An Exploration of Psychotic-like Experiences in Borderline Personality Disorder

Aisya Nadia Musa

Doctorate in Clinical Psychology

Faculty of Medicine and Health Sciences
University of East Anglia
Year of submission: 2019

Thesis portfolio word count: 35,551

Thesis Portfolio Abstract (Word Count: 298)

An Exploration of Psychotic-Like Experiences in Borderline Personality Disorder

Aisya Nadia Musa

Year of Submission: 2019

Background: Past research has shown a significant occurrence of psychotic-like experiences (PLEs) in individuals diagnosed with Borderline Personality Disorder (BPD). Young people with traits of BPD (BPD traits) whom experience PLEs had higher counts of risky behaviours and disengagement from treatment. Despite this, limited research has focused on the nature of PLEs, how they are appraised and responded to in young people with BPD traits. This is partly due to current clinical practice and diagnostic criteria which postulates that PLEs is stress-transient and do not warrant closer inspection in BPD.

Design: The thesis portfolio include a systematic review involving a quantitative narrative synthesis of 12 empirical studies, which considered the relationship between psychological and psychiatric co-morbidities and the occurrence of psychotic symptoms in individuals diagnosed with BPD, and qualitative study exploring the nature, appraisals and responses towards lived experience of PLEs in seven help-seeking young people with BPD traits.

Results: The systematic review findings suggest that while there was evidence for the role of childhood trauma and stressful life experiences in the relationship between psychotic symptoms and BPD, evidence lacked for other types of co-morbidities. The empirical study used an interpretative phenomenological analysis (IPA), which produced four superordinate themes to capture participants' experiences of PLEs: the description of experiences, making sense of the experiences, deterioration of sense of self and well-being, and managing and finding respite.

Conclusion: Heterogeneity of study methodologies proved difficult to provide consistent evidence for the association between co-morbidities and psychotic symptoms in BPD. The

poor psychological well-being and distress associated with PLEs in young people with BPD traits found in the empirical study show a need for clinical practice to make adjustments to ensure varied experiences that are of concern, such as PLEs, are captured and appropriate support are provided to these young people.

Table of Contents

Acknowledgments

First of all, I would like to thank the study participants for their contribution towards the thesis and research area in general. I am forever in awe of their bravery and strength in facing their demons. Thank you for allowing me to share your story.

I would like to thank my study collaborator Dr Sarah Maxwell and all clinicians and teams for promoting the study and involvement in the recruitment process. I am deeply indebted to the supervisory and research team for this thesis: Dr Joanne Hodgekins, Professor Sian Coker, Dr Paul Fisher, and Rose Papadopoullos, for their on-going guidance and support through the process of designing, writing and editing of the thesis portfolio.

To my fellow trainee cohort, thank you for your willingness to share your knowledge and encouragement with each other. In particular, I would like to thank Laura Barnes, Iona Tynewydd and Chloe Llamorna Rani for ensuring I was able to write, even during the most difficult of times.

To my cat Cookie who is a constant bundle of joy. To my friends, near and far, for always believing in me and having my back. To my family-in-law who are always loving and understanding. To my parents who never gave up on me, and whose sacrifice ensured I am who I am and where I am at now. I am eternally grateful.

And not forgetting my husband, who followed me on this journey and supported me through thick or thin. You are my rock, now and always. Thank you.

Summary of Thesis Portfolio

The thesis was submitted in partial fulfilment of the requirements for the Doctorate in Clinical Psychology at the University of East Anglia. The thesis portfolio consists of two main papers: a systematic review and an empirical study.

Chapter One: The first chapter presents a rationale and introduction to the area of research. This includes exploring the nature of psychotic symptoms and psychotic-like experiences in mental health conditions and the significant psychosocial impact of such experiences.

Chapter Two: The second chapter presents a systematic review which focused on the relationship between co-morbidities and psychotic symptoms in individuals diagnosed with BPD. Psychotic symptoms are often present in individuals with BPD. Some research has suggested that the presence of these psychotic symptoms are due to the many complexities and co-morbidities often present in individuals with BPD such as trauma, complex trauma, substance use disorder and mood disorder; however, there has been no systematic review which explores this. Twelve studies are reviewed before discussing the review's clinical implications, limitations and future directions.

Chapter Three: The third chapter provides a brief bridging chapter to summarise the connection between the systematic review and empirical study.

Chapter Four: The fourth chapter presents the empirical study. The study adopted an interpretative phenomenological analysis (IPA) approach to explore how young people with BPD traits understand and respond to their psychotic-like experiences. The results reported on four super-ordinate themes and 12 subthemes alongside a number of verbatim extracts to represent the participants' individual experiences.

Chapter Five: This fifth chapter outlines the qualitative methodology and design in depth to show the rationale behind the researcher's choice of approach. The theoretical underpinnings of IPA will be discussed in detail.

Chapter Six: The final chapter provides a summary of the main findings and discusses these in the context of the wider literature and offers a critical evaluation of the systematic review and empirical study.

Chapter One

Introduction to the Thesis Portfolio

Word Count: 1480

Chapter One - Introduction

This introduction discusses the role of psychotic-like experiences within borderline personality disorder, accompanying symptomatic traits (i.e., emotion dysregulation, interpersonal difficulties) and the importance of conducting research in this area; thus, providing a context to the thesis portfolio. Additionally, it provides the rationale for the aims of the thesis.

Psychotic-like Experiences as a Continuum of Complexities

Psychotic-like experiences (PLEs) are defined as sub-clinical symptoms of psychosis that occur in the absence of a manifested psychotic disorder or illness (Kelleher, & Cannon, 2011), and may include perceptual changes, delusional ideation, auditory and visual hallucinatory experiences, and magical thinking. Early studies on the nature of PLEs emphasised them as risk factors for psychosis (Yung, Phillips, Yuen, & McGorry, 2004; Poulton, Caspi, Moffitt, Cannon, Murray, & Harrington, 2000). However, other studies have refuted this claim as PLEs have been frequently reported in the general healthy population (Brett, Johns, Peters, & McGuire, 2009; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Van Os, Hanssen, Bijl, & Ravelli, 2000) and observed in individuals with complex mental health problems (Wilson et al., 2017) such as trauma and post-traumatic stress disorder (PTSD; Alemany et al., 2011; Scott, Chant, Andrews, Martin, & McGrath, 2007), depression and anxiety (Johnson, Cohen, Kasen, & Brook, 2005; Hanssen, Bijl, Vollebergh, & Van Os, 2003) and emotion dysregulation (Kramer et al., 2012), without further progression to psychotic disorders. Thus, Stochl et al. (2015) proposed that PLEs are on a continuum of common mental distress with anxiety and depression, with their presence reflecting more complex presentations.

Psychotic-like Experiences in BPD and Traits of BPD

Borderline personality disorder (BPD) is a mental health condition marked by prolonged and distinct patterns of impulsivity, emotional instability, interpersonal difficulties, and self-image impairment (American Psychiatric Association, 2013). Given the complexities that are frequently present in individuals diagnosed with BPD, such as co-morbid mood disorders, complex trauma and PTSD, and depression and anxiety, it is unsurprising that PLEs are also a common occurrence. The condition was first referred to individuals who were on the border of psychosis (Stern, 1938). As such, features of PLEs are often thought of as an important feature in BPD as a mental health condition. Recent studies showed that nearly half of individuals diagnosed with BPD reported PLEs, such as auditory and visual hallucinations (AVH), thought insertion and thought blocking/withdrawal, and symptoms of derealisation and depersonalisation (e.g., Niemantsverdriet et al., 2017; Yee, Korner, McSwiggan, Meares, & Stevenson, 2005; Barnow, Arens, Sieswerda, Dinu-Biringer, Spitzer, & Lang, 2010). In many cases, PLEs such as auditory hallucinations are of similar severity and duration to those found in psychotic disorders such as Schizophrenia (Slotema, Daalman, Blom, Diederen, Hoek, & Sommer, 2012; Kingdon et al., 2010).

Research on the experiences of psychotic-like experiences within young people with emerging traits of BPD, such as difficulties in regulating emotions and intense and unstable interpersonal relationships, are scarce. Nevertheless, there are some studies that suggest BPD traits are often prevalent in young people who are at risk of developing a psychotic illness, also known as at-risk mental states (ARMS). It is estimated that 14.6% to 21% of young people with ARMS have co-morbid BPD traits, such as difficulties with emotions and relationships. (Rosen, Miller, D'Andrea, McGlashan, & Woods, 2006; Schultze-Lutter, Klosterkötter, Michel, Winkler, & Ruhrmann, 2012; Thompson et al., 2012). In a study that employed a large sample of 171 psychiatric outpatients aged 15 to 18 years, adolescents with full-threshold BPD had more psychotic symptoms than subthreshold BPD (p<.001), and both groups had more psychotic symptoms that adolescents with no BPD traits (p<.001). Amongst the psychotic symptoms reported were states of confusion, paranoia, visual hallucinations and strange thoughts (Thompson, Cavelti, & Chanen, 2018).

Perhaps a more pressing matter is the debilitating nature of these PLEs. Kingdon et al. (2010) showed that adult patients with BPD who also experienced auditory hallucinations, were likely to show greater distress and more negative content of voices compared to those with schizophrenia and both diagnoses. In another study by Slotema, Daalman, Blom, Diederen, Hoek and Sommer (2012), patients with BPD reported daily experiences of AVH for a mean duration of 18 years and perceived these hallucinations as highly distressing. Francey, Jovev, Phassouliotis, Cotton, and Chanen (2018) showed that young people with first-episode psychosis (FEP) and co-morbid BPD were likely to have other comorbidities and were at higher risk of suicide and violent behaviour. This clinical group also had poorer access to standard treatment compared to young people with FEP only.

The Role of Diagnostic Systems

In spite of the debilitating presence of PLEs, diagnostic systems have failed to incorporate these difficulties into a framework of BPD. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM; American Psychiatric Association, 2013) states as one of the criteria for diagnosed BPD (Criteria 9) that during times of extreme stress, transient paranoid ideation and/or symptoms of dissociation (eg, depersonalization) may occur, but that these symptoms are generally of sub-clinical severity or duration to warrant any additional diagnosis. Such strict definition of what constitutes PLEs poses difficulty and resistance in clinical practice to investigate these experiences in individuals with BPD (Schroeder, Fisher, & Schäfer, 2013).

Thesis Rationale

While there is evidence that PLEs occur in individuals with BPD, the phenomenology or subjective experience of these experiences is unclear. Complexities are common in individuals diagnosed with BPD and research has found positive correlations between these complexities and sub-clinical and clinical psychotic symptoms (Schroeder, Fisher, & Schäfer, 2013). Hence, this thesis portfolio attempts to address the gap by conducting a systematic review of quantitative studies which investigates the relationship between psychological factors (i.e., trauma, stressful life experiences) and psychiatric co-morbidities (i.e. mood disorders, substance use disorders) and psychotic symptoms in adult individuals diagnosed with BPD. The lack of understanding of the nature of PLEs in young people with traits of BPD provided a rationale for the empirical paper which focuses on a qualitative investigation of PLEs in young people with BPD traits.

Before proceeding with the following thesis chapters, the term psychotic symptoms (used primarily within the systematic review) and psychotic like experiences (used within the qualitative empirical paper) are explained in detail. The systematic review primarily includes studies which pre-defined symptoms of psychosis, based on diagnostic criteria set by the DSM or the International Classification of Diseases (ICD-10; Tzitzivacos, 2007). These psychotic symptoms often include AVH, delusions and dissociation. However, the term ‘psychotic symptoms’ is limiting to the aims of the qualitative empirical paper. The term ‘psychotic-like experiences’ is used mainly in the qualitative empirical study as it endeavours to understand a continuum of experiences in BPD traits described by the participants which may be outside of what is typically seen as symptoms of psychosis (i.e.

AVH and delusions). Other experiences may be relevant to young people with BPD traits, such as symptoms of depersonalisation and derealisation, paranoid ideas and/or bizarre thinking and magical thinking. By not limiting the definition of what constitutes ‘psychotic’, it allows the participants to describe and define their experiences in their own terms.

The Researcher’s Epistemological and Ontological Position

This thesis seeks to utilise both quantitative and qualitative research methodologies to answer its research questions. These methodologies have traditionally adopted different positions on ontology and epistemology, i.e. assumptions made about the nature of reality and how knowledge is acquired (McEvoy & Richards, 2006). As such, it is important for the researcher’s ontological and epistemological position to be described. The researcher’s position for this research was underpinned within the philosophy of critical realism, which posits the view that there is more to reality than can be empirically known, but reality is not entirely constructed through and within human knowledge or discourse (Fletcher, 2017).

As a philosophical stance, critical realism serves as “a general methodological framework for research but is not associated with any particular set of methods” (Fletcher, 2017, p. 182). True to its ontological stance, critical realism argues for the pragmatic approach that enables for any strategies necessary to investigate the truth; it is concerned with taking the best possible approach to arrive to a conclusion (Scott, 2007). As a critical realist, the researcher is interested in exploring detailed descriptions of what, why and how of PLEs in individuals diagnosed with BPD and young people with BPD traits. This is explored through the use of a systematic review of quantitative studies which gathers information on co-morbidities associated with PLEs in individuals diagnosed with BPD. A narrative synthesis of quantitative studies was utilised given the available published literature in the area. As much less is known about the nature of PLEs in young people with BPD traits, a qualitative approach was employed within the empirical study. The study endeavours to understand participants' (young people with BPD traits) own subjective reality of what PLEs means to them (i.e. What are the nature of these experiences? How are they appraised? How are they responded to?).

Chapter Two

Systematic Review

Comorbidities Associated with Psychotic symptoms in Borderline Personality Disorder: A Systematic Review

Prepared for submission to Clinical Psychology Review

Word Count: 9902

Comorbidities Associated with Psychotic symptoms in Borderline Personality Disorder: A Systematic Review

AISYA MUSA[1], SIAN COKER[2], ROSE PAPADOPOULLOS[3], JOANNE HODGEKINS[4*]

[1] *Trainee Clinical Psychologist, Doctorate in Clinical Psychology University of East Anglia, UK.*

[2] *Professor of Clinical Psychology and Deputy Head of Department , School of Medicine, University of East Anglia, UK.*

[3] *Trainee Clinical Psychologist, Doctorate in Clinical Psychology University of East Anglia, UK.*

[4] *Clinical Senior Lecturer in Clinical Psychology,Postgraduate Research Director Department of Clinical Psychology, School of Medicine, University of East Anglia, UK.*

***Requests for reprints should be addressed to:**

Joanne Hodgekins, University of East Anglia, Department of Clinical Psychology, School of Medicine, Norwich Medical School, University of East Anglia Norwich NR4 7TJ

Email: J.Hodgekins@uea.ac.uk

Keywords

Borderline Personality Disorder; Psychosis; Psychotic Symptoms; Comorbidity; Psychological; Psychiatry; Mental health; Systematic Review; Adults

Abstract

This systematic review explores the psychological and psychiatric comorbidities associated with the presence of psychotic symptoms in individuals with borderline personality disorder (BPD). PsycINFO, PubMED, Scopus and GoogleScholar databases were searched to find articles published in the English language between January 1980 and October 2018. All quantitative studies addressing co-morbidities, including psychological factors and psychiatric diagnoses, associated with psychotic symptoms in adults with BPD were included. From the 12 included studies, the data extracted included: study characteristics, participants information, diagnostic criteria, the measures used to assess comorbidities and psychotic symptoms, and relevant reported findings. The methodological quality of studies was evaluated using the Quality Assessment Tool for Studies with Diverse Designs (QATSDD) tool. All included studies received medium to good quality ratings. A positive association was found between childhood trauma, stressful life experiences and psychotic symptoms in BPD. A lack of consistent evidence exists for other co-morbidities. This may be a reflection of the many complexities often present in BPD and lack of understanding of psychotic symptoms in BPD. Future studies should endeavour to employ prospective study designs to allow for the exploration of causal roles of co-morbidities in the relationship between psychotic symptoms and BPD.

1. Introduction

1.1. Borderline Personality Disorder and Psychotic Symptoms

Psychotic symptoms have been found to be a prominent feature of borderline personality disorder (BPD; Slotema, Daalman, Blom, Diederen, Hoek, & Sommer, 2012). Early views of BPD described individuals as existing on the border between neurosis and psychosis (Stern, 1938). Psychotic-like phenomena in the context of a diagnosis BPD are however, not well understood. This is due partly to a lack of consensus on the phenomenology and severity of these experiences (Slotema et al., 2012). According to the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5), 'positive' psychotic symptoms, (also known as 'pseudo-psychosis') such as paranoia, may only occur briefly in BPD during times of distress, (American Psychiatric Association, 2013). However, the concept and validity of pseudo-psychosis is somewhat questionable, with limited empirical evidence for its existence (Barnow et al., 2010). Despite a lack of definition, it has nonetheless been argued that psychotic symptoms in BPD may be broadly divided into perceptual abnormalities and paranoid ideation (Schroeder, Fisher & Schäfer, 2013).

Several cross-sectional studies found the presence of persistent psychotic symptoms in a significant proportion of individuals with BPD contradicting the DSM definition of a stress transient pseudo-psychosis. According to Pearse, Dibben, Ziauddeen, Denman, and McKenna (2014), 60% of individuals with BPD experienced psychotic symptoms, unrelated to drugs or mood disorder. The majority of this sample reported experiencing persistent negative and derogative auditory hallucinations and a fifth reported experiences of delusions. In another study, auditory and visual hallucinations (AVH) in individuals with BPD were found to be phenomenologically similar compared to individuals with schizoaffective disorders, with AVH occurring daily for up to a mean duration of 18 years (Slotema, Daalman, Blom, Diederen, Hoek, & Sommer, 2012). In contrast, Glaser, Van Os, Thewissen and Myin-Germeys (2010) found more transient stress-related psychosis similar to the descriptions in the DSM, as individuals with BPD experienced significant increase in psychotic symptoms as a consequence to daily life stress.

Despite difficulties conceptualising psychotic symptoms in BPD, investigating the factors that contribute to these psychotic experiences is important in providing clarity for the complexities often faced by individuals with BPD and informing research into appropriate treatments.

1.2. The role of comorbidities

As individuals with BPD often meet diagnostic criteria for other mental health conditions, such as complex trauma and post-traumatic stress disorder (PTSD; Barnicot, & Priebe, 2013), mood disorders (MD; Gunderson et al., 2014), and substance use disorders (SUD; Walter et al., 2009), it has been suggested that the appearance of psychotic symptoms may be related to these comorbidities (Barnow, Arens, Sieswerda, Dinu-Biringer, Spitzer, & Lang, 2010).

Trauma and PTSD. There is accumulating evidence to suggest that trauma, particularly childhood trauma, predicts the occurrence of psychotic symptoms in both clinical and non-clinical populations (Berenbaum, Thompson, Milanak, Boden, & Bredemeier, 2008). Some studies argue that more severe childhood trauma leads to more severe psychotic symptoms (e.g., Gracie, et al., 2007), whereas other studies find an association between different types of childhood trauma and different types of psychotic symptoms. For example, experiences of childhood sexual and physical abuse have been shown to increase the likelihood of AVH in later life (Shevlin et al., 2011). A comparison study found that individuals with persecutory delusions had significantly higher levels of childhood emotional abuse than those without persecutory delusions (Ashcroft, Kingdon,

& Chadwick, 2012). Trauma experienced as an adult is less associated with psychotic symptoms compared to childhood trauma, which may suggest that childhood trauma affects neurodevelopmental changes which in turn increase the risk of psychosis (Read, Agar, Argyle, & Aderhold, 2003). Considering that 40-76% individuals with BPD experience childhood trauma (Zanarini, 2000), and 58-79% have comorbid PTSD (Sack, Sachsse, Overkamp, & Dulz, 2013), it is possible that psychotic symptoms may be associated with these experiences.

Mood Disorders. Individuals with BPD often meet diagnostic criteria for other mental health conditions such as MD (Grant et al., 2008), which may indicate that psychotic symptoms are related to comorbid MD, rather than BPD per se. Comparison studies support this view. Benvenuti et al. (2005) found that in individuals with BPD with and without a MD, lifetime domains of manic-hypomanic mood dysregulation were associated with psychotic symptoms. In another study, the researchers compared symptoms of psychosis in patients with BPD, depression or both conditions and found that psychotic symptoms were related to depression in patients with BPD (Nishizono-Maher, Ikuta, Ogiso, Moriya, Miyake, & Minakawa, 1993).

Substance Abuse. BPD and SUD co-occur frequently, with estimates of 9% (community samples) to 65% (treatment samples) of individuals with SUD also meeting diagnostic criteria for BPD (Trull, Sher, Minks-Brown, Durbin, & Burr, 2000). Both longitudinal studies and meta-analyses have found evidence of cannabis use as being a significant risk factor in the onset of psychotic symptoms (Kuepper, van Os, Lieb, Wittchen, Höfler, & Henquet, 2011; Large et al., 2011). A cross-sectional study found that the risk of developing psychotic symptoms increases between twofold to threefold with recreational methamphetamine use (Mcketin, Hickey, Devlin, & Lawrence, 2010). Smith et al. (2009) found that 27% of opiate users and up to 100% of severely dependent amphetamine users had psychotic symptoms during the use of or withdrawal phases of these substances. Therefore, individuals with BPD and co-occurring SUD may have an increased risk of developing psychotic symptoms.

1.3. Rationale for systematic review

Previous reviews have extensively reviewed the prevalence and phenomenology of psychotic symptoms in individuals with BPD. For example, Merrett, Rossell, and Castle (2016) investigated the phenomenology of voices in individuals with BPD by systematically reviewing papers that compared the experiences of voices in individuals with psychotic disorders and BPD. Another review examined hallucinations as a whole in individuals with BPD to further understand phenomenology (Gras, Amad, Thomas, & Jardri, 2014). A narrative review by Barnow and colleagues (2010) explored psychosis in BPD, and potential biopsychosocial moderators, comorbidities and treatment. However to date, there is no review that has systematically investigated comorbidities associated with the experience of psychotic symptoms in individuals with BPD. This is the aim of the current review.

1.4. Systematic Review Research Question

1. What are the comorbidities, such as psychological factors and psychiatric diagnoses, that are associated with the experience of psychotic symptoms in adult individuals with BPD?

2. Method

Protocol and registration

In line with good practice, a review protocol was written and registered with PROSPERO: International prospective register of systematic review prior to the literature search and data extraction began (registry ID: CRD42018085672).

2.1. Eligibility Criteria

The review included peer-reviewed research articles that were published in English only. Unpublished studies or grey literature were not included. The systematic search of empirical studies was restricted between the publication years of 1980 to October 2018. The year 1980 was chosen as a starting point because it was the year that the American Psychiatric Association (APA, 1980) provided reliable criteria for BPD. The inclusion and exclusion criteria of the review follow the PICOS (participants, interventions, comparisons, outcomes, and study design) framework (Moher, Liberati, Tetzlaff, Altman, & Group, 2009), and are described below.

Type of participants: All studies which included adult individuals diagnosed with BPD who also experienced psychotic symptoms, from the age of 18 and above, were included. The age of 18 was set to capture breadth of research which had investigated psychotic symptoms within adults with diagnosed BPD and allowed sufficient papers to be included in the review. Furthermore, limited information was available for those below the age of 18, children and adolescents diagnosed with BPD. This may be due to the potentially controversial nature of the diagnosis and the reluctance of clinicians to label young people with this diagnosis (Chanen, 2015). All participant samples were required to be diagnosed with BPD using the diagnostic criteria specified under the Diagnostic and Statistical Manual of Mental Disorders (DSM) and/or International Statistical

Classification of Diseases and Related Health Problems (ICD). Accordingly, the review excluded any empirical studies where the sample was below 18 years old and did not have a formal diagnosis of BPD.

Type of comorbidities: This review focused on investigating the co-morbidities associated with psychotic symptoms in BPD. In this review co-morbidities are defined as any psychological factors and psychiatric diagnoses that may be related to psychotic symptoms in BPD. Psychological factors included trauma, such as traumatic life events, physical assault, sexual abuse, emotional abuse, and physical and emotional neglect experienced in childhood (Bernstein et al., 2003). Trauma experienced during adulthood was also considered. Psychiatric co-morbidities may include PTSD, MD such as major depressive disorder and bipolar disorder, and SUD. Studies that investigated other psychological factors and psychiatric diagnoses could be considered if they were explored in relation to psychotic symptoms in BPD.

Type of outcomes: Studies were required to have assessed symptoms of psychosis, via past medical records, structural clinical interviews based on diagnostic criteria (First, Spitzer, Gibbon, & Williams, 1995), semi-structured interviews such as the Comprehensive Assessment of At Risk Mental States (CAARMS; Yung, Yuen, Phillips, Francey, & McGorry, 2003), or validated questionnaires such as the Community Assessment of Psychic Experiences questionnaire (CAPE; Konings, Bak, Hanssen, Van Os, & Krabbendam, 2006). Psychotic symptoms included perceptual abnormalities such as AVH, and paranoid ideation such as delusionary beliefs (Slotema, Daalman, Blom, Diederen, Hoek, & Sommer, 2012). Dissociative experiences, unrelated to dissociative disorders, may be included as potential psychotic symptoms if experiences were explained in relation to other psychotic symptoms (Hlastala, & McClellan, 2005).

Type of studies: Quantitative empirical studies addressing co-morbidities, such as psychological factors and psychiatric diagnoses, associated with psychotic symptoms in individuals with BPD were included in the review. Study designs included randomised controlled trials, quasi-controlled trials, cross-sectional, prospective, and longitudinal studies. Qualitative studies, case-controlled studies and reviews were excluded as the review was interested in collating quantitative evidence on the relationship between co-morbidities and psychotic symptoms in BPD.

2.2. Search Terms

A systematic search was performed using the following electronic databases PsycINFO, PubMED, Scopus, and GoogleScholar, from the period of January 1980 to October 2018. The titles, abstracts, and key words were searched using the following search terms in order to identify eligible papers: ‘borderline personality disorder’ or ‘BPD’ or ‘emotionally unstable personality disorder’(EUPD) or ‘EUPD’; combined with ‘psychotic symptoms’ or ‘psychotic-like experiences’ or ‘psychosis’ or ‘hallucination’ or ‘dissociation’ or ‘delusion’; and further combined with ‘psychological risk factors’ or ‘trauma’ or ‘childhood trauma’ or ‘physical abuse’ or ‘sexual abuse’ or ‘emotional abuse’ or ‘neglect’ or ‘stressful life event’ or ‘comorbidity’ or ‘mood disorders’ or ‘anxiety disorders’ or ‘post-traumatic stress disorder’ or ‘PTSD’ or ‘complex trauma’ or ‘substance abuse’ or ‘substance use dependence’ or ‘SUD’. Full search terms for each electronic database can be found in Appendix C.

2.3. Study Selection

After conducting systematic searches, the number of studies found in the electronic databases were recorded in the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram. The search results were transferred to an online reference manager (Zotero) and all relevant studies were screened for duplicates and these were removed. Studies were then reviewed by the first author (ANM). To identify the final research articles to be included in the review, a two-step screening method was employed, as suggested in the PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The eligibility of studies was assessed by ANM via screening the title and abstracts of studies. If it was unclear if a study was relevant for inclusion based on its title and abstract, it was included for further assessment. The PRISMA diagram records the number of included and excluded studies. Secondly, the full text of relevant studies were read and screened independently by the first and final authors respectively (ANM and JH), to establish if the studies met the eligibility criteria for inclusion. Both authors discussed and agreed on the final number of studies to be included in the systematic review. If the same data set was used in more than one eligible article, the article that was judged to provide the best description of methods and results was included. The reference lists of included studies were searched to identify any further studies which may have been missed.

2.4. Data Extraction Process

Information extracted from studies included; author and year of publication, study setting, study design, participant information, diagnostic criteria, measures used to assess for comorbidities and psychotic symptoms, and relevant results of the empirical studies. The data were extracted by the first author (ANM).

2.5. Quality assessment of Individual Studies

The quality of included studies was assessed using the 16-item Quality Assessment Tool for Studies with Diverse Designs tool (QATSDD; Sirriyeh, Lawton, Gardner, & Armitage, 2012). The QATSDD tool was developed to critically appraise studies that employ various methodological designs (Appendix D). It assesses study quality using 16 items, which are scored depending on whether the criteria are met (complete=3 points, moderately=2 points, very slightly = 1 point) or not (not at all = 0 point). For each included study a score was awarded for each of the criteria; 14 of the criteria apply to quantitative studies, and 14 apply to qualitative studies, while all 16 items are applicable to studies which employed mixed methods design. The maximum total quality score is 42 for both quantitative and qualitative studies, and 48 for mixed-method studies.

Where authors failed to provide the detail required to make a scoring judgment for an item, a score of 0 was awarded for that item. The sum of the scores was then expressed as a percentage of the maximum possible score, and it was this score that provided an overall score of quality for each paper. Studies scoring above 75% were considered as “high” quality, those between 50% and 75% considered as “good”, 25%–50% considered as “moderate”, and below 25% considered as “poor” (Gillham, & Wittkowski, 2015). Quality assessments were independently rated by the first author and a member of the research team (ANM and RP). Any differences in quality ratings of studies were discussed and resolved until agreement on the scoring was reached .

