerations for barriers to personal growth have thus far been neglected. This research provides a 'fresh' look at present service users' perspectives of what could be changed or encouraged at service delivery levels to promote personal recovery, thus deepening clinical understandings and allowing services to provide the best possible practice and care to its clients.

Many believe people who hear voices are "violent, unstable and should be locked away" (Cockshutt, 2004, p.9), despite considerable evidence disputing a causal relationship between hallucinations and violence (e.g. Arboleda-Florez, 1998; Skeem, Kennealy, Monahan, Peterson & Appelbaum, 2016). Individuals with hallucinatory experiences are most likely to report occurrences of stigmatisation and be more greatly affected by it (Dinos, Stevens, Serfaty, Weich & King, 2004). Most concerning perhaps, is the stigma held by clinicians (Chadwick, 1997; Lake, 2012; Klapheck, Lincoln & Bock, 2014). If clinicians hold negatively biased attitudes, without hope, they will struggle to see and support clients' psychological development (Klapheck, Lincoln & Bock, 2014; Perkins, 2006). This stigma is arguably perpetuated by the existing literature regarding hallucinations. The present study aimed to explore the benefits that may result from experiencing hallucinations, and how personal growth may be experienced in such populations.

***Research Questions:***

- 1) How, if at all, is personal growth with auditory and visual hallucinations experienced?
- 2) What are people's expectations of personal growth with auditory and visual hallucinations?
- 3) What facilitates & hinders personal growth with auditory and visual hallucinations?

## Method

### *Design*

The present qualitative study used semi-structured interviews to explore individuals' experiences of personal growth with auditory and visual hallucinations. Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) informed the interview questions and analysis of the data, which was comprised of participants' transcribed interview responses.

### *Participants*

The seven participants were aged between 28 and 53 ( $M=43.57$ ,  $SD=8.94$ ). Five were male, and all were white British (see Table 1 for participant demographics). Purposive sampling was used to ensure a suitably homogenous study population for in-depth analysis. Participants were all recruited from a mental health trust in the north of England and met certain criteria: a) currently involved in mental health services solely or largely due to experiencing auditory or verbal hallucinations; b) presently at a clinician-established level of stability (indicated by no suicide attempts and/or involvement with a Crisis Team for 6 months); c) their hallucinatory experiences were not considered to be solely attributable to substance use; d) had capacity and the ability to provide informed consent (see Appendices F & G for participant information and consent procedures); e) fluent English speaking; and f) over 18 years of age. Two other individuals registered an interest in participating in the study; however, one was unable to attend their service base, and the other did not wish to verbally participate in an interview, therefore in accordance with the study's ethical approval (see Appendix H) these individuals were not included.

Table 1: *Participant demographics*

<b>Participant pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Age at onset of hallucinatory experiences</b>
Bill	M	51	Early 40s
Debbie	F	35	Early childhood
Robin	M	46	20s
Steve	M	47	Early childhood
Sophie	F	28	Early 20s
Dave	M	53	Early childhood
Paul	M	45	Adolescence

## *Procedure*

Care co-ordinators made initial contact with potential participants who met criteria, providing them with the study information sheet detailing the aims and procedures of the study. Individuals who registered an interest in participating were invited to a pre-interview meeting held at their service locality to discuss the study further with the lead author. Potential participants were then invited to the research interview approximately one week later.

Interviews were conducted by the lead author, guided by a semi-structured schedule (see Appendix I). The interview schedule was founded on current quantitative and qualitative investigations into hallucinatory experiences and personal growth, and aimed to allow participants to explore both the positives and challenges to having hallucinatory experiences (Bride, Dunwoody, Lowe-Strong, & Kennedy, 2008; Joseph, Williams, & Rule, 1993; Joseph et al., 2012; McMillen & Fisher, 1998; Roesch, Rowley, & Vaughan, 2004; Tedeschi & Calhoun, 1996; Tomich & Helgeson, 2004). The interview schedule covered participant's perception of any changes, exploring interpersonal relationships, personal attributes and outlook, how challenges have been overcome, facilitators and hindrances to changes, and their expectations for the future. Interviews took place between September 2015 and March 2016, all were audiotaped and lasted between 17 and 90 minutes (mean = 55 minutes).

Pseudonyms were assigned to participants to maintain anonymity. Interviews were transcribed and analysed using the IPA approach outlined by Smith, Flowers & Larkin (2009). Individual transcripts were examined closely, making descriptive, linguistic and conceptual comments, and identifying emergent themes (see Appendix J). Transcripts were collated and compared, noting aspects of commonality and difference amongst the identified themes. Emergent themes were sorted into super- and sub-ordinate themes and original transcripts were re-examined for quotation data regarding these themes (see Appendix K). The structure and relationships between these themes was explored in a process of ongoing reflection and interaction with the data, facilitating the thematic organisation of that was best representative of the data.

### ***Researcher's position***

Due to the interpretative nature of the present study, the lead researcher's socio-cultural position undoubtedly shaped the development, implementation and analysis of the research. It is acknowledged that their values were most likely to be similar to those of young, educated white British adults. She was aware of a personal tendency towards optimism, founded in her upbringing, which established a belief that 'good' may come from experiences of distress and that we, as people, are shaped by the varied experiences we encounter. Not only does this allow for the concept of personal growth following distress, but it assumes this growth is desirable. Without such values, the construction and findings of the present research would have likely differed.

### **Results**

The following themes were generated from the participant's accounts in response to the research questions. Table 1 presents a summary of these themes and subthemes.

#### **Theme 1: A process of change**

##### ***Subtheme 1: A journey***

Participants described a journey that had "*little stages*" (Dave), with negligible change occurring for great lengths of time, but upon reflection participants could notice how their lives had progressed; they described attaining a positive sense of self, happiness, a comfort and developing a new perspective on the world. Sophie talks about the early stages of noticing a change:

*"I can see eventually me getting better... it's starting to become a part of my life if you know what I mean, like an everyday thing"*

Sophie spent time contemplating the smaller changes with the sense of each day getting easier, but she also kept her focus on where the journey will take her.

##### ***Subtheme 2: Taking time***

It was often acknowledged that this was experienced as a long journey and the process took time.

*“It’s been a weird journey, but y’know, been interesting (laughter)... seems to have taken a long time but y’know it’s, finally y’know I, now I think I’ve finally just, lets see where they journey takes you and, y’know... if it goes up, good” (Paul)*

Paul seems to be hesitant to suggest he is reaching the end of his journey, noting that this process is ongoing, and whilst positive change feels attainable, there is still caution that the journey may take him in a different direction.

*Table 2. Summary of themes and subthemes generated from participant’s accounts*

<b>Theme</b>	<b>Subthemes</b>	<b>No. participants contributing</b>
A process of change	A journey	6
	Taking time	6
	A battle	6
The developing self	Acceptance & Identity	7
	Reflecting on the self & world	7
	Strength & resilience	7
Changing relationships	Isolation vs. belonging	6
	Gaining support	7
	Developing relationships with hallucinations	4
	Understanding others	5
Holding onto hope	Future focus	5
	Seeing change (or lack of)	7
	Hope & positive focus	6
Difficult to talk about	Future	4
	Changes	6
Finding the right help	Services	6
	Learning to cope and manage	7
	Judgements and stigma	5

***Subtheme 3: A battle***

Participants described this process as a continuous battle, often within the self and against the experiences. Some, like Debbie, found positive change in fighting the experiences:



*“It’s more or less arguing with it. Saying, the voice and that, sometimes, it isn’t all the time, it’ll say to me ‘you will do this’ and ‘you will go back on this’ and stuff, and I keep saying to myself ‘nah, I’m not going to let it happen’”*

Whilst others, like Steve, found that positive change came from stopping the ongoing fight:

*“Now the battle that’s going on in side is over, so you can just like stop feeling crap which had happened over a period of time... just give up the fight, and look after yourself”*

With both positions this battle is described as a key part in the process towards change in strengthening their identity; although, the difference may reflect participants’ various stages along this journey of change. Debbie often referred to the recency of her changes and it was as though she was playing a game of football with her hallucinatory experiences, with her as the goal keeper, defending any hits that may be sent her way, because if she let one past it would feel like the end of her game, a loss. Whereas some seem to have given up this fight and respectively accepted the experiences, seeing that there could be no winner, and allowing for more encouraging emotions and self-compassion.

## **Theme 2: The developing self**

### ***Subtheme 1: Acceptance & Identity***

This matter of acceptance was a repeated theme throughout all interviewees’ accounts as a form of the developing personal identity. Debbie, and others, talked about the struggle of accepting “*there’s something not right*” where they may need help; consequently participants took to hiding their hallucinatory experiences and distress as a coping strategy, like Dave:

*“You can even use this mask like a crutch, so you’re a different person”*

Dave, along with others, expressed putting on a persona in the past, resisting the hallucinatory experiences, and hiding them. There is a sense that this was for self-protection to avoid any judgement from others, but also to distance the personal identity from that of the ‘voice hearer’. Sophie expressed actively seeking this separate identity:

*“I’m trying to separate the person, I like the person that I am when I’m not hearing voices”*

Whilst others, like Paul, described integrating the hallucinatory experiences into part of their identity:

*“A lot of people say what if I could change things but I’m not sure I would, y’know, if, I’ve just learnt to accept that it’s part of me now”*

Similarly, Dave described that it would make him “*hollow*” if he no longer had his hallucinatory experiences. Yet others simply emphasised the importance of being comfortable with their identity:

*“Don’t give up on wanting to become yourself, rather than your society or whatever, forget all of them forget everything else, you’ve got to be comfortable with yourself” (Steve)*

### ***Subtheme 2: Reflecting on the self & world***

They all agreed that their hallucinatory experiences had shaped who they are today, and for some interviewees’ the person they were now was seen more positively, as Paul explains:

*“I think I’d have been a lot more destructive rather than constructive if I maybe wasn’t hearing or seeing things”*

Paul’s comment here demonstrates a process of self-reflection that other participants identified, considering how their values in life may have changed. Paul talks about being less “*destructive*” as a result of his hallucinations, and Steve expressed that he was now “*seeing life in a completely different way and it’s through my experiences*”.