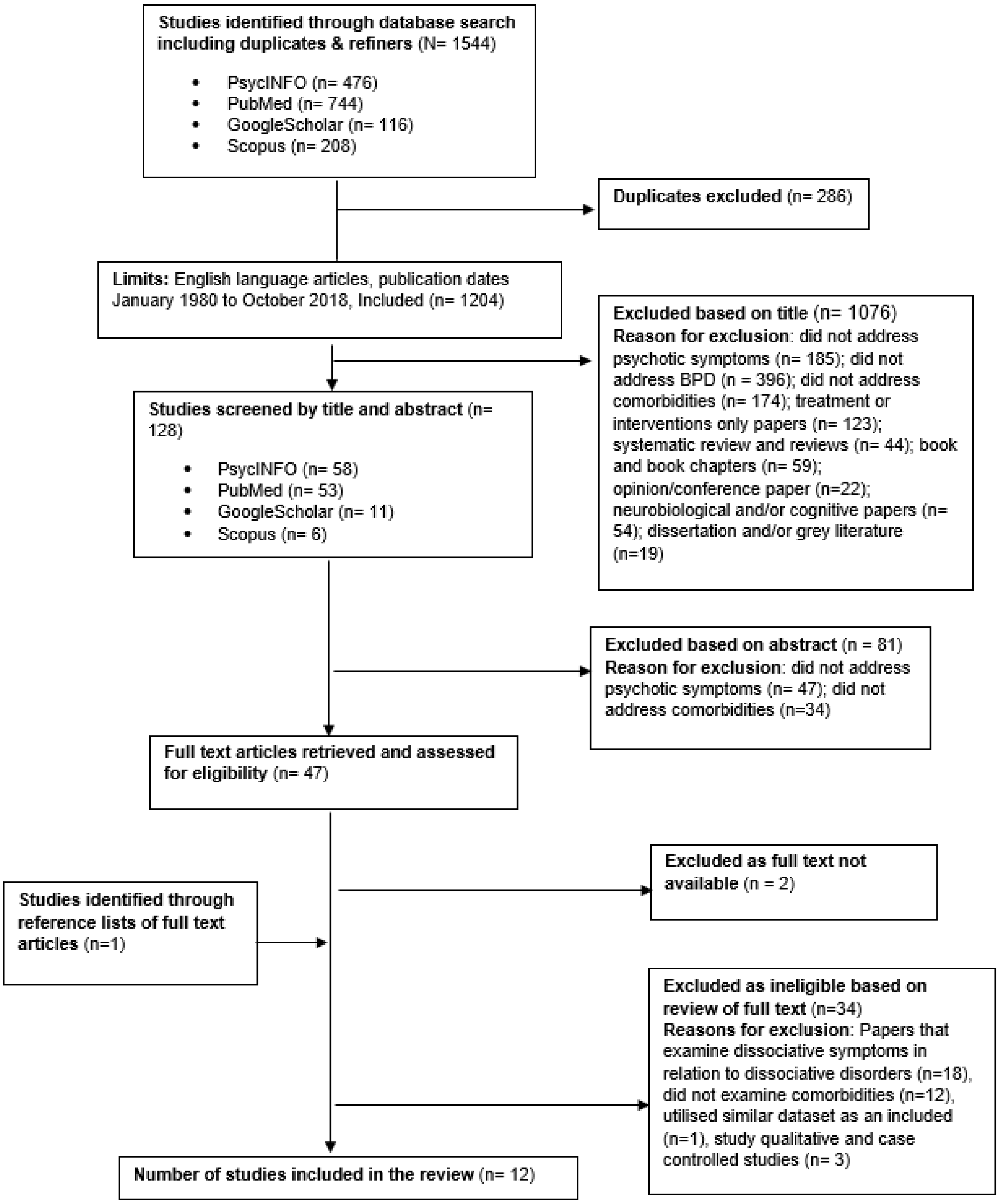


Figure 1: PRISMA Flow Diagram

Table 1: Quality Assessment of Included Studies, by means of the QATSDD tool

QATSDD Items Included Studies	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	Total	Quality Rating (%)
Wearne et al., 2017	2	1	3	0	0	1	2	0	0	1	N/A	3	3	N/A	0	2	18	Moderate (42.9)
Catalan et al., 2017	3	3	0	0	2	0	1	1	1	1	N/A	3	2	N/A	0	0	17	Moderate (40.5)
Niemantsverdriet et al., 2017	3	3	3	0	2	1	0	3	1	3	N/A	3	1	N/A	0	2	25	Good (59.5)
Glaser et al., 2010	3	3	3	0	2	2	1	1	2	1	N/A	3	3	N/A	0	2	26	Good (61.9)
Perry, 1988	1	3	3	0	1	1	0	1	0	3	N/A	3	0	N/A	0	0	16	Moderate (38.1)
Perugi et al., 2013	3	3	3	0	3	3	0	3	0	3	N/A	3	3	N/A	0	3	30	Good (71.4)
Nishizono-Maher et al., 1993	3	3	3	0	0	1	2	3	0	3	N/A	3	0	N/A	0	0	21	Moderate (50)
Pope et al. (1985)	3	1	0	0	0	1	1	1	0	2	N/A	2	0	N/A	0	0	11	Moderate (26.2)
Miller et al., 1993	2	2	3	0	0	3	2	3	0	3	N/A	3	0	N/A	0	0	21	Moderate (50)
Barral et al., 2018	3	3	3	0	0	3	1	3	0	2	N/A	2	1	N/A	0	2	23	Good (54.8)
Benvenuti et al., 2005	2	3	3	0	0	3	2	0	3	3	N/A	3	1	N/A	0	2	25	Good (59.5)
Goodman et al., 1991	3	2	2	0	0	1	1	1	0	2	N/A	2	0	N/A	0	0	14	Moderate (33)

Note. N/A = Non-applicable; 1= Explicit theoretical framework; 2 = Statement of aims/objectives in main body of report; 3=Clear description of research setting; 4 = Evidence of sample size considered in terms of analysis; 5= Representative sample of target group of a reasonable size; 6 = Description of procedure for data collection; 7 = Rationale for choice of data collection tool(s); 8 = Detailed recruitment data; 9 = Statistical assessment of reliability and validity of measurement tool(s); 10 = Fit between stated research question and method of data collection; 11 = Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative); 12 = Fit between research question and method of analysis; 13= Good justification for analytical method selected; 14 = Assessment of reliability of analytical process (Qualitative); 15 = Evidence of user involvement in design; 16 = Strengths and limitations critically discussed

Table 2. Summary of study characteristics

Author	**Study Design**	**Study Sample**				**Diagnostic Criteria for BPD**	**Measure of Comorbidity**	**Measure of Psychotic Symptoms**	**Statistical Analysis**
		Sample Description	**Sample size, N (% attrition)**	**Female, n (%)**	**Age (years)**				
1. Wearne et al. (2017) Australia	Between Subjects, Cross-Sectional Design	Outpatient/ Community sample of PTSD, BPD and schizophrenia	Overall N = 65 Cluster 1: BPD, N = 5 Schizophrenia, N = 10 PTSD, N = 21 Cluster 2: BPD, N = 4 Schizophrenia, N= 3 PTSD, N = 13	Overall N = 35 (53.8) Cluster 1: N = 28 (77.8) Cluster 2: N = 7 (35)	Cluster 1: 47.84 (13.87) Cluster 2: 43.83 (13.71)	DSM-5 Criteria	Childhood trauma and trauma in adulthood = Data collected on emotional, sexual and physical abuse Dissociative Experiences = DDI	Hallucinations, including distress, preoccupation and insight = PSYRAT	K-Means cluster analysis, p<0.05
2. Catalan et al. (2017) Netherlands	Between subjects, Cross-sectional Design	Inpatient FEP; Outpatient BPD; Community HC	Overall N = 270 FEP, N=61 BPD, N=36 HC, N =173	Overall N = 129 (47.8) FEP = 25 (41) BPD = 25 (69.4) HC = 79 (45.7)	Between 18 and 60 years FEP= 36.1 (12.5) BPD = 37.5 (10.7) HC = 31.9 (11.6)	DSM-IV-TR Criteria	Childhood trauma = CTQ-SF Parental rearing styles = PBI	Psychotic dimension = CAPE	GLM, adjusting for variables such as age, sex, cannabis abuse, IQ, socio-demographic level and group, p<.05

3. Niemanstverdriet et al. (2017) Netherlands	Within Subjects, Cross-sectional Design	Outpatient/ Community sample of BPD	Overall N = 324 telephone interview N= 107 (8% attrition) face-to-face interview	Telephone interview, N = 300 (92.6); Face-to-face interview, N = 100 (93.5)	≥18 Telephone interview = 37.4 (10.8) Face-to-face interview = 37.3 (11.1)	DSM-IV-TR Criteria	Childhood trauma = CTQ-SF Life stressors = LSC-R Co-morbid psychiatric disorders = MINI PLUS 2000	AVH = PSYRAT Severity of psychotic symptoms = PANSS	Kendall’s tau for correlation analyses, p<.05
4. Glaser et al., 2010 Netherlands	Between Subjects, Cross-sectional Design	Outpatient BPD; Inpatient PSY; Outpatient CPD; Community HC	Overall N = 224 BPD, N = 56 PSY, N = 81 CPD, N = 38 HC, N = 49	BPD, N= 48 (85.7); PSY =18 (22.2); CPD= 23 (60.5); HC= 25 (51)	BPD= 36.9 (8.8) [19–55] PSY = 35.8 (10.7) [18–63] CPD= 39.3 (12.0) [18–59] C= 35.2 (8.8) [21–50]	DSM-IV Criteria	Daily life stresses = ESM	Paranoia and AVH = ESM	Multilevel or hierarchical linear modelling, p<.05

5. Perry, 1988 UK	Prospective Design, with follow up conducted every 3 to 6 months	Community/Outpatient BPD, other borderline (eg., traits or with ASP), ASP only, Bipolar II	Overall N = 52 BPD, N = 16; Other borderline, N = 15; ASP only, N = 7; Bipolar II, N = 14	Not known	18-39 years	DSM-III Criteria	Daily life stresses = Life events interview	Weekly changes in psychotic symptoms (e.g., illusion, idea of reference, hallucinations, delusions) = LIFE-ASP	Spearman's correlation, p<.05
6. Perugi et al., 2013 Italy	Between Subjects, Cross-sectional Design	Inpatient and Outpatient MDE, MDE with BPD	Overall N = 2658 BPD+, N= 528	BPD+, N = 259 (67.6) BPD-, N = 1364 (60.5)	BPD+ = 40.8 (12.0) BPD- = 45.0 (13.3)	DSM-IV-TR Criteria	Psychiatric co-morbid diagnoses based on DSM-IV-TR Hypomania/mania = MINI PLUS 2000 and self-report HCL-32	Psychotic features = structured protocol	Chi-squared test and Student's t-test. Bonferroni-corrected threshold of p=0.0016
7. Nishizono-Maher et al., 1993 Japan	Between Subjects, Cross-sectional Design	Outpatient BPD, BPD + MD, MD, No BPD and MD	Overall N = 75 Gp 1 (BPD + MD), N = 16; Gp 2 (BPD, no MD), N = 15;	75 (100)	18 and 30 Gp 1 = 23 (3) Gp 2 = 22.5 (3.1) Gp 3 = 22.6 (2) Gp 4 = 22.8 (2.9)	DSM-III Criteria	Psychiatric co-morbid diagnoses based on DSM-III	Narrowly defined and broadly defined psychotic symptoms = DIB second version	Kruskal-Wallis test and Bonferroni's correction was then applied, p<.05

			Gp 3 (MD, no BPD), N = 15; Gp 4 (no BPD, no MD), N = 29						
8. Pope et al., 1985 USA	Prospective Design, with 4 to 7 year follow up	Inpatient BPD Outpatient/ Community HC	Overall N = 48 BPD, N = 33; HC, N = 15	BPD, N 27 (81.8) HC, N = 12 (80)	BPD = 25.7; 18-42 HC = 28.5; 17-35	DSM-III Criteria	MD: Chart review of DSM-III diagnoses	Organic and Functional DSM-III psychosis = DIB	Fisher’s exact test, p<.05
9. Miller et al., 1993 US	Between-Subjects Cross-sectional Design	Inpatient BPD, BPD + SUD, BPD + MD, BPD + SUD + MD	Overall N = 92 BPD only, N = 8; BPD + SUD, N = 17; BPD + MD, N = 32; BPD + SUD + MD, N = 35	74 (80)	29 (6); 18 and 45	DSM-III Criteria	BPD including MD + SUD: Chart review of DSM-III diagnoses	Narrowly defined psychotic symptoms = Chart review	Chi-squared analysis, p<.05

10. Barral et al., 2018 Spain	Within Subjects, Cross-Sectional Design	Outpatient SUD-BPD	Overall N = 91	46 (50.5)	34.01 (9.37)	DSM-IV Criteria	SUD = ad-hoc questionnaire about clinical variables and SCID-I	SIP and transient psychotic experiences = ad-hoc questionnaire and SCID-I	Logistic regression analysis, p<0.05
11. Benvenuti et al., 2005 Italy	Between Subjects, Cross-Sectional Design	Outpatient BPD with or without lifetime MD	Overall N = 60 BPD + MD, N= 39; BPD only, N = 21,	41 (68.3)	30.5 (7.8); range 18–55	DSM-IV	MD = SCID-II, and DIB and MOODS-SR.	Psychotic symptoms, including hallucinations and delusions = SCI-PSY	Pearson's r correlation coefficient, p<.05
12. Goodman et al., 1991 US	Within Subjects, Cross-Sectional Design	Inpatient BPD	107	107 (100)	25.02 (6.85)	DSM-III-R Criteria	MD = SCID-Patient Version semi-structured Interview CAB = APD DSM-III-R criteria	Psychotic symptoms: SCID-Patient Version semi-structured interview	Pearson's correlation and logistic regression analysis, p<.05

Note. AVH = Auditory and visual hallucination; DSM = The Diagnostic and Statistical Manual of Mental Disorders; PSYRAT = Psychotic Symptoms Rating Scale; CAPE = The Community Assessment of Psychic Experiences; DDI = Depersonalization–Derealization Scale; PBI = Parental Bonding Instrument; PANSS = Positive and Negative Syndrome Scale; CTQ-SF = Childhood Trauma Questionnaire Short-Form; MINI PLUS 2000 = MINI-International Neuropsychiatric Interview; LSC-R = Life Stressor Checklist-Revised; LIFE-ASP = Longitudinal interval Follow-up Examination – Adapted for the Study of Personality; HCL-32 = Hypomania Checklist for self-assessment; DIB = Diagnostic Interview for Borderlines; SCID/SCID-I = Structured Clinical Interview for DSM-III; SCID-II = Structured Clinical Interview for DSM-IV; SCI-PSY = Structured Clinical Interview for Psychotic Spectrum; MOODS-SR = Structured Clinical Interview for Mood Spectrum; BPD = Borderline personality disorder; FEP = first episode psychosis; SIP = Substance induced psychosis; MD= mood disorders; PTSD = Post-traumatic stress disorder; SUD = Substance use disorder; HC = Healthy controls; CPD = Cluster C personality disorder; PSY = Psychotic disorder; MDE = Major depressive episode; BP = Bipolar disorder; APD= Antisocial personality disorder; CAB = Childhood antisocial behaviour; ESM = Experience sampling method; GLM = General linear model; p = p-value

Table 3. Summary of Findings

	Trauma	Post-traumatic Stress Disorder (PTSD)	Stressful life experiences	Mood Disorder (MD)	Substance Use Disorder (SUD)	Other Psychotic Factors and Psychiatric Diagnoses
Wearne et al. (2017)	Positive Correlation. • Childhood trauma was better predictor of negative voices than psychiatric diagnoses. Higher rates of childhood sexual abuse were found in participants with BPD and PTSD, compared to Schizophrenia. • Higher rates of pseudo-hallucinations were more likely in participants experiencing adult military trauma	N/A	N/A	N/A	N/A	N/A
Catalan et al. (2017)	Positive Correlation. • Higher frequency of trauma in BPD, compared to FEP and HC, especially sexual abuse. Childhood emotional, physical and sexual abuse associated with positive psychotic symptoms.	N/A	N/A	N/A	N/A	Positive Correlation. • BPD reported affectionless control parenting style and lowest rate of optimal parenting style. Positive correlation between the mother ́s parenting styles, affectionless control parenting style and positive psychotic symptoms. Optimal care was inversely

						related to positive psychotic symptoms.
Niemanstverdriet et al. (2017)	Positive correlation between childhood trauma and severity of hallucinations, especially emotional abuse compared to sexual and physical abuse. Inverse relationship found in emotional neglect.	Positive correlation between PTSD and presence and severity of hallucinations.	Positive correlation between current life stressors and more severe types of hallucination.	No correlation between the presence and severity of hallucinations and MD and SUD	No correlations between the presence and severity of hallucinations and MD and SUD	N/A
Glaser et al. (2010)	N/A	N/A	Positive correlation • BPD reacted significantly more strongly with psychosis to stress than PSY and CPD. Effect sizes were small (<0.2SD) but not negligible. • AVH reactivity to daily life stress was higher in BPD than HC and CPD. • Paranoia was significantly more reactive to daily life stress in all clinical groups compared with HC	N/A	N/A	N/A
Perry (1988)	N/A	N/A	Positive Correlation. • Psychotic symptoms were more common	N/A	N/A	N/A

			within 8 weeks of a preceding life event, but difference was not significant due to low sample size.			
Perugi et al. (2013)	N/A	N/A	N/A	Positive Correlation. • BPD+ (BPD with MDE and BP) showed more psychotic symptoms (p=0.01), compared to BPD-	N/A	N/A
Nishizono-Maher (1993)	N/A	N/A	N/A	Inconclusive/ No Correlations • Narrowly defined psychotic symptoms: Rare in BPD. Observed in a patient who had co-morbid MD and cannabis abuse. • Broadly defined psychotic symptoms: No difference between groups that have BPD,	Inconclusive/ No Correlations • Narrowly defined psychotic symptoms: Rare in BPD. Observed in a patient who had co-morbid MD and cannabis abuse.	N/A

				BPD and MD and MD diagnoses, indicating MD does not have ‘additive effect’ on psychotic symptoms.		
Pope et al. (1985)	N/A	N/A	N/A	Positive Correlation: • Functional DSM-III psychosis: All seven patients with BPD displayed psychotic symptoms only at times when DSM-III full manic syndrome or depressive syndrome were displayed. On follow-up, six of seven patients were again given diagnosis of MD.	Inconclusive/ No correlations: • Organic DSM-III psychosis: No significant difference between BPD and HC. Present in one 19-year old male BPD patient who met criteria for several days after heavy drug use (drugs unknown).	N/A
Miller et al. (1993)	N/A	N/A	N/A	No correlation: • Patients with BPD and MD, regardless of whether they had SUD, were no more likely to experience psychotic symptoms than	No correlation: • Patients with BPD and SUD, regardless of whether they had MD, were no more likely to experience psychotic symptoms than	N/A

				were patients with no comorbid MD.	those without comorbid SUD.	
Barral et al. (2018)	N/A	N/A	N/A	Positive correlation between substance use and SIPs. Cocaine and cannabis dependence were risk factors in increasing SIPs development, particularly auditory hallucinations, in individuals with co-morbid SUD-BPD.	N/A	N/A
Benvenuti et al. (2005)	N/A	N/A	N/A	No correlation towards diagnosis of MD and psychotic symptoms. Mood spectrums within BPD and MD were positively correlated with psychotic features.	N/A	N/A
Goodman et al. (1991)	N/A	N/A	N/A	N/A	N/A	Positive correlation found between CAB severity and psychotic symptoms (p<.05).

Note. N/A= Not assessed; BPD = Borderline personality disorder; AVH = Auditory and visual hallucination; FEP = first episode psychosis; SIP = Substance induced psychosis; MD= mood disorders; PTSD = Post-traumatic stress disorder; SUD = Substance use disorder; HC = Healthy controls; CPD = Cluster C personality disorder; PSY = Psychotic disorder; MDE = Major depressive episode; BP = Bipolar disorder; APD= Antisocial personality disorder; CAB = Childhood antisocial behaviour; p = p-value

3. Results

3.1. Literature Search and Study Selection

A total of 1544 records were identified from the literature (see Figure 1 for PRISMA flow diagram). Of these, 128 potentially relevant reports were screened by title and abstract, resulting in 12 published empirical studies which met the inclusion criteria for the review.

3.2. Quality assessment

All included studies were assessed for their methodological quality (see Table 1). As all included studies utilised quantitative methodologies, QATSDD items related to qualitative studies (items 11 and 14) were non-applicable. Scores on the QATSDD ranged from moderate (e.g., Pope et al., 1985) to good quality (e.g., Perugi et al., 2013), with an overall mean of 50.7%. Overall, seven studies scored as moderate quality, and five studies were scored as good quality. No studies were rated as having poor or high quality.

3.3. Study Characteristics

Summaries of the characteristics of studies included, such as descriptions of study design, participants, study methodology, and measures used are provided in Table 2.

Description of Method. Various co-morbidities, including psychological factors and psychiatric diagnoses, were investigated to determine their associations with psychotic symptoms in BPD. Common co-morbidities included stressful life events, childhood trauma, trauma during adulthood and PTSD. Other co-morbidities included childhood antisocial behaviours (Goodman et al., 1999), parental care (Catalan et al., 2017), and dissociative experiences (Wearne et al., 2017). Seven studies employed a correlational, between-subjects design, while three studies (Niemantsverdriet et al., 2017; Goodman et al., 1991; Barral et al., 2018) employed a correlational, within-subjects design. Measures in these studies were only completed at one time-point. As studies were correlational, the studies could not determine causality, instead only commenting on associations. Only two studies employed a prospective design with one study (Perry, 1988) having a follow up every 3 to 6 months, and another (Pope et al., 1985) a follow up of 4 to 7 years. These studies provided some indication of cause and effect and strengthened the methodology. However, both these studies were conducted in the 1980s and with the change in conceptualisation of BPD and psychosis in the last few decades, it makes the generalisability of these findings questionable.

Comparison groups were heterogeneous across all nine studies. Five studies compared participants with BPD with individuals diagnosed with PTSD, schizophrenia, antisocial personality disorder, bipolar II disorders, first episode psychosis, cluster C personality disorder, psychotic disorder, and healthy individuals (Wearne et al., 2017; Perry, 1988; Catalan et al., 2017; Glaser et al., 2010; Pope et al., 1985). While these studies allowed for the comparison of BPD and different mental health conditions, it was difficult to ascertain whether co-morbidities impacted on psychotic symptoms in BPD alone. Four studies compared individuals diagnosed with BPD only, with individuals with BPD and other co-morbidities (Miller et al., 1993; Nishizono-Maher et al., 1993; Perugi et al., 2013; Benvenuti et al., 2005).

Description of Participants. The review included a total of 4066 participants diagnosed with BPD, with sample size ranging from 48 (Pope et al., 1985) to 2658 (Perugi et al., 2013). Six studies (Wearne et al., 2017; Perry, 1988; Catalan et al., 2017; Nishizono-Maher et al., 1993; Niemantsverdriet et al., 2017; Barral et al., 2018) used a sample of community/outpatient samples, while four studies (Glaser et al., 2010; Miller et al., 1993; Goodman et al., 1991; Pope et al., 1985) used inpatient samples. Two studies (Perugi et al., 2013; Benvenuti et al., 2005) used mixed outpatient and inpatient samples, which strengthened the sample selection.

Participants in all studies were 18 years old and above. One study did not report information on gender of participants (Perry, 1988). Three studies utilised female samples only (Goodman et al., 1991; Benvenuti et al., 2005; Nishizono-Maher et al., 1993). Females formed the majority of the sample in seven studies. Only one study, (Catalan et al., 2017) included more males than females. The over-representation of females may be a reflection of the fact that more females tend to be diagnosed with BPD (Sansone, & Sansone, 2011). All studies used different versions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) depending on year of publication of the study.

Description of Measures. Three studies (Catalan et al., 2017; Wearne et al., 2017; Niemantsverdriet et al., 2017) used validated questionnaires including the Community Assessment of Psychic Experiences (CAPE; Konings, Bak, Hanssen, Van Os, & Krabbendam, 2006), the Psychotic Symptoms Rating Scale (PSYRATS; Haddock, McCarron, Tarrier, & Faragher, 1999) and the Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein, & Opler, 1987).

Four studies used structural clinical interviews in screening for psychotic symptoms (Goodman et al., 1991; Benvenuti et al., 2005; Nishizono-Maher et al., 1993; Pope et al., 1985). The structural clinical interviews included the patient version of the Structured Clinical Interview for DSM-III-R (SCID; Spitzer, Williams, Gibbon, & First, 1992), the Structured Clinical Interview for Psychotic Spectrum (SCI-PSY; Sbrana et al., 2005), and items on psychosis within the first and second versions of the Gunderson’s Diagnostic Interview for Borderlines (DIB; Armelius, Kullgren, & Renberg, 1985). One study (Perry et al., 1988) utilised a semi-structured interview: The Longitudinal interval Follow-up

Examination – Adapted for the Study of Personality, which measures weekly changes in type and course of psychotic symptoms (LIFE-ASP; Shapiro & Keller, 1979).

Three studies employed alternative methods of assessing psychotic symptoms. Glaser et al. (2010) used eight items reflecting psychotic features, rated on a seven-point Likert scale. One study (Perugi et al., 2013) followed a structured protocol covering a thorough description of psychotic features; however, no specific information on assessed features of psychosis were provided. Barral et al. (2018) measured substance-induced psychotic symptoms such as self-reference, persecutory delusions, and hallucinations through the use of detailed questions developed as part of the research. Lastly, Miller et al. (1993) employed a chart review, whereby patient records that include accounts of psychotic episodes using the narrow definition of psychotic symptoms, such as delusions and AVH, were screened. While these studies provide indication of symptoms of psychosis, validity and reliability of these methods are uncertain and comparison across studies difficult.

3.4. Syntheses of Results

Summaries of relevant study findings for all 12 studies are provided in Table 3.

Trauma and PTSD. Three studies investigated the relationship between trauma and PTSD and psychotic symptoms in BPD, with quality assessment of studies being moderate (Wearne et al., 2017; Catalan et al., 2017) and good (Niemanstverdriet et al., 2017). All studies found a positive relationship between trauma, particularly childhood trauma, PTSD, and psychotic symptoms in individuals diagnosed with BPD.

Although Catalan et al. (2017) was rated as moderate quality, the overall sample size was large (N=270) and validated questionnaires such as the CAPE were used to measure psychotic symptoms which improved methodological vigour. They reported that patients with BPD were more likely to suffer childhood physical abuse, emotional abuse, sexual abuse, physical neglect, and emotional neglect, compared to patients with first episode psychosis (FEP) and healthy controls (HC). Childhood sexual abuse was experienced most frequently by patients with BPD (36%) followed by those with FEP (8%) and HC (2%). Regardless of diagnosis, there were positive associations between childhood emotional, physical and sexual abuse and positive psychotic symptoms, such as AVH and delusional beliefs.

Similarly, Wearne et al.'s (2017) found that childhood trauma was a better predictor of external, negative and uncontrollable voices than a diagnosis itself. The voices described within participants with BPD and PTSD were similar to those in participants diagnosed with schizophrenia; however, higher rates of childhood sexual abuse were found in participants with BPD and PTSD. Higher rates of pseudo-hallucinations (i.e., voices occurring internally and insight) occurred in participants who were more likely to have experienced adult military trauma, regardless of diagnosis. The study was rated as moderate quality as it did not specify methods to measure trauma, and the overall sample size was relatively small (N=65), including only nine individuals with BPD.

The study by Niemanstverdriet et al. (2017) found a positive association between prior childhood adversity and present severity of AVH ($p = 0.014$), especially emotional abuse. The study was rated as methodologically 'good' for their large sample size (N=324), detailed recruitment and attrition data, and use of validated questionnaires to assess comorbidities and psychotic symptoms.

In contrast, to these studies Catalan et al., 2017 and Wearne et al., 2017 found that the severity of hallucinations was higher for participants reporting childhood emotional abuse compared to sexual and physical abuse, with odds ratio of 1.237. The severity of AVH was not found to be significantly associated with subtypes of sexual abuse, physical abuse, and physical neglect (p’s<0.05). The authors also noted an inverse relationship between childhood emotional neglect and severity of AVH (OR = 0.867); however, no explanation for this finding was provided. Niemanstverdriet et al. (2017) also emphasised the high rates of co-morbid PTSD in individuals with BPD (63%) and found a clear positive relationship between PTSD and AVH (p =0.017).

Stressful Life Experiences. Three studies assessed stressful life experiences and how they related to psychotic symptoms in BPD (Niemanstverdriet et al., 2017; Glaser et al., 2010; Perry, 1988) and found positive associations between stressful life experiences and AVH. Quality assessments of studies were moderate and good. Niemantsverdriet et al. (2017) found a positive, significant correlation between current life stressors and severe AVH (p = 0.001). Interestingly, the LSC-R questionnaire used in the study measures both traumatic and stressful life events such as occurrences of natural disasters, physical or sexual assault, and death of a relative, giving further weight to the proposed relationship between trauma and psychotic symptoms in BPD.

Two studies emphasised the relationship between stressful life experiences and psychotic symptoms, irrespective of diagnosis or clinical group (Glaser et al., 2010; Perry, 1988). However, Glaser et al.’s study (2010) showed that individuals with BPD responded with a higher increase in hallucinations and delusions to daily hassles and minor stresses when compared to individuals with cluster C personality disorder (CPD) and psychotic disorders (PSY). Though the effect size of this relationship was small (Cohen’s d<0.2), the authors stressed the potential cumulative effect of daily stresses, whereby prolonged and increased daily stresses may increase the likelihood of psychotic symptoms being present. The study’s methodological quality was rated as good due to the overall large sample size (N=224) and appropriate choice of analysis based on their research questions (i.e., hierarchical linear modelling).

Perry (1988) used a prospective study design to compare psychotic symptoms over time in individuals with BPD (n=16), antisocial personality disorder (ASP; n=7), bipolar II disorder (n=14), and 'other borderline' (traits of BPD or ASP; n=15) Study quality was rated as moderate, given the study's low sample size (N= 52) and lack of information regarding recruitment. The study conducted in the 1980s, followed the DSM-III criteria in categorising psychotic symptoms: i) schizophreniform (a term previously used to describe symptoms similar to Schizophrenia, but lasting less than 6 months), ii) soft psychotic symptoms such as hearing their name being called; or iii) psychotic symptoms such as visual illusions or ideas of reference. Psychotic symptoms were more common within 8 weeks after a stressful life event occurred; however, the p-value was not significant (p=.54, n=20) which may be due to the low sample size of the study.

Mood Disorders. The evidence for the role of MD towards psychotic symptoms in BPD were unclear. Out of six studies which investigated the relationship between MD and psychotic symptoms in BPD, only two studies found clear, positive relationships between MD and psychotic symptoms in BPD (Perugi et al., 2013; Pope et al., 1985). All six studies were rated between moderate (Pope et al., 1985; Nishizono-Maher et al., 1993; Miller et al., 1993) and good (Perugi et al., 2013; Benvenuti et al., 2005; Niemanstverdriet et al., 2017) in their methodological rigour.

In a prospective study (Pope et al., 1985), individuals with BPD were followed up for 4 to 7 years with the aim of understanding the course of psychotic symptoms. Seven out of 33 patients with BPD appeared to have characteristics of narrowly defined DSM-III psychosis, such as hallucinations and delusions, in the presence of MD, such as DSM-III full manic syndrome or depressive syndrome, ($p<0.05$). However, dissociative experiences in BPD were not found to be related to presence of MD. While the study was rated as moderate quality, it received the lowest quality rating due to its poor consideration of sample size, lack of clarity regarding research setting, and lack of validated questionnaires used to measure co-morbidities and psychotic symptoms. Hence, the study findings should be regarded with caution. While Perugi et al.’s (2013) study was rated as good in methodological rigour, and found more experiences of psychotic symptoms in individuals with major depressive episode (MDE) and co-morbid BPD compared to individuals with MDE only (p=0.01), the type of psychotic symptoms experienced were not specified.

Four studies could not find evidence of correlations between MD and delusions and AVH (Miller et al. 1993; Niemanstverdriet et al., 2017), experiences of depersonalisation and derealisation and brief paranoia in BPD (Benvenuti et al., 2005; Nishizono-Maher et al., 1993). Miller et al.’s (1993) study found no association between the presence of comorbid MD (with or without SUD) and delusions and AVH (27% with MD vs 28% without MD). The study received a moderate quality rating for its methodology due to the unequal number of participants in each participant group for the analysis selected. These findings were echoed in Niemantsverdriet et al. (2017), who found no association between presence and severity of AVH and MD.

Nishizono-Maher et al. (1993) was considered to be of moderate quality due to its relatively small sample size (overall N = 75) which was then split into groups [patients with BPD and MD (Group 1), patients with BPD only (Group 2), patients with MD only (Group 3) and patients with no BPD or MD (Group 4)]. Experiences of derealisation, depersonalisation and brief paranoia were higher in Groups 1, 2 and 3 compared to Group 4, suggesting that these symptoms were more likely to occur in individuals with BPD, MD and in individuals with both BPD and MD. However, there were no differences in prevalence of psychotic symptoms between the three groups, suggesting that a diagnosis of MD had little bearing on the presence of symptoms.

When comparing individuals with BPD with (n=39) and without co-morbid lifetime MD (n=21), Benvenuti et al. (2005) did not find positive associations between MD and psychotic symptoms in BPD per se. However, they found positive associations between mood spectrum within the BPD and MD diagnoses and psychotic symptoms. In patients with BPD without co-morbid MD, features of manic-hypomanic spectrum were associated with delusionary experiences and hypertrophic self-esteem (i.e., an attitude of superiority and contempt for the other), and features of depressive spectrum were associated with delusionary experiences and odd thoughts. However, for patients with BPD and MD, associations were found between manic-hypomanic component of mood spectrum and subdomains of the psychotic spectrum: hypertrophic self-esteem, self-reference, interpretive attitude, anger/over-reactivity, unusual and odd thoughts, illusions, delusions, hallucinations and catatonia. The study was rated as good in their methodological quality due to the use of validated questionnaires and complete description of data collection. However, the p-value was not adjusted to take into account multiple comparisons increasing possibility of Type I error.

The inconsistent findings may be accounted by the varied types and domains of MD investigated across the studies. Despite both studies being of good methodological quality, Perugi et al. (2013) primarily focused on individuals with MDE and found positive relationships with psychotic symptoms in BPD, whereas Benvenuti et al. (2005) had not found the same result when including individuals with various types of MD (e.g., bipolar disorder, MDE, etc).

Substance Use Disorder. Evidence for an association between SUD and psychotic symptoms in BPD was also mixed. Quality ratings of all studies were either moderate (Pope et al., 1985; Nishizono-Maher et al., 1993; Miller et al., 1993) or good (Niemanstverdriet et al., 2017; Barral et al., 2018) Although three studies provided some evidence of a positive correlation between SUD and psychotic symptoms in BPD, two of them were based on small sample sizes (Pope et al., 1985; Nishizono-Maher et al., 1993). Narrowly defined psychotic symptoms were observed in one patient with BPD who abuses illicit substances (Pope et al., 1985) and in one patient with both MD and cannabis abuse (Nishizono-Maher et al., 1993). Barral et al. (2018) found a clear correlation between substance use and SIPS. Both cocaine and cannabis dependence were risk factors that increased development of SIPS, in particular auditory hallucinations, in individuals with co-morbid SUD-BPD. However, no such correlation was found between transient, stress-related paranoid ideation or severe dissociative symptoms in individuals with BPD and drug dependence, with the exception of cannabis. The study methodology was rated as having good quality due to its large sample size (N=91), thorough information on recruitment and rationale for use of data collection tools and method of analysis to answer its research question (i.e. logistic regression analysis). In addition, two studies (Niemantsverdriet et al., 2017; Miller et al., 1993) found no association between SUD and AVH and delusions in BPD.

Other Psychological Factors and Psychiatric Diagnoses. Quality assessments for all three studies that investigated other psychological factors and psychiatric diagnoses were judged to be moderate. All studies investigated different types of co-morbidities, so comparisons and conclusions are difficult. Goodman et al.'s (1999) study had a large sample size (N=107) and used appropriate methods of analysis, however all participants were female. The clear gender bias limits generalisability of the study and resulted in a moderate quality rating. The study employed a within-subjects design and investigated whether comorbid childhood antisocial behaviours (CAB) were typically seen in inpatients with BPD, to determine if CAB were related to co-morbidities such as psychotic symptoms. CAB symptoms predicted the presence of past and current psychotic symptoms but did not predict any other Axis I diagnoses.

Inadequate parental care may also play a role in the presence of psychotic symptoms in individuals with BPD (Catalan et al., 2017). Mothers' parenting styles, in particular affectionless control rearing styles, were strongly related to positive psychotic symptoms across diagnoses ($p<0.01$). Optimal care from the mother was also inversely associated with positive psychotic symptoms ($p<0.01$). Higher rates of dissociative experiences (derealisation/depersonalisation) were seen in patients with BPD who experienced trauma-intrusive hallucinations.

While no overarching conclusions were made, parenting styles and dissociative experiences appear to be related to trauma. Catalan et al. (2017) theorised that individuals who underwent affectionless parenting may be more susceptible to childhood trauma, while Wearne et al. (2017) concluded that dissociation was a mediating factor between childhood trauma and the development of hallucinations.

4. Discussion

4.1. Summary of Findings

To the researcher's knowledge, this is the first systematic review that drew together research to investigate the relationship between co-morbidities, including psychological factors and psychiatric diagnoses, and psychotic symptoms in adult individuals with diagnosis of BPD. The review attempted to answer its research question by including quantitative studies that specifically investigated these associations. However, there were considerable heterogeneity in methodology and study designs, and varying methodological quality within the studies. Measures of psychotic symptoms were variable, and included AVH, delusions (i.e., ideas of reference, paranoid ideation) and dissociative (i.e., derealisation and depersonalisation) experiences. No study was rated as high quality. As such, it was difficult to draw firm conclusions and only a general pattern of findings had emerged from the results. Included studies found positive associations between childhood trauma, stressful life experiences and psychotic symptoms in BPD, while associations with other co-morbidities such as MD and SUD, were less clear. Hence, determining a relationship between other psychological factors, aside from trauma and stressful life experiences, and psychiatric diagnoses with occurrences of psychotic symptoms in BPD was not possible.

A clear positive association between stressful life experiences and AVH (Niemanstverdriet et al., 2017; Glaser et al., 2010; Perry, 1988), and delusions (Glaser et al., 2010; Perry, 1988) in BPD was found. While two studies concluded that child sexual abuse (Wearne et al., 2017) and emotional abuse (Niemanstverdriet et al., 2017) were associated with experiences of hallucination in BPD, one study (Catalan et al., 2017) reported that most types of childhood trauma (i.e., emotional, physical and sexual abuse) accounted for the presence of positive symptoms of psychosis in individuals with diagnoses such as BPD. Pseudo-hallucinations in individuals with diagnoses such as BPD were also linked with the presence of trauma during adulthood (Wearne et al., 2017). Niemanstverdriet et al. (2017) found a high number of co-morbid PTSD in individuals with BPD and a clear relationship between PTSD and AVH. Interestingly, a number of studies (Glaser et al., 2010; Perry, 1988; Wearne et al., 2017; Catalan et al., 2017) found a relationship between stressful life experiences, childhood trauma and psychotic symptoms, irrespective of an individual’s mental health diagnosis.

Evidence for the relationship between MD, SUD and psychotic symptoms in BPD was mixed. Two studies found a positive relationship between MD and psychotic symptoms (Perugi et al., 2013; Pope et al., 1985) but, three studies did not find evidence of an association between MD and delusions and AVH (Miller et al. 1993) and experiences of dissociation and paranoid experiences in BPD (Pope et al., 1985; Nishizono-Maher et al., 1993). Benvenuti et al. (2005) did not find a relationship between MD and psychotic symptoms in BPD per se; however, associations were found between mood spectrum and psychotic spectrum in BPD and BPD with co-morbid MD. Although three studies provided some evidence of a correlation between SUD and psychotic symptoms in BPD, two of these were based on small sample sizes (Pope et al., 1985; Nishizono-Maher et al., 1993). Other comorbidities investigated varied across studies included in the review, making comparisons difficult (Catalan et al., 2017; Wearne et al., 2017; Goodman et al., 1999).

4.2. Clinical Implications

The strongest evidence to emerge from this systematic review is the association between trauma, particularly childhood trauma, and experiences of psychosis (e.g., hallucinations and delusions) in individuals with BPD. Studies particularly emphasised the link between trauma and symptoms of psychosis across various diagnoses (e.g., Catalan et al., 2017). As a high prevalence of childhood trauma is often found in BPD, it may account for the presence of psychotic symptoms reported by these individuals (Kingdon et al., 2010). Treatment plans informed by a trauma-focused framework may be useful tools in understanding and supporting the experiences of individuals with diagnosed BPD (Kring, & Sloan, 2009).

Although not the focus of the systematic review, it does highlight the prevalence and importance of psychotic symptoms in adult individuals with BPD. While findings from the review indicate increased psychotic symptoms in individuals with BPD in the presence of stressful life experiences, many of these studies showed other factors that could account for presence of psychotic symptoms in individuals with BPD (e.g., Niemanstverdriet et al., 2017). Therefore, reductive terms such as pseudo-psychotic or quasi-psychotic symptoms as specified in the DSM should be avoided, as it leads to confusion and dismissal of experiences by clinicians and professionals who provide support this clinical group (Schroeder, Fisher, & Schäfer, 2013). As such, it is important for clinicians to ask and attempt to understand these experiences through the narrative provided by participants, as opposed to the reliance of strict diagnostic systems.

4.3. Limitations and Future Directions

Limitations. There were several limitations to the review, which may have affected how well the review answered its research question. As the systematic review excluded grey literature and only included English articles, there was a possibility that some pertinent studies have been excluded, resulting in potential publication bias. The researcher had also pre-specified specific co-morbidities in the search terms which influenced and restricted the search, and studies that investigated other types of co-morbidities and how they relate to symptoms of psychosis in BPD may have been missed.

The decision to include only quantitative studies was made in order to identify studies that investigated associations between co-morbidities and psychotic symptoms in BPD. However, this led to a relatively low number of studies being included in the final selection with quality ranging from moderate to good. The research question also specified an investigation of associations of comorbidities, such as psychological factors and psychiatric diagnoses, with the experience of psychotic symptoms in adult individuals with BPD which resulted in the exclusion of qualitative studies.

While quantitative studies provided evidence of associations between co-morbidities and psychotic symptoms in BPD, these studies do not tell you about the nature and meaning of the experiences towards the individuals. Qualitative studies allow for lived phenomena to be expressed by individuals. By including qualitative studies, a clearer picture of how experiences of psychosis are appraised and understood in individuals with BPD can be provided. For example, in a qualitative study by Adams and Sanders (2011), five individuals with BPD mentioned a direct relationship between psychotic symptoms and past trauma. Case studies were also able to tease apart what was important to individuals in the study. Individuals in a number of case studies expressed difficulties with interpersonal relationships (Suzuki, Tsukamoto, Nakano, Aoki, & Kuroda, 1998) and trauma and neglect (Yee, Korner, McSwiggan, Meares, & Stevenson, 2005) as factors that contributed towards their symptoms of psychosis.

A narrative synthesis was deemed the most suitable approach to the systematic review; as methodological heterogeneity in terms of study design, participant groups, type of co-morbidities and psychotic symptoms measured meant that a meta-analysis was not feasible. Although efforts were taken to reduce subjective bias, extracting information and placing emphasis on results will have been influenced by subjective views of relative importance to some extent.

Included studies within the review often did not report on participant information including socio-demographic characteristics, missing data, and attrition rates which caused difficulty in assessing appropriateness of data analyses. Sample sizes were small in some studies (e.g., Perry, 1988) which meant that some studies were underpowered to appropriately answer their research questions. Future studies need to justify their sample sizes so conclusions can be appropriately drawn. There was a gender inequality within sample for most studies, with females forming the majority of the samples. However, that could be reflective of the higher prevalence of BPD in females (Gunderson, 2009).

The majority of studies were cross-sectional studies, with only two studies using a prospective study design. Causality of the relationship between co-morbidities and psychotic symptoms could not be determined due to the cross-sectional designs employed. Although a few studies compared psychotic symptoms in participants with BPD only and BPD with different types of co-morbidities, it was not certain whether the positive correlation between co-morbidities and symptoms of psychosis were necessarily only due to these co-morbidities, as other factors may account for these relationships. Furthermore, most studies did not report effect sizes of the relationships found which made conclusions regarding clinical significance, difficult.

The heterogeneity of methodologies employed, participant groups, and different measures of co-morbidities and psychotic symptoms makes it difficult to compare findings across studies. Similarly, the fact that different types of psychotic symptoms were assessed using different methods of assessment (i.e., validated questionnaires, checklist, and structural clinical interview) further complicates understanding of the study findings. This may reflect a lack of understanding of the presentation of psychosis within individuals with BPD (Slotema, Daalman, Blom, Diederen, Hoek, & Sommer, 2012).

Future Directions. The cross-sectional approach used in most of the included studies allowed for adequate exploration of the types of co-morbidities in the relationship between psychotic symptoms and BPD; however, causality could not be determined. As such, future studies should work towards employing prospective designs and longitudinal studies to understand the causal role of trauma, MD, SUD and other types of co-morbidities. Studies should endeavour to utilise specific and appropriate validated questionnaires in the assessment of psychosis, such as the CAPE (Konings et al., 2006) to ensure all psychotic symptoms are captured. Some studies employed a between-subjects, cross-sectional design comparing co-morbidities and psychotic symptoms in individuals with BPD and individuals with other mental health conditions. Whilst this was helpful to understand whether a variety of co-morbidities and psychotic symptoms are associated, it failed to reveal whether such co-morbidities play a role in the relationship between psychotic symptoms and BPD specifically. Other cross-sectional approaches, such as comparing individuals with BPD only with individuals with BPD and specific co-morbidities, would be useful to explore the difference in psychotic symptoms. Although not specific to the aim of this systematic review, the studies also highlighted that psychotic symptoms are reported in individuals with BPD. However, it is unknown whether these experiences of psychotic symptoms differs from those in individuals who are diagnosed with psychotic disorders. Given the lack of understanding of psychotic symptoms in BPD, future studies should seek to gain an understanding these phenomena. Qualitative study designs may be an important tool in exploring the subjective experience of psychotic symptoms in individuals with BPD and individuals with traits of BPD and further inform research in this area.

4.4. Conclusion

There is evidence to suggest that childhood trauma and stressful life experiences are associated with psychotic symptoms in individuals BPD. However, the evidence for the role of other types of co-morbidities e.g. major depression and substance misuse and the role of parental care, is much less clear. Future studies should seek to improve study design and methodologies to further understand the causal roles of these co-morbidities. Other studies would need to explore psychotic symptoms phenomenologically in individuals with BPD through the use of qualitative study designs, to better inform future research in this area.

Contributors

Author ANM created the idea for the systematic review and conducted the literature searches. Author ANM and JH assessed eligibility of studies. Author ANM and RP conducted quality assessments of included studies. ANM wrote the first draft of the manuscript. Author JH and SC supervised the writing and editing of the first draft. All authors contributed to subsequent revisions.

Conflict of interest

The authors declare that there is no conflict of interest.

Role of funding sources

This research did not receive any specific grant from public funding agency, commercial, or not-for-profit sectors was received for the purpose of this research.

References

Adams, B., & Sanders, T. (2011). Experiences of psychosis in borderline personality disorder: a qualitative analysis. *Journal of Mental Health*, *20*(4), 381-391.

American Psychiatric Association (Ed.). (1980). *Quick reference to the diagnostic criteria from DSM-III*. The Association.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Armelius, B. Å., Kullgren, G., & Renberg, E. (1985). Borderline diagnosis from hospital records: Reliability and validity of Gunderson's Diagnostic Interview for Borderlines (DIB). *Journal of Nervous and Mental Disease*.

Ashcroft, K., Kingdon, D. G., & Chadwick, P. (2012). Persecutory delusions and childhood emotional abuse in people with a diagnosis of schizophrenia. *Psychosis*, *4*(2), 168-171.

Barnicot, K., & Priebe, S. (2013). Post-traumatic stress disorder and the outcome of dialectical behaviour therapy for borderline personality disorder. *Personality and mental health*, *7*(3), 181-190.

Barral, C., Rodríguez-Cintas, L., Grau-López, L., Daigre, C., Ros-Cucurull, E., Calvo, N., ... & Roncero, C. (2018). Substance-induced psychotic symptoms in Borderline Personality Disorder among substance use disorder samples in Spain. *Psychiatry research*, *260*, 313-317.

Barnow, S., Arens, E. A., Sieswerda, S., Dinu-Biringer, R., Spitzer, C., & Lang, S. (2010). Borderline personality disorder and psychosis: a review. *Current Psychiatry Reports*, *12*(3), 186-195.

Benvenuti, A., Rucci, P., Ravani, L., Gonnelli, C., Frank, E., Balestrieri, M., ... &

Cassano, G. B. (2005). Psychotic features in borderline patients: is there a connection to mood dysregulation. *Bipolar Disord*, *7*(4), 338-343.

Berenbaum, H., Thompson, R. J., Milanak, M. E., Boden, M. T., & Bredemeier, K. (2008). Psychological trauma and schizotypal personality disorder. *Journal of Abnormal Psychology*, *117*(3), 502.

Bernstein, D. P., Stein, J. A., Newcomb, M. D., Walker, E., Pogge, D., Ahluvalia, T., ... & Zule, W. (2003). Development and validation of a brief screening version of the Childhood Trauma Questionnaire. *Child abuse & neglect*, *27*(2), 169-190.

Catalan, A., Angosto, V., Díaz, A., Valverde, C., de Artaza, M. G., Sesma, E., ... & van Os, J. (2017). Relation between psychotic symptoms, parental care and childhood trauma in severe mental disorders. *Psychiatry research*, *251*, 78-84.

Chanen, A. M. (2015). Borderline personality disorder in young people: are we there yet?. *Journal of Clinical Psychology*, *71*(8), 778-791.

First, M. B., Spitzer, R. L., Gibbon, M. W. J. B., & Williams, J. B. (1995). Structured clinical interview for DSM-IV axis I disorders. *New York: New York State Psychiatric Institute*.

Gillham, R., & Wittkowski, A. (2015). Outcomes for women admitted to a mother and baby unit: a systematic review. *International journal of women's health*, *7*, 459.

Glaser, J. P., Van Os, J., Thewissen, V., & Myin-Germeys, I. (2010). Psychotic reactivity in borderline personality disorder. *Acta Psychiatrica Scandinavica*, *121*(2), 125-134.

Goodman, G., Hull, J. W., Clarkin, J. F., & Yeomans, F. E. (1999). Childhood antisocial behaviors as predictors of psychotic symptoms and DSM-III-R borderline criteria among inpatients with borderline personality disorder. *Journal of personality disorders*, *13*(1), 35-46.

Gracie, A., Freeman, D., Green, S., Garety, P. A., Kuipers, E., Hardy, A., ... & Fowler, D. (2007). The association between traumatic experience, paranoia and hallucinations: a test of the predictions of psychological models. *Acta Psychiatrica Scandinavica*, *116*(4), 280-289.

Grant, B. F., Chou, S. P., Goldstein, R. B., Huang, B., Stinson, F. S., Saha, T. D., ... & Ruan, W. J. (2008). Prevalence, correlates, disability, and comorbidity of DSM-IV borderline personality disorder: results from the Wave 2 National Epidemiologic Survey on Alcohol and Related Conditions. *The Journal of clinical psychiatry*, *69*(4), 533.

Gras, A., Amad, A., Thomas, P., & Jardri, R. (2014). Hallucinations and borderline personality disorder: a review. *L'Encephale*, *40*(6), 431-438.

Gunderson, J. G. (2009). *Borderline personality disorder: A clinical guide*. American Psychiatric Pub.

Gunderson, J. G., Stout, R. L., Shea, M. T., Grilo, C. M., Markowitz, J. C., Morey, L. C., ... & McGlashan, T. H. (2014). Interactions of borderline personality disorder and mood disorders over ten years. *Journal of Clinical Psychiatry*, *75*(8), 829.

Haddock, G., McCarron, J., Tarrier, N., & Faragher, E. B. (1999). Scales to measure dimensions of hallucinations and delusions: the psychotic symptom rating scales (PSYRATS). *Psychological medicine*, *29*(4), 879-889.

Hlastala, S. A., & McClellan, J. (2005). Phenomenology and diagnostic stability of youths with atypical psychotic symptoms. *Journal of Child & Adolescent Psychopharmacology*, *15*(3), 497-509.

Kay, S. R., Fiszbein, A., & Opler, L. A. (1987). The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia bulletin*, *13*(2), 261-276.

Kelleher, I., Keeley, H., Corcoran, P., Ramsay, H., Wasserman, C., Carli, V., ... & Cannon, M. (2013). Childhood trauma and psychosis in a prospective cohort study: cause, effect, and directionality. *American Journal of Psychiatry*, *170*(7), 734-741.

Kingdon, D. G., Ashcroft, K., Bhandari, B., Gleeson, S., Warikoo, N., Symons, M., ...& Mason, A. (2010). Schizophrenia and borderline personality disorder: similarities and differences in the experience of auditory hallucinations, paranoia, and childhood trauma. *The Journal of nervous and mental disease*, *198*(6), 399-403.

Konings, M., Bak, M., Hanssen, M., Van Os, J., & Krabbendam, L. (2006). Validity and reliability of the CAPE: a self-report instrument for the measurement of psychotic experiences in the general population. *Acta Psychiatrica Scandinavica*, *114*(1), 55-61.

Kring, A. M., & Sloan, D. M. (Eds.). (2009). *Emotion regulation and psychopathology: A transdiagnostic approach to etiology and treatment*. Guilford Press.

Kuepper, R., van Os, J., Lieb, R., Wittchen, H. U., Höfler, M., & Henquet, C. (2011). Continued cannabis use and risk of incidence and persistence of psychotic symptoms: 10 year follow-up cohort study. *Bmj*, *342*, d738.

Large, M., Sharma, S., Compton, M. T., Slade, T., & Nielssen, O. (2011).

Cannabis use and earlier onset of psychosis: a systematic meta-analysis. *Archives of general psychiatry*, *68*(6), 555-561.

Mcketin, R., Hickey, K., Devlin, K., & Lawrence, K. (2010). The risk of psychotic symptoms associated with recreational methamphetamine use. *Drug and alcohol review*, *29*(4), 358-363.

Merrett, Z., Rossell, S. L., & Castle, D. J. (2016). Comparing the experience of voices in borderline personality disorder with the experience of voices in a psychotic disorder: A systematic review. *Australian & New Zealand Journal of Psychiatry*, *50*(7), 640-648.

Miller, F. T., Abrams, T., Dulit, R., & Fyer, M. (1993). Psychotic symptoms in patients with borderline personality disorder and concurrent axis I disorder. *Psychiatric Services*, *44*(1), 59-61.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine*, *151*(4), 264-269.

Niemantsverdriet, M. B., Slotema, C. W., Blom, J. D., Franken, I. H., Hoek, H. W., Sommer, I. E., & Gaag, M. (2017). Hallucinations in borderline personality disorder: prevalence, characteristics and associations with comorbid symptoms and disorders. *Scientific reports*, *7*(1), 13920.

Nishizono-Maher, A., Ikuta, N., Ogiso, Y., Moriya, N., Miyake, Y., & Minakawa, K. (1993). Psychotic symptoms in depression and borderline personality disorder. *Journal of affective disorders*, *28*(4), 279-285.

Pearse, L. J., Dibben, C., Ziauddeen, H., Denman, C., & McKenna, P. J. (2014). A study of psychotic symptoms in borderline personality disorder. *The Journal of nervous and mental disease*, *202*(5), 368-371.

Perry, J. C. (1988). A prospective study of life stress, defenses, psychotic symptoms, and depression in borderline and antisocial personality disorders and bipolar type II affective disorder. *Journal of Personality Disorders*, *2*(1), 49-59.

Perugi, G., Angst, J., Azorin, J. M., Bowden, C., Vieta, E., & Young, A. H. (2013). Is comorbid borderline personality disorder in patients with major depressive episode and bipolarity a developmental subtype? Findings from the international BRIDGE study. *Journal of affective disorders*, *144*(1-2), 72-78.

Pope, H. G., Jonas, J. M., Hudson, J. I., Cohen, B. M., & Tohen, M. (1985). An empirical study of psychosis in borderline personality disorder. *The American journal of psychiatry*.

Read, J., Agar, K., Argyle, N., & Aderhold, V. (2003). Sexual and physical abuse during childhood and adulthood as predictors of hallucinations, delusions and thought disorder. *Psychology and Psychotherapy: Theory, research and practice*, *76*(1), 1-22.

Sack, M., Sachsse, U., Overkamp, B., & Dulz, B. (2013). Trauma-related disorders in patients with borderline personality disorders. Results of a multicenter study. *Der Nervenarzt*, *84*(5), 608-614.

Sbrana, A., Dell'Osso, L., Benvenuti, A., Rucci, P., Cassano, P., Banti, S., ... & Rossi, L. (2005). The psychotic spectrum: validity and reliability of the Structured Clinical Interview for the Psychotic Spectrum. *Schizophrenia research*, *75*(2-3), 375-387.

Schroeder, K., Fisher, H. L., & Schäfer, I. (2013). Psychotic symptoms in patients with borderline personality disorder: prevalence and clinical management. *Current opinion in psychiatry*, *26*(1), 113-119.

Shapiro, R., & Keller, M. (1979). Longitudinal interval follow-up evaluation

(LIFE). *Boston: Massachusetts General Hospital*.

Shevlin, M., Murphy, J., Read, J., Mallett, J., Adamson, G., & Houston, J. E. (2011). Childhood adversity and hallucinations: a community-based study using the National Comorbidity Survey Replication. *Social psychiatry and psychiatric epidemiology*, *46*(12), 1203-1210.

Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: the development and evaluation of a new tool. *Journal of evaluation in clinical practice*, *18*(4), 746-752.

Slotema, C. W., Daalman, K., Blom, J. D., Diederen, K. M., Hoek, H. W., & Sommer, I. E. C. (2012). Auditory verbal hallucinations in patients with borderline personality disorder are similar to those in schizophrenia. *Psychological medicine*, *42*(9), 1873-1878.

Smith, M. J., Thirthalli, J., Abdallah, A. B., Murray, R. M., & Cottler, L. B. (2009). Prevalence of psychotic symptoms in substance users: a comparison across substances. *Comprehensive psychiatry*, *50*(3), 245-250.

Spitzer, R. L., Williams, J. B., Gibbon, M., & First, M. B. (1992). The structured clinical interview for DSM-III-R (SCID): I: history, rationale, and description. *Archives of general psychiatry*, *49*(8), 624-629.

Stern, A. (1938). Psychoanalytic investigation of and therapy in the border line group of neuroses. *The Psychoanalytic Quarterly*, *7*(4), 467-489.

Suzuki, H., Tsukamoto, C., Nakano, Y., Aoki, S., & Kuroda, S. (1998). Delusions and hallucinations in patients with borderline personality disorder. *Psychiatry and clinical neurosciences*, *52*(6), 605-610.

Trull, T. J., Sher, K. J., Minks-Brown, C., Durbin, J., & Burr, R. (2000).

Borderline personality disorder and substance use disorders: A review and integration. *Clinical psychology review*, *20*(2), 235-253.

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., ... & Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective-and cross-sectional cohort studies. *Schizophrenia bulletin, 38*(4), 661-671.

Walter, M., Gunderson, J. G., Zanarini, M. C., Sanislow, C. A., Grilo, C. M., McGlashan, T. H., ... & Skodol, A. E. (2009). New onsets of substance use disorders in borderline personality disorder over 7 years of follow-ups: Findings from the Collaborative Longitudinal Personality Disorders Study. *Addiction*, *104*(1), 97-103.

Wearne, D., Curtis, G. J., Genetti, A., Samuel, M., & Sebastian, J. (2017). Where pseudo-hallucinations meet dissociation: a cluster analysis. *Australasian Psychiatry, 25*(4), 364-368.

Yee, L., Korner, A. J., McSwiggan, S., Meares, R. A., & Stevenson, J. (2005). Persistent hallucinosis in borderline personality disorder. *Comprehensive Psychiatry*, *46*(2), 147-154.

Yung, A. R., Yuen, H. P., Phillips, L. J., Francey, S., & McGorry, P. D. (2003). Mapping the onset of psychosis: the comprehensive assessment of at risk mental states (CAARMS). *Schizophrenia Research*, *1*(60), 30-31.

Zanarini, M. C. (2000). Childhood experiences associated with the development of borderline personality disorder. *Psychiatric Clinics of North America*, *23*(1), 89-101.

Chapter Three

Bridging Chapter

Word Count: 846

Chapter Three - Bridging Chapter

The systematic review presented the existing quantitative research on the relationship between psychological and psychiatric co-morbidities and psychotic symptoms in adults diagnosed with borderline personality disorder (BPD). While the review found some evidence to suggest a link between co-morbidities, in particular childhood trauma and stressful life experiences, and psychotic symptoms in adults with BPD, heterogeneity of study methodologies caused difficulties in comparing evidence across studies. Included studies have utilised various tools to measure different types of psychotic symptoms. The various methodologies used and types of psychotic symptoms assessed could be a reflection of the lack of consensus or understanding towards symptoms of psychosis within individuals with BPD (Schroeder, Fisher & Schäfer, 2013). The measures used in included studies also assume that symptoms are similar to a "true psychosis" construct, i.e., symptoms of perceptual abnormalities and delusions as specified in the DSM (American Psychiatric Association, 2013). A broader approach to understanding psychotic phenomena in the context of BPD would be to explore a range of psychotic like experiences rather than narrowly defined psychotic symptoms in isolation.

While the systematic review provides some indication towards factors that might increase the likelihood of experiencing psychotic symptoms, the quantitative studies included do not provide an understanding of how lived experiences of psychotic symptoms are made sense in individuals with BPD. Only one qualitative study (Adams & Sanders, 2011) has attempted to explore the experience of psychotic-like experiences (PLEs) in adults diagnosed with BPD. Adams and Sanders (2011) conducted a thematic analysis with five individuals with BPD whom expressed enduring experiences that interfered with their psychological well-being. These symptoms, as described by participants, may be a reaction to distressing incidences or a response to trauma of the past. The authors note no clear distinctions from psychotic symptoms described by patients suffering from psychotic disorders. While participants described a pervasive description of their symptoms, treating psychiatrists had no real understanding towards them and utilised language that implied symptoms were ‘not real nor true’, despite the emotional distress induced by these phenomenon. Disconnect between clinicians and the distressed individual may pose difficulty and resistance towards building appropriate interventions designed to support individuals with these distressing experiences.