Participants described shifts in their concept of ‘*getting better*’ (Sophie), often thought of in literature as the notions of clinical and personal recovery; as Dave explained:

*“I know the voices and all that lot have not gone away and they won’t go away, it’s only learning to [pause] in a strange way appreciate them”*

Initially, interviewees appeared to aim for a reduction in their hallucinatory experiences, but progressed to a position of finding new value in the experiences. This conflict of what ‘getting

better' meant was experienced over years along the journey, but also by some during the interviews themselves, with participants shifting in focus from an emphasis on complaints to instead accepting the lived experience and acknowledging personal accomplishments. Dave concluded:

*“Because I’m talking about it, it make me realise even a bit more...it’s helping in being here today... because I’m actually going away now feeling more er slightly a lot well a lot more happier”*

Interviewees described changes in their outlook on life, growing to find peace within themselves and the world, feeling more independent and mature as a result of the experiences, and increasingly appreciating time outside and avoiding conflict, which seems to be linked to the battle and developing acceptance referenced above. Dave summarised this as:

*“It’s changed the way I see others, think about other attitudes and I the way I’ve seen meself”*

### ***Subtheme 3: Strength & resilience***

All of the participants referenced the hallucinatory experiences requiring them to be strong and resilient. After Debbie initially struggled to identify the experience as helpful she then noted the primary positive outcome from her hallucinatory experiences is that she:

*“Hasn’t let it beat me... it’s made me more tougher... the voice has given me more strength, and it’s it’s sort of like, made me into the person I am, stronger”*

There is a sense of Debbie gradually drawing this conclusion and reaffirming it, almost as though repeating the message makes her stronger. This is an experience most participants shared, facing adversity and struggling, but continuing to persevere and find inner strength. However, Bill questioned whether he could persevere and survive, identifying the biggest challenge of having hallucinations as:

*“Trying to get to cope with it. But I don’t, I can’t get the, cope with it”*

Bill suggests that he cannot cope with his experiences, yet has somehow managed for the past 10 years, and you can feel the struggle for him through the structure of the sentence. This raises questions of what successful coping is and its relation to this expressed development of inner strength.

### **Theme 3: Changing relationships**

#### ***Subtheme 1: Isolation vs. belonging***

Some participants commented that their existing relationships have shifted as they have developed through this journey. Participants talked about how their experience of hallucinations can be isolating, losing friends, separating them from society and making them feel abnormal; but as they themselves have developed so have their relationships, as Dave explains:

*“I met some nice people through it, that suffer the same thing when you suddenly realise you’re not on your own”*

Dave describes this process of finding a community and feeling much less alone. Participants talked about feeling like they are a part of something now, expressing that their hallucinations had acted as a medium through which their role in society had enriched.

#### ***Subtheme 2: Gaining support***

All expressed gratitude for support they have received, often from others in similar situations. Interestingly, people did identify gaining practical support (e.g. guidance on coping strategies), but they largely referred to people offering emotional support through relationships. For example, Paul identified support as:

*“I think it’s just sometimes the simple thing of somebody listening”*

Paul suggests that it is the act of sharing something with another person, and feeling attended to, which is supportive, but also labels it as ‘simple’ in an attempt to express that it is not much he is asking for. Steve noted that support for him was when people “cared” as he at times couldn’t care about himself.

### ***Subtheme 3: Developing relationships with hallucinations***

Steve also identified gaining support from his hallucinations:

*“I remember being at me best friend’s house and she said ‘well why don’t you just talk to them’ y’know the voices, rather than sitting around or arguing, so I did and I spoke to them so I went ‘hello’ and they go ‘oh hello you finally talking to us’ and I was like what?! But then from then I, they’re more helpful now than disturbing... it’s like I’ve got a lot of friends I talk to every day”*

Participants, like Steve here, talked about developing a relationship with their hallucinations, acknowledging that whilst the content can often be negative they have increasingly found comfort or reassurance from the hallucinations.

### ***Subtheme 4: Understanding others***

Participants also described that their experiences have changed how they view others, as Robin explains:

*“I show more empathy maybe, more than I used to. More understanding with people with difficulties and stuff like that”*

They regularly identified gaining a deeper understanding of others, beyond mental health difficulties, and becoming more sensitive to peoples’ suffering. This translated as participants expressing a hope to help others in the future, as they themselves have been helped.

## **Theme 4: Holding onto hope**

### ***Subtheme 1: Future focus***

When describing this image of being helpful to others in the future, participants often referred to having a job and further developing relationships with others, a description which was likened to being “*more settled*” (Dave). This raises some interesting considerations for what a settled life is; it seems the participants express hopes of having a future conforming to societal norms. Dave added:

*“I’ll be more of aware of things that I’ve not even thought of being aware of now”*

This shows him holding in mind an expectation of further change and developed understanding, building on his experiences of such thus far.

***Subtheme 2: Seeing change (or lack of)***

This approach of looking back on past changes to predict future growth was a subtheme shared by all participants; this mostly inspired optimism and hope, but not in Bill’s case:

*“It’s just one long day, nowt alters, nothing changes at all”*

With this there is a sense of life dragging on, monotonously. His struggle to see any past change hindered his ability to see future developments; a stage in the journey that other participants could relate to.

***Subtheme 3: Hope & positive focus***

Participants talked about the importance of maintaining a positive focus, as Dave describes:

*“I’ve heard it said you be grateful for what you’ve got, so, but, and so I would, yeah it has got its negatives but I do try to steer away from it”*

Hallucinations were often experienced as negative yet some interviewees focussed on turning this adversity into positivity, as Dave identifies here. This process was interpreted as being “*more hopeful generally*” (Robin) which required actively seeking positivity, steering away from the negatives, and noticing encouraging change, fostering the individual’s hopefulness for further personal developments.

**Theme 5: Difficult to talk about**

***Subtheme 1: Future***

Participants struggled with the positivity aspect of the discussion, finding it hard to identify future expectations with any certainty. They expressed wanting to make “*realistic*” (Robin) expectations, but found it difficult to predict their next steps in life, as Paul recognises:

*“I don’t even know what tomorrow’s going to bring yet let alone 5 years down the line”*

Their journey with hallucinations has thus far been unpredictable, and so this, mixed with a reluctance to ‘tempt fate’, appears to make the explicit request for interviewees to consider their future uncomfortable. This also explains the tendency to refer to past personal changes to inform future expectations, as above.

### ***Subtheme 2: Changes***

Participants also found it difficult to talk specifically about the changes they’ve encountered; some noted “*it’s hard to describe how the changes happen*” (Robin), describing it as too much of a gradual journey to notice change. In interviewees’ responses an internal battle could be witnessed, where responses were often hesitant and conditional, with participants detailing the negatives of hallucinatory experiences immediately prior or subsequent to identifying a positive factor of change, such as with Debbie:

*“I think it can be a good thing sometimes, but I think sometimes you can go over that line”*

Participants found it hard to talk positively about something that has caused them much distress over the years. This may also be a reflection of the unnatural nature of the conversation, with people in services often focussed on the deficits from the hallucinatory experiences and not often providing space for positive change discussions.

## **Theme 6: Finding the right help**

### ***Subtheme 1: Services***

This concept of services themselves hindering this process of change was shared by participants. They recalled instances where procedures in services meant that support was unstable, referring to services being disjointed (e.g. substance misuse services being separate to mental health) and feeling like they’re in “*slow motion*” (Paul) at times when they most needed them. Participants felt there had been a “*lack of information*” (Dave) regarding the help available, and found that clinician-held stigma had exacerbated distress, as Steve explains when a staff member perceivably responded negatively to his disclosure of hallucinations:

*“I was going to see my CPN which I thought was a counsellor at the time, and the reaction from him was like ‘WOAH’ and that’s what took it over the edge... instant paranoia”*

Steve identified this experienced confusion in services, and the unhelpful feelings of shock for both him and the staff member. He went on to acknowledge that positive processes were facilitated once working with staff that listened with mutual understanding. Dave reflected something similar:

*“I think time went on and you realise that, ‘ok maybe there are people out there that do understand’, although, y’know... the treatment before had been intermittent”*

Participants equally identified that services had facilitated their positive journey of change. They repeatedly identified the value of gaining more stability through medication and engaging in the social aspects of services such as therapeutic groups. Paul stated:

*“Now that I’m getting, I’ve got the right support in place and things like that, it’s starting to get better”*

With this, Paul reiterates this process of change which can involve discovering the ‘right’ support. Participants highlighted learning different ways of thinking and new coping strategies (e.g. rationalising and mindfulness) as particularly helpful forms of support from services.

### ***Subtheme 2: Learning to cope and manage***

Participants talked about there being a shift in the coping strategies they have adopted. They reported not having coping strategies to start with, but developed them through “*trial and error*” (Robin), often first discovering easily accessible substances. Interviewees spoke about realising that their past avoidant coping (e.g. alcohol, drugs, wearing a ‘mask’) was hindering their personal development, like Dave:

*“I’d be mixing alcohol with prescription drugs to again to knock mesen out, which seemed to me yeah the solution but it wasn’t it was only making things worse”*



Dave talks here about the goal of coping being unconsciousness, ultimately avoiding the experience, but then learning how this may be obstructing positive change. Participants described instead adopting more positive coping strategies that have supported them in attaining personal happiness and a different sense of self. Debbie advises:

*“In the past I used to think it was only drugs and drink, just that to help, but there isn’t, you can do other things”*

She went on to describe taking a slow pace in life, engaging in socialising and sports, and now enjoying things for the first time.