In recent years, there has been increasing evidence that borderline personality traits (BPD traits) are common among young people, and that a diagnosis of BPD can be made before the age of 18 (Newton-Howes, Clark, & Chanen, 2015). Several reviews have found similarities in how a diagnosis of BPD is expressed phenomenologically in young people and adults (e.g., Chanen, Jovev, McCutcheon, Jackson, & McGorry, 2008; Kaess, Brunner, & Chanen, 2014). As such, the diagnosis of BPD towards young people before the age of 18 has been sanctioned in Section III of the DSM-5 (American Psychiatric Association, 2013). However, recognition and research on BPD and BPD traits in young people have been scarce due in part to the stigma attached to the diagnosis (Chanen, 2015). Chanen et al. (2009) argue the significance of understanding the experiences of young people with diagnosed BPD and emerging traits of BPD (i.e., difficulties in managing emotions and interpersonal relationships) as it would help inform preventative treatments designed to alleviate difficulties in these young people at an earlier stage. Previous research has reported that young people with BPD traits who experience PLEs often find difficulties in accessing services (Francey, Jovev, Phassouliotis, Cotton, & Chanen, 2017) and are more likely to disengage from treatment (Gleeson et al., 2012). By understanding the experiences of young people with BPD traits, specific preventative treatments could be developed that would provide effective support to this clinical group.

Given the importance of understanding the experiences of young people with BPD traits (Chanen et al., 2009), the empirical study follows a qualitative research design to understand the nature of psychotic-like experiences (PLEs) in young people with BPD traits. It extends from the findings of the systematic review by adopting a continuum approach in querying psychotic-like experiences rather than symptoms and delving into experiences that are of concern to young people. Through the exploration of how young people understand these experiences, it would also provide insight into how they are appraised and responded to and whether these experiences are similar to those experienced by adults diagnosed with BPD (as described in the study by Adams & Sanders, 2011) and individuals with diagnosed psychotic disorders or “true psychosis”.

The empirical study employs an interpretative phenomenological analysis (IPA) approach due to the methodology’s emphasis to move beyond descriptive analysis and aim to understand how individuals make sense of their lived experiences (Smith, Flowers, & Larkin, 2013). It is inductive in nature and has the capacity to ask questions about the lived experience of complex human phenomena. IPA has epistemological underpinnings that include an emphasis on phenomenology and efforts to understand the world from the perspective of the individual, its commitment to double hermeneutics (i.e., the efforts of the researcher to make sense of the individual who is making sense of their own experiences). IPA is also committed towards idiography, an approach which prioritises in-depth exploration of individual cases.

Chapter Four

Empirical Study

Psychotic-Like Experiences in Help Seeking Young People with Borderline Personality Traits: An Interpretative Phenomenological Analysis of Experiences

Prepared for submission to the International Journal of Qualitative Studies in Health and Well-Being

Word Count: 8049

Psychotic-Like Experiences in Help Seeking Young People with Borderline Personality Traits: An Interpretative Phenomenological Analysis

AISYA NADIA MUSA[1], PAUL FISHER[2], SIAN COKER[3], SARAH MAXWELL[4], JOANNE HODGEKINS[5]*,

[1] *Trainee Clinical Psychologist, Doctorate in Clinical Psychology University of East Anglia, UK.*

[2] *Clinical Senior Lecturer in Clinical Psychology, Department of Clinical Psychology, School of Medicine, University of East Anglia, UK.*

[3] *Professor of Clinical Psychology and Deputy Programme Director, School of Medicine, University of East Anglia, UK.*

[4] *Consultant Child and Adolescent Psychiatrist, Norfolk and Waveney Mental Health Trust, UK*

[5] *Clinical Senior Lecturer in Clinical Psychology, Department of Clinical Psychology, School of Medicine, University of East Anglia, UK.*

***Requests for reprints should be addressed to:**

Joanne Hodgekins, University of East Anglia, Department of Clinical Psychology, School of Medicine, Norwich Medical School, University of East Anglia Norwich NR4 7TJ

Email: J.Hodgekins@uea.ac.uk

Keywords

Borderline Personality Disorder; Psychosis; Psychotic Symptoms; Mental health; Psychiatry; Interpretative Phenomenological Analysis; IPA; Qualitative; Young People; Adolescents; Young Adults

Abstract

It is common for psychotic-like experiences (PLEs) to occur in young people who present with traits of borderline personality disorder (BPD traits). While existing literature shows the detrimental effects of these experiences, little is known about the presentation and response towards PLEs in young people with BPD traits. This study explored the nature of PLEs in help-seeking young people and how they are appraised and responded to. Semi-structured interviews were conducted with seven young people aged 16-25 years who described themselves as having PLEs and BPD traits and were currently receiving care from secondary community mental health services in the East of England. Verbatim transcripts were analysed for themes using Interpretative Phenomenological Analysis. Four superordinate themes emerged from the analysis: description of experiences, making sense of the experiences, deterioration of sense of self and well-being, and managing and finding respite. The findings highlight the varied and enduring nature of PLEs in young people with BPD traits, and the despair and loss of control felt as a consequence of the experiences. Study limitations and future directions for research were discussed in detail.

Introduction

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), borderline personality disorder (BPD) is a mental health condition characterised by the following criteria: fear of abandonment, interpersonal difficulties, identity disturbance, impulsive and risky behaviours, recurrent suicidality, emotion dysregulation, feelings of emptiness, and transient, stress-related paranoid ideation. Whilst traditionally this diagnosis was used solely for adults above 18 years of age, recently the DSM introduced BPD as a valid diagnosis in adolescents. Section III of the DSM-5 specified that adolescents who met diagnostic criteria should they have a 1-year pattern of disturbances in at-least five of the criteria mentioned above (Guilé et al., 2018). However, this diagnosis in younger people has been seen as controversial amongst clinicians and researchers, due to the stigma and discrimination that surrounds the diagnosis (Kaess, Brunner, & Chanen, 2014). There has also been the perception that personalities were often fluid and changeable in children and adolescents, despite research that had contradicted this claim (Chanen, 2015). Accordingly, some authors (Pine, 1985; Kernberg et al., 2000) have suggested that developmentally, emerging personalities were apparent by pre-school and often solidified by adolescence. Notwithstanding this, inflexible coping strategies, insecure attachments, and childhood trauma have all been linked to personality difficulties in later life (Chanen, & Kaess, 2012; Musa, Coker, Papadopoullos, & Hodgekins, 2019). Furthermore, Lenzenweger and Castro (2005) have suggested that BPD traits were considerably more malleable in young people compared to their adult counterparts, suggesting that this may be the key development period in which to intervene. As such, it would appear to be important to understand the experiences of these young people, and seek to find appropriate preventative treatments for them (Chanen, 2015)

In recent years, research and clinical practice has become interested in the phenomena of psychotic-like experiences (PLEs) within BPD, such as hallucinations, delusions and dissociative experiences. These experiences were commonly reported in adults diagnosed with BPD (Pearse et al., 2014; Nishizono-Maher et al., 1993), occurred for prolonged periods of time and led to significant disability (e.g., Yee et al., 2005). Several factors may account for the co-occurrence of BPD and PLEs, including exposure to various childhood trauma and stressful life events (Musa et al., 2019). The findings that the experiences were prolonged and disabling does not align with the DSM-5's stance which implies that any occurrence of PLEs within BPD does not warrant concern, due to the transient nature of these experiences (Schroeder, Fisher, & Schafer, 2013).

PLEs were also commonly reported in young people within different clinical populations (Escher et al., 2002), including young people with BPD traits, and indicated complex presentations and were a marker of disability (Baumeister, Sedgwick, Howes, & Peters, 2017). For example, one study found that 25.2% of young people who are at risk of developing psychosis, also known as at-risk mental states (ARMS; Ryan, Graham, Nelson, & Yung, 2015) also showed significant BPD traits. Similarly, a case study reported a smaller, but clinically important rate of full-threshold BPD in 14.9% in a sample of young people with ARMS (Thompson et al., 2012). These young people with ARMS and co-morbid BPD showed no clinical remission in a 6-year follow up and also had difficulties accessing appropriate mental health-care (Rutigliano et al. (2016). In addition, for those who did access services, disengagement from psychological treatment was high (Gleeson et al., 2012). This may be due to a significant focus being placed on the clinical presentation of BPD and its diagnosis-specific difficulties, rather than their presenting psychotic experiences (Thérien et al., 2012).

Although studies report evidence of PLEs in young people with BPD traits, they do little to highlight their nature and have failed to grasp their significance for these young people (Musa et al., 2019). Exploring young people's understanding of their PLEs, provides context and a rationale for further research in this area, and potentially helps to inform treatment plans for these young people. The age group of 25 and below were chosen for this study, as they were considered to be most at risk for developing various mental health conditions, including BPD and psychosis (McGorry et al., 2007; Kessler et al., 2005).

The current study utilised interpretative phenomenological analysis (IPA) to understand experiences of PLEs in young people with BPD traits. Only one study had previously explored the psychotic experiences in individuals diagnosed with BPD (Adams, & Sanders, 2011) and this was in an adult population. To date there have been no studies investigating the nature of PLEs in young people with BPD traits and their understanding of these experiences. The present study aimed to build on the work of Adams and Sanders (2011) and extend this to a population of young people. Specifically, the study aimed to address the following questions: "What are the nature of PLEs in help-seeking young people with BPD traits?", and "What are the appraisals and responses towards PLEs in help-seeking young people with BPD traits?"

Method

Design

The study used an IPA approach (Smith, Flowers, & Larkin, 2013) to understand how help-seeking young people with BPD traits made sense of their PLEs. IPA is committed to a phenomenological epistemology, concerned with the subjective experience of individuals as opposed to defining an objective reality (Smith, & Osborn, 2003). It is idiographic as it focuses on the meaning and significance of experience to the particular individual (Larkin, & Thompson, 2012). It acknowledges ‘double hermeneutics’ where the researcher attempts to interpret the participant whom tries to interpret their lived experiences (Smith & Osborn, 2003; Smith, 2007). Ethical approval of the study was obtained from the National Research Ethics Service (NRES) and Health Research Authority (HRA; Appendix E).

Participants

Participants were approached from a secondary mental health service in the East of England. The service utilised a multi-disciplinary approach and accepted referrals of young people ages 14 to 25, who have non-psychotic, complex mental health difficulties and serious impairments in social, occupational or school functioning. Referrals excluded were young people with psychosis, eating disorders or substance misuse as primary difficulties. All referrals were discussed at weekly team meetings and placed into different treatment pathways depending on their main difficulties. The BPD traits treatment pathway accepted young people whose BPD traits caused significant difficulties in daily functioning, with support involving allocation of case manager, one-to-one and group-based interventions. All study participants approached were within this treatment pathway.

The study inclusion criteria were: young people aged 16-25 years receiving care from the secondary community mental health service in the East of England. The minimum age of 16 was chosen, as it was the cut-off age where informed consent could be provided. Potential participants needed to score 6 or above on the PQ-16 and 11 or above on the HYPE screen and received support from the BPD trait treatment pathway, and fluent in English. The exclusion criteria included young people with formal diagnoses of psychosis, primary diagnosis of substance use dependence, neurological difficulties, head injury, epilepsy, and learning disabilities. A purposive sample of seven participants (three male, three female and one transgender male) were recruited from one team across the service.

The researcher had originally aimed to recruit 8 to 12 young people. However, engagement of eligible participants was difficult. While 12 eligible participants provided consent to be contacted, five individuals did not wish to pursue further contact. Reasons for disengagement were not available for all individuals; however, three expressed feeling uncomfortable about exploring experiences they found distressing with someone new. Participants' interviews ranged from 38 minutes to an hour and 15 minutes. Pseudonyms were provided to preserve participants' anonymity. Table 1 provides demographic information to help contextualise the sample.

Table 1. Sample characteristics

Name[a]	Age (years)	Gender	Ethnicity	HYPE Screen Score	PQ-16 Score	Length of use of mental health service (in years)
Thomas	21-25	Male	White British	15	8	5
Paul	21-25	Male	White British	15	16	1
Richard	21-25	Male	White British	11	15	10
Alex	16-20	Transgender Male	White British	15	15	1.5
Susan	16-20	Female	White British	13	16	4-5
Mary	21-25	Female	White British	14	10	1.5
Laura	21-25	Female	White British	14	8	0.5 (6 months)

Note. a = All names provided are pseudonyms to protect participant anonymity

Data Collection

Eligible participants were screened for BPD traits and PLEs using two validated, self-report measures: the 16-item Prodromal Questionnaire (PQ-16; Ising et al., 2012; Appendix F) and Helping Young People Early Screen (HYPE Screen; Chanen et al., 2009; Appendix G). Cut-off scores were based on past research and clinical practice within the clinical service, which recommended a score of 6 or more on the PQ-16 to indicate sub-clinical levels of psychosis (Loewy, Pearson, Vinogradov, Bearden, & Cannon, 2011) and 11 or more on the HYPE screen to indicate emerging traits of BPD (Chanen et al, 2009). Screening of eligible participants was conducted by clinicians within the team. A socio-demographic questionnaire was also used to collect information on gender, age, ethnicity, English language fluency, and length of mental health care (Appendix H).

Semi-structured interviews were used to explore participants' subjective experience of PLEs. The interviews were prepared as recommended by Smith et al. (2013) and conducted by the first author (ANM). The Appraisals of Anomalous Experiences (AANEX; Brett at al., 2007) semi-structured interview was used to develop the topic guide for interviews. The AANEX probe items were used as a way to induce reflections on past and current PLEs. The researcher would then explore these experiences in detail through the topic guide (see Appendix I and J for probe items and topic guide). Open-ended questioning was used to facilitate the movement from description to reflective responses (e.g., 'How did you make sense of the experiences at the time?'). The schedule functioned as a guide; and interviews followed participants' personal interests.

Procedure

Participants were recruited through clinician referral, between July and October 2018. Relevant clinicians within the clinical service were provided with clinician information sheet which included the study’s eligibility criteria, participant information sheet and consent to contact form. The service already used screening tools to measure PLEs and BPD traits, and so only individuals who met cut-off scores on the PQ-16 and HYPE screen were approached.

Clinicians within the team determined eligibility through screening questionnaires scores of young people prior to study participation. Once eligibility was determined and participants provided written consent to participate, the interview meeting was conducted at the clinic where they received care or participants’ own home. The meeting included the interview session and the socio-demographic questionnaire. Once the interview was completed, each participant was debriefed on the study purpose and any questions were answered. As compensation for their time, participants received a £5 Amazon voucher.

Analysis

Interview transcripts were analysed using the six stage IPA process (Smith et al., 2013). The first step involved immersion in the data through reading and re-reading each interview transcript multiple times. Once the first transcript was completed, the researcher began focused reading and commenting on the transcript in depth, alongside subsequent data collection (Smith, 2007). Analysis remained embedded within the data itself (Pietkiewicz, & Smith, 2012). True to idiography, interview transcripts were analysed in-depth individually. Emergent themes were identified in each transcript and consideration given to how these relate to one another by deriving sub-themes and super-ordinate themes for each case (Smith et al., 2013). Any preconceptions from analysed transcripts were ‘bracketed’ throughout analysis of subsequent interview transcripts. Emergent themes within the group of young people were considered and key themes identified.

Reflexivity

IPA assumes that the researcher brings their personal context, values and assumptions into the research (Smith et al., 2013), and it is vital for them to be aware of this (Braun & Clarke, 2013). The researcher came from a developing country and learned English as a second language, which caused difficulties picking up dialects or meaning behind sentences in interviews. To avoid misunderstandings when interpreting data, multiple-coders through use of supervision was used. As a clinician who worked with individuals experiencing PLEs in various settings, the researcher may have indirect biases towards certain experiences and drive discussions and analysis towards them. Being a clinician may have also influenced how participants discussed aspects of their experiences and chose to omit certain reflections in interest of privacy. A reflective diary was used to assist in bracketing assumptions ensuring interpretations were entrenched in the data, and thereby remained vigilant towards the ‘double hermeneutic’ nature of IPA (Smith et al., 2013).

Results

Four superordinate themes emerged from the analysis: (i) description of experiences, (ii) making sense of the experiences, (iii) deterioration of sense of self and well-being, and (iv) managing and finding respite. Each superordinate theme had three sub-themes, and was present in all participant interviews. Each sub-themes was evidenced by at least five of the participant’s individual main themes. A detailed examination of themes were presented alongside supporting verbatim extracts taken from interview transcripts. Table 2 provides a detailed hierarchical representation of the organisation of superordinate and sub-themes.

IPA allows for an abstraction of the emerging themes so that relationships between themes may be explored (Smith et al., 1999). A diagram was developed as a way of representing the process of how PLEs are understood and responded to, as discussed within the interviews. This diagram represents an interpretation by the researcher based on what was reflected on by participants, as well as a way of bringing together and exploring different themes within the study (Wyer, Earll, Joseph, & Harrison, 2001) and is in line with other published IPA studies (e.g. Reitz, 1999; Fitzsimons, Parahoo, & Stringer, 2000).

Table 2: Hierarchy of super-ordinate and sub-themes.

Description of experiences	Making sense of the experiences	Deterioration of sense of self and well-being	Managing and finding respite
• Hearing and seeing things that others do not • A sense of paranoia • Feelings of numbness and being out of touch with reality	• The enduring presence of experiences • The role of trauma and stressful life experiences • Self-stigma: 'Experiences mean I am crazy'	• A change in sense of self • Deterioration of control • Fear, despair and isolation	• Seeking relief from the experiences • Having supportive relationships is important • Acceptance in overcoming experiences

Theme 1. Description of experiences

Participants described different PLEs; from visual and verbal anomalies to paranoia and a state of being numb and out of touch with reality. Participants expressed a deep sense of fear and distress as a direct result of the experiences. The theme elaborated on these experiences and how they related to one another.

Hearing and seeing things others do not. All participants described having one or multiple voices separate from their own thoughts, and/or vivid images. In many cases, the location of the voices was varied: they may come from somewhere outside of their body, such as occurring out of their home, or internally inside their own head but distinguishable from their own thoughts. The nature of the voices were often derogative and commanding manner to participants, using words such as ‘you’re worthless’ and ‘kill yourself’.

> *“I’ll hear voices usually my own voice or I’ll hear random noises like I’ll hear a ticking or something like a clock or for example I can hear the walls breathing […] and then that will sort of heighten up and quite derogatory things like affect me like you’re worthless you should go and kill yourself.”* **(Richard)**

Most participants described similar derogative content from their voices. In contrast, Paul and Thomas indicated multiple voices that were not always decipherable or derogative but increased their paranoia towards their surroundings and others.

> “*I think that there’s group of other people next door and I can hear ‘em. They won’t be like this, it’ll be the stolen voices, it’ll be like muffling or do you know I mean like there they’re talking like a group of people. They’re talking all to each other…. Even if no one’s there […] I thought people there were planning to rob me.”* **(Thomas)**

Visual anomalies such as figures, distorted faces or objects, or images accompanied these voices. Most participants reflected how they occurred less frequently than the voices, but were nevertheless frightening and confusing within the moment. Here, Susan spoke about her first visual anomalies. While she had not explicitly articulate her fear, her voice intonation was lower and quicker, potentially reflecting a fearful recounting of the experience: *‘I saw like little they weren’t little bit they were like black people like figures…that’s when I first started hearing voices as well.’*

A sense of paranoia. All participants described overwhelming beliefs of others harming or judging them negatively, leading to hyperawareness towards any perceived threat. Thomas reflected on his own need to keep vigilant towards any potential physical attack from others, reading body language as a way to protect himself:

> *"Yeah, I mean it's just like that's your bit of body language [...] When you're thinking stuff, some people might decide your body language what you can pick up on their thoughts. Even though you saying nothing, you can just look at their body language and you can tell they're about to do something."* **(Thomas)**

For most participants, paranoia occurred in accompaniment of other PLEs, such as voices and other sensory experiences. However, Laura described her paranoid thoughts as a separate and fearful phenomenon on its own. She expressed always having paranoid thoughts, and how they worsened after being in an abusive relationship. Here, Laura described the unremitting paranoia experienced, where she feared her partner reading her thoughts and harming her:

> *"I wanna go out later, how am I gonna be asked to tell him? [...] and like cos my brain's always thinking I find that I'm always thinking, thinking, thinking. I remember the amount of times I'd sit down and please don't keep thinking cos you know you feel like your thoughts are loud but that yeah just I did worry."* **(Laura)**

Feelings of numbness and being out of touch with reality. Six participants described frequent states of being out of touch with reality or numbness that was beyond their control. Most participants described shutting down within the moment and found difficulties in doing daily tasks. Here, Laura described this state of numbness and disconnect, experienced from an early age through to her adult years:

> *"I used to spend a lot of time in bed [...] just sleep and try to make myself as like as insignificant as possible cause that's how I felt and just like a weight comes down."* **(Laura)**

Interestingly, a subtle change in Laura's tone was noted during this conversation, quiet and subdued, perhaps as a reflection of the state of apathy she was in. While most participants expressed their being out of touch with reality and numbness as temporary, Richard and Paul expressed complete dissociation, where memories of the incidences were limited and a new identity would take over.

> *"Basically I change into a different person almost um one of which is called Sam um quite aggressive and derogative towards me and it usually leads with me hurting myself and running off somewhere so I usually get lost quite easily."* **(Richard)**

There is a deep routed distress in all experiences described by participants, given the hostile nature of the voices, overwhelming paranoia and disconnect within the moment. This led to a need to make sense of the experiences, which is explored in theme 2.

Theme 2. Making sense of the experiences

This theme is related to how participants understood their experiences of PLEs. Participants reflected on the prolonged negative effects of the experiences and feelings of uncertainty of when the next experience occurred. Most participants felt that the vulnerability felt during times of trauma contributed to their occurrences. Internalised beliefs were also explored, with most participants expressing beliefs of being ‘crazy’, which subsequently led to avoidance towards their experiences.

The enduring presence of experiences. All participants described varying frequencies for different types of PLEs. The experiences could last for several minutes to hours and sometimes days at a time. For Thomas, Mary and Susan, their PLEs occurred in cyclic patterns of periods when they were present and when they were not. This led to extensive frustrations and uncertainties towards the situation and belief that the experiences would always inevitable return:

> “*When I got older, I started feeling in the end, it’s like bad, but it happens all the time, it’s spontaneous; happened all the time.”* **(Thomas)**

> *“They’d stop of a little bit but there’s always like come back.”* **(Susan)**

While most participants receive pockets of solace away from their PLEs, for Paul and Laura, the presence of voices and paranoia were a never-ending presence they received no relief from. Paul explained the voices that followed him till the time he goes to bed:

> “*What was overwhelming was like where they come from, like how come I can hear this conversation and no one else can and then like opening the door and there not actually being anyone there and then I’ve been to bed a couple of times from sitting up and having a joint and you sort of take the voices with you so like you get in bed and they’d sort of be there.”* **(Paul)**

The immediate, after-effects of the experiences were particularly significant to participants, as they could be felt for long periods of time:

> *"Um well I usually remember about ten or twenty minutes of it like give or take but I can be down for I can be down for like hours at a time."* **(Richard)**

The role of trauma and stressful life experiences. Significant traumatic experiences frequently occurred before and during the PLEs, including emotional, physical or sexual abuse, and interpersonal difficulties, as described by all participants. Most participants noted that traumatic experiences endured from childhood, led to a state of uncertainty and consequently, they believed, resulted in a vulnerability towards the experiences:

> *"My parents split up when I was about 13 and I've just never been the same since really it was weird yes I used to be like such an innocent like just head down kind of guy you know and I can remember my parents split up […] it was how it went about like I moved with my dad and like my sister moved with my mum and it was I was too young to understand how I was feeling […] I just went from being like a normal lad to just being chaotic."* **(Paul)**

While most participants echoed Paul's sentiments, others had reflected on more recent experiences prior to occurrences of PLEs. Mary reached a "low point" in recent years, where deterioration in relationships were prominent, leading to the voices' appearance.

> *"It started when I was at a really low point in life and I was quite suicidal and the voices told me to go and jump off a bridge so I tried…it might have been a bit more than six months but um my boyfriend split up with me cos my brother was in prison and I didn't take it too well."* **(Mary)**

Most participants were left undecided as to whether it was the trauma itself that caused PLEs or the vulnerability felt during those times. As Alex and Mary described, it was not the trauma itself that elicited experiences, but rather the distress associated with them:

> **"***I don't think my experiences are the cause of them. Like distress and stuff I think maybe but like not the experiences. Like if someone says 'Oh they're cheating on you' […] my head will go through all of the scenario and then I'll start seeing things. Like I would physically see that person with like someone else who they'd said they're cheating with and I will see it replay […] over and over again in my head […] So, like the experiences itself can impact what it is, but like I don't think it caused them."* **(Alex)**

Additionally, six participants reflected their belief that everyday stresses, such as a lack of sleep, losing a job, or getting into arguments, worsened the experiences and led to feelings of being out of control:

> *"It could be like I can't get to sleep and it starts stressing me out or it could be an argument or someone starts getting aggressive towards me or if I think like something physical is going to escalate it tends to ramp up very quickly"* **(Richard)**

Self-stigma: ‘Experiences mean I am crazy’. All participants described the fear of being seen as ‘crazy’ due to their PLEs. These statements of self-stigma were evidenced through verbal and non-verbal narrative provided in interviews. Paul expressed the perceived public stigma and how that shaped beliefs about the experiences:

> *“It makes you feel abnormal […] the stigma around mental health has always been crap you know like people have always perceived people with mental health as like nutters […] you take on these opinions you know you know you shouldn’t but you take on the opinions of what the democracy have so it’s like you find out you’re hearing voices yourself and it’s like you’re convincing yourself you’re nuts like I’m crazy.”* **(Paul)**

Not all participants expressed their beliefs explicitly. Thomas appeared uncomfortable describing his experience. He frequently avoided eye contact and excused himself from the interview more than once. When inquiring about the clarity of the voices he heard, he made an impassioned response based on his negative perception of such symptoms.

> *“I’m not fucking schizo. It don’t tell me what to do. I’d kill myself if I did. I would – fuck – If I heard voices telling me to hurt people and tell me to make sacrifices and shit like that. That means, it’s time for me leave this earth. I won’t do it. That’s messed up.”* **(Thomas)**

His statement provided context to discomfort felt during the interview and showed great fear of the possibility of being ‘schizo’. The word ‘schizo’ was mentioned as a derogative term, associating it to something shameful. Given the self-stigma, most participants found it difficult to reflect on their experiences with themselves and others.

Theme 3: Deterioration of sense of self and well-being

The theme explained how participants' PLEs impacted negatively on sense of self and emotional well-being. Most participants elaborated on a loss of motivation and deterioration of life goals. The ability to control experiences was lacking and all participants felt powerless towards their PLEs. Furthermore, participants expressed fear and despair about their experiences leading to a desire to isolate themselves from people.

A change in sense of self. Six participants described a loss in what inherently made them who they were as individuals. Most participants described changes in important aspects of themselves, which ultimately led to feelings of worthlessness and loss of motivation. Mary spoke more about the loss of her life goals and lack of passion in the wake of their experiences:

> "*I have lost sort of my passions and my goals have become further apart […] I was confident um and life was going well and things were really positive and now it's almost the opposite things aren't going so well things are more negative."* **(Mary)**

Other participants described a more significant loss; describing how they do not know who they were as people anymore in the wake of the experiences. Susan expressed this in great detail:

> “*That’s the thing like I don’t know who like she’s the complete opposite of me really […] she was always going out she had lots of friends she was confident and I just feel like that isn’t me now it’s weird to think about it.”* **(Susan)**

However, for Alex, it was more his own uncertainties towards his sense of self, specifically his gender identity, that influenced the manifestations of his paranoia and visions:

> *“I want to be a cis male but I’m like very clearly not, so stuff like that is a bit upsetting. Like knowing that I’m not. […] the other day we were on Facetime and um I was just sitting there and then she [girlfriend] was like ‘Are you alright?’ and I was like ‘Yea, yea I’m good I’m good’ and then it just like happened and I started imagining it again. And like if I closed my eyes it was there and if I opened my eyes it was there.”* **(Alex)**

Deterioration of control. All participants felt powerless in light of their PLEs. Control existed on a spectrum and depended on severity of experiences; beginning with the assertion to suppress them and ending with a state of helplessness. While Paul insisted on having complete control over his voices, there were still moments where his entire being was taken over:

> *“I could control it but like I said I’ve had moments before where I’ve felt like something has took over which sounds weird doesn’t it […] it feels like I’m being controlled but I feel like someone else is inside me dictating movements.”* **(Paul)**

Most participants described their level of control similarly. In contrast, minimal control and inescapability were evident within the narrative of two participants. They described cyclic patterns of attempting to suppress the voices and them intensifying until they had no choice but to listen to their commands, resulting in self-harm and attempts on their lives:

> *"They tell me to like get a brick and smash it against my head or hang myself or overdose stab myself [...] and they'd go over and over and over until I do something and I'd always end up doing something."* **(Susan)**

> *"I tried to tell the voices to go away and they tend to get stronger [...] occasionally I can get on top of them by telling them to go away and then sometimes they do just go away, at other times they get more intense when I try and tell them to go away."* **(Mary)**

Fear, despair and isolation. All participants described a deterioration of their psychological well-being through verbal and non-verbal language. The degree of fear and despair towards PLEs in participants depended on type and severity. Signs of distress were visible through the body language of participants, for example in the avoidance of eye contact or subtle changes in voice intonation. While distress from trauma and life experiences were viewed as leading to the onset of these experiences, fear also occurred as direct consequence of the PLEs, as Susan described, *"It could be like seeing like people or hearing things and then I'll start to get really panicky."*

Although degree of distress and despair decreased with repeated exposure to PLEs, it never really went away. To some participants, the longer they were exposed to their

PLEs, the more hopeless they felt towards the chance of recovery. Richard, whom had experienced PLEs since early childhood, described the despair whenever his experiences appeared after moments of solace:

> "*I got a bit more used to it but still it's distressing like it affects my emotions like incredibly like I start crying and like just become like flustered with everything it just becomes overwhelming like in the later parts of it."* **(Richard)**

To most participants, the overwhelming fear and despair led to a desire to isolate themselves from friends and family. Alex described how he needed to disengage from everyone, including his close friends, during moments where the voices became overwhelming. He often sighed and paused in this excerpt, perhaps giving further insight into how much these experiences had taken over his life:

> "*I can just kinda shrug it [voices] off and be like 'You're wrong because a few years ago, you might have been right because I didn't really have any friends but now I have all these friends and like that' […] … But like sometimes I'm like I can't see you [friends] today […] 'Because I really don't feel great so I'll see you tomorrow'."* **(Alex)**

All participants spoke about a need to manage these experiences due in part to the psychological deterioration and changes in sense of self. Distress towards the experiences, in particular, motivated participants to seek methods and distractions to find respite towards the experiences, as described in Theme 4

Theme 4: Managing and finding respite

This theme described different coping strategies that participants used to suppress their PLEs. When PLEs became too much to bear, participants would use self-harm or illicit substances as a way to self-regulate them. Though further harm may be caused, they were preferable than the despair resulting from the experiences. Participants also reported the need for supportive relationships and acceptance in dealing with the PLEs.

Seeking relief from the experiences. All participants explained a need to seek temporary relief from the PLEs through different coping strategies. The strategies used were extensive and depended on severity and type of experiences participants found particularly distressing, and in many cases they were harmful to their physical well-being. Paul spoke about the drug use as one of his strategies to calm himself down during episodes of paranoia:

> *"Cannabis for me had a really good effect on me cos it used to do what prescription tablets couldn't and just calm you down it used to take my temper away take my paranoia away it used to just chill me out but I'm not stupid I wouldn't sit here and condone using it."* **(Paul)**

Regular intake of drugs and alcohol were also used by Paul, Thomas, Alex and Laura as a way to distract from the experiences and bring about a level of calmness in the moment. Other harmful coping strategies included a need to self-harm by cutting or physically hitting themselves, especially during times when experiences were severe:

> *"I was like pulling at my hair and I was like hitting my head […] to make it stop. And like I'd bang my head on walls and people will be like 'Alex stop' and I'm like*

> *'No because this is not stopping'. And I look like a mad man but I physically cannot get it to stop any other way than just hitting myself in the head."* **(Alex)**

Most participants were aware of the negative impact self-harm and prolonged substance use have towards their well-being; however, whatever harm was welcomed if it meant escape from the experiences. However, it is understood that while participants were able to relief themselves in the moment, the experiences would inevitable come back, further reinforcing their beliefs that these experiences are enduring (as elaborated in Theme 2.

Having supportive relationships is important. All participants described how vital close relationships, such as family and friends, were in coping with PLEs. The support provided by a network of relationships allowed participants to garner emotional strength in dealing with their PLEs and to feel less alone. While Thomas had no current close relationship, he reflected on the essential need to have them and compensated by having companionship through his pets to not feel alone:

> *"Having a relationship [...] Sounds corny innit, sounds fucking gay [...] When you was by yourself, and you got no partner or anything, do you know what I mean – it's a bit depressing [...] I ain't got a girlfriend or anything. I hadn't for a while, so, do you know what I mean? Makes you a bit lonely, but that's why – you know what I mean? I compensate. And I have four dogs, they're like my babies."* **(Thomas)**

All participants have similar sentiments to Thomas. In particular, acceptance from their loved ones allowed for a safe space and place of reassurance to talk about their experiences. To Mary the acknowledgment that the voices were not real and would eventually go away, provided the reassurance needed for her to challenge the voices and to cope with them when they come.

> *"One of my friends knows…they were fine about it they were just like it's just one of those things and tried to reassure me by explaining that they're [voices] not real that they'll go away they're not there forever."* **(Mary)**

Acceptance in overcoming experiences. Five participants spoke about the need to understand and accept their lived experience to effectively cope with their PLEs. Acceptance could be anything from learning more about their experiences, realising they were not alone with them and the willingness to move forward in life with their experiences. Having experienced PLEs for several years, Richard described the need to accept his unusual experiences for fear of what it may do to him if he did not:

> *"I just see it as part of me and part of my personality I've had to learn to deal with it although it's something that's prevalent I mean you've got to learn to deal with these things I guess if not it will destroy you."* **(Richard)**

His sentiments were echoed by Thomas, Paul, Susan and Laura. While acceptance was difficult, it helped to understand that the experiences were a part of them, and with time, the power and distress the experiences invoked lessened. One pathway towards acceptance was to learn more about what these experiences meant, as Laura described:

> *"I see my doctor a lot at the time trying to get into a counselling or something um I just spoke with her and mainly and my partner I went into wellbeing groups as well and society groups [...] it was nice to understand that it's not just me making all these things appear in my head like it is a thing where they come back [...] I think that's what's always helped me."* **(Laura)**

While Laura went to great lengths to understand her experiences, Susan and Paul gained that acceptance through the realisation that they were not alone in their experiences:

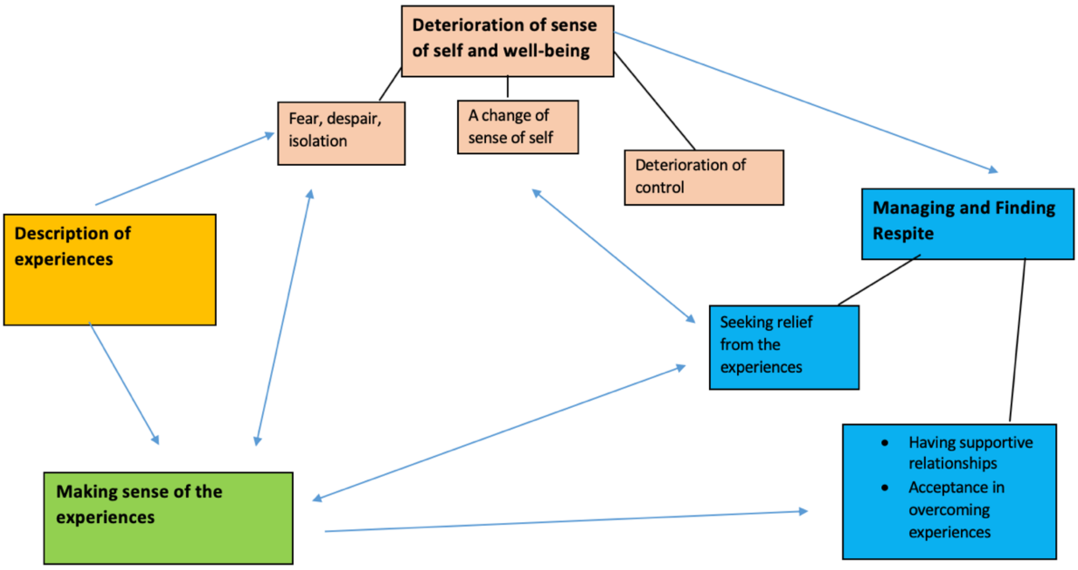
> *"I think now I have accepted more and I realise that there are other people that it is it's not normal but it's not like I'm not crazy although I do feel like that I'm struggling a lot logically I can think that I'm not and I think that's helped."* **(Susan).**

Relationships between Themes: Bringing it all Together

Figure 1 shows the interpretation of the relationship between the themes. A single arrows denotes linear relationships, and double sided arrows represents transactional relationships. For participants, distress following traumatic and life events allowed vulnerability towards PLEs. The negative effects of the experiences were enduring, and allowed for internalised beliefs of being "crazy" leading to a loss of identity, control, and poor psychological well-being. Fear and distress may also be a direct consequence of the PLEs itself.

This negative sense making allowed for the deterioration of sense of self and well-being, particularly fear, despair and isolation, and desire to manage and seek relief from the experiences. Seeking relief through distractions and self-harm may work to temporarily allow experiences to lessen; however, it may lead to further deteriorate of well-being and reinforced negative interpretations of their experiences. Participants whom surrounded themselves with close companions and learned to accept their experiences, while do not completely negate the distress towards the experiences, may cope with their PLEs better.

Figure 1: Diagram illustrating the Connections between Themes



Discussion

The present study explored the nature, appraisals, and responses towards PLEs in young people with BPD traits. All participants were able to describe experiences personally important to them and brought them great concern. Similar to Adams and Sander's (2011) study on experiences of psychosis in individuals with BPD, experiences described by participants were enduring and distressing and were perceived to be related to past trauma and daily life stresses.

The theme 'Descriptions of experiences' relates to the various PLEs expressed as personally important to participants and included experiences of voices and images, paranoia through the fear of others and being out of touch with reality. Previous research on PLEs in individuals with BPD described hallucinations, delusions and dissociative experiences (Barnow et al., 2010), but participants' accounts in the current study highlighted the derogative nature of these experiences. Some perceived their voices as being either internal or external from them. There is a debate within the literature of whether "true psychosis" includes perceptual anomalies that are exterior to the individual, as opposed to "inner images or thoughts with vivid liveliness" which are experienced "inside of the head" (El-Mallakh, & Walker, 2010). However, this distinction is problematic as individuals diagnosed with psychotic disorders also frequently reported varying locations towards their perceptual anomalies (Kingdon et al., 2010). The varied PLEs described in participants' accounts align with theories that psychosis exists on a continuum with normal experience, where experiences that appear 'psychotic-like' are expressed in both general healthy and clinical population, respectively (DeRosse, & Karlsgodt, 2015). The category of true psychosis implies a clinically relevant threshold while the continuum model of psychosis suggests no such threshold and emphasised appraisals in maintaining and exacerbating these experiences.

In the theme ‘Making sense of the experiences’, participants reported having prolonged PLEs that appeared in frequent cyclic patterns and in some cases, became an ever-constant phenomenon. While the DSM-5 criteria specifically described stress-transient paranoid ideation as the only recognised psychotic experiences in BPD (American Psychiatric Association, 2013), the study highlighted the varied and enduring nature of these experiences, as reported by participants (Schroeder, Fisher, & Schafer, 2013). Participants reflected on the distress and vulnerability that came with significant traumatic incidences in their lives. This negative sense-making of experiences can be understood by Garety et al.’s (2001) cognitive model of psychosis which situates appraisals and emotional changes as having a central role in defining the transition points on the ‘psychosis continuum’. Emotional changes from life experiences also contributed to the individual’s negative psychotic appraisals. The analysis highlighted that participants expressed concerns of being abnormal due to their experiences. While self-stigma was commonly found in individuals who experience PLEs (Perry, Taylor, & Shaw, 2007), the findings of the present study emphasised participants’ avoidance of reflecting on their experiences due to this self-stigma. This may pose challenges in clinical practice, where individuals become reluctant to share their experiences which may lead to them being missed by clinicians. Avoidance is emphasised in Garety’s (2001) model as way to detract from the negative appraisals of the psychotic experiences in the short-term; however, results in the maintenance of these experiences in the long run.

The negative impact on psychological well-being and sense of self as a consequence of the PLEs was expressed by all participants. Participants described a significant loss towards their sense of self, as motivation and life goals were unattainable. Their ability to control the experiences were limited and at times impossible, given severity of experiences. The distress and despair of their experiences, coupled with the need for isolation were amongst the detrimental emotional effects of PLEs (Kingdon et al., 2010) and provided rationale for clinicians to explore experiences relevant to young people, and the imminent need for specific interventions that focused on supporting young people to overcome these experiences (Chanen, 2015).

In the theme 'Managing and finding respite', the analysis showed varied coping strategies. Most participants describe the need to physically harm themselves if it meant that their PLEs would leave them for a period of time, further illustrating the fear and despair brought upon by these experiences. The findings add to past research which specifies the use of self-harming behaviours and illicit substances in young people with diagnosed BPD and first episode psychosis (e.g., Francey, Jovev, Phassouliotis, Cotton, & Chanen, 2017), by illustrating that young people with PLEs may also respond to their PLEs with these self-harming behaviours. Having supportive relationships with friends was important in managing these experiences. The importance of close relationships in improving symptomatology and functioning in psychosis has been widely evidenced within the literature (Cohen, Hassamal, & Begum, 2011). The study findings further highlighted the need to accept and understand experiences to move forward in life and provide solace from the distressing experiences.

Limitations. Though participants described many of their psychotic-like experiences, there may be other aspects of their experiences that were not captured in the interview given participants' reluctance to reflect on aspects of their experiences in fear of seeming abnormal. Additionally, participants approached were receiving care from the mental health services which may have impacted on the way they understood and reflected on their experiences of PLEs. Furthermore, the study did not consider factors such as ethnicity and gender, which may have impacted on the meaning participants hold towards their PLEs.

There was a potential for recruitment bias as the researcher did not have access to information on the number of referrals and current patients within the BPD traits pathway and had recruited without knowledge of how diverse patients with BPD traits were within the service. Additionally, while the researcher sought to provide feedback to participants on study outcomes, the practice of member checking (i.e., for participants to validate the study results) was not conducted due to time constraints. According to Doyle (2007), there is a place for member checking in interpretive phenomenology. In Heideggerian phenomenology, the interpretation of the researcher cannot be suspended from the research process, but becomes a vital part of understanding the meaning of the phenomenon. Member checking encourages negotiation of meaning and analysis involves the convergence of perspectives between participant and researcher. This is consistent with hermeneutic circle, which requires the constant movement between interpretation and text, or in the case of the member check a return to interaction with the participants (Doyle 2007). Nevertheless, Webb (2003) also stressed that attempts to validate data interpretation with participants are not consistent with a phenomenological approach due to the underpinnings of double hermeneutics. Even if different versions are produced by another researcher or participant produces, it does not invalidate the main researcher's version, it simply adds another plausible description.

Future Directions and Conclusions. Figure 1 emphasised the links between negative sense-making of experiences, decline of psychological well-being, and unhelpful coping strategies. However, the study could not determine any causal links between these themes. Future studies should quantitatively investigate how the role of appraisals and emotional responses towards PLEs may impact on symptomatology and well-being, as well as behavioural responses in young people with BPD traits. As study participants expressed different types of PLEs that were personally significant and caused great concern, it provides further rationale for future investigations to specifically focus on finding appropriate treatments for this clinical group.

This research has implications for how young people with BPD traits are supported in mental health services and emphasises the need for future studies to build interventions specifically supporting young people in overcoming difficulties attached to these experiences. Clinical practice may overlook experiences not within the symptomatology of diagnosis, in this case it is possible a BPD diagnosis takes precedence. However, the study's findings suggested a varied range of experiences that were of great concern for participants. By placing importance and respecting complexities of individual experiences, only then can person-centred care be effectively delivered. The use of extended assessments and psychological formulation may be useful in guiding the clinician towards understanding the difficulties of young people (Johnstone, & Dallos, 2013). As participants reflected on the significance of trauma prior to the PLEs and usefulness of acceptance in coping with PLEs, it suggested that specific therapeutic interventions that follow trauma-focused models (Cohen, Mannarino, Kliethermes, & Murray, 2012) and acceptance and commitment frameworks (Pankey, & Hayes, 2003) may promote a sense of control towards these experiences.

Disclosure Statement: The research team report no conflicts of interest.

Funding: No specific grant from any public funding agency, commercial, or not-for-profit sectors was received for the purpose of this research.

References

Adams, B., & Sanders, T. (2011). Experiences of psychosis in borderline personality disorder: A qualitative analysis. *Journal of Mental Health*, *20*(4), 381-391.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Barnow, S., Arens, E. A., Sieswerda, S., Dinu-Biringer, R., Spitzer, C., & Lang, S. (2010). Borderline personality disorder and psychosis: a review. *Current Psychiatry Reports*, *12*(3), 186-195.

Baumeister, D., Sedgwick, O., Howes, O., & Peters, E. (2017). Auditory verbal hallucinations and continuum models of psychosis: a systematic review of the healthy voice-hearer literature. *Clinical psychology review*, *51*, 125-141.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Brett, C. M. C., Peters, E. P., Johns, L. C., Tabraham, P., Valmaggia, L. R., & McGuire, P. K. (2007). Appraisals of Anomalous Experiences Interview (AANEX): a multidimensional measure of psychological responses to anomalies associated with psychosis. *The British Journal of Psychiatry*, *191*(51), s23-s30.

Brett, C., Heriot-Maitland, C., McGuire, P., & Peters, E. (2014). Predictors of distress associated with psychotic-like anomalous experiences in clinical and non-clinical populations. *British Journal of Clinica Psychology*, *53*(2), 213-227.

Chanen, A. M., Jackson, H. J., McCutcheon, L. K., Jovev, M., Dudgeon, P., Yuen, H. P., ... & Clarkson, V. (2008). Early intervention for adolescents with borderline personality disorder using cognitive analytic therapy: randomised controlled trial. *The British Journal of Psychiatry*, *193*(6), 477-484.

Chanen, A. M., Mccutcheon, L. K., Germano, D., Nistico, H., Jackson, H. J., & Mcgorry, P. D. (2009). The HYPE Clinic: an early intervention service for borderline personality disorder. *Journal of Psychiatric Practice®*, *15*(3), 163-172.

Chanen, A. M., & Kaess, M. (2012). Developmental pathways to borderline personality disorder. *Current psychiatry reports*, *14*(1), 45-53.

Chanen, A. M. (2015). Borderline personality disorder in young people: are we there yet?. *Journal of Clinical Psychology*, *71*(8), 778-791.

Cohen, C. I., Hassamal, S. K., & Begum, N. (2011). General coping strategies and their impact on quality of life in older adults with schizophrenia. *Schizophrenia research*, *127*(1-3), 223-228.

DeRosse, P., & Karlsgodt, K. H. (2015). Examining the psychosis continuum. *Current 104ehavioural neuroscience reports*, *2*(2), 80-89.

Doyle, S. (2007). Member checking with older women: A framework for negotiating meaning. *Health care for women international*, *28*(10), 888-908.

El-Mallakh, R. S., & Walker, K. L. (2010). Hallucinations, psuedohallucinations, and parahallucinations. *Psychiatry: Interpersonal and Biological Processes*, *73*(1), 34-42.

Escher, S., Romme, M., Buiks, A., Delespaul, P., & van Os, J. (2002). Formation of delusional ideation in adolescents hearing voices: a prospective study. *American Journal of Medical Genetics*, *114*(8), 913-920.

Francey, S. M., Jovev, M., Phassouliotis, C., Cotton, S. M., & Chanen, A. M. (2017). Does co-occurring borderline personality disorder influence acute phase treatment for first-episode psychosis?. *Early Intervention in Psychiatry*.

Fitzsimons, D., Parahoo, K., & Stringer, M. (2000). Waiting for coronary artery bypass surgery: a qualitative analysis. *Journal of advanced nursing*, *32*(5), 1243-1252.

Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. E. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological medicine*, *31*(2), 189-195.

Gleeson, J. F., Chanen, A., Cotton, S. M., Pearce, T., Newman, B., & McCutcheon, L. (2012). Treating co-occurring first-episode psychosis and borderline personality: a pilot randomized controlled trial. *Early intervention in psychiatry*, *6*(1), 21-29.

Guilé, J. M., Boissel, L., Alaux-Cantin, S., & de La Rivière, S. G. (2018). Borderline personality disorder in adolescents: prevalence, diagnosis, and treatment strategies. *Adolescent health, medicine and therapeutics, 9,* 199.

Ising, H. K., Veling, W., Loewy, R. L., Rietveld, M. W., Rietdijk, J., Dragt, S., ... & van der Gaag, M. (2012). The validity of the 16-item version of the Prodromal Questionnaire (PQ-16) to screen for ultra high risk of developing psychosis in the general help-seeking population. *Schizophrenia bulletin*, *38*(6), 1288-1296.

Johnstone, L., & Dallos, R. (2013). *Formulation in psychology and psychotherapy: Making sense of people's problems*. Routledge.

Kaess, M., Brunner, R., & Chanen, A. (2014). Borderline personality disorder in adolescence. *Pediatrics, 134*(4), 782-793.

Kernberg, P.F., Weiner, A.S., & Bardenstein, K.K. (2000). Personality Disorders in Children and Adolescents. New York: Basic Books

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of general psychiatry*, *62*(6), 593-602.

Kingdon, D. G., Ashcroft, K., Bhandari, B., Gleeson, S., Warikoo, N., Symons, M., ... & Mason, A. (2010). Schizophrenia and borderline personality disorder: similarities and differences in the experience of auditory hallucinations, paranoia, and childhood trauma. *The Journal of nervous and mental disease*, *198*(6), 399-403.

Larkin, M., & Thompson, A. (2012). Interpretative phenomenological analysis. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*, 101-116.

Lenzenweger, M. F., & Castro, D. D. (2005). Predicting change in borderline personality: Using neurobehavioral systems indicators within an individual growth curve framework. *Development and Psychopathology*, *17*(4), 1207-1237.

Loewy, R. L., Pearson, R., Vinogradov, S., Bearden, C. E., & Cannon, T. D. (2011). Psychosis risk screening with the Prodromal Questionnaire—brief version (PQ-B). *Schizophrenia research, 129*(1), 42-46.

McGorry, P. D., Purcell, R., Hickie, I. B., Yung, A. R., Pantelis, C., & Jackson, H. J. (2007). Clinical staging: a heuristic model for psychiatry and youth mental health. *Medical Journal of Australia*, *187*(S7), S40-S42.

Musa, A., Coker, S., Papadopoullos, R., & Hodgekins, J. *Comorbidities associated with psychotic symptoms in borderline personality disorder: A systematic review.* Unpublished manuscript, The University of East Anglia, United Kingdom.

Nishizono-Maher, A., Ikuta, N., Ogiso, Y., Moriya, N., Miyake, Y., & Minakawa, K. (1993). Psychotic symptoms in depression and borderline personality disorder. *Journal of affective disorders*, *28*(4), 279-285.

Pankey, J., & Hayes, S. C. (2003). Acceptance and commitment therapy for psychosis. *International Journal of Psychology and Psychological Therapy*, *3*(2), 311-328.

Pearse, L. J., Dibben, C., Ziauddeen, H., Denman, C., & McKenna, P. J. (2014). A study of psychotic symptoms in borderline personality disorder. *The Journal of nervous and mental disease*, *202*(5), 368-371.

Perry, B. M., Taylor, D., & Shaw, S. K. (2007). "You've got to have a positive state of mind": an interpretative phenomenological analysis of hope and first episode psychosis. *Journal of Mental Health*, *16*(6), 781-793.

Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej Analizy fenomenologicznej w badaniach jakościowych w psychologii. *Czasopismo Psychologiczne*, *18*(2), 361-369.

Pine, F. (1985). Developmental Theory and Clinical Process. New Haven: Yale University Press

Reitz, R. R. (1999). Batterers' experiences of being violent: A phenomenological study. *Psychology of Women Quarterly*, *23*(1), 143-165.

Ryan, J., Graham, A., Nelson, B., & Yung, A. (2015). Borderline personality pathology in young people at ultra high risk of developing a psychotic disorder. *Early intervention in psychiatry*.

Rutigliano, G., Valmaggia, L., Landi, P., Frascarelli, M., Cappucciati, M., Sear, V., ... & McGuire, P. (2016). Persistence or recurrence of non-psychotic comorbid mental disorders associated with 6-year poor functional outcomes in patients at ultra high risk for psychosis. *Journal of affective disorders*, *203*, 101-110.

Schroeder, K., Fisher, H. L., & Schäfer, I. (2013). Psychotic symptoms in patients with borderline personality disorder: prevalence and clinical management. *Current opinion in psychiatry*, *26*(1), 113-119.

Smith, J. J., & Jarman, M. M. and Osborn, M.(1999). Doing interpretative phenomenological analysis. *Murray, M. and Chamberlain, K. Qualitative health psychology: Theories and methods. London: Sage publications*.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods.* London: Sage.

Smith, J.A. (2007). Hermeneutics, human sciences and health: linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being, 2,* 3–11.

Smith, J.A., Flowers, P., Larkin, M. (2013). *Interpretative Phenomenological Analysis: Theory Method and Research.* Sage Publications: London.

Thérien, P., Tranulis, C., Lecomte, T., & Bérubé, F. A. (2012). The experience of treatment of persons with concomitant psychotic and borderline personality disorders. *Psychosis, 4*(1), 63-73.

Thompson, A., Nelson, B., Bechdolf, A., Chanen, A. M., Domingues, I., McDougall, E., & Yung, A. R. (2012). Borderline personality features and development of psychosis in an 'Ultra High Risk'(UHR) population: a case control study. *Early intervention in psychiatry*, *6*(3), 247-255.

Webb, C. (2003). Introduction to guidelines on reporting qualitative research-Reply. *Journal of advanced nursing, 44*(4), 437-437.

Wyer, S. J., Earll, L., Joseph, S., & Harrison, J. (2001). Deciding whether to attend a cardiac rehabilitation programme: an interpretative phenomenological analysis. *Coronary Health Care, 5*(4), 178-188.

Yee, L., Korner, A. J., McSwiggan, S., Meares, R. A., & Stevenson, J. (2005). Persistent hallucinosis in borderline personality disorder. *Comprehensive*

Psychiatry, *46*(2), 147-154.

.

.

Chapter Five

Extended Methodology for Empirical Study

Word Count: 5779

Chapter Five - Extended Methodology

This additional chapter elaborates on the methodology section of the empirical study which includes the rationale for the choice of utilising an interpretative phenomenological analysis (IPA) approach, and providing additional information of the qualitative design in greater detail, including descriptions of the participants, recruitment procedure and data collection.

Ontology and Epistemology

Ontology is concerned with the nature of things, and forms the root of investigating the state of existence. There is a continuum of ontological positions, with realism and relativism located on both ends of the spectrum. Realism asserts that reality can be examined independently of human investigation; being “self-evident”, while relativism is context-dependent on the language and frameworks used to understand reality. Occupying either ontological positions would therefore influence research methodology, as one would be applying different methodological and philosophical frameworks to investigate reality (Scotland, 2012).

A related concept is epistemology, which is concerned with how we come to understand and know things. It is concerned with ‘how we understand knowledge’, where ontology is concerned with the question of ‘what is reality’. Epistemology and its philosophical inquiry interrogates the frameworks used to understand knowledge. Like ontology, there is also a continuum of epistemological positions. This being positivism (i.e., the view that only “factual” knowledge gained through the senses or ‘observation’ is trustworthy) on one end, constructionism (i.e., the view that reality is a construct of human mind, as such the perception of reality is subjective) on the opposite, and contextualism in its middle. Contextualism, as an epistemological framework, posits that there is an objective truth but will be limited or influenced by the social context in which research takes place (Madill & Gough, 2008).

Conclusively, ontology focuses on investigating objective reality, while epistemology is about examining the relationship between knowledge, the researcher and the social contexts surrounding its methodology. Both are distinct philosophical methods of inquiry, to be sure, but are nevertheless intertwined.

Interpretative Phenomenological Analysis (IPA)

IPA seeks to understand in detail how individuals make sense of their lived experiences because it engages at a relatively deep level with questions of epistemology and ontology (Smith, Flowers, & Larkin, 2009). It is based on the assumption that people are ‘self-interpreting beings’ (Taylor, 1985), which means they actively engage in interpreting the world around them (i.e., events, objects, and people in their lives). In order to examine this process, there are three key philosophical frameworks that underlie IPA; (i) Phenomenology, the study of lived experience; (ii) Hermeneutics, the theory of interpretation of experiences; and (iii) Idiography, how a lived experience may be understood from a person’s perspective (Smith et al., 2009).

Phenomenology. Phenomenology is concerned with detailed examination of an individual’s lived experiences (Smith, Jarman & Osborn, 1999). Husserl (1927), one of the main philosophers in phenomenology, considered that as humans we are quick to attribute meaning and attempt to organise our experiences in line with our own world view. Phenomenology aims to identify the very essence of the experiences or phenomena which makes them distinguishable from others, through eidetic reduction. Studies on phenomenology highlight how individuals experience and discuss objects and events, as opposed to adhering to a descriptive and categorical mode of criteria. This is done with ‘bracketing’, setting aside preconceptions and allowing the experiences to illustrate themselves. Husserl believed that by bracketing our preconceptions, we are able to achieve ‘transcendental reduction’, which is the content of conscious experience (Smith et al., 2009). Many phenomenological psychologists disagreed with Husserl’s work, and argued that we may only partially ‘bracket out’ our preconceptions, as it is through interpretation that we are able to access an individual’s lived experience. As such, Finlay (2013) argues that researchers should engage in continual reflexivity throughout the process due to the inevitable influence of the researcher. Therefore, it is vital for the researcher to reflect on their own experiences, knowledge and meanings of the experienced phenomenology.

Hermeneutics. Following Husserl’s phenomenological tradition, Heidegger built on it using the theoretical framework of hermeneutics (Smith et al., 2009). Hermeneutics is concerned primarily with interpretation. Within the context of IPA, this puts the researcher in a position of attempting to understand and ‘translate’ the experiences of their subjects. This process is referred to as *double hermeneutics* or dual interpretation, as it requires the researcher to both understand and interpret the individual’s meaning making of their lived experiences. Following this is the *‘hermeneutical circle’*, a conceptual framework further developed by Heidegger. The ‘hermeneutical circle’ is self-referential and posits that an experience can only be understood through its particularities and vice versa. In effect, it adopts the view that an experience can be understood through the sum of its parts, and that parts of the experience is understood by viewing the whole. This effectively allows the participants and researcher’s meaning-making process to be informed by a tapestry of personal contexts, be it cultural, historical or in the case of IPA, biographical. While hermeneutics allows researchers to understand the participant’s perspective, it also encourages researchers to form a critical framework in response to the participant’s experience. Hence, hermeneutical methodologies in IPA serves the purpose of drawing out richer and more comprehensive data through a dynamic and adaptive relationship between both researcher and participant.

Idiography. The third theoretical framework which IPA relies upon is idiography. IPA is idiographic in nature as it is concerned with the in-depth examination of the particular or unique events (Shinebourne, 2011). There is a very specific focus on how particular people experience particular phenomenon in particular context (Larkin & Thompson, 2011). The experience of the phenomena is considered on its own terms and should not be classified with pre-defined categories through the use of inductive and iterative process. This is in contrast with a nomothetic approach to research, used in most empirical work in psychology, in which populations are studied to establish the probability of certain phenomena under particular conditions (Shinebourne, 2011). IPA is concerned with the meaning of the phenomena for an individual, rather than establishing generalisations (Smith, Harré, & Van Langenhove, 1995). As such, the IPA researcher will start with the examination of an individual before moving to an equally attentive exploration of the second case, and so on. In the end, the researcher is moving between important themes generated from the analysis and exemplify them with individual narratives and showing similarities and differences.

Rationale for IPA. According to Smith and Osborn (2008), IPA is a vital approach to studying novel and under-researched phenomena that are not easily understood. This approach aligned well to the exploration of psychotic-like experiences (PLEs) in young people with BPD traits, given that these phenomena is rarely understood and given proper acknowledgment, and is regarded as complex phenomena that is not easily described or defined (Schroeder, Fisher, & Schäfer, 2013). The study is phenomenological as it is interested in how each participants subjectively experienced their PLEs, in contrast to searching for an objective unbiased truth. It is interpretative (i.e., double hermeneutics), where the researcher made sense of the participants interpretations of their experiences, and elicited themes based on her perception and reflection of their experiences of PLEs. The analysis of the study was committed to an idiographic approach by representing the unique experiences of an individual while simultaneously highlighting shared qualities between individuals (Smith et al., 2009). Methods used in data collection and cross-case analysis were examples that demonstrated the study's commitment towards the detailed examination of the particular.

Reflexivity

It is important to consider how a researcher's epistemological, ontological and theoretical assumptions influence the data analytical process (Mauthner & Doucet, 2003). This aspect of methodology, known as *reflexivity* is an important aspect of ethical research (Shaw, Houghton, Casey & Murphy, 2010). Reflexivity forces the researcher to critically evaluate the interpretations about the data by considering their preconceptions and inter-subjectivity. The researcher's assumptions may only be apparent at the interpretation stage (Etherington, 2007). Reflective diaries, regular supervision and qualitative research forums were instructive in developing the researcher's reflexive skills and consider how their preconceptions influence the analytical process. A reflection on the impact of this preconceptions and inter-subjectivity on aspects of the study have been included.