### ***Subtheme 3: Judgements and stigma***

Finally, as eluded to above, participants identified that their expectations and experiences of stigma have limited their process of change. Interviewees expressed that one of the hardest parts in the journey was *“taking that first step”* (Paul) and engaging with services. Some of the participants, including Sophie, explained the prospect of receiving a diagnosis (and the subsequent judgements) was the source of their trepidation:

*“I don’t want to accept it’s schizophrenia because it will always be branded, I’ll always be branded with that name, and if you tell anyone you’ve got schizophrenia they automatically think that you’re a mental case and that you’re going to kill them... if you tell people you have schizophrenia or you hear voices, they’ll stay away from you or, and so I don’t want to be I don’t want that name branded on my on me... a lot of people judge you”*

Dave identified the alternative was to not mention it and struggle through. He listed many derogatory terms used against people with hallucinatory experiences, stating hallucinations were seen as *“a sign of weakness”* and recalled being threatened that if he continued talking about his experiences he would end up in a mental asylum. It appears the past and present threat of encountering stigma restricted participants from accepting the hallucinatory experiences, and being comfortable with themselves, which was earlier identified as an integral part to the process of developing the self.

## **Discussion**

The purpose of this study was to deepen understandings of positive personal change as a result of experiencing auditory and visual hallucinations. The present study has found new evidence for personal growth for people currently involved in community mental health teams following hallucinatory experiences. This growth was in line with Sheldon et al.'s (2002) global definition; individuals referred to a positive shift in their sense of self, relationships with others, and the world around them. Participants could identify this personal growth as happening in the moment. Their accounts were not retrospectively, but rather participants acknowledged their past change, compared this to the present self, and considered the challenges for their future change with hopefulness. To the best of our knowledge, this study is novel in its exploration and identification of both facilitators and hindrances of personal growth with hallucinations. This study found that personal growth was recognised as a process of changes, a journey which often took time and on occasion felt like an internal battle, but generated rewarding developments in the self which, through acceptance, a more resilient and understanding person emerged.

Participants identified a battle against acceptance and the integrative identity for years, but reported recent changes. It seems this represents the archetypal development of hallucinatory experiences, as described by Romme and Escher (1989), whereby participants move from this 'startling' place of rejecting the experience, to a position of 'stabilisation' and acceptance. This understanding has important implications for the support offered to individuals experiencing hallucinations, suggesting personal growth may be facilitated by earlier intervention promoting acceptance of the experiences as opposed to 'symptom' eradication. The present research suggests services should reflect on their position regarding clinical and personal recovery, ensuring the available interventions are in line with this standing.

The present findings are consistent with those of previous literature. Descriptions of personal growth in Dunkley et al. (2007) have been replicated here with participants gaining new perspectives and appreciation following their hallucinatory experiences, including enhanced empathy and inner strength. Similarly Mapplebeck et al.'s (2015) findings have been replicated

but with present day accounts. There are many parallels with Mapplebeck et al.'s (2015) description of participants' internal struggle and their move to greater understanding by reflecting on the purpose of such experiences. Furthermore, both studies explore support in changing relationships, the importance of feeling understood in services, and once again the development of inner strength and self-acceptance, with participants in Mapplebeck et al. (2015) also developing an "integrative" identity with the hallucinatory experiences. This study also confirms findings from the broad base of recovery literature; Leamy et al. (2011) identified five mental health recovery processes: connectedness; hope and optimism about the future; identity; meaning in life; and empowerment, many of which have been apparent here. More specifically, in psychosis populations recovery has been experienced as an ever changing process, where transforming the self, change, and hopefulness are central components (Pitt, Kilbride, Nothard, Welford & Morrison, 2007), as was the case here.

Whilst mindfulness and self-disclosure were not explicitly identified as facilitating factors (as with Nixon et al., 2010; Pietruch & Jobson, 2012; respectively) they were noted as important aspects of the personal growth process. Participants commented on the value of finding peace and being focused on the present to reduce distress and uncertainty, as well as the value of self-disclosure, as opposed to hiding the experience, as an important part of self-acceptance.

Interestingly, the present study revealed a complex relationship between facilitating and hindering factors for personal growth; the two core factors identified (services and coping strategies) served at times as both facilitators and hindrances. This acknowledges the struggle of adapting and finding the 'right' help, with mental health services and the individuals themselves not feeling equipped to initially manage the complexities associated with hallucinations. The research proposes clear clinical recommendations. Firstly there is evidently a need for earlier education of supportive coping strategies to prevent the more unhelpful use of avoidant strategies such as substance misuse, which often exacerbated hallucinations and hindered growth. Secondly, individuals would benefit from better integrated health services with more effective, transparent, communication to enhance the speed of service delivery and the individuals' experience of

inclusion. Finally, the present study confirmed the role of stigma and hopelessness as a hindrance to personal growth, including that of clinician-held stigma (Klapheck, Lincoln & Bock, 2014; Perkins, 2006). It is clear that in order to facilitate personal growth there must also be a challenge to societal-level prejudgment of hallucinations as debilitating and fearsome, conveying the continuum of experiences and awareness of potential positives, and thus freeing individuals from the preconception that they should be fought and hidden. This change can start in services; narrative positioning may support the process of acceptance by giving the space for staff to work towards new, more helpful, shared understandings, and thicken individuals' preferred stories (White & Epston, 1990). This recommendation is complemented by participants' reports of enjoying, and finding value in, the positively constructed interview.

### ***Methodological limitations***

The present research is limited by the small study population; the sample is purposely homogenous to provide rich data whereby the findings were not intended to be generalisable to the wider population of people experiencing hallucinations. Of particular note, all of the participants were white British and as such the experiences depicted here are likely to differ to individuals in other ethnic cultures.

Additionally, the recruitment methods for participants were open to bias. Firstly any study that involves potential participants registering an interest in participating opens itself up to self-selection bias, the present findings must be interpreted cautiously considering why the participants voluntarily contributed and who the recruitment may have missed. For instance, some participants explicitly stated their participation was motivated by the hope that others won't face the same stigma they have in the future; perhaps others who had not experienced such stigma were less motivated to participate, but should they have, stigma may not have been identified as a subordinate theme. Secondly, whilst the inclusion/exclusion criteria were overtly discussed with each care co-ordinator, anecdotal evidence suggests they filtered caseloads and only approached people they thought would be 'good' for the research (i.e. who had identified some form of personal growth). Some care co-ordinators were initially very critical of the possibility of personal

growth with hallucinations, expressing that no-one in their service would identify with the research subject matter. This has clear links with the clinician-held stigma throughout the article and may have influenced the selection (or lack) of potential participants and the attitudes of participants. Lastly, this methodology acknowledges the researcher's own partiality in the interpretation of these results, actively exploring more positive narratives; although, other literature in support of the presented findings minimise such concerns.

The present research adopted a single-complaint approach (i.e. hallucinations) as opposed to a diagnostic approach used in earlier literature (e.g. 'psychosis' in Dunkley at al., 2007; and Mapplebeck et al, 2015). A difficulty encountered with this was that participants found it hard at times to separate single complaints, such as auditory hallucinations and paranoid ideation. Single complaints do appear to occur in the context of each other for some people (for instance, altered perceptions of speech may lead to beliefs others are criticising or laughing at them), which is why it is understandable that these broad diagnostic terms develop. Whilst this means the findings may be related to other experiences often associated with hallucinations, the benefits of this approach are strong. There are suggestion that it is more scientific (as previously adopted diagnostic terms have failed validity testing), it permits more specific research into the explicit psychological mechanisms, and allows for broader consideration of an individual's contextual factors (Bentall, 2004; 2006), giving deeper understanding to the individual's lived experience.

### ***Future research***

Future research may wish to consider how services can promote individual's earlier acceptance of the hallucinatory experiences, and encourage an integrative identity which had been linked with this development of personal growth. For example, does narrative therapeutic intervention facilitate this sense of acceptance and reduce the inherent battle against hallucinatory experiences, as discussed above? It may also be of interest to explore whether services prone to clinician-held stigma and attitudes of hopelessness do indeed influence service-users' attitudes towards, or perceived experiences of, personal growth. It could be valuable to first explore apparent clinician attitudes in mental health services, considering how clinicians may identify stigmatised attitudes,

in order to raise awareness of such potentially unhelpful cultures. Future research may start to examine this by qualitatively exploring clinicians' experiences of talking about personal growth and concepts of recovery in their work.

### ***Conclusions***

The present research provides evidence in support of personal growth occurring with auditory and visual hallucinations. Personal growth was identified as a process of change, sometimes feeling like a disparaging internal battle, experienced through changes in relationships, and largely enabled meaningful personal development. The values of maintaining hope and fighting stigma were echoed throughout. As far as we are aware, this study is one of the first to examine not only facilitators but also hindrances to personal growth with hallucinations, and holds pertinent implications for service delivery of care.

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## **Part Three: Appendices**

## Appendix A: Submission guidelines for *Clinical Psychology Review*

### GUIDE FOR AUTHORS

#### DESCRIPTION

*Clinical Psychology Review* publishes substantive reviews of topics germane to **clinical psychology**. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology.

Reviews on other topics, such as psychophysiology, learning therapy, experimental psychopathology, and social psychology often appear if they have a clear relationship to research or practice in **clinical psychology**. Integrative literature reviews and summary reports of innovative ongoing clinical research programs are also sometimes published. Reports on individual research studies and theoretical treatises or clinical guides without an empirical base are not appropriate.

#### *Submission*

Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

#### PREPARATION

##### *Use of word processing software*

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork. To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

##### *Article structure*

Manuscripts should be prepared according to the guidelines set forth in the Publication Manual of the American Psychological Association (6th ed., 2009). Of note, section headings should not be numbered.