The researcher's position. The researcher locates herself, ontologically, within a critical realist position. IPA as a methodology that has its roots in critical realism (Bhaskar, 1978). Critical realists accept that there is an external world which is independent of human consciousness while acknowledging our socially determined knowledge about that reality (Danermark, Ekstrom, Jakobsen & Karlsson, 2002). Therefore, critical realism suggests that a quantifiable reality does exist, independent of human perception (McEvoy

& Richards, 2003), but simultaneously adopts a critical position towards ‘factual truth’. Thus, accepting that observations are fallible because they are shaped by our conceptual frameworks. Critical realism encourages a focus on theories regarding reality and methods we adopt to investigate it (Pilgrim & Bentall, 1999). Therefore, it is these human interpretations that require closer study (Danemark et al., 2002). Critical realism is referred to as a less naïve form of realism and has similarities with Constructionist approaches, recognising the role of subjectivity in the production of knowledge regarding material-reality (Madill, Jordan, & Shirley, 2000).

Given that the study aims to understand how participants make sense of their lived experiences of PLEs, the critical realist stance is consistent with the aims of the research, as it is concerned with the participants’ experiences of their reality and not reality itself. Regarding “truth”, the participants’ accounts recorded in this study are taken as truthful accounts of their experience given that a critical realist approach accepts multiple, and equally plausible truths.

Context and perspective of the researcher. According to Braun and Clarke (2013), it is the participants and researchers that bring their own personal histories, values and assumptions into the research. As such, it is important for the researcher’s context to be considered in order to conduct good qualitative research. Furthermore, true to IPA’s commitment to hermeneutics (Smith et al., 2009), it accepts that the researcher’s thoughts and feelings influence how they understand an individual’s reality and believes the researcher’s influence on the data is an important part of the analysis. To ensure the quality of the study, it is important for the transparency of context and perspective of the researcher to be considered as is described below:

> *In order to explore my position as a researcher, I will first provide my own personal cultural and social circumstance. I come from a developing country in*

South East Asia where spiritual and religious beliefs are prevalent in the country, and significant contributors to my sense of self. As such, I grew up being surrounded by cultural beliefs that psychotic-like experiences are 'whispers from the devil' or 'punishments from God'. Nevertheless, I was also exposed to the Western perspective from an early age due to the privilege of having been raised in a middle-class household and having studied abroad in the UK myself for more than half a decade. Hence, I am curious and willing to listen to different perspectives which would assist in exploring the subjective perception surrounding psychotic-like experiences in participants. I will also remain vigilant to my own biases and assumptions, as a result of my socio-cultural circumstance, which may influence data collection and analysis.

My own personal experience with psychosis and psychotic-like experiences came about in my years volunteering in a charity organisation in my home country. I have spoken with individuals whom experience psychosis and have listened to their views and perceptions of their experiences. These personal experiences have helped create an understanding of the different nature of psychotic-like experiences. Nevertheless, I will be conscious to the influence my assumptions may have towards data collection and interpretation. A challenge I foresee in data collection and interpretation is my own difficulties with the English language. As English is my second language, I may have difficulties in picking up dialects and the meaning behind sentences. In order to avoid misunderstandings when interpreting the data, multiple-coders through the use of supervision will be employed.

A written summary of the researcher's own views of carrying out qualitative research on this topic is provided. This excerpt was written prior to the commencement of the study interviews:

> *As a trainee clinical psychologist, I have a genuine curiosity towards the very nature of various clinical presentations, such as psychosis and personality disorders. When considering my research topic, I felt a pull towards understanding the complexities often seen in mental health services – in particular, the clinical observations of psychotic-like experiences in young people with traits of borderline personality disorder. Whilst an area I was not too familiar with (having only received second hand information on this presentation), I was interested albeit a little apprehensive at the possibility of taking this on as my thesis research area.*
>
> *Having worked with individuals who experience psychosis back in my home country, I believe that it is a very complex and heterogeneous presentation. My assumption of it is that no one individual will have a particularly similar experience as the next, which made me wonder how psychotic-like experiences in young people with borderline personality traits differ. My previous knowledge of any sort of psychotic-like experiences in BPD has been framed in a strict definition of 'stress-transient paranoia' which I personally believe to be restrictive and seem to go against anecdotal experiences of clinicians I have heard in the past that often spoken about the complexities in individuals with BPD and BPD traits. It makes sense then to employ a qualitative research methodology to give a voice to an otherwise perplexing and complex presentation.*
>
> *I have only ever conducted quantitative research in the past. However, I became drawn to a qualitative approach, as the very idea of exploring individual's experiences and giving a voice to them to express what their perspective of their*

experiences appeal more to me. As a clinician, it is an important value of mine to allow the individual to narrate their story and to formulate their beliefs based on what is important to them. As a researcher, I am a novice towards the philosophical underpinnings of qualitative methodologies. Intrinsically, it will be a challenge to adjust my way of thinking from a more quantitative, systematic perspective to an explorative stance in hopes to gain knowledge and recognise subjective perspectives. I will have regular reflective conversations in supervision and through the use of the Qualitative Forum conducted at UEA, as well as a reflective diary to assist in bracketing my own assumptions in order to ensure that interpretation is entrenched in the data itself.

Method

Ethical Considerations

As participants were recruited from a clinical population, NHS ethical review and Health Research Authority approval were sought to ensure ethical principles and legislative requirements were met.

Informed Consent. Potential participants were not approached by the researcher until they provided consent to be contacted. The Participant Information Sheet (PIS) and discussions with the researcher provided all necessary study information required for participants to make informed decision regarding participation, such as aims of the study, what participation would involve, and procedures of confidentiality. The researcher had also answered any questions participants had about the study, and made participants aware they were under no obligations to take part in the study, and that they may withdraw at any point without impacting on their care. As clinicians were involved in the recruitment process, full study disclosure was presented and provided in the Clinician Information

Sheet (CIS). Both information on the CIS and PIS provided to clinicians and participants followed the Research Governance Frameworks (2005) by the NHS Health Research Authority.

Data Storage and Confidentiality. Data storage followed regulations from the General Data Protection Regulation (GDPR) and UEA policy. Participants were provided with a unique anonymised ID to ensure confidentiality of data. All personal details such as names, and contact details and research data were stored on a password protected database. Documents that contain participant identification were kept separate from respective study responses. Any paper document that contains identifiable information was stored securely at UEA. All recordings of interview sessions were transferred securely onto a NHS computer after the session and deleted from audio recorder. Research data would only be accessed by research supervisors, who are custodians of the data. All study data would be kept for 10 years, after which time it will be destroyed.

Potential risks and benefits of study. Participants may be anxious answering potentially sensitive questions, such as questions about PLEs and BPD traits. It is acknowledged that terms like psychosis and BPD are highly stigmatised, and providing a diagnosis of BPD is not the purpose of the study, but rather to explore associated traits. To ensure their safety, potential participants had been made fully aware of this before consenting to the study. Study participants had also been made aware that they do not have to answer all questions, and could withdraw from the study at any time. If study caused distress, the session would be stopped immediately, and prompt action to speak with case managers or on-call duty workers would have been taken. Participants were also be made aware of the limits of confidentiality and situations where breaches in confidentiality may need to be taken (e.g. where there may be risk to self or others).

It is important to note that even though asking questions relating to BPD traits may cause distress in some individuals, Chanen et al. (2008) argue that there are significant benefits of understanding the experiences of young people with BPD traits such as being able to understand any presenting difficulties within this age group, in order to develop early intervention programmes. Furthermore, study participants were under the care of a secondary mental health service with a dedicated pathway for individuals with BPD traits and therefore this study would not have been the first time they have heard of this terminology.

Potential benefits for participants include contributing to research which aims to improve understanding of PLEs in young people with BPD traits and inform future psychological interventions towards this clinical group. Furthermore, each participant was provided with £5 Amazon vouchers as a token of appreciation.

As participants may choose the venue of the initial meeting, there was potential risk to the researcher when conducting the meeting at the participants' home. In this case, the researcher had adhered to the UEA and service policies regarding lone working at all times, which involved informing the research supervisor and care team about the appointment times and location of meeting. Lone working guidelines was adhered to at all times.

Materials

Self-Report Measures. Given the need to screen for young people with both PLEs and BPD traits, two validated, self-report screening measures were used to meet all eligibility requirements and identify eligible participants. Below the screening measures are described in detail:

The 16- item Prodromal Questionnaire (PQ-16; Ising et al., 2012). The self-report screening measure (PQ-16) is used to measure the presence of PLEs. The PQ-16 is a 16-item self-report measure which assesses PLEs on a two-point scale of 'True'/'False'. If responded 'True' on any item, they may rate their distress on a four-point scale of 1 (No) to 4 (Severe). Loewy, Pearson, Vinogradov, Bearden, and Cannon (2011) estimated a cut-off score of six on the 'True'/'False' item scales to indicate sub-clinical levels of psychosis. The PQ-16 predicted ARMS/psychosis with a high sensitivity (87%) and high specificity (87%). Internal consistency of items is acceptable, with a Cronbach's alpha of .774 (Ising et al., 2012).

The 15-item Helping Young People Early Screen (HYPE Screen; Chanen et al., 2009). The HYPE Screen is a 15-item self-report, screening questionnaire which maps onto items on the SCID-II PD-BPD (First et al., 1996), and corresponds to the nine DSM-IV diagnostic criteria for BPD: frantic efforts to avoid abandonment, interpersonal difficulties, identity disturbance, impulsivity, recurrent suicidal behaviour, emotional instability, chronic feelings of emptiness, inappropriate anger, and transient paranoid ideas or severe dissociative symptoms. The HYPE Screen assesses BPD traits on a two-point response scale of 'Yes'/'No' and has been shown to be a reliable screening tool for BPD traits in young people (Chanen et al., 2008). Individuals who score between the ranges of 9 to 12 would indicate BPD traits (Chanen et al, 2009). Currently, the HYPE Screen is used as the primary measure of BPD traits and young people who scored 11 or more on the HYPE Screen are referred to a specified BPD treatment pathway within the service. The BPD treatment pathway offers specific support on managing emotions and interpersonal difficulties through one-to-one interventions and/or groups and medication.

Topic Guide. The Appraisals of Anomalous Experiences (AANEX; Brett at al., 2007) semi-structured interview was used as a way to elicit experiences of psychotic-like experiences by participants and helped shape and develop the topic guide. The AANEX is a clinician rated semi-structured interview which assesses the nature of PLEs (see Table 1 for PLEs covered by the AANEX) and appraisals and responses to them. Items and sections of the AANEX can be used in isolation to suit the aims of the assessment and the participants' experiences. In the first part of the interview, probe items from the AANEX were used as a way to elicit different type of PLEs being experienced by participants.

Once types of PLEs were established, the researcher began to explore the nature of these experiences in more depth, and the participant's appraisals and responses towards them through the topic guide (see Appendix F for the topic guide). Open-ended questioning were used to facilitate the movement from description to interpretation of experience and to more reflective responses (e.g., 'How did you make sense of the experiences at the time?', 'How did you feel when the experiences first started?'). The schedule functioned as a guide only; and interviews followed the personal interests of the participants. Schedule development was discussed and reviewed at the study proposal stage by internal review at the host institution and amendments were made for content and clarity. Participants took approximately 38 minutes to an hour and 15 minutes to complete the overall interview.

Table 1. AANEX-Inventory items

AANEX-Inventory Section	Items

Schneiderian first rank symptoms	thought transmission, controlled actions, 'activity' experiences, receptivity, passivity, loud thoughts, thought withdrawal, reference experiences, and voice experiences
anomalous perception	depersonalisation, visual anomalies, somatic anomalies, derealisation, auditory anomalies, lost automatic skills, global visual anomalies, oversensitivity, language disturbance, dividing attention deficit, concretism, and olfactory anomalies
anomalous cognition	distractability, thought interference, thought blockage, captivation/ fixation, disorientation, thought pressure, time distortion, insight experiences, 'mission' experiences
anomalous affect	spiritual elation, monitored, doom/negation, mixed/unknown emotions, emotional reactivity, loss of emotions
Paranormal	precognition, out-of-body experience
Anomalous individuation	loss of boundary, subjective isolation

Participant

IPA is an approach that challenges the often perceived linear relationship between 'number of participants' and value of research. Smaller samples are arguably advantages within an idiographic framework, with ten participants seen at the higher end of most recommendations for sample sizes (Smith, 2004). Looking at the larger IPA literature, the number of participants that are often involved is 15. However, Pietkiewicz and Smith (2012) argue that there should be no rule on the number of participants included, and that it should largely depend on the richness of individual cases, how the researcher wants to compare and contrast cases, and pragmatic restrictions such as time constraint or limited access to participants.

As such, the researcher aimed to recruit between 8 to 12 young people. However, the final sample consisted of seven participants (three male, three female and one transgender male) as engagement of eligible participants to the aims of the study were found to be difficult. While 12 eligible participants were approached and provided consent to be contacted, five individuals had dropped out prior to the meeting. While reasons for disengagement were not available for all five individuals, three expressed feeling uncomfortable about exploring experiences they found distressing. Here, the researcher reflected on the difficulty of recruitment with the third participant whom disengaged:

> *I was contacted by a potential participant whom expressed that she no longer could take part in the study as she felt the intense fear of reflecting on her experiences to someone she hardly knows. She mentioned that she was currently going through a lot in her life and understandably that had led to the experiences to be even more frightening. Prior to this final message, she had cancelled our appointment twice but had not given a reason other than having forgotten the appointment. This again begs the question as to why she had forgotten, if this was indeed a coping strategy to the impending anxiety she felt of meeting with me, and if her agreeing to meet at another time was her fear of upsetting me. I cannot help but wonder if this had been the case for the other potential participants before her whom had declined involvement in the study after some time.*

Recruitment and Procedure

Recruitment of participants were conducted from July to October 2018. The researcher had liaised with team managers via e-mail regarding the study, explaining the aims of the study (see Appendix P for gatekeeper letter). Once the researcher received permission to recruit, clinicians within the service teams were provided with the CIS which includes the study eligibility criteria, PIS and consent to contact form. The clinical service already screened for young people with PLEs and BPD traits through the self-report PQ-16 and HYPE screen, and so only individuals who met cut-off scores on the PQ-16 and HYPE screen were approached about the study. Research posters (Appendix Q) were also placed in clinical areas so potential participants could self-refer; although, to be eligible for the study, self-referred participants would have to consent to relevant clinicians confirming their eligibility before offering a study appointment. The interview for each participant ranged from 38 minutes to an hour and 15 minutes. After the study interview was completed, participants were provided with the study debrief form (Appendix R) which contained information on the purpose of the study and any questions were answered.

Researcher's Reflection of Interviewing

As qualitative research values subjectivity and acknowledges how the researchers' assumptions shape and influence the research (Braun & Clarke, 2013), reflexivity throughout the research process is required in order to be transparent about how the research has been influenced by the researcher (Finlay, 2013). As such, the main researcher has provided excerpts from her reflective journal to demonstrate her reflections on the research process. This particular reflection was conducted after the first participants' interview.

> *When conducting the interview, I felt an overwhelming sense of anxiety as I felt an urge to 'do things right'. Seeing as it was my first interview and having only ever conducting quantitative research in the past, I noticed I had at times been directive within the interview and had often been quite directive in my line of questioning (I.e. 'Did you feel distressed by the experience?' as oppose to 'What did you feel when the experiences first came?'). This is something to be aware of in the following few interviews. I also noticed one worded answers from my participants and myself jumping into the conversion immediately after a pause (which discouraged any further reflection from my participant). As such, this is a reminder to myself to allow for pauses to occur and to sit in silence to allow for that space of reflection from the participant. I was deeply curious about my participant's experience and at times, would step into my role as a trainee psychologist and feel the need to attend to my participants' distress, something that I would need to be mindful of in my next interview. I am reminded that my role is a researcher and not the clinician.*

Analysis

In order for IPA to be consistent with its theoretical underpinnings, the approach provides a framework or 'set of common processes' for analysis (Smith et al., 2009). Smith and Osborne (2003) argue that there is no single method for working with the data and emphasis is given towards the process being flexible and open to adaptation. Nevertheless, Smith et al. (2009) recommend a six stage analysis for those new to IPA:

- **Stage 1: Reading and re-reading.** Reading and re-reading of the transcript and note taking of any initial thoughts would help capture any first impressions of the transcript. Through this method, the researcher may begin to enter the participant's world. Alongside repeated reading of the transcript, the researcher also listened to the audio recording to get a feel of the tone (i.e., filled pauses, hesitation in speech, change in vocal intonation) of what was being said.

- **Stage 2: Initial coding.** A detailed line-by-line commentary of the transcript was conducted by the researcher to identify ways in which participants understood their lived experience of psychotic-like symptoms. The commentaries were descriptive, linguistic and conceptual (Appendix S).
- **Stage 3: Developing emergent themes.** Initial coding notes were used to develop emergent themes, and involved the researcher adopting a more central role in making sense of these codes through her own interpretation. The researcher would also often come back to the transcript to read to ensure that the analysis stayed close to the actual experience and context of the reflections.
- **Stage 4: Searching for connections across emergent themes.** Themes were drawn together by listing the themes in the order they came up and then moving them around to form clusters of related themes. (Appendix T)
- **Stage 5: Moving to the next case.** The above process is repeated by the researcher for each interview transcript before moving on to the final stage of cross-case analysis.
- **Stage 6: Looking for patterns across cases.** The sixth and final stage involved looking for connections across all participants, which would lead to the development of superordinate themes (see Appendix U for the occurrence of themes across participants).

Through the stages of analysis, any thoughts and feelings caused by reading and coding of the participants' transcript are recorded by the researcher in her reflective journal. By doing so, it had helped in bracketing off any preconceptions or ideas from previous transcripts and allowed for the construction of new ideas and themes.

Researcher's Reflection of Analysis

Below is an excerpt within the researcher's reflective diary which spoke about the process of analysing:

> *I started the journey perhaps a little naïve into thinking that I was able to conduct the process of analysing the data as 'difficult but doable'. In reality, the process was all-consuming and the need of immersing myself within the data as extremely difficult at times. It was for the most part difficult in bracketing off my assumptions, and being a clinician myself, it became almost 'second nature' for me to start 'formulating' the difficulties my participants (i.e. making my own assumptions about the experiences) had rather than allowing the participant to make sense of their own experiences. However, supervision has helped ground me within the data as oppose to the 'trainee clinical psychologist' hat I have had these past few years. The question of 'Is that what the participant mean when they say that?' was often thrown at me in supervision and it would help me to go back to the analysis and immerse myself again within the data. Through practise however, it became easier to immerse myself within the data.*
>
> *True to idiography and the iterative process, I had focused on analysing one participant at the time. There were moments when after analysing I could still 'hear' my fellow participant when I had proceeded to someone else, and that had at times allowed me to make assumptions of one participant based on the other. It had helped to move away from the data and come back at a later time to prevent it from happening.*

> *I was often lost within my own head. And I would sometimes stare at the document feeling like it could never all go together. I was at one point convinced that I was doing an awful job at analysing and not being able to get anywhere with it. I started to wonder whether what I was doing was 'IPA enough' and if there was even such a thing as 'IPA enough' (What IS IPA enough?). However, once the last participant (Laura) was analysed and her superordinate themes completed, I felt like I 'knew' my participants' stories and understood what was important to them and for me to tell. It felt almost like a missing puzzle finally slotting into place.*
>
> *When listening to the audio recordings and reading the transcripts, I was genuinely curious and surprised by the number of psychotic-like experiences participants had spoken about and how much they had affected them. It had often caused a sense of heaviness in me to read and re-read the transcripts. Although this is not the aim of the study (or IPA), I did wonder whether PLEs were a common experience within the help-seeking young people population. I started to wonder, whether we as clinicians were doing enough for our young people and are their difficulties truly being heard?*

Quality and Validity

To ensure research quality and validity, specifically in qualitative studies, Yardley (2008) outlines four flexible methodological principles: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. These principles deal with the potential problems of qualitative subjectivity, and how it can influence the project's validity. Firstly, on sensitivity to context: IPA methodologies account for this by careful data collection, stringent participant screening and establishing dynamic rapport during interviews. As IPA focuses on the individual's experience and meaning-making, this accounts for the participant's narrative and the focus given to specific clinical events. Verbatim extracts of interviews further provides validity to the data, and serves to accurately represent the participant's lived experience (Smith et al., 2009). Secondly, the close reading and reflective interpretation of the participant's experience demonstrates Yardley's (2008) adherence to commitment and rigour. The IPA methodology incorporating double hermeneutics encourages the researcher to develop a rigorous reading of the data during the analytical process. Thirdly, regarding transparency and coherence, the researcher used a reflexive diary throughout the processes of data collection and analysis. This reflective space allowed the researcher to form a reflexivity that also enabled critical awareness towards the project. The reflective diary, also functioning as an 'audit' tool provided a development trail of the project and helped pull together a coherent thread of progress, from the project's early conceptual to final analytical stages. Additionally, research supervision sessions provided another avenue for the data to be cross-checked, giving focus to coding and interpretation strategies. This is instructive in ensuring that the data possesses credibility through rigorous interrogation of multiple perspectives other than the researcher's. Finally, the project's impact and importance would be reflected in the Discussion and Critical Evaluation section, where the study bridges knowledge gaps in its investigated areas, by presenting interesting and impactful insights.

Chapter Six

Discussion and Critical Evaluation of Thesis Portfolio

Word Count: 2677

Chapter Six - Discussion and Critical Evaluation

This chapters aims to bring the findings from the systematic review and qualitative empirical paper together and position them within the existing literature. Critical evaluation of the thesis portfolio is provided through the discussion of clinical implications and concluding with the overall strengths and limitations of the study.

Final reflections

Before proceeding with the thesis findings, the researcher provides the final reflections on the process of writing and completing the empirical study. This reflection was written when the first draft of the empirical paper was completed:

> *Once completing the analysis and write-up of the study, I was immediately struck by how powerful the interviews are. I felt a sense of relief but also strangely a hint of melancholy and tiredness after having written the participants' story. Melancholy because of the 'heaviness' of the story provided by these individuals, and tiredness because of the need to immerse myself within their story. I felt protective of my participants, wanting to capture the very essence of their narrative and thereby, giving justice to it. In a way, I felt a sense of anxiety as, even though I know rationally that the write up consisted of my interpretation of their own interpretation of their experiences, I can't help but wonder whether I had given them a proper voice.*
>
> *Perhaps it is due to the melancholy, tiredness and anxiety that I became particularly consumed by their story. I remember a late night where the only source of light came from my work table and I could have sworn I saw a black figure out*

of the corner of my eyes. It was an admittedly frightening experience that I later wondered had any link with my late readings of transcripts and quotes that reflected such experiences. For the briefest of moment, it felt like I had a glimpse of what my participants have gone through. I also recall my relief when it became a one-off experience but immediately I felt it was particularly important to reflect on this experience.

My first draft of the findings was a whopping 8000 words, but I felt that at the very least most of their (the participants) experiences were written down and I felt relieved. Which was why the very idea of cutting the words down was immensely difficult. I remember in a particularly difficult supervision meeting where we discussed the possibility of splitting the results into two potential empirical papers and my supervisor asking if there was even a need to do so and if cutting it down was better. I vehemently argued the reasoning for a possible split in the results (despite the possible extra work) because I thought that would help in keeping the detail and again giving justice to the data I had. However, my supervisor gave an advice to step back from the data for a while and write down a summary of what I felt was important to tell, before I decide to split the paper. Needless to say, after stepping back and writing that summary, it became easier to cut down the words and later I realise it made no sense to split the results, given how related the themes were with each other.

Whilst I deeply empathised with my participants, I focused on ensuring that the analysis and write up followed IPA's steps and guidelines and that I had completed a project that was of 'good standard'. Despite this, there were still moments where I would shift to a positivist paradigm where I became more focused on providing evidence based comparisons and descriptions, particularly in the *discussion of the study. However, my supervisors recognised this and together we were able to ensure the study followed steps from IPA throughout.*

Now that I have come to the end of the thesis process, I have become more aware of the complexities that are often presented in service users within mental health settings. It is the subjectivity of their experiences that allow me to further appreciate and understand the need for patient-centred care.

Summary of Findings

The thesis portfolio aimed to explore psychotic-like experiences (PLEs) in adult individuals diagnosed with borderline personality disorder (BPD) and young people with borderline personality traits (BPD traits). Firstly, the systematic review aimed to scope existing literature investigating the relationship between psychological and psychiatric co-morbidities and psychotic symptoms in adult individuals diagnosed with BPD. Secondly, an empirical research study was conducted to qualitatively explore the lived experiences of PLEs in young people with BPD traits. The empirical study specifically looked at the nature of these experiences, as well as the appraisals and responses towards them.

Outcome of Systematic Review

The systematic review identified methodological limitations of included studies, and highlighted the relationship between psychological and psychiatric co-morbidities and psychotic symptoms in BPD. Included studies had mainly examined stressful life events, trauma and PTSD, mood disorders and substance use disorders in their role of developing and/or exacerbating psychotic symptoms in adult patients with BPD. While evidence was found for the role of childhood trauma and stressful life experiences in the presence of psychotic symptoms in BPD, causality could not be determined and heterogeneity of methodologies caused difficulties in comparing findings across the 12 studies. No conclusive evidence was found between mood disorders, substance use disorder and psychotic symptoms in BPD. Other co-morbidities found to have a positive correlation with psychotic symptoms in BPD include symptoms of childhood antisocial behaviour and difficult parenting styles. Although not explicitly mentioned, these co-morbidities may have been a consequence or precursor to childhood trauma which further provide evidence to the role of trauma in exacerbating psychotic symptoms in individuals with a diagnosis of BPD. Indeed a significant positive correlation was found between childhood trauma and an affectionless control parenting style in both parents. Higher rates of dissociative experiences were seen in patients with BPD who experience trauma-intrusive hallucinations, which indicate its mediating role in the relationship between trauma and hallucinations in BPD. The different psychotic symptoms (i.e., hallucinatory, delusions and dissociative experiences) examined in individuals diagnosed with BPD, resulting in a difficulty to compare results between included papers, could be a reflection of the lack of consensus on the definition of psychotic symptoms (Schroeder, Fisher, & Schäfer, 2013; Barnow, Arens, Sieswerda, Dinu-Biringer, Spitzer, & Lang, 2010). These results contribute to the importance of conducting research into psychotic symptoms in individuals with diagnosis of BPD.

Outcome of Empirical Paper

While the systematic review showed that psychotic symptoms are prevalent in BPD, the studies included in the review do not tell us anything about the lived experience of psychotic-like experiences (PLEs). Recently, diagnostic systems such as the DSM has sanctioned the use of BPD as a diagnosis towards young people before the age of 18. As such, Chanen (2015) emphasises the importance of understanding the experiences of and challenges of young people with BPD. Currently, several focused prevention programmes were developed to support young people with emerging traits of BPD; however, much is yet to be known about this clinical group and further research is needed in understanding unique presentations within these young people to allow for appropriate interventions to be provided (Chanen, McCutcheon, Jovev, Jackson, & McGorry, 2007).

Hence, the aim of the empirical study was to address the gaps highlighted in the research literature by exploring in greater depth the nature, appraisals and responses towards PLEs in help-seeking young people with BPD traits. There were four superordinate themes that emerged from the analysis: the description of experiences, making sense of the experiences, deterioration of sense of self and well-being, and managing and finding respite. The study used an interpretative phenomenological analysis (IPA) approach to explore the lived experience in these young people.

The IPA research contributes to this area of research by offering unique insights into the nature of these experiences and how they are appraised and responded to by young people with BPD traits. The study moved away from the notion that PLEs were ‘stress-related’ or ‘transient’ (American Psychiatric Association, 2013) and instead emphasised on the varied, enduring and distressing nature of these experiences in young people. The study also extends from findings of the systematic review, which found evidence of an associated role of trauma in the presence of psychotic symptoms in individuals with BPD, by emphasising on participants’ belief that it was the feelings of distress and vulnerability as a result of their traumatic experiences that led to the PLE. Furthermore, the study provides a novel perspective by relating participants’ appraisals and responses towards their experiences with the cognitive model of psychosis by Garety, Kuipers, Fowler, Freeman, and Bebbington (2001) which specifies the role of emotional responses in shaping psychotic appraisals in individuals.

Critical Evaluation

Critical evaluation of the thesis portfolio include sections on the clinical implications, future directions in research and a discussion on the overall strengths and limitations of the thesis.

Clinical Implications

Systematic Review. The systematic review found evidence to suggest that trauma exposure, in particular childhood trauma, was associated with psychotic symptoms in BPD. Individuals diagnosed with BPD have often experienced prolonged and repeated exposure to various traumatic incidences, which include emotional, sexual and physical abuse (Goodman, & Yehuda, 2002; Kuo, Khoury, Metcalfe, Fitzpatrick, & Goodwill, 2015; Vermetten, & Spiegel, 2014). Some research has even suggested that exposure to trauma, especially in early childhood, is often the main factor to developing traits of BPD (Van der Kolk, Hostetler, Herron, & Fisler, 1994; Ball, & Links, 2009). Additionally, many research has specified strong links between trauma and development of psychosis (Kraan, Velthorst, Smit, de Haan, & van der Gaag, 2015; Morrison, Frame, & Larkin, 2003). Given the high rates of trauma in BPD, it is unsurprising that psychotic-like experiences are part of the presentation. As such, a trauma informed framework would need to be emphasised when thinking of treatment or intervention towards individuals with diagnosed BPD (Kring, & Sloan, 2009).

Methodological limitations of included studies and by consequence, a lack of ‘good quality’ papers in the systematic review highlight a need for further research. In many studies, diagnostic criteria from the DSM have been used to assess co-morbid mental health conditions (such as mood disorders and substance use disorders) and features of psychosis. While the use of diagnostic criteria from the DSM was useful in providing evidence towards such conditions, studies should endeavour to use validated questionnaires to measure specific symptomatology within these conditions, such as the Mood Disorder Questionnaire (MDQ; Miller, Klugman, Berv, Rosenquist, & Ghaemi, 2004) and the Community Assessment of Psychic Experience questionnaire (CAPE; Konings, Bak, Hanssen, Van Os, & Krabbendam, 2006). ,This is to allow for thorough investigation on various symptoms within these conditions.. Furthermore, the use of prospective and longitudinal studies, where regular follow-ups of individuals diagnosed with BPD and co-morbidities are conducted, would enable the causal underpinnings of psychotic symptoms to be unpicked.

Empirical Paper. The distressing and prolonged experiences in addition to the self-stigma expressed in participants emphasises the need for clinicians within mental health services to query a range of experiences that may be concerning to the individual. Individuals diagnosed with co-morbid BPD and psychotic disorders have been shown to be a particularly vulnerable group with complex pathways to care and rarely received specific treatments for their psychosis and it may be due to their diagnosis of BPD taking precedence or the perception of clinicians that their experiences of psychosis as false or presentations of “acting out” (Thérien, Tranulis, Lecomte, & Bérubé, 2012). As such, the study findings provide rationale for future quantitative research to explore specific preventative treatments in young people with BPD traits.

Conclusively, both the systematic review and empirical paper highlight the relevance and importance of psychotic-like experiences within the context of BPD, as well as the potential risk of dismissing or misunderstanding these experiences if a purely diagnostic approach is taken.

Strengths and Limitations

As far as the researcher is aware, this is the first review to conduct a narrative synthesis on quantitative studies with various methodological design that specifically examined the relationship between comorbidities and psychotic symptoms in BPD. The systematic review managed to highlight the methodological limitations of included quantitative studies and the need for future research to improve on these limitations. One of the main strengths of the empirical study relates to the fact that this is the first study to qualitatively explore the subjective experiences of PLEs in young people with BPD traits who are currently accessing mental health services. The use of interpretative phenomenological analysis (IPA) approach allows for the exploration of how participants make sense of their lived experiences of PLEs and attach meaning to them (Smith et al., 2009). Furthermore, the use of the Appraisals of Anomalous Experiences (AANEX) semi-structured interview (Brett et al., 2007) to help develop the topic guide and the use of its probe questions is unique to the methodology of the study and allows participants to reflect deeply on their past and present experiences of PLEs prior to the interview.

As such, the study provide invaluable information on how help-seeking young people with BPD traits make sense of their PLEs and provide rationale for future research to devote in investigating specific interventions for these young people and gives rationale for clinicians to ask questions on difficulties and experiences that is of concern to the individual, rather than focusing on diagnostic-specific treatments.

One of the main limitations of the systematic review is the possibility of publication bias as the review excludes any and all grey literature and includes English articles only. The researcher had also pre-specified co-morbidities in the search term which may have influenced the number of studies included in the review, and potential papers which looked at other types of co-morbidities may have been missed. The exclusion of qualitative and case-controlled studies is another limitation to the design of the review, as additional information regarding co-morbidities and psychotic symptoms in BPD may be missed.

There are also limitations to the empirical study. While participants expressed a wide range of experiences, the interview may not have been able to capture the full extent and descriptions of their PLEs. The interview was guided by the participants and so any experience expressed were those that was of concern to them. After the interview, Richard (one of the participants) had reflected that he had forgotten to mention other past experiences but felt that these experiences were not important in comparison to the ones he had spoken about within the interview. Participants' experience of the mental health service may have also allowed for their understanding and experience of their PLEs to be impacted compared to those who have not received support from mental health services. This was certainly the case with many of the participants who had both expressed knowledge and insight to their experience based on the support they received. The lack of diversity within the study was apparent as all participants were White British and were fluent in the English language. Future research should endeavour to include a wide range of participants (i.e. different ethnicities, socio-economic backgrounds) so that we may understand the experiences of PLEs further within a more culturally diverse populations.

Overall Conclusion

The thesis emphasises the lack of research and understanding into the phenomena of psychosis and its symptoms within individuals diagnosed with BPD or individuals with

BPD traits. Heterogeneity and limitations of methodology allow for difficulties in making any overarching conclusions about the role of co-morbidities within the presence of psychotic symptoms within BPD. The empirical paper further addressed the gap within the research by employing a qualitative approach in exploring in depth the experiences of these PLEs in young people who have traits of BPD, and showed that these experiences were not only prolonged and derogative in most cases but were often distressing and debilitating. It is anticipated that the study would provide rationale for further research into this area, by focusing primarily on conducting specific interventions that would bring about appropriate support for young people with BPD traits that have endured these intrusive experiences.

Thesis Portfolio References

Adams, B., & Sanders, T. (2011). Experiences of psychosis in borderline personality disorder: a qualitative analysis. *Journal of Mental Health*, *20*(4), 381-391.

Alemany, S., Arias, B., Aguilera, M., Villa, H., Moya, J., Ibáñez, M. I., ... & Fañanás, L. (2011). Childhood abuse, the BDNF-Val66Met polymorphism and adult psychotic-like experiences. *The British Journal of Psychiatry*, *199*(1), 38-42.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Ball, J. S., & Links, P. S. (2009). Borderline personality disorder and childhood trauma: evidence for a causal relationship. *Current psychiatry reports*, *11*(1), 63-68.

Barnow, S., Arens, E. A., Sieswerda, S., Dinu-Biringer, R., Spitzer, C., & Lang, S. (2010). Borderline personality disorder and psychosis: a review. *Current Psychiatry Reports*, *12*(3), 186-195.

Bhaskar, R. (1978). *A Realist Theory of Science*, Hassocks: Harvester Press.

Bhaskar, R. (1978). On the possibility of social scientific knowledge and the limits of naturalism. *Journal for the Theory of Social Behaviour*, *8*(1), 1-28.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

Brett, C. M. C., Peters, E. P., Johns, L. C., Tabraham, P., Valmaggia, L. R., & McGuire, P. K. (2007). Appraisals of Anomalous Experiences Interview

(AANEX): a multidimensional measure of psychological responses to anomalies associated with psychosis. *The British Journal of Psychiatry*, *191*(51), s23-s30.

Brett, C. M. C., Johns, L. C., Peters, E. P., & McGuire, P. K. (2009). The role of metacognitive beliefs in determining the impact of anomalous experiences: a comparison of help-seeking and non-help-seeking groups of people experiencing psychotic-like anomalies. *Psychological medicine*, *39*(06), 939-950.

Chanen, A. M., McCutcheon, L. K., Jovev, M., Jackson, H. J., & McGorry, P. D. (2007). Prevention and early intervention for borderline personality disorder. *Medical Journal of Australia*, *187*(S7), S18-S21.

Chanen, A. M., Jackson, H. J., McCutcheon, L. K., Jovev, M., Dudgeon, P., Yuen, H. P., ... & Clarkson, V. (2008). Early intervention for adolescents with borderline personality disorder using cognitive analytic therapy: randomised controlled trial. *The British Journal of Psychiatry*, *193*(6), 477-484.

Chanen, A. M., Jovev, M., Djaja, D., McDougall, E., Yuen, H. P., Rawlings, D., & Jackson, H. J. (2008). Screening for borderline personality disorder in outpatient young people. *Journal of personality disorders*, *22*(4), 353-364.

Chanen, A. M., Mccutcheon, L. K., Germano, D., Nistico, H., Jackson, H. J., & Mcgorry, P. D. (2009). The HYPE Clinic: an early intervention service for borderline personality disorder. *Journal of Psychiatric Practice®*, *15*(3), 163-172.

Chanen, A. M. (2015). Borderline personality disorder in young people: are we there yet?. *Journal of Clinical Psychology*, *71*(8), 778-791.

Danermark, B., Ekstrom, M., Jakobsen, L., Karlsson, J.C. (2002). *Explaining Society: Critical realism in the social sciences.* London: UK, Routledge.

Etherington, K. (2007). Ethical research in reflexive relationships. *Qualitative inquiry*, *13*(5), 599-616.

Finlay, L. (2013). Unfolding the phenomenological research process: Iterative stages of “seeing afresh”. *Journal of Humanistic Psychology*, *53*(2), 172-201.

First, M. B., Gibbon, M., Spitzer, R. L., & Williams, J. B. (1996). User’s guide for the structured clinical interview for DSM-IV axis I Disorders—Research version. *New York: Biometrics Research Department, New York State Psychiatric Institute*.

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, *20*(2), 181–194.

Francey, S. M., Jovev, M., Phassouliotis, C., Cotton, S. M., & Chanen, A. M. (2018). Does co-occurring borderline personality disorder influence acute phase treatment for first-episode psychosis?. *Early intervention in psychiatry*, *12*(6), 1166-1172.

Garety, P. A., Kuipers, E., Fowler, D., Freeman, D., & Bebbington, P. E. (2001). A cognitive model of the positive symptoms of psychosis. *Psychological medicine*, *31*(02), 189-195.

Gleeson, J. F., Chanen, A., Cotton, S. M., Pearce, T., Newman, B., & McCutcheon, L. (2012). Treating co-occurring first-episode psychosis and borderline personality: A pilot randomized controlled trial. *Early Intervention in Psychiatry*, *6*(1), 21-29.

Goodman, M., & Yehuda, R. (2002). The relationship between psychological trauma and borderline personality disorder. *Psychiatric Annals*, *32*(6), 337-345.

Hanssen, M. S. S., Bijl, R. V., Vollebergh, W., & Van Os, J. (2003). Self-reported psychotic experiences in the general population: a valid screening tool for DSM-III-R psychotic disorders?. *Acta Psychiatrica Scandinavica*, *107*(5), 369-377.

Husserl, E. (1927). Phenomenology": The Encyclopaedia Britannica Article. *Psychological and Transcendental Phenomenology and the Confrontation with Heidegger (1927-1931).*

Ising, H. K., Veling, W., Loewy, R. L., Rietveld, M. W., Rietdijk, J., Dragt, S., ... & van der Gaag, M. (2012). The validity of the 16-item version of the Prodromal Questionnaire (PQ-16) to screen for ultra high risk of developing psychosis in the general help-seeking population. *Schizophrenia bulletin*, *38*(6), 1288-1296.

Johnson, J. G., Cohen, P., Kasen, S., & Brook, J. S. (2005). Personality disorder traits associated with risk for unipolar depression during middle adulthood. *Psychiatry research*, *136*(2), 113-121.

Kaess, M., Brunner, R., & Chanen, A. (2014). Borderline personality disorder in adolescence. *Pediatrics, 134*(4), 782-793.

Kelleher, I., & Cannon, M. (2011). Psychotic-like experiences in the general population: characterizing a high-risk group for psychosis. *Psychological medicine*, *41*(1), 1-6.

Kingdon, D. G., Ashcroft, K., Bhandari, B., Gleeson, S., Warikoo, N., Symons, M., ... & Mason, A. (2010). Schizophrenia and borderline personality disorder: similarities and differences in the experience of auditory hallucinations, paranoia, and childhood trauma. *The Journal of nervous and mental disease, 198*(6), 399-403.

Konings, M., Bak, M., Hanssen, M., Van Os, J., & Krabbendam, L. (2006).

Validity and reliability of the CAPE: a self-report instrument for the measurement of psychotic experiences in the general population. *Acta Psychiatrica Scandinavica*, *114*(1), 55-61.

Kraan, T., Velthorst, E., Smit, F., de Haan, L., & van der Gaag, M. (2015). Trauma and recent life events in individuals at ultra high risk for psychosis: review and meta-analysis. *Schizophrenia research, 161*(2-3), 143-149.

Kramer, I. M. A., Simons, C. J. P., Myin-Germeys, I., Jacobs, N., Derom, C., Thiery, E., ... & Wichers, M. (2012). Evidence that genes for depression impact on the pathway from trauma to psychotic-like symptoms by occasioning emotional dysregulation. *Psychological medicine*, *42*(02), 283-294.

Kring, A. M., & Sloan, D. M. (Eds.). (2009). *Emotion regulation and psychopathology: A transdiagnostic approach to etiology and treatment*. Guilford Press.

Kuo, J. R., Khoury, J. E., Metcalfe, R., Fitzpatrick, S., & Goodwill, A. (2015). An examination of the relationship between childhood emotional abuse and borderline personality disorder features: the role of difficulties with emotion regulation. *Child abuse & neglect*, *39*, 147-155.

Larkin, M., & Thompson, A. (2012). Interpretative phenomenological analysis. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners,* 99-116.

Loewy, R. L., Pearson, R., Vinogradov, S., Bearden, C. E., & Cannon, T. D. (2011). Psychosis risk screening with the Prodromal Questionnaire—brief version (PQ-B). *Schizophrenia research*, *129*(1), 42-46.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*, 1-20.

Madill, A., & Gough, B. (2008). Qualitative research and its place in psychological science. *Psychological methods, 13*(3), 254.

Mauthner, N. S., & Doucet, A. (2003). Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology, 37*(3), 413-431.

McEvoy, P., & Richards, D. (2003). Critical realism: a way forward for evaluation research in nursing? *Journal of Advanced Nursing, 43*(4), 411-420.

McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research in Nursing*, *11*(1), 66–78.

Miller, C. J., Klugman, J., Berv, D. A., Rosenquist, K. J., & Ghaemi, S. N. (2004). Sensitivity and specificity of the Mood Disorder Questionnaire for detecting bipolar disorder. *Journal of Affective Disorders, 81*(2), 167-171.

Morrison, A. P., Frame, L., & Larkin, W. (2003). Relationships between trauma and psychosis: A review and integration. *British Journal of Clinical Psychology*, *42*(4), 331-353.

Newton-Howes, G., Clark, L. A., & Chanen, A. (2015). Personality disorder across the life course. *The Lancet*, *385*(9969), 727-734.

Niemantsverdriet, M. B., Slotema, C. W., Blom, J. D., Franken, I. H., Hoek, H. W., Sommer, I. E., & Gaag, M. (2017). Hallucinations in borderline personality disorder: prevalence, characteristics and associations with comorbid symptoms and disorders. *Scientific reports*, *7*(1), 13920.

Pietkiewicz, I., & Smith, J. A. (2012). Praktyczny przewodnik interpretacyjnej analizy fenomenologicznej w badaniach jakościowych w psychologii. *Czasopismo Psychologiczne, 18*(2), 361-369.

Pilgrim, D., & Bentall, R. P. (1998). The medicalisation of misery: A critical realist analysis of the concept of depression. *Journal of Mental Health*, *8*(3), 261–274.

Pilgrim, D., & Bentall, R. (1999). The medicalisation of misery: a critical realist analysis of the concept of depression. *Journal of Mental Health, 8*(3), 261-274.

Poulton, R., Caspi, A., Moffitt, T. E., Cannon, M., Murray, R., & Harrington, H. (2000). Children's self-reported psychotic symptoms and adult schizophreniform disorder: a 15-year longitudinal study. *Archives of general psychiatry*, *57*(11), 1053-1058.

Rosen, J. L., Miller, T. J., D'Andrea, J. T., McGlashan, T. H., & Woods, S. W. (2006). Comorbid diagnoses in patients meeting criteria for the schizophrenia prodrome. *Schizophrenia Research, 85*(1-3), 124-131.

Schultze-Lutter, F., Klosterkötter, J., Michel, C., Winkler, K., & Ruhrmann, S. (2012). Personality disorders and accentuations in at-risk persons with and without conversion to first-episode psychosis. *Early intervention in psychiatry*, *6*(4), 389-398.

Schroeder, K., Fisher, H. L., & Schäfer, I. (2013). Psychotic symptoms in patients with borderline personality disorder: prevalence and clinical management. *Current opinion in psychiatry*, *26*(1), 113-119.

Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English language teaching*, *5*(9), 9-16.

Scott, D. (2007). Resolving the quantitative–qualitative dilemma: a critical realist approach. *International Journal of Research & Method in Education*, *30*(1), 3-17.

Shaw, D., Houghton, C. E., Casey, D., & Murphy, K. (2010). Ethical challenges in qualitative research: examples from practice. *Nurse researcher*.

Shinebourne, P. (2011). The Theoretical Underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis: Journal of the Society for Existential Analysis*, *22*(1).

Slotema, C. W., Daalman, K., Blom, J. D., Diederen, K. M., Hoek, H. W., & Sommer, I. E. C. (2012). Auditory verbal hallucinations in patients with borderline personality disorder are similar to those in schizophrenia. *Psychological medicine, 42*(9), 1873-1878.

Smith, J. A., Harré, R., & Van Langenhove, L. (Eds.). (1995). *Rethinking psychology* (Vol. 3). Sage.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. I: Qualitative health psychology.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenology analysis. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (pp. 53-80). London: Sage.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, *1*(1), 39-54.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. Qualitative Psychology.

Smith, J., Flowers, P., & Larkin, M. (2009). Interpretative Phoneomological Analysis: theory, method and research.

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*, *5*(1), 9-27.

Smith, J.A., Flowers, P., Larkin, M. (2013). *Interpretative Phenomenological Analysis: Theory Method and Research.* Sage Publications: London.

Stern, A. (1938). Psychoanalytic investigation of and therapy in the border line group of neuroses. *The Psychoanalytic Quarterly, 7*(4), 467-489.

Stochl, J., Khandaker, G. M., Lewis, G., Perez, J., Goodyer, I. M., Zammit, S., … Jones, P. B. (2015). Mood, anxiety and psychotic phenomena measure a common psychopathological factor. *Psychological Medicine, 45*, 1483-1493.

Taylor, C. (1985). Human agency and language.

Thérien, P., Tranulis, C., Lecomte, T., & Bérubé, F. A. (2012). The experience of treatment of persons with concomitant psychotic and borderline personality disorders. *Psychosis*, *4*(1), 63-73.

Thompson, K. N., Cavelti, M., & Chanen, A. M. (2018). Psychotic symptoms in adolescents with borderline personality disorder features. *European child & adolescent psychiatry*, 1-8.

Thompson, A., Nelson, B., Bechdolf, A., Chanen, A. M., Domingues, I., McDougall, E., & Yung, A. R. (2012). Borderline personality features and development of psychosis in an 'ultra high risk'(UHR) population: a case control study. *Early intervention in psychiatry*, *6*(3), 247-255.

Tzitzivacos, D. (2007). International Classification of Diseases 10th edition (ICD-10). *CME: Your SA Journal of CPD, 25*(1), 8-10.

Van der Kolk, B. A., Hostetler, A., Herron, N., & Fisler, R. E. (1994). Trauma and the development of borderline personality disorder. *Psychiatric Clinics*, *17*(4), 715-730.

Van Os, J., Hanssen, M., Bijl, R. V., & Ravelli, A. (2000). Strauss (1969) revisited: a psychosis continuum in the general population?. *Schizophrenia research*, *45*(1-2), 11-20.

Vermetten, E., & Spiegel, D. (2014). Trauma and dissociation: implications for borderline personality disorder. *Current psychiatry reports*, *16*(2), 434.

Wilson, J., Clarke, T., Lower, R., Ugochukwu, U., Maxwell, S., Hodgekins, J., ... & Fowler, D. (2017). Creating an innovative youth mental health service in the United Kingdom: The Norfolk Youth Service. *Early Intervention in Psychiatry*.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. *Qualitative psychology: A practical guide to research methods*, *2*, 235-251.

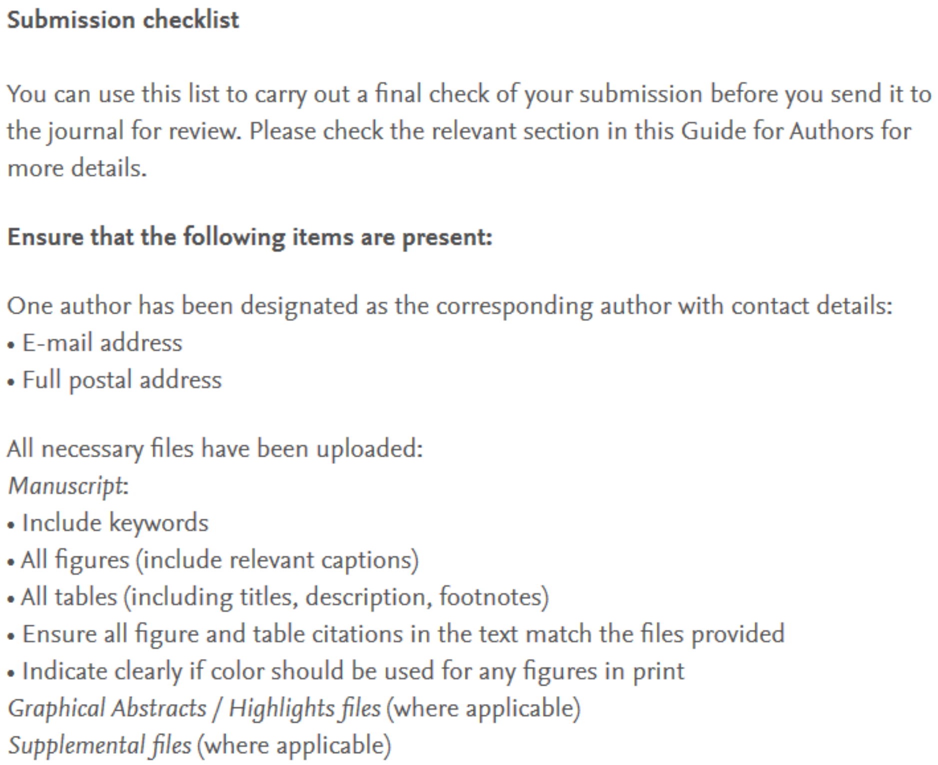
Yee, L., Korner, A. J., McSwiggan, S., Meares, R. A., & Stevenson, J. (2005). Persistent hallucinosis in borderline personality disorder. *Comprehensive Psychiatry, 46*(2), 147-154.

Yung, A. R., Phillips, L. J., Yuen, H. P., & McGorry, P. D. (2004). Risk factors for psychosis in an ultra high-risk group: psychopathology and clinical features. *Schizophrenia research*, *67*(2), 131-142

Appendices

Appendix	Description
A	Author guidelines for Clinical Psychology Review
B	Author Guidelines for the International Journal of Qualitative Studies in Health and Well-Being
C	Search Strategy for systematic review
D	The QATSDD tool
E	NHS Health Research Authority Approval
F	16-item Prodromal Questionnaire (PQ-16)
G	Helping Young People Early **(**HYPE) Screen
H	Socio-Demographics Questionnaire
I	AANEX-inventory probe questions
J	Topic Guide
K	Consent to be Contacted
L	Participant Information Sheet
M	Written Consent
N	Clinician Information Sheet
O	Participant Receipt Form
P	Letter to Gatekeeper
Q	Research Posters
R	Study Debrief Form
S	Example of initial analysis: coding and emergent themes
T	Master table of themes for the group
U	Occurrence of Themes across Participants
V	Non-Substantial Amendments for Supervisory Change (in Progress)

Appendix A: Author guidelines for the Clinical Psychology Review



Submission checklist

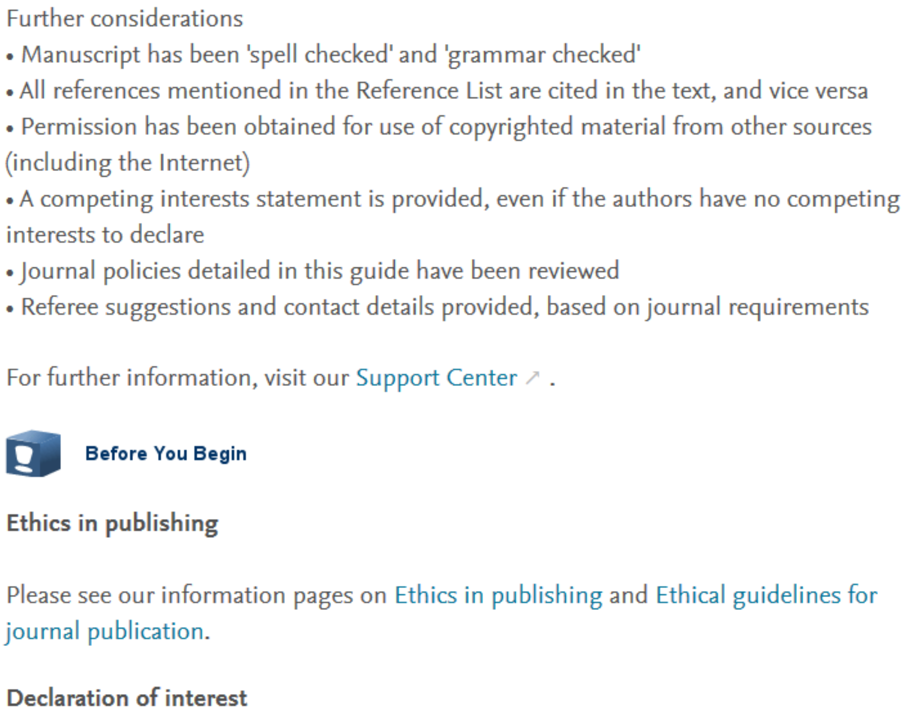
You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

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:
Manuscript:
- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

Graphical Abstracts / Highlights files (where applicable)
Supplemental files (where applicable)



Further considerations
- Manuscript has been 'spell checked' and 'grammar checked'
- 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)
- A competing interests statement is provided, even if the authors have no competing interests to declare
- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

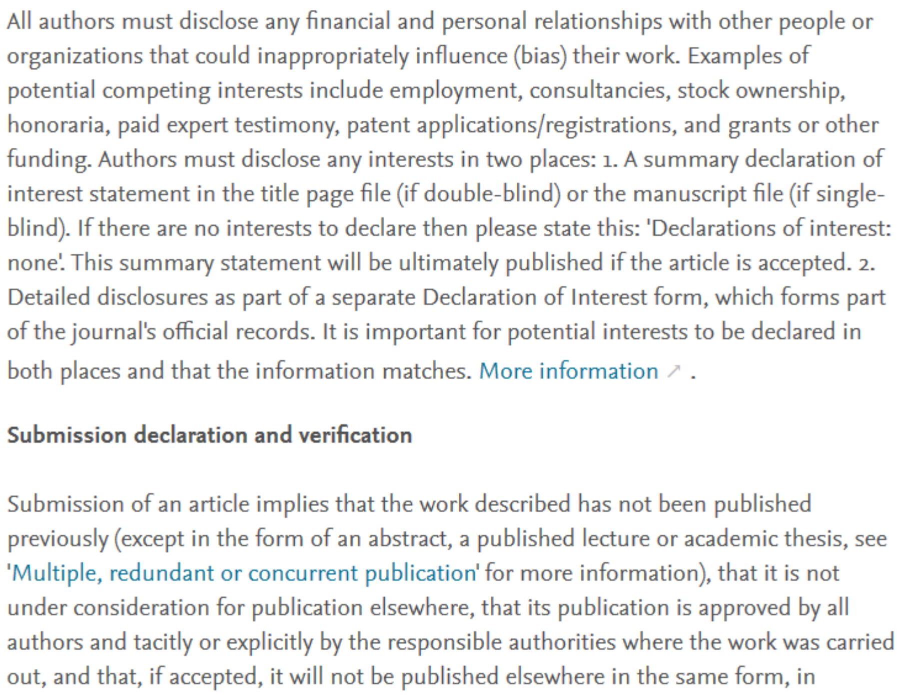
For further information, visit our Support Center ↗ .

Before You Begin

Ethics in publishing

Please see our information pages on Ethics in publishing and Ethical guidelines for journal publication.

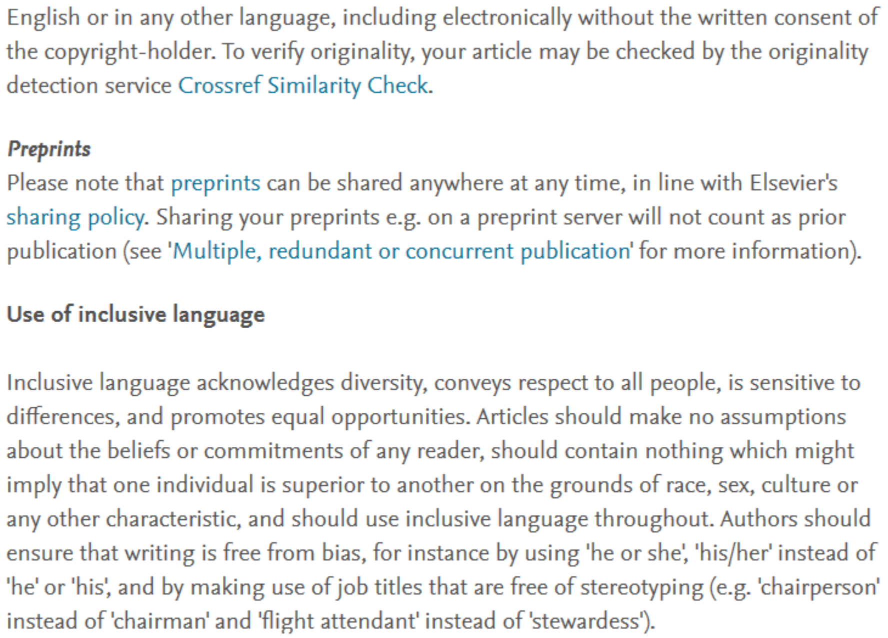
Declaration of interest



All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential competing interests include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. Authors must disclose any interests in two places: 1. A summary declaration of interest statement in the title page file (if double-blind) or the manuscript file (if single-blind). If there are no interests to declare then please state this: 'Declarations of interest: none'. This summary statement will be ultimately published if the article is accepted. 2. Detailed disclosures as part of a separate Declaration of Interest form, which forms part of the journal's official records. It is important for potential interests to be declared in both places and that the information matches. More information ↗ .

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract, a published lecture or academic thesis, see 'Multiple, redundant or concurrent publication' for more information), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in



English or in any other language, including electronically without the written consent of the copyright-holder. To verify originality, your article may be checked by the originality detection service Crossref Similarity Check.

Preprints

Please note that preprints can be shared anywhere at any time, in line with Elsevier's sharing policy. Sharing your preprints e.g. on a preprint server will not count as prior publication (see 'Multiple, redundant or concurrent publication' for more information).

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Articles should make no assumptions about the beliefs or commitments of any reader, should contain nothing which might imply that one individual is superior to another on the grounds of race, sex, culture or any other characteristic, and should use inclusive language throughout. Authors should ensure that writing is free from bias, for instance by using 'he or she', 'his/her' instead of 'he' or 'his', and by making use of job titles that are free of stereotyping (e.g. 'chairperson' instead of 'chairman' and 'flight attendant' instead of 'stewardess').

Changes to authorship

Authors are expected to consider carefully the list and order of authors **before** submitting their manuscript and provide the definitive list of authors at the time of the original submission. Any addition, deletion or rearrangement of author names in the authorship list should be made only **before** the manuscript has been accepted and only if approved by the journal Editor. To request such a change, the Editor must receive the following from the **corresponding author**: (a) the reason for the change in author list and (b) written confirmation (e-mail, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed.
Only in exceptional circumstances will the Editor consider the addition, deletion or rearrangement of authors **after** the manuscript has been accepted. While the Editor considers the request, publication of the manuscript will be suspended. If the manuscript has already been published in an online issue, any requests approved by the Editor will result in a corrigendum.