Manuscripts should ordinarily not exceed 50 pages, *including* references and tabular material. Exceptions may be made with prior approval of the Editor in Chief. Manuscript length can often be managed through the judicious use of appendices. In general the References section should be limited to citations actually discussed in the text. References to articles solely included in meta-analyses should be included in an appendix, which will appear in the on line version of the paper but not in the print copy. Similarly, extensive Tables describing study characteristics, containing material published elsewhere, or presenting formulas and other technical material should also be included in an appendix. Authors can direct readers to the appendices in appropriate places in the text.

It is authors' responsibility to ensure their reviews are comprehensive and as up to date as possible (at least through the prior calendar year) so the data are still current at the time of publication. Authors are referred to the PRISMA Guidelines (<http://www.prisma-statement.org/statement.htm>) for guidance in conducting reviews and preparing manuscripts. Adherence to the Guidelines is not required, but is recommended to enhance quality of submissions and impact of published papers on the field.

#### *Appendices*

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

#### **Essential title page information**

*Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact information.**

*Author names and affiliations.* Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

*Corresponding author.* Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

*Present/permanent address.* If an author has moved since the work described in the article was done, or was visiting at the time, a "Present address" (or "Permanent address") may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

#### *Abstract*

A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

#### *Graphical abstract*

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site. Authors can make use of Elsevier's Illustration and Enhancement

service to ensure the best presentation of their images and in accordance with all technical requirements: Illustration Service.

#### *Highlights*

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view example Highlights on our information site.

#### **Keywords**

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

#### *Abbreviations*

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

#### *Acknowledgements*

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

#### *Formatting of funding sources*

List funding sources in this standard way to facilitate compliance to funder's requirements: Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding. If no funding has been provided for the research, please include the following sentence: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

#### *Footnotes*

Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

#### *Electronic artwork*

##### *General points*

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.

- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.

A detailed guide on electronic artwork is available.

**You are urged to visit this site; some excerpts from the detailed information are given here.**

#### *Formats*

If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.

Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

EPS (or PDF): Vector drawings, embed all used fonts.

TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi.

TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

#### **Please do not:**

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

#### *Color artwork*

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. **For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article.** Please indicate your preference for color: in print or online only. Further information on the preparation of electronic artwork.

#### *Figure captions*

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

#### **Tables**

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

#### *References*

Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from <http://books.apa.org/books.cfm?id=4200067> or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK. Details concerning this referencing style can also be found

at <http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>

#### *Citation in text*

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

#### *Web references*

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

#### *References in a special issue*

Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

#### *Reference management software*

Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley and Zotero, as well as EndNote. Using the word processor plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide.

Users of Mendeley Desktop can easily install the reference style for this journal by clicking the following link:

<http://open.mendeley.com/use-citation-style/clinical-psychology-review>

When preparing your manuscript, you will then be able to select this style using the Mendeley plugins for Microsoft Word or LibreOffice.

#### **Reference style**

References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. **References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).**

*Examples:* Reference to a journal publication: Van der Geer, J., Hanraads, J. A. J., & Lupton R. A. (2000). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51-59.

Reference to a book: Strunk, W., Jr., & White, E. B. (1979). *The elements of style*. (3rd ed.). New York: Macmillan, (Chapter 4).

Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

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on ScienceDirect. If you have concerns about your data being downloadable, please provide a video instead.

### **Submission checklist**

The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

#### **Ensure that the following items are present:**

One author has been designated as the corresponding author with contact details:

- E-mail address
- Full postal address

All necessary files have been uploaded, and contain:

- Keywords
- All figure captions
- All tables (including title, description, footnotes)

Further considerations

- Manuscript has been 'spell-checked' and 'grammar-checked'
- References are in the correct format for this journal
- All references mentioned in the Reference list are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)

Printed version of figures (if applicable) in color or black-and-white

- Indicate clearly whether or not color or black-and-white in print is required.

For any further information please visit our Support Center.

## Appendix B: Quality assessment checklist

Title:

Author:

Score Key:

2 = Yes

1 = Partially

0 = No / Not reported / not applicable

Item #	Criteria	Score	Comments
<b>Introduction</b>			
1	Is the scientific background and rationale for the study reported?		
2	Have the specific objectives of the study, including pre-specified hypotheses, been stated?		
<b>Methodology</b>			
3	Are the key elements of the study's design presented, in a manner conducive of replication? Including the settings, locations, relevant dates, periods of recruitment and data collection.		
4	Are the eligibility criteria, and the sources and methods of selection/recruitment of participants clearly described?		
5	Does it explain how the study size was arrived at?		
6	Do the selected participants represent the eligible population? <i>Have all important groups been represented equally?</i>		
7	Have the sources of data and details of assessment been clearly described, for each variable?		
8	Were the measures and procedures reliable and valid?		
9	Were all or most of the outcome measurements complete (80% or above)?		
10	a) Were likely confounding factors identified and controlled? Were there likely to be confounding factors not considered or appropriately adjusted for, sufficiently enough to cause bias? b) Are any efforts to address potential sources of bias described?		
11	Are all statistical methods described?		
<b>Results</b>			
12	Have numbers of individuals at each stage of study (e.g. # potentially eligible, confirmed eligible, included in the study, and analysed), including reasons for non-participation, been reported?		
13	Were the statistical tests used to assess the main outcomes appropriate?		
14	a. Have the unadjusted estimates and, if applicable, confounder-adjusted estimates		

	and their precision (e.g., 95% confidence interval) been reported? Makes clear which confounders were adjusted for and why they were included. b. Have actual P values been reported for the main outcomes, except where P<0.001?
15	Are all other studied variables commented on and analyses reported, identifying the significance of group effects? e.g. analyses of subgroups and interactions, and sensitivity analyses.
<b>Discussion</b>	
16	Are the key results summarised clearly with reference to study objectives and hypotheses?
17	Have the limitations of the study been appropriately discussed, taking into account any potential bias/imprecision and the direction/magnitude of such?
18	Has a cautious interpretation of the results been provided, considering the stated objectives, limitations, analyses, and findings from similar studies?
19	Are the findings generalisable to the source population? Are sufficient details provided to assess external validity, considering participants, comparisons, resources, and policy implications.
<b>Other information</b>	
20	Are the sources of funding and the role of funders acknowledged for the present study, and if applicable, for the original study of which the present article is based?

Total score =

Percentage of possible score: (Total score divided by total possible score) x100 =

*Adapted from:*

von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. (2008). STROBE Initiative. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: Guidelines for reporting observational studies. *Journal of Clinical Epidemiology*, 61(4), 344-349. doi: 10.1016/j.jclinepi.2007.11.008

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of epidemiology and community health*, 52(6), 377-384. doi: 10.1136/jech.52.6.377

National Institute for Health and Care Excellence (2012). *Methods for the development of NICE public health guidance* (3<sup>rd</sup> ed.). London: Author. Retrieved from: <https://www.nice.org.uk/article/pmg4/resources/non-guidance-methods-for-the-development-of-nice-public-health-guidance-third-edition-pdf>

Pluye, P., Gagnon, M. P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies*, 46(4), 529-546. doi:10.1016/j.ijnurstu.2009.01.009

## Appendix C: Data extraction form

<b>Title</b>	
<b>Author</b>	
<b>Year</b>	
<b>Journal</b>	
<b>Sample</b>	
<b>N</b>	
<b>Help-seeking group</b>	Gender/Age/Ethnicity/SES... /Length of time AVH/Service History
<b>Non-help-seeking group</b>	Gender/Age/Ethnicity/SES... /Length of time AVH
<b>Method</b>	
<b>Outcome Measures</b>	Reliability/validity of measures
<b>Results</b>	
<b>Statistical analysis</b>	
<b>Evidence for difference in distress?</b>	
<b>Factors significantly different between groups</b>	
<b>Factors not significantly different between groups</b>	
<b>Hallucinatory characteristics similar?</b>	
<b>Other findings</b>	
<b>Conclusions</b>	
<b>Limitations identified</b>	
<b>Quality (as assessed by checklist)</b>	

#### Appendix D: Quality assessment scores of included studies for review

Article	Checklist Item Score																				Total (%)
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
Andrew et al. (2008)	2	2	1	2	2	0	2	2	2	2	2	2	2	1	2	2	2	2	0	0	<b>80</b>
Barkus et al. (2010)	2	2	1	2	1	0	2	2	0	0	2	1	2	2	2	2	2	2	1	0	<b>70</b>
Brett et al. (2009)	2	2	2	2	2	0	2	2	1	2	2	1	2	2	2	2	2	1	1	2	<b>85</b>
Brett et al. (2014)	2	2	1	2	2	0	2	2	0	0	2	2	2	2	0	2	1	2	0	2	<b>70</b>
Cottam et al. (2011)	2	1	1	2	0	1	2	1	1	2	2	0	2	2	2	2	2	2	0	0	<b>67.5</b>
Daalman et al. (2011)	2	1	2	2	2	0	2	1	2	2	2	2	2	2	2	2	1	2	2	2	<b>87.5</b>
Davies et al. (2001)	2	2	1	2	1	0	2	0	2	2	2	1	2	1	0	2	1	2	0	0	<b>62.5</b>
Gaynor et al. (2013)	2	2	1	2	0	2	2	2	2	2	2	0	2	2	2	2	2	2	1	0	<b>80</b>
Hill et al. (2012)	2	2	1	2	1	2	2	2	2	2	2	1	2	1	2	2	2	2	1	0	<b>82.5</b>
Honig et al. (1998)	1	2	1	2	2	0	1	0	0	0	1	2	2	1	2	2	1	1	1	0	<b>55</b>
Langer et al. (2015)	2	1	1	2	0	1	1	1	0	2	2	1	2	0	1	1	1	2	1	1	<b>57.5</b>
Robson & Mason (2015)	2	2	1	1	0	1	2	2	1	0	2	0	2	2	1	1	1	2	1	0	<b>60</b>
Sorrell et al. (2010)	2	2	2	2	2	1	2	2	1	0	2	2	2	1	2	2	1	2	1	0	<b>77.5</b>
Taylor et al. (2014a)	2	2	2	2	2	1	2	2	1	0	2	0	2	1	1	2	1	2	1	2	<b>75</b>
Taylor et al. (2014b)	2	2	2	2	0	0	2	2	0	2	2	0	2	2	2	2	1	1	1	2	<b>72.5</b>
Ward et al. (2014)	2	2	1	2	2	2	2	1	0	1	2	2	2	2	1	2	1	2	0	2	<b>77.5</b>
<b>Total (%)</b> (to nearest percentage)	<b>97</b>	<b>91</b>	<b>66</b>	<b>97</b>	<b>59</b>	<b>34</b>	<b>94</b>	<b>75</b>	<b>47</b>	<b>59</b>	<b>97</b>	<b>53</b>	<b>100</b>	<b>75</b>	<b>75</b>	<b>94</b>	<b>69</b>	<b>91</b>	<b>38</b>	<b>41</b>	

## **Appendix E: Submission guidelines for *Psychology and Psychotherapy: Theory Research and Practice*.**

### *Author Guidelines*

Psychology and Psychotherapy: Theory Research and Practice (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

All papers published in Psychology and Psychotherapy: Theory, Research and Practice are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

#### 1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

#### 2. Length

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The journal operates a policy of returning any papers that are over this word limit to the authors. The word limit does not include the abstract, reference list, figures and tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length (e.g., a new theory or a new method). The authors should contact the Editors first in such a case.

Word limits for specific article types are as follows:

- Research articles: 5000 words
- Qualitative papers: 6000 words
- Review papers: 6000 words
- Special Issue papers: 5000 words

#### 3. Brief reports

These should be limited to 1000 words and may include research studies and theoretical, critical or review comments whose essential contribution can be made briefly. A summary of not more than 50 words should be provided.

#### 4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. The Journal operates a policy of anonymous (double blind) peer review. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review to avoid unnecessary delays. Before submitting, please read the terms and conditions of submission and the declaration of competing interests. You may also like to use the Submission Checklist to help you prepare your paper.

## 5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded [here](#).
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- All Articles must include Practitioner Points – these are 2-4 bullet points, in addition to the abstract, with the heading 'Practitioner Points'. These should briefly and clearly outline the relevance of your research to professional practice.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
- Manuscripts describing clinical trials must be submitted in accordance with the CONSORT statement on reporting randomised controlled trials (<http://www.consort-statement.org>).
- Manuscripts describing systematic reviews and meta-analyses must be submitted in accordance with the PRISMA statement on reporting systematic reviews and meta-analyses (<http://www.prisma-statement.org>).

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

#### 6. Multiple or Linked submissions

Authors considering submitting two or more linked submissions should discuss this with the Editors in the first instance.

#### 7. Supporting Information

PAPT is happy to accept articles with supporting information supplied for online only publication. This may include appendices, supplementary figures, sound files, videoclips etc. These will be posted on Wiley Online Library with the article. The print version will have a note indicating that extra material is available online. Please indicate clearly on submission which material is for online only publication. Please note that extra online only material is published as supplied by the author in the same file format and is not copyedited or typeset. Further information about this service can be found at <http://authorservices.wiley.com/bauthor/suppmat.asp>

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## 14. Early View

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been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. E.g., Jones, A.B. (2010). Human rights Issues. *Human Rights Journal*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x

## Participant Information Sheet

### **Title of the study: Exploring Personal Growth with Auditory and Visual Hallucinations**

We would like to invite you to take part in our research study. **This study is looking into possible positive changes following the experience of hearing or seeing things that other people do not.**

Before you decide if you want to participate in the study, we would like you to understand why this research is being done. We would also like you to understand what it will involve for you if you decide to participate. You can talk to others if you would like before you decide if you want to take part and **the researcher will answer any questions you may have.**

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

Some people **hear or see things** that others do not. These experiences are sometimes referred to as '**hallucinations**' – a medical word used to describe when a person may find it difficult to tell the difference between reality and their imagination.

There is a small amount of research into how these experiences of hearing/seeing things that others do not may help a person change positively and personally grow. Typically, research around experiencing hallucinations is negative; focusing on matters such as risk, costs, or how the experience distresses the person. This study hopes to develop our understanding of the possible long-term individual benefits of hearing/seeing things that others do not, and how a person may positively grow and change, so that healthcare professionals will know more about these experiences and how to best help people.

#### Why have I been invited to take part?

This information is being given to service users who are over the age of 18 and have experiences of hearing or seeing things that others do not. You have been given this information sheet as you may fulfil the criteria to take part in the study and may be interested in participating.

#### Do I have to take part?

- *No, **participation is completely voluntary.***
- If you decide to participate you will be asked to sign a consent form to indicate that you agree to take part.

- You are free to withdraw and stop your involvement with the study up to the point where the study results are analysed and written up and you do not have to give a reason for this.
- Your decision will not affect your medical care or your legal rights.

### **What will happen if I agree to take part?**

1. If you agree to take part please provide your contact details on the sheet attached and leave it with a member of staff.
2. You will then be contacted by the researcher to arrange a time to meet that suits you; this meeting will give you an opportunity to meet the researcher and ask them questions you may have before taking part in the study.
3. You and the researcher will then arrange another time to meet to actually participate in the study. This second meeting will be more like an interview, where the researcher will ask you questions about your experiences of hallucinations and personal growth.
4. The researcher will audiotape this discussion using a dictaphone, and quotes from your interview may be anonymised and used when reporting the research.
5. Both of these meetings will be done at the clinic which you normally attend or at the University of Hull, whichever is more convenient for you.

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

- Participating in the study will require about 85 minutes of your time (including the initial meeting and the later interview); it won't necessarily take this long and we can take breaks, but this may be inconvenient for you.
- Some people may find it distressing to talk about their experiences of hallucinations and issues of personal growth. If this happens, your researcher will offer support within the session and help you to gain access to further support from your clinical care team and/or your GP. Also, the research interview can be stopped at any point.
- A further information sheet with contact numbers of helpful voluntary organisations will be given to all participants.

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

- We cannot promise that you will have any direct benefits from taking part in the study.
- However it has been suggested from people who have experienced hallucinations that taking part in this study and sharing their experiences with other people may be personally helpful.
- It is hoped that the research will help us to understand more about hallucinations and how best to care for and support those experiencing these.
- The hope is that by improving our understanding of personal growth with hallucinations the research may help to improve treatment plans and support from services, whilst also helping the public to see the experience of hallucinations more positively.

### **What will happen if I decide I no longer wish to take part?**

You are free to withdraw from the study before the results are analysed and the study is written up; you do not have to give a reason to withdraw. This will not affect your legal rights or the medical care that you receive from your clinical team.

### **What if there is a problem or I want to make a complaint about the study?**

If you have any concerns about the study you can contact the researcher or their supervisors, who will do their best to answer your questions.

### **Will my personal details be kept confidential?**

- Yes, all the personal information that you provide will be kept strictly confidential.
- Any information that could be used to identify you will not be used in the research.
- Participants will be assigned a code to protect their anonymity. Any identifiable data from the study will be kept on a secure encrypted memory stick, and any information linking data and personal information will be stored securely in a separate location.
- Any information that could identify you as a participant will be destroyed once the research is completed, and anonymised data that cannot be linked back to you will be kept securely for 10 years.
- The only time that information cannot be kept confidential is if you disclose something in our meetings that suggests that you or someone else is at risk of serious harm. If this happens during the interview the researcher will need to contact the appropriate authorities to ensure that you and other people are safe. It is unlikely that this will happen and the researcher will try to discuss this with you.

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

- The results from all participants will be analysed and presented in a report written for a scientific journal and as part of a thesis project. The results will also be presented at research conferences and professional development events, and possibly wider media.
- Your personal details and any identifiable data will **not** be used in the research write-up or in these events, but anonymised quotes may be used.
- If you wish, you will be given a brief written summary of the findings of this study once it has been completed.

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

This study is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and regulated through the University of Hull and sponsored by the Humber NHS Foundation Trust. Some sections of data collected during the study that are relevant to taking part in this research may be looked at by responsible individuals from the University of Hull or from regulatory authorities, to ensure that appropriate guidance was followed by the researcher.

### **Who has reviewed the study?**

The study is reviewed by an independent organisation called a **Research Ethics Committee**. The Research Ethics Committee protects the interest of people who participate in research. This study has been reviewed by **NRES Committee Yorkshire & The Humber – Bradford Leeds** and has received a favourable opinion.

If you have any further questions, comments or queries, please contact Lily Dixon. Thank you for taking the time to read this information.

Yours Sincerely,

Lily Dixon  
*Trainee Clinical Psychologist*

This study is supervised by:

Dr. Chris Sanderson, *Clinical Psychologist*

Dr. Lucy Holt, *Clinical Psychologist*

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## Exploring Personal Growth with Auditory and Visual Hallucinations

If you are interested in taking part in the study please leave your contact details on the space provided below. You will be contacted by the researcher to answer any questions you may have and/or arrange a meeting at a convenient place and time.

Name:

.....

Address:

.....

.....

.....

.....

Telephone Number:

.....

Mobile Phone Number:

.....

Are there any times of the day that you prefer to be contacted? (If yes, please give details)

.....

How would you prefer to be contacted? (Please tick)

Home Phone

Mobile Phone

Letter

Do you have any further comments?

.....

.....

Signature: .....

Date: .....

**Thank you very much for your interest!**

**Appendix G: Participant consent form**



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**CONSENT FORM**

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Title of the study: Exploring Personal Growth with Auditory and Visual Hallucinations

Name of Researcher: Lily Dixon

Participant Identification Number:

*Please initial boxes*

1. I confirm that I have read and understand the information sheet dated 14/02/2015 (version 3.2) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my interview will be audiotaped, and that anonymised quotes may be used for the research.
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
5. I agree to take part in the above study.

*Please circle an option*

I am happy for my G.P. to be informed that I am participating in this study. YES / NO

I would like to read a copy of the transcript from our discussion today to ensure my interview has been recorded and documented accurately, before the results are analysed for the research. YES / NO

I would like be given a brief written summary of the findings of this study once it has been completed. YES / NO

Name of Participant \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_

Name of Person Taking Consent \_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_



**Appendix H: Ethic approval documentation**

*Research Ethics Committee (REC) Approval; Research and Development (R&D) Approval*

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## Appendix I: Interview schedule

In this interview I'd like to talk a bit about the experiences you have had in your life whilst hearing and seeing things that other people do not. Different people experience things at different times in their lives. Today I'm interested in your journey.

### Interview route 1

#### **Q1: Tell me what your experiences have been like so far**

Prompt: How would you describe the experience of hearing or seeing things to someone who has never come across it?

#### **Q2: Has your experience of hearing or seeing things been helpful in any way?**

Prompt: Has anything in your life changed in a positive way since you started hearing or seeing things?

*If no, proceed using interview route 2 after Q2a.*

*If yes, prompt: In what ways? Can you tell me about how this experience has been helpful to you?*

#### **Q2a: What does positive change mean to you?**

*Allow the conversation to be guided by the participant, but if any further prompting is required the interviewer may employ the topic specific questions below:*

#### **Q2b: Have there been any positive changes to your relationships with other people?**

Prompt: Any positive changes in how you relate to other people?

Prompt: Any positive changes in how other people relate to you?

#### **Q2c: Have there been any positive changes to how you see yourself as a person?**

Prompt: Have you learnt anything important about yourself?

#### **Q2d: Have there been any positive changes to your lifestyle?**

Prompt: In the way you live your life?

Prompt: In how you spend your time?

Prompt: In the activities you do?

#### **Q2e: Have there been any positive changes to your outlook on life?**

Prompt: In your priorities?

Prompt: In what you consider to be important in life?

#### **Q2f: Have there been any positive changes to your beliefs?**

Prompt: Have you learnt any important lessons since you started hearing or seeing things?

**Now that we've talked about a few positive changes, I wonder:**

#### **Q3: What do you make of these changes?**

Prompt: How do you think they came about?

**Q3a: Can you tell me about anything that might have helped you to positively change from the experience of hearing or seeing things?**

**Q3b: Can you tell me about anything that might have stopped you from positively developing/changing from the experience of hearing or seeing things?**

**Q4: Do you think your life will be any different in 5 years' time?**

Prompt: How might your life have changed?

**Thank you for talking to me today. Before we finish, is there anything else that you would like to add?**

Interview route 2

**So you mentioned it's difficult to think how your experience of hearing or seeing things has been helpful to you.**

**QA: Can you tell me about any challenges that you have experienced as a result of hearing or seeing things that other people do not?**

Prompt: Has there been anything that has been particularly difficult for you?

**QA2: How have you overcome these challenges/difficulties?**

Prompt: What did you do / what happened to help you move past these challenges/difficulties?

**QB: Do you think your life will be different in 5 years' time?**

Prompt: How might your life have changed?

**QC: Is there any way that this experience of hearing or seeing things could help you to learn about yourself in the future?**

Prompt: Can you tell me how?

**QD: Can you tell me about anything that might have stopped or limited you from positively developing/changing?**

**QE: Can you tell me about anything that might help you to positively develop/change from the experience of hearing or seeing things?**

**Thank you for talking to me today.**

**Before we finish, is there anything else that you would like to add?**

## Appendix J: Example of data analysis

### Transcript

Dave: Erm, but... it has given me more understanding (R: OK), and er it it helps it helps that way.

Researcher: What is it more understanding of?

D: Other people's needs and feelings. Erm it's making me understand mesen as well. Why am I like this why's doing that? I've spent a lot of years, searching, trying to find the answers to what my- what is my type what am I? I've learnt to accept that this is me, this is the way I am, and I've found my strength through other people's strength. And with some strength of some that, it's the, I don't know if the wording's [...] but there's always somebody worse off than yourself. And, knowing that they can cope and they, how they handle things [...] I can pick up from that as well (R: OK) and sooo it, it makes me the stronger person.

R: Right so this this, (4: community that way) more understanding has given you – (yeah it- sorry?) So this deeper understanding that you're talking about has made you involved in this community that's made you a stronger person. Have I got that right?

D: Yeah yeah. Aaaaand it'll be, then other people have taken it from me as well, so y'know it's, we're learning off each other and we're all getting stronger. Aaand this is why I'd love to see it more out there, more publicised instead of hated. Erm, the only small bit I like about the

### Comments

More understanding, from experiencing the stigma and difficulties, able to understand others in similar situation?

Understanding others needs and feelings, as he has understood his own.

Searching for understanding. Asking questions?

What am I? Not: Who am I? Why am I like this?

Learning to accept himself. Appreciating who he is, not focussed on how he is not.

Finding strength from others. Learning from groups, witnessing others in similar situations, role models? Strength for what? Carrying on? Accepting himself? Fighting the voices/ignorance?

Looking to a turn of phrase: always someone worse off. Count your blessings? Appreciating. Putting difficulties in context. Knowing that others cope and can handle it (learning how to handle it), picks up, builds on. Getting stronger, for the battle or learning not to battle?

Not just a learner, a teacher too. Value of being able to share knowledge, coping, passing it on and helping others.

Groups as a perpetual cycle of support and strengthening. Wanting to advocate for more of this support, publicised not hated. What would be publicised? That living with these experiences is OK? Shift focus.

Leaders and highly respected people in the country supporting MHA.

### Emergent Themes

Far reaching arm of stigma.

Gaining understanding (of self & others).

Empathy?

Searching for understanding.

What am I?

Learning to accept self.

Finding strength from others.

Appreciating life.

Putting difficulties in context.

Getting stronger.

Mentor & mentee.

Sharing knowledge, helping others.

Groups = strength.

Leadership

supporting MH.

royal family is the junior ones out that's there now I think was it William and Kate (cough) for Mental Health Awareness week, they was doing things so more people look out and this is why I push as much as I can on social media, and I'm not afraid now to let anybody know how I feel and what I'm doing, as in the past it it y'know "get a backbone shut up what you talking about you need a kick up the arse"... which made me wear the mask, or when people were like "Now then Dave how are you?" and I'll "oh yeah I'm fine mate hunky dory and you?" I wasn't inside, I was hurting.

R: So that's wearing a mask did you say?

D: That's wearing a mask, and that's a mask wearer. You can even use this mask like a crutch, so you're a different person. And it can but the difficulty with it it can take over, so when you're going to see a specialist because you look good on the outside and you sound cheerful they think "oh this person is well we can sign him off"... that has been a *huge* problem in my past. So now I tend to leave this other mask, this other person at home. I will still bring it out, it will still come out in in situations but a lot of time now if if I'm feeling down I'll tell people, and if they don't like it, tough.

This publicity helping others by getting the wider community to 'look out', for others.  
 Important for him to play a role in this publicity as well, using self as an example? Not wanting to be passive, taking active roles for MHA (and against ignorance).  
 Not afraid to speak out/communicate. Come from a place where he would have been, and others still are, afraid. Listing previous (and still present really) stereotypical responses to his experiences, 'pull yourself together'. Previous attitudes made wearing a mask necessary, so he indicates noticing a change over the years.  
These sentences are so simple, we just say them, but Dave indicates that there can be much more going on inside. Social norm to conform to.

Mask typically hides the face, entrance to the emotions.  
'Crutch' – links with disability, a support for being disabled. Only if it were a physical crutch people probably wouldn't express the attitudes towards him that he identified just above.  
 Being a different person. Losing your identity, wearing another.  
 Once you're wearing a mask it can be hard to take off, it takes over, holds you back by not showing your pain.  
 Wearing the mask as protection, but hindering personal growth. This brings awareness of a relationship between mask wearing, stigma, hiding feelings and accessing help.  
Warning against professionals making assumptions, especially for such sensitive issues.  
 Separate identities, left at home. Can enter the world without the protection. How did this change happen? Identifying that at times we still need this 'crutch'. *Stammering.*  
 Communicating distress as an alternative to the mask wearing. Not hiding self to hide from stigma.

Societal responsibility.  
 Taking a role against stigma.  
 Abusive messages.  
 Noticing change.  
 Hearing what is not being said.  
 Hiding behind a mask.  
 Needing a 'crutch' at times.  
 Safety is wearing a different identity.  
 Losing your-self.  
 Being held back by own coping.  
 Mask wearing as protection, hinders change.  
 Mask and self as separate identities.  
 Communication as alternative coping.

## Appendix K: Example of themes and supporting quotation data

### Superordinate theme: A process of change

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Subordinate themes

Examples of supporting quotation data

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A journey

Robin:

“I’m just about finished with it. Not, like I said I still get them all the thoughts outside, but like, I think I’m, I’ve, got to start, I’ve got to move forward and start looking at life outside of coming to a place like this and meeting people who work here. And that’s something that I’ve got to start to do”

Paul:

“Sooo, y’know, it’s been a weird journey, but y’know, been interesting”  
“Now it’s just a case of um, learning to move forward in a positive way, y’know and ok I now I’m going to have those days when it just feels like I’ll take 1 step forwards and about 25 steps back, y’know what I mean, but it’s just y’know you, you learn to cope in some way.”

“I think I’ve finally just, lets see where they journey takes you and, y’know... if it goes up, good. If it goes a bit Pete Tong, you’ve got somewhere to fall back on”

“It might keep going up y’know. So, it’s going to be interesting to see where this journey finally goes y’know it’s, it’s looking alright up to now so”

Debbie:

“I suppose everybody is on a life journey and we’ll see where we go from here y’know”

“I’ve come this far, I’m close to having me Psychology now, and it’s t- took me all these years t- t- to get that, to that stage, there’s no point me, letting it beat me”

Dave:

“It’s like it’s like climbing a mountain, you’ve no conquered it until you got to the top.”

Sophie:

“Yeah I’ve come along way, I’ve come a long way from that. It’s just at the minute I am going through a hard time of hearing voices and I’m trying to get past that.”

“Whereas at first I never thought I’ll never get through this, but I can see eventually me getting better. I can I’ve seen from when I started, to fe- I know like my voices wasn’t as frequent now, but I’m starting to... I’m st- it’s hard it’s like it’s starting to become a part of my life if you know what I mean, like an everyday thing, so I’m I’m doing it every day so I’m getting used to it, and it’s not as scary as it used to be.”

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	<p>Steve:</p> <p>“I’m a hell of a lot more settled, hell of a lot more so anyway but still a long way to go”</p>
Taking time	<p>Robin:</p> <p>“I’d chant and that’s stop, an I’ve only just realised this”</p> <p>Paul:</p> <p>“Yeah it’s, seems to have taken a long time but y’know it’s, finally y’know I, now I think I’ve finally just, lets see where they journey takes you and, y’know... if it goes up, good”</p> <p>Debbie:</p> <p>“It’s only this last year or so I’ve started to, realise helps there so I need to do something, and it’s took me all, these years, struggling through stuff, thinking why have I done that, or, what’s this happening for”</p> <p>Dave:</p> <p>“I don’t realise I have, I have come, I mean I’ve heard people tell me that I’ve come a long way but, it wasn’t til I started summarising this year up or this last few years that you realise well perhaps I have”</p> <p>“A day turns into a week a week turns into a year a year turns into a decade”</p> <p>“I will have times now when I am that far down and I look and go ‘what’s the point, what have I achieved I’m doing the same thing now than I was doing last year’ and then the only way I can get around that is by going ‘okay well what was I doing the year before that?’, and then, realising like well, I’ve done them in little stages, so looking back on a few months”</p> <p>Steve:</p> <p>“A memory of a feeling of what normality was and I held on to that for a long time for 20 odd I’m still holding onto it to this day”</p> <p>“There is a light at the end of the tunnel, even though it took me 2 years y’know I’m finally walking into that light”</p> <p>“As I say all this has happened over the last 4 years really, from giving up the fight to now. Took a long time, like 20 years in all, but these last 4 years have been more enjoyable”</p>
A battle	<p>Paul:</p> <p>“I think I’ve learnt to just, sit back, relax, and, watch the world go by, rather than trying to fight the system”</p> <p>Debbie:</p> <p>“Well, it’s more or less arguing with it. Saying, the voice and that, s-sometimes, it isn’t all the time, it’ll say to me ‘you will do this’ and ‘you will go back on this’ and stuff, and I keep saying to myself ‘nah, I’m not go- going to let it happen”</p> <p>“I’ve always had the v-voice saying ‘you need to do this and do that’ and then, a- and now it’s like ‘woah I don’t”</p>

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“It’s sort of like the v-voice and that is there, but it’s trying to get, in front of me again, and I’ve sort of like pushed it”

Dave:

“I have little like scutters or trojens that are always guarded y’know like your immune system and if something comes through they all go out, get together and go to attack it to shut it out. The more people that I’m getting from social media gives me that immune boost, so if I am attacked I go, y’know it it helps to fight it, to to push it on”

“Because in a way when a lot of these voices come and they get stronger it also affects me depression (R: right) and I start feeling lower and lower and once you start hitting low the voices can get stronger”

Sophie:

“If the voices do go they’ll eventually come back and I’ll probably have to fight then again because I’ve had them once, they stopped and then they came back again”

Steve:

“Now the battle that’s going on in side is over, so you can just like stop feeling crap which had happened over a period of time”

“That’s the biggest one that really helped, finding yourself, because you’ll never win all you’ll do is kill yourself... just give up the fight, and look after yourself”

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## **Appendix L: Epistemological statement**

Throughout the development of this research I had grappled with the concept of what ‘real’ research is, battling this sense that true research only has data which is in some way testable, or in truth, provable. This is undoubtedly due to the most part of my education centring a positivistic stance, in the belief that an objective truth exists and can be estimated and understood through conscientious application of scientific process (Guba & Lincoln, 2005). The present research is a reflection of my own questioning of these assumptions, critically exploring my own concept of reality and what is possible for us to know. This statement acknowledges the assumptions underlying the presented research, and outlines this move away from positivism; reaching the position that positivism may limit the understandings we can reach, considering a generalisable truth is unattainable as our understanding of ‘truth’ is temporal and lies within the individual.

Through the process of this research, the first moment I remember challenging this positivist position was when I sat to reflect on my own understanding and belief of what a hallucination actually *is*. Is it a ‘real’ sensory experience, where does the reality of the sensation lie, should we as clinicians advocate the position that they are not real if there is no sensory stimuli perceived by others? My position is that hallucinations *are* real sensory experiences, accepting that perception and experience form subjective ‘truth’ – proposing, all that truly exists is one’s perception, expanding on Berkeley’s claim ‘to be is to be perceived’ (Berkeley, 1996). Therefore the implication being that individual’s hallucinatory experiences are in fact tangibly real for them.

This research was developed off the back of existing literature and theory into personal growth. With this came quantitative tools to assess growth, but yet they were not designed specifically for growth with hallucinations in mind, and didn’t seem to capture what the experience was like, how the experience was *experienced*. Literature that seemed most rich in our understanding of personal growth with hallucinations came from qualitative studies, perhaps because the positive changes are not always easily measurable or even observable, as the participants themselves highlighted.

Therefore the present research would adopt a phenomenological outlook, with the object of study being individuals' lived, and perceived, experiences. This allows for the acceptance of multiple valid perspectives, taking the stance that understanding is created within the individual and knowledge is formed through this social understanding, thus denying the concept of an 'objective truth', considerations commonly represented in a relativist, constructionist ontological standpoint (Guba & Lincoln, 2005). Many epistemological positions were considered at the conception of this research, each with implications on methodology. As a result of the above process a qualitative method was thought most appropriate as this would allow for an in depth exploration of the individuals subjective experience of personal growth and hallucinations.

Various qualitative methodologies were reviewed, including discourse analysis, narrative analysis, and grounded theory, to investigate if their underlying ideologies were in line with my own and the intentions of the research. Discourse analysis was considered inappropriate with its focus primarily on the linguistic and discursive properties of what has been said, and not the content of a discussion or individual's account of the experience (Ritchie, Lewis, Nicholls & Ormston, 2013). Narrative approaches explore the life (or episodic) story of an individual, considering the beginning, middle, and end, to understand more about how the individual structures their world (Ritchie et al., 2013). The focus of analysis is therefore how the story is told (e.g. where the narrator places themselves, how the story is ordered) and how the narrator makes sense of their story. Whilst this approach seemed to have its merits for exploring the journey of personal growth with hallucinations, it was thought to be descriptive and thus limited the understanding of the phenomenon which could be reached. Additionally, grounded theory was considered but its aim of making more general claims, analysing at a macro level to construct theories about a process seemed inappropriate considering the scarce literature into personal growth with hallucinations; it was felt the literature may benefit from more of an exploration into the lived experiences. Furthermore, grounded theory advocates that the researcher should be objective to the data, which given the position outlined above whereby understanding is created

within the individual (including the researcher), this is thought to be unattainable and frankly not desirable for the present research.

After reflecting on available stances, and considering the exploratory and phenomenological nature of the questions hoped to be answered by the empirical research, an IPA framework was adopted. In terms of theoretical foundations, IPA explores how individuals make sense of the world around them, and the meanings they deduce from experiences, as opposed to producing an objective statement (Smith, Flowers & Larkin, 2009). Particularly attractive to me were the core components of IPA, it is interpretative and phenomenological, allowing the research (and researcher) to make sense of the data and give a voice to the individuals encountering the studied experience (Larkin, Watts & Clifton, 2006). It acknowledges hermeneutics, the theory of interpretation, in which experiences are made sense of through the idiosyncratic assumptions and interpretations of those who have contact with them (Smith, Flowers & Larkin, 2009). This was in line with my first assumption that hallucinations are real for the individual if they have interpreted them as such. With respect to the interpretative nature of analysis, IPA permits the researcher's position with, and influence over, the data. The 'double hermeneutic' acknowledges the process in which the researcher is making sense of a participant's account which is undergoing a process of interpretation and sense making by the participant themselves (Smith, Flowers & Larkin, 2009). When taking into account the phenomenology of IPA, with its attempts to understand the individual's world, research becomes focused on specific individuals as they make sense of specific experiences (Larkin, Watts & Clifton, 2006).

An important postulation underlying this research is that reality can be co-constructed (Guba & Lincoln, 1994). Participants were given a chance to explore the 'voyage' of personal growth as part of participating in the research, reflecting on their position, past change, and future expectations all at once. This co-construction of reality happened, with many noting how the interview helped them see things differently, collaboratively making new meaning and constructing it in real time, through the conversation.

Most of the statement thus far has been largely in relation to the empirical paper, but the underlying assumptions still apply to that of the systematic literature review. Whilst the review is a synthesis of quantitative papers (which are commonly associated with more of a positivist epistemology) the study takes on a thematic analysis, attempting to make sense of how the literature has been previously interpreted and presented. It also adopted complaint-specific approach, so as not to be precast by societal categorisations of diagnosis and clarifying what was being studied. The study was interested in how society has constructed the dichotomous categorisations of service-use and non-service-use, questioning how help-seeking has been defined. The literature review plays with the idea of where knowledge and understanding sits, within the self (i.e. help-seeker engaging with services) or society (with the guidelines of what threshold a person must meet to be included in services) and remaining critical of the lines that society has drawn in the sand.

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## **Appendix M: Reflective statement**

The passive voice is used in research to emphasise the objective nature of the experimenter, suggesting they, as individuals, had no part to play in the results – almost as if the research conducted itself. In research such as that presented here, it is considered that this idyllic concept is unattainable and almost unwanted, with the researcher unequivocally having an influence on all components of the study, and yet the passive voice is still used (which is why these final appendices come as a light relief to me). There is no intention to mislead readers, which is why I wish to highlight that this research cannot be free from bias. My own interpretation of the data was likely to have been shaped by my interaction with the literature available to me, as well as my own hopes for the research which I will explain further in this reflective statement.

When I embarked on this journey towards becoming a Clinical Psychologist I felt mental health difficulties were largely perceived as debilitating illnesses requiring at least short-term but often longer treatment as the mental ill-health runs through its phases of dormancy and activity for potentially the entirety of an individual's life; and somewhere in this process, my future profession would intervene to promote wellbeing: getting the individual back on track to 'being well'. At times this notion didn't sit well with me, it felt pessimistic and overly simplified, like we were feeding into this societal view that somehow there were people *with* mental health difficulties and others without them, and then those with them were in some way weaker, they needed fixing, and then the past illness should be left behind instead of embraced for the value it may hold in shaping a person. Perhaps it was due to some of the experiences I had witnessed growing up, or my relentless sanguinity, but I had a hunger to explore whether something good could come from experiencing mental health difficulties; that it wasn't simply something that was fixed and overcame, but an experience that helped develop a person for the better. This question stayed with me for a while, I had considered exploring it in my undergraduate degree but at the time experimental psychological research was more highly valued. Then, during a research fair where new doctoral students had gathered to consider the focus of their thesis, the question revisited me and I felt that this was my opportunity to put years of pondering to the test.

It seemed that the best way to explore this idea was in the context of psychosis. I originally set out to research this area as it seemed psychosis was viewed by people as synonymous with ‘madness’, like a continuum whereby psychosis was the utmost sign of mental health difficulty. As I began to explore the literature around psychosis I became aware of the paradigm shift away from diagnostic categories and towards complaint-specific experiences, a move that felt very comfortable to me and one which I wanted to support as it seemed to highlight the individual’s subjective experience. As such, I chose to focus my research on the experience of hallucinations as they were reported to be highly prevalent across a range of populations, including non-clinical populations (which I found fascinating, and later went on to inspire my systematic literature review). Also, empirical and experiential evidence suggested hallucinations were highly stigmatised, with this ‘symptom’ promoting these perspectives of ‘madness’ or even violence and certainly extreme distress. So, I thought, ever optimistically and possibly naïvely, that if some good could be found though the experience of hallucinations, then people would surely reconsider the value of other mental health complaints also.

When I was reading about clinician-held stigma I found it abhorrent at first, making judgements that these clinicians must lack empathy and are probably causing harm to their clients. At least until I truthfully reflected on my own position and painfully came to the realisation that I myself am a receptacle of this described clinician-held stigma. I remember getting messages throughout my life that hallucinations couldn’t possibly be a positive thing; even in our treasured children’s books, as Harry Potter is warned:

*'Hearing voices no one else can hear isn't a good sign, even in the wizarding world.'*

*(Rowling, 1998, p.110)*

My limited time of working clinically with people experiencing hallucinations had certainly challenged some preconceptions, but had also endorsed others. I found it challenging to communicate with people experiencing hallucinations at times, which felt daunting as I felt my ability to communicate with such a population would have a big impact on my research. Furthermore, I found this clinical work on occasion an uncomfortable contradiction to my

academic view that a person may recover or find benefit from their experiences; I could feel the hopelessness creeping in. Sure enough, as my contact with research participants began and I listened to the experiences they recounted, these concerns dissipated and I once again found faith in my proposal that the experience may provide positive opportunities for personal development. Although, I reflected on how a hopeless culture in teams that have been working solely with people with these types of complaints could become more engrained over time, especially when progress was recorded in terms of clinical recovery ('symptom reduction').

I also explicitly encountered this clinician-held stigma as I visited mental health teams, promoting my research and asking for support in participant recruitment. I was met with hostility at times, clinicians advocating that nothing good could possibly come from experiencing hallucinations, emphasising its debilitating effects, and seemingly offended at my suggestion that this negative traumatic experience may positively change a person. Clinicians also expressed a concern to me that my positively focused research may cause participants distress, specifically by asking them to talk about their hallucinations, and instead advocated suppressing hallucinatory experiences. This seemed to be active demonstrations of feeding into this culture that mental health challenges should be quashed and certainly not embraced. I realised that my expectations would be that anyone working in mental health would likely share my perspectives on personal growth. I was initially shocked to discover this may not be the case, but considered how up until this rather late point of participant recruitment I had only discussed my research with fellow Psychologists or experts by experience, and perhaps my experiences of positive feedback were just a reflection of the insular bubble we can at times work in.

At another time, I had a member of staff ask me "Is my research intended to undermine medication?". When asked this I was struck by the power it had over me. I had never intended the research to come across as this, and was shocked that someone's initial interpretation of the research was such. Although, I became aware of my own views about medication, and thought of my preliminary unease when participants had mentioned it as a facilitating factor of their own personal growth. My own values can be critical of medication, opposing the view that medication

is the 'be-all-and-end-all', one-stop cure-all to fix pathology, and so in a way my research was attempting to open up this discourse that hallucinations need only to be medicated 'better'. I felt that the research needs not be as dichotomous as was suggested in the original statement, that medication can play an integral part in personal growth, and therefore intended in no way to undermine its role, but to instead put it in context.

These encounters with staff teams continued to motivate me further to do this research, I found they reinforced my speculations regarding the absolute clinical relevance of the research, and I became determined to hear the participants' side of the story. I was spurred on by one clinician who caught themselves in the act of this hopeless process, and identified this as their own bias; they noticed how in services they rarely discuss any possible positive changes and were therefore unlikely to be aware of such. This demonstrated to me that change within services, and the way clinicians are thinking about hallucinations, was possible, and positive change could happen by having these conversations. I went home with a skip in my step that day!

Overall, I found this stigmatised and hopeless culture in services a barrier to participant recruitment as staff members felt unable to identify any potentially 'good' participants. I therefore changed the recruitment procedure part way through, altering my language and emphasising when I spoke to teams the inclusion/exclusion criteria (i.e. experiences of hallucinations) instead of talking predominantly about personal growth, as the identification of personal growth was not a criteria for participation but was being treated as such. I found this reduced the perception of the research as 'fluffy' and nonsensical, and prevented care co-ordinators from filtering service-users they thought would be 'good' demonstrations of personal growth, and thus more were identified.

I have been fortunate to have the space to reflect on my changing perspectives on topics pertinent to this research (such as hallucinations, mental health, recovery...). Over the course of this research I listened again to an audiobook about an inpatient service that I first encountered during my undergraduate degree. I found that whilst I was listening to the same words, I was hearing very different things. I found my first experience of the book had instituted some of my preconceptions that hallucinations were an 'extreme *symptom*' of mental ill-health, experienced



by seriously disturbed people that will most likely never get better – views which have certainly changed. I found my focus when listening a second time was far more on the philosophies, concepts and messages of mental health presented. I saw parallels with discussions I had been having with participants regarding media portrayals and societal beliefs leading to an unfortunate misunderstanding of these people's distress. I took from it an important message of joining people in their reality and that this can happen to anyone; this change was likely a reflection of my altering epistemological stance and undoubtedly contributed to my interest in differentiation of service-use status in my systematic literature review.

When undertaking my literature review I first held the assumption that there would be clear distinctions between service use and non-service-use; I particularly expected there to be differences in the characteristics of the experiences, which later was shown to be inconclusive. The original conception of the review was a direct comparison of factors effecting service use, but as I began to explore the topic I found the level of distress was given plentiful mention. I then started assuming a strong relationship between service-use and distress, to the point where it had become nigh on synonymous in my mind. Through reflection I had become aware of this process and went about separating them again, appreciating them as distinct components that may be strongly linked, but that is for the data to answer. When I was conducting the literature search I was struck by the number of articles related to care-giver burden being presented; I began acknowledging the evident strain the experience of hallucinations must be on care-givers, but also found myself getting frustrated at the abundance of literature on it. I found that the literature was talking about the affects hallucinations have on others and presenting it again as a debilitating experience. I started questioning whether we as a society have misunderstood how best to interpret and care for those with hallucinations; these questions are still with me, and have been reflected in this research. I hope that over time, collectively, research can continue to facilitate a shift in how we perceive and intervene with hallucinations, with acceptance in place of denunciation.

During data collection for the empirical paper I struggled initially with the different professional identity, being a researcher and not a therapist. I found it a very different way to engage with

people; I played a much more active role in the first two interviews, summarising their comments throughout and guiding them in the conversation more. As my confidence grew in this completely new way of interrelating I was able to take less of an active role in the interviews, allowing the interviewee to explore the questions and make their own connections. I have found that this experience has altered my clinical practice too, now seeing an increased value in moments of silence.

At one point during data collection I started finding it difficult to identify when positive changes were occurring. I found myself getting caught up in the judgement that personal growth only occurs if the comparison was being made to the person's life before they were experiencing hallucinations, but many participants talked about times when they perceived their hallucinations to be at their highest severity, and comparing this time to now. I started questioning my interview schedule, thinking about how I could emphasise the hypothetical of how their life might be different if they never experienced hallucinations, with the aim of capturing what changes may have occurred as a result of experiencing hallucinations. In the end I concluded that this deliberation was futile; the research was interested in how changes were experienced along the journey of hallucinations, and this difficulty was just an apparition of my need to draw comparisons more natural to me in my quantitative background. Instead, I took from this the data was simply sharing this sense that it gets a lot worse before it gets better.

I learnt throughout many stages of this research that there will be times where you doubt the routes you have taken, but through prevailing patience and self-belief you will continue to find the right path; a lesson which many of my participants imparted to me. This research project was undoubtedly important to me, and I am delighted that I have had the chance to start empirically answering that question that had been suspended in my mind for years; yes, some good can also come from experiencing mental health challenges, of course.