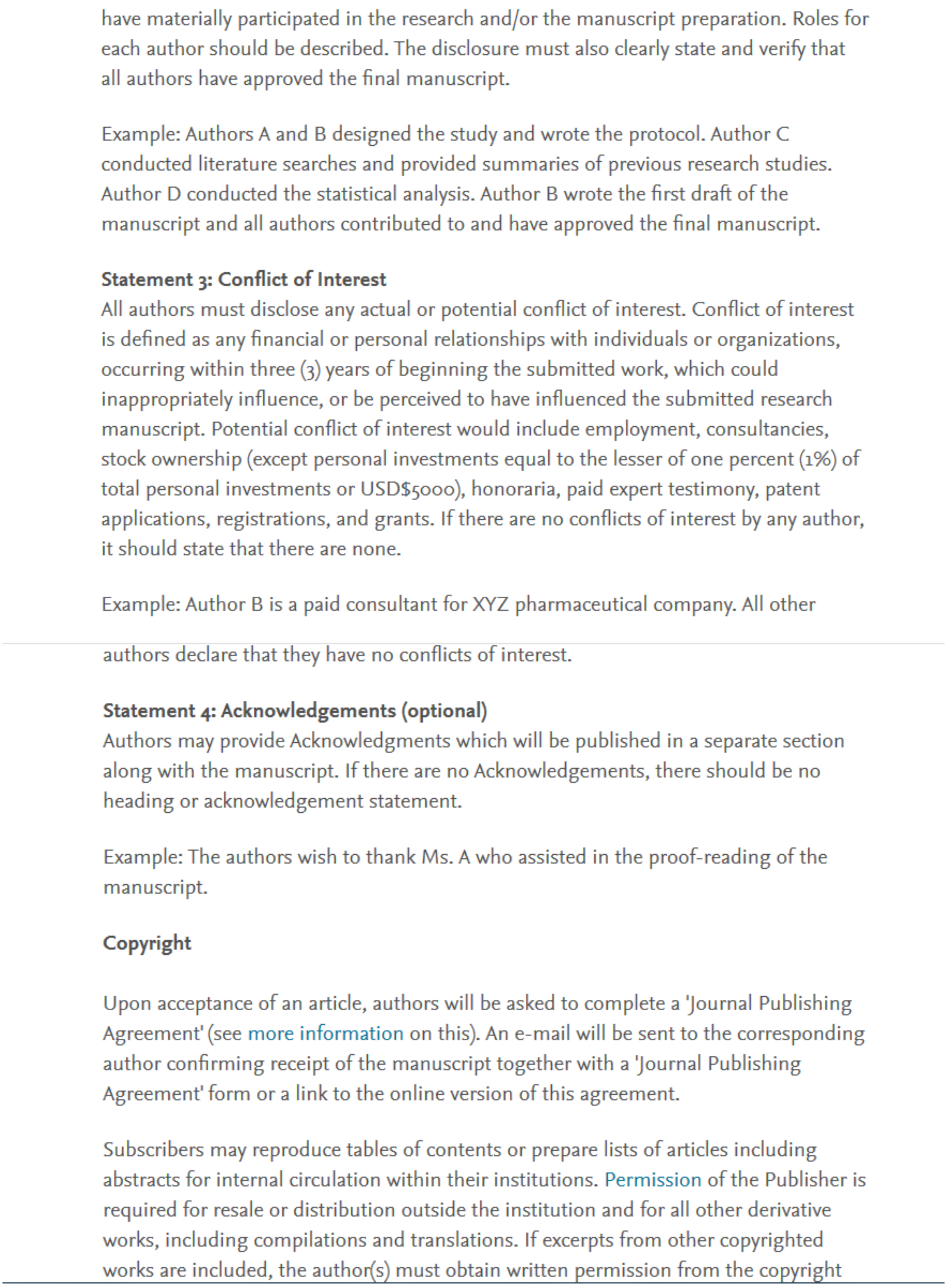
Author Disclosure Policy
Authors must provide three mandatory and one optional author disclosure statements. These statements should be submitted as one separate document and not included as part of the manuscript. Author disclosures will be automatically incorporated into the PDF builder of the online submission system. They will appear in the journal article if the manuscript is accepted.

The four statements of the author disclosure document are described below. Statements should not be numbered. Headings (i.e., Role of Funding Sources, Contributors, Conflict of Interest, Acknowledgements) should be in bold with no white space between the heading and the text. Font size should be the same as that used for references.

Statement 1: Role of Funding Sources
Authors must identify who provided financial support for the conduct of the research and/or preparation of the manuscript and to briefly describe the role (if any) of the funding sponsor in study design, collection, analysis, or interpretation of data, writing the manuscript, and the decision to submit the manuscript for publication. If the funding source had no such involvement, the authors should so state.

Example: Funding for this study was provided by NIAAA Grant R01-AA123456. NIAAA had no role in the study design, collection, analysis or interpretation of the data, writing the manuscript, or the decision to submit the paper for publication.

Statement 2: Contributors
Authors must declare their individual contributions to the manuscript. All authors must



have materially participated in the research and/or the manuscript preparation. Roles for each author should be described. The disclosure must also clearly state and verify that all authors have approved the final manuscript.

Example: Authors A and B designed the study and wrote the protocol. Author C conducted literature searches and provided summaries of previous research studies. Author D conducted the statistical analysis. Author B wrote the first draft of the manuscript and all authors contributed to and have approved the final manuscript.

Statement 3: Conflict of Interest
All authors must disclose any actual or potential conflict of interest. Conflict of interest is defined as any financial or personal relationships with individuals or organizations, occurring within three (3) years of beginning the submitted work, which could inappropriately influence, or be perceived to have influenced the submitted research manuscript. Potential conflict of interest would include employment, consultancies, stock ownership (except personal investments equal to the lesser of one percent (1%) of total personal investments or USD$5000), honoraria, paid expert testimony, patent applications, registrations, and grants. If there are no conflicts of interest by any author, it should state that there are none.

Example: Author B is a paid consultant for XYZ pharmaceutical company. All other authors declare that they have no conflicts of interest.

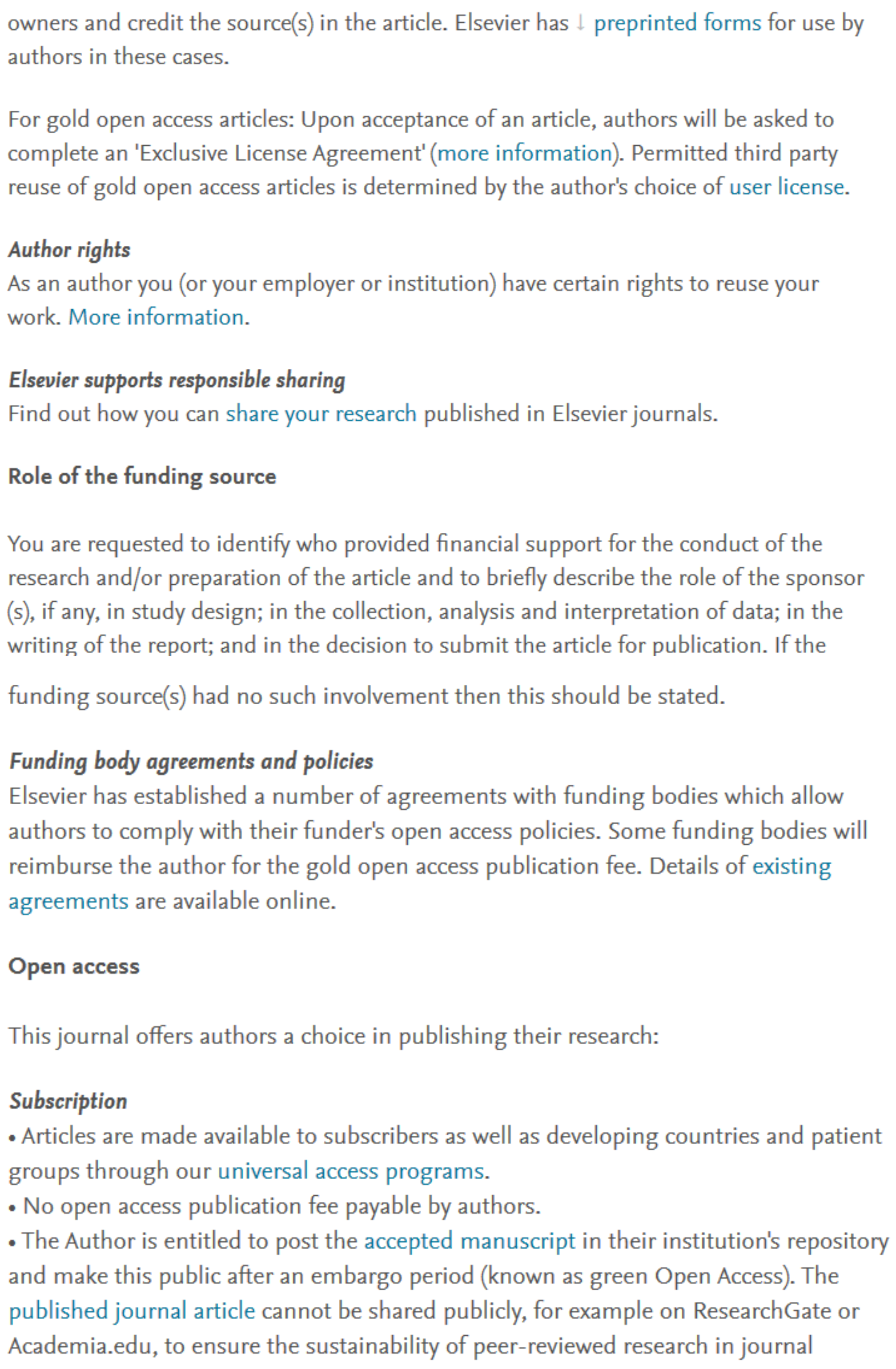
Statement 4: Acknowledgements (optional)
Authors may provide Acknowledgments which will be published in a separate section along with the manuscript. If there are no Acknowledgements, there should be no heading or acknowledgement statement.

Example: The authors wish to thank Ms. A who assisted in the proof-reading of the manuscript.

Copyright

Upon acceptance of an article, authors will be asked to complete a 'Journal Publishing Agreement' (see more information on this). An e-mail will be sent to the corresponding author confirming receipt of the manuscript together with a 'Journal Publishing Agreement' form or a link to the online version of this agreement.

Subscribers may reproduce tables of contents or prepare lists of articles including abstracts for internal circulation within their institutions. Permission of the Publisher is required for resale or distribution outside the institution and for all other derivative works, including compilations and translations. If excerpts from other copyrighted works are included, the author(s) must obtain written permission from the copyright


owners and credit the source(s) in the article. Elsevier has ↓ preprinted forms for use by authors in these cases.

For gold open access articles: Upon acceptance of an article, authors will be asked to complete an 'Exclusive License Agreement' (more information). Permitted third party reuse of gold open access articles is determined by the author's choice of user license.

Author rights

As an author you (or your employer or institution) have certain rights to reuse your work. More information.

Elsevier supports responsible sharing

Find out how you can share your research published in Elsevier journals.

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor (s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

Funding body agreements and policies

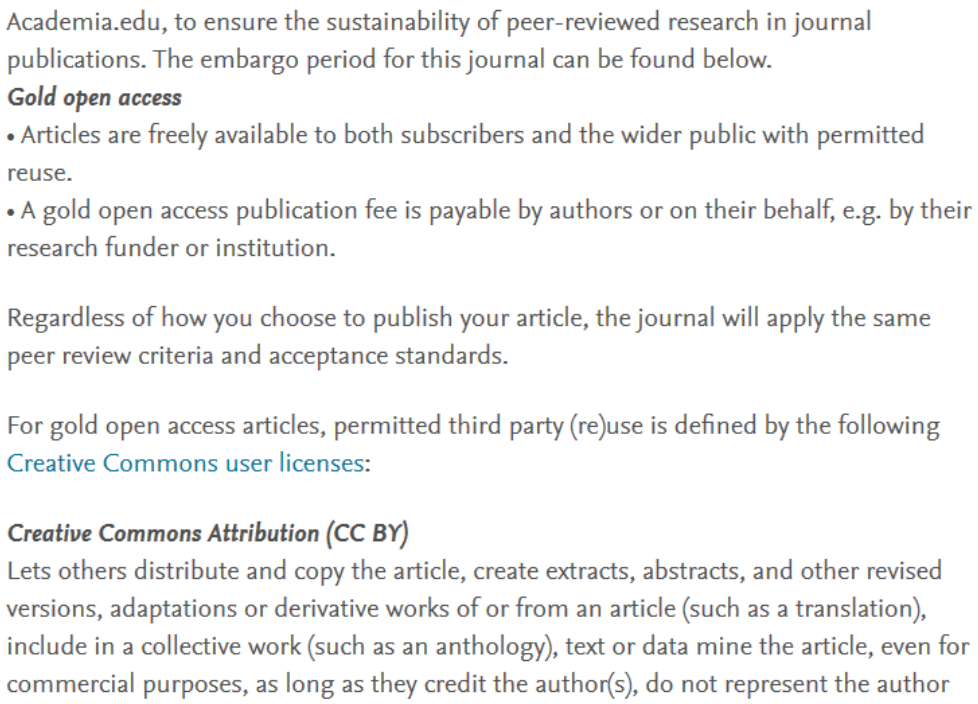
Elsevier has established a number of agreements with funding bodies which allow authors to comply with their funder's open access policies. Some funding bodies will reimburse the author for the gold open access publication fee. Details of existing agreements are available online.

Open access

This journal offers authors a choice in publishing their research:

Subscription

- Articles are made available to subscribers as well as developing countries and patient groups through our universal access programs.
- No open access publication fee payable by authors.
- The Author is entitled to post the accepted manuscript in their institution's repository and make this public after an embargo period (known as green Open Access). The published journal article cannot be shared publicly, for example on ResearchGate or Academia.edu, to ensure the sustainability of peer-reviewed research in journal



Academia.edu, to ensure the sustainability of peer-reviewed research in journal publications. The embargo period for this journal can be found below.

Gold open access

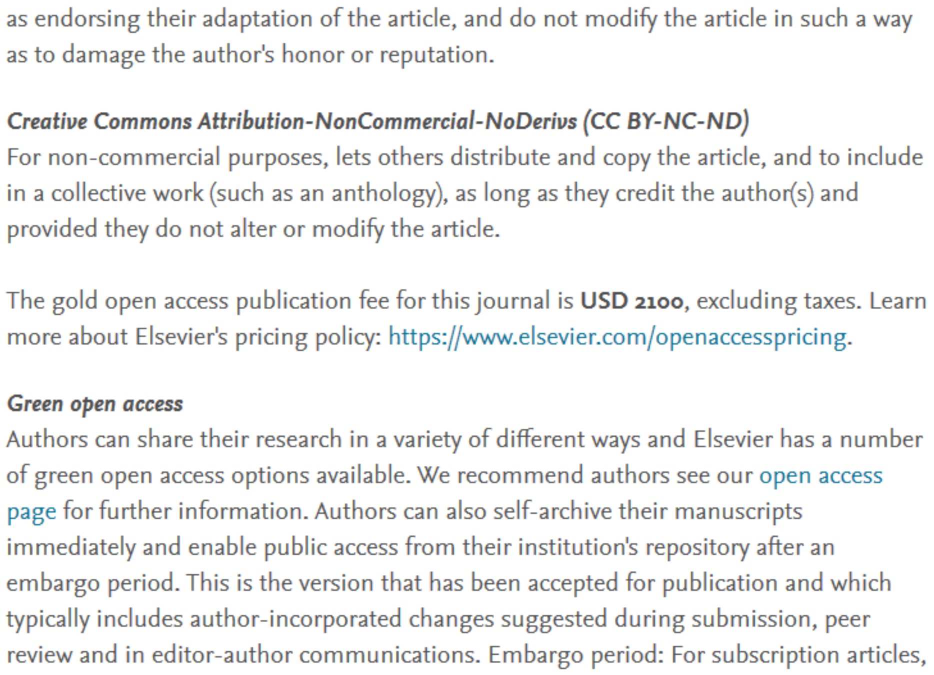
- Articles are freely available to both subscribers and the wider public with permitted reuse.
- A gold open access publication fee is payable by authors or on their behalf, e.g. by their research funder or institution.

Regardless of how you choose to publish your article, the journal will apply the same peer review criteria and acceptance standards.

For gold open access articles, permitted third party (re)use is defined by the following Creative Commons user licenses:

Creative Commons Attribution (CC BY)

Lets others distribute and copy the article, create extracts, abstracts, and other revised versions, adaptations or derivative works of or from an article (such as a translation), include in a collective work (such as an anthology), text or data mine the article, even for commercial purposes, as long as they credit the author(s), do not represent the author as endorsing their adaptation of the article, and do not modify the article in such a way as to damage the author's honor or reputation.



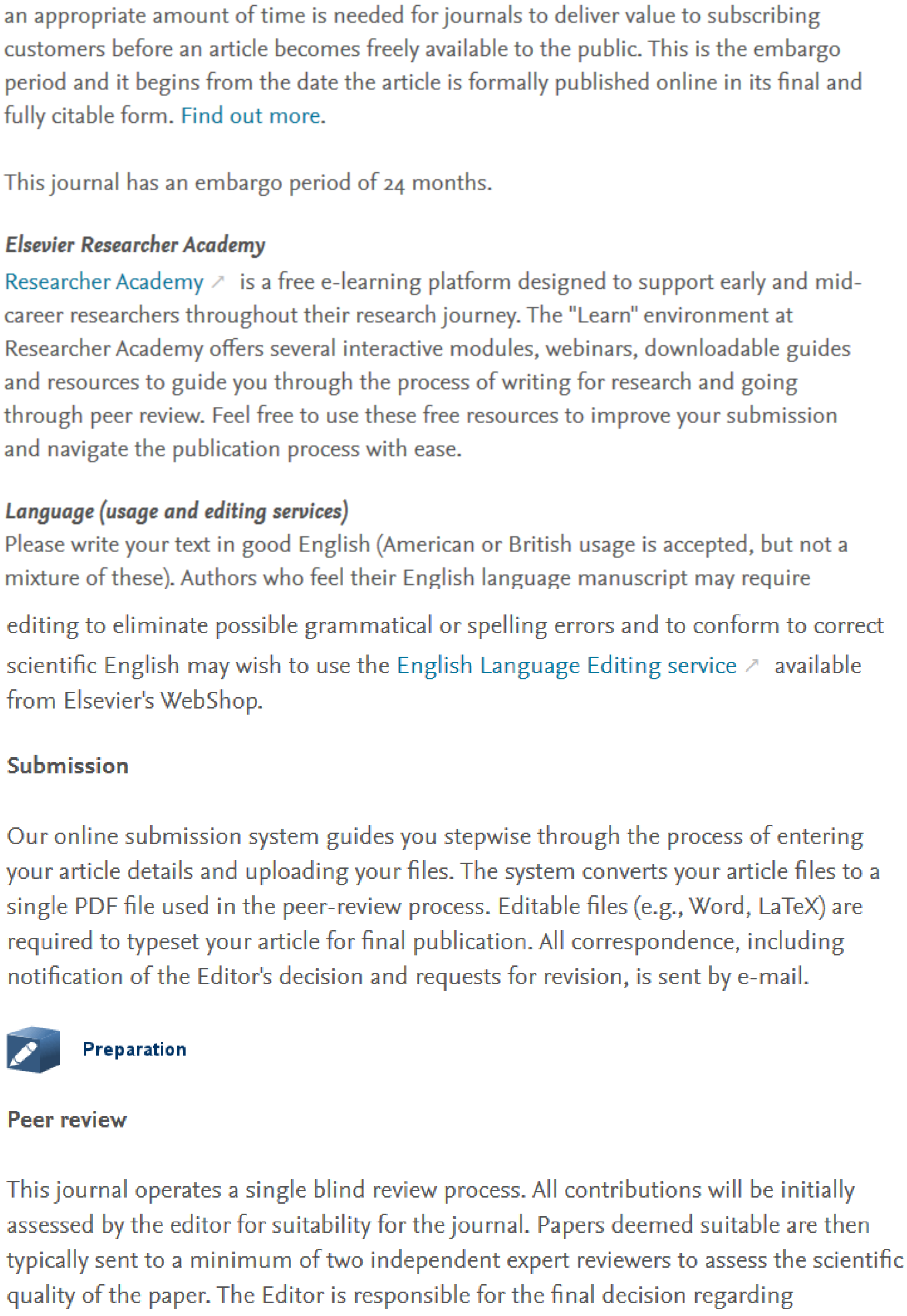
Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

For non-commercial purposes, lets others distribute and copy the article, and to include in a collective work (such as an anthology), as long as they credit the author(s) and provided they do not alter or modify the article.

The gold open access publication fee for this journal is **USD 2100**, excluding taxes. Learn more about Elsevier's pricing policy: https://www.elsevier.com/openaccesspricing.

Green open access

Authors can share their research in a variety of different ways and Elsevier has a number of green open access options available. We recommend authors see our open access page for further information. Authors can also self-archive their manuscripts immediately and enable public access from their institution's repository after an embargo period. This is the version that has been accepted for publication and which typically includes author-incorporated changes suggested during submission, peer review and in editor-author communications. Embargo period: For subscription articles,



an appropriate amount of time is needed for journals to deliver value to subscribing customers before an article becomes freely available to the public. This is the embargo period and it begins from the date the article is formally published online in its final and fully citable form. Find out more.

This journal has an embargo period of 24 months.

Elsevier Researcher Academy

Researcher Academy ↗ is a free e-learning platform designed to support early and mid-career researchers throughout their research journey. The "Learn" environment at Researcher Academy offers several interactive modules, webinars, downloadable guides and resources to guide you through the process of writing for research and going through peer review. Feel free to use these free resources to improve your submission and navigate the publication process with ease.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service ↗ available from Elsevier's WebShop.

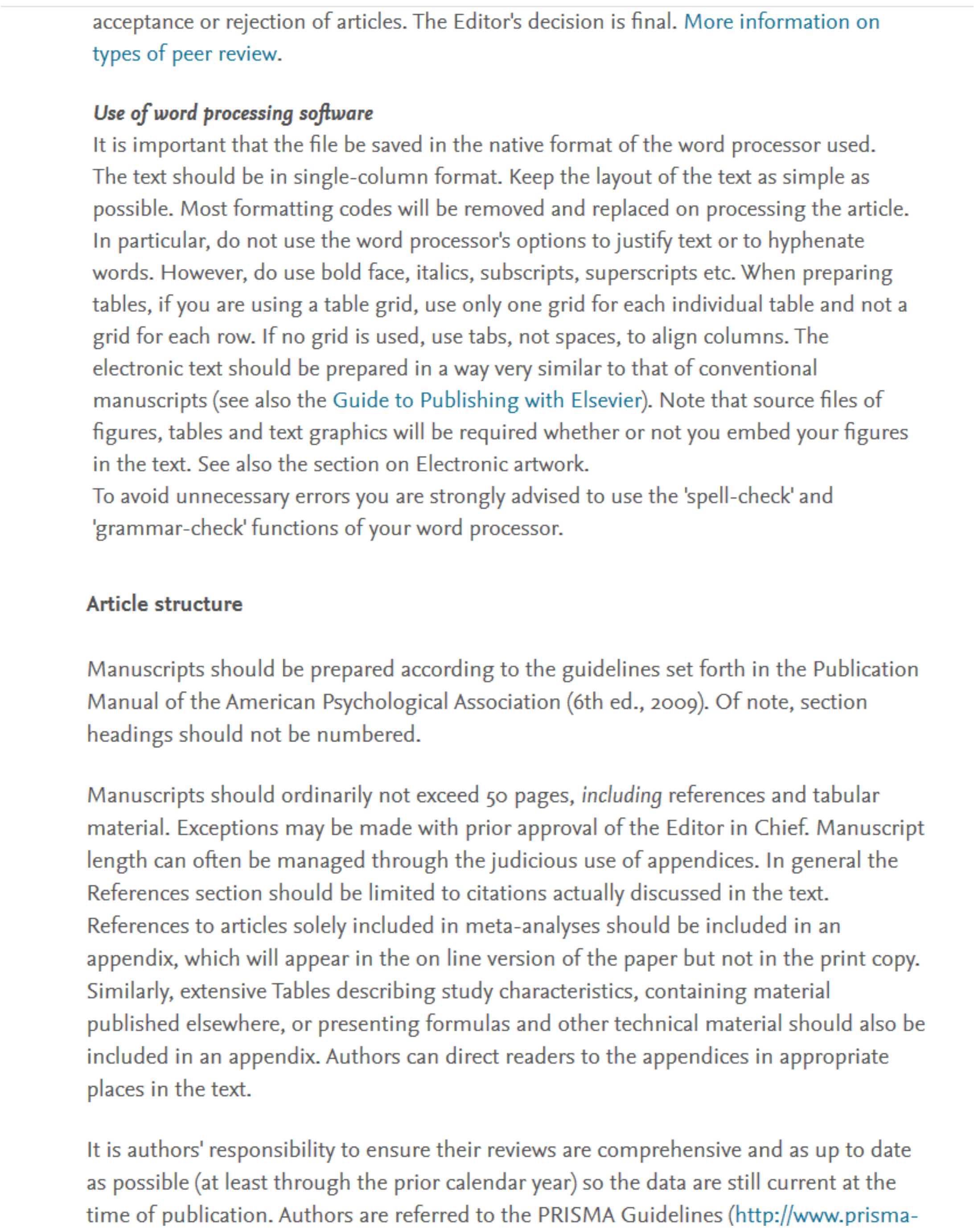
Submission

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

Peer review

This journal operates a single blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding



acceptance or rejection of articles. The Editor's decision is final. More information on types of peer review.

Use of word processing software

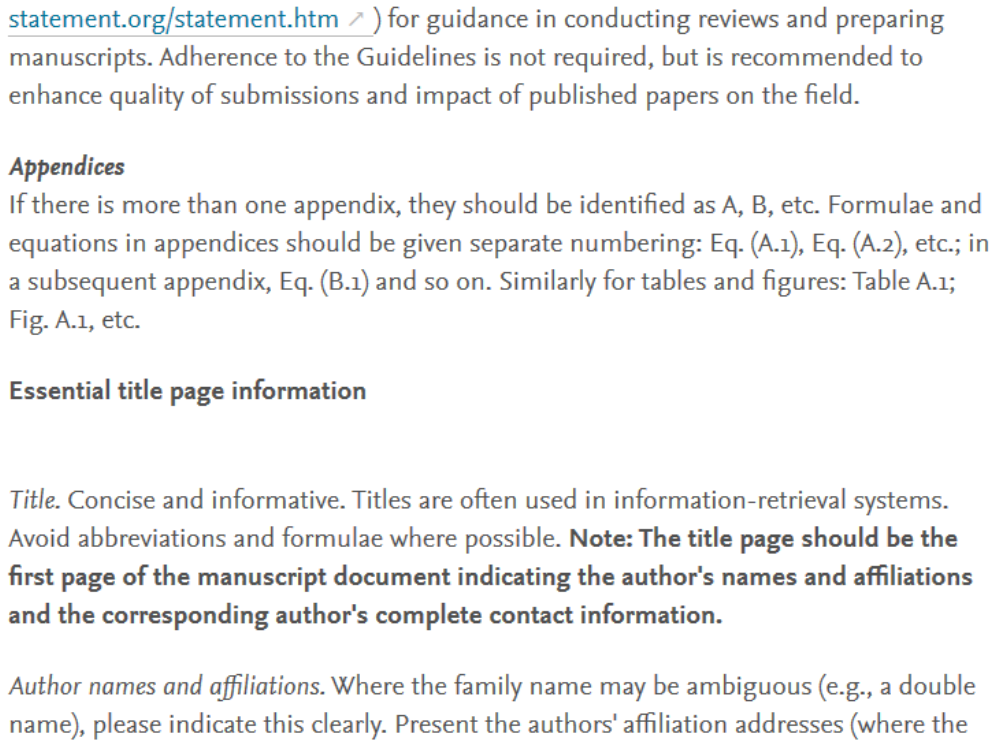
It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's 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.

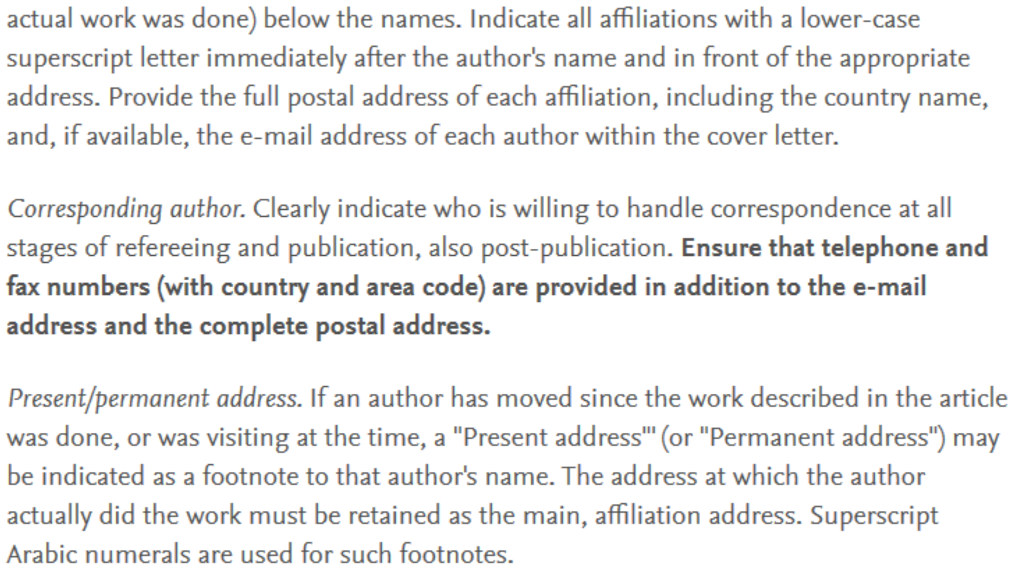
Appendices

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

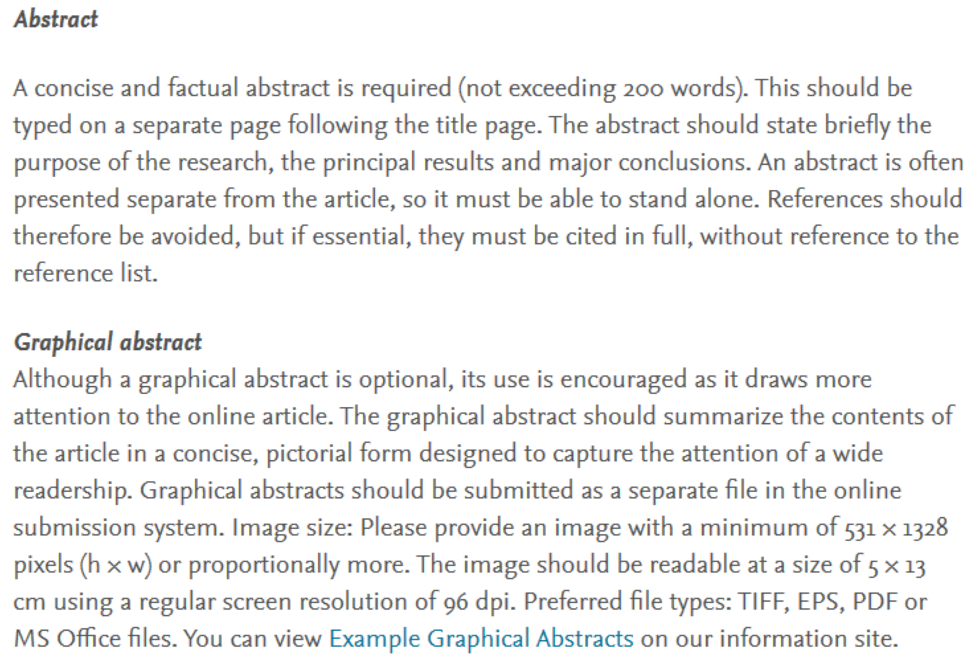
Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible. **Note: The title page should be the first page of the manuscript document indicating the author's names and affiliations and the corresponding author's complete contact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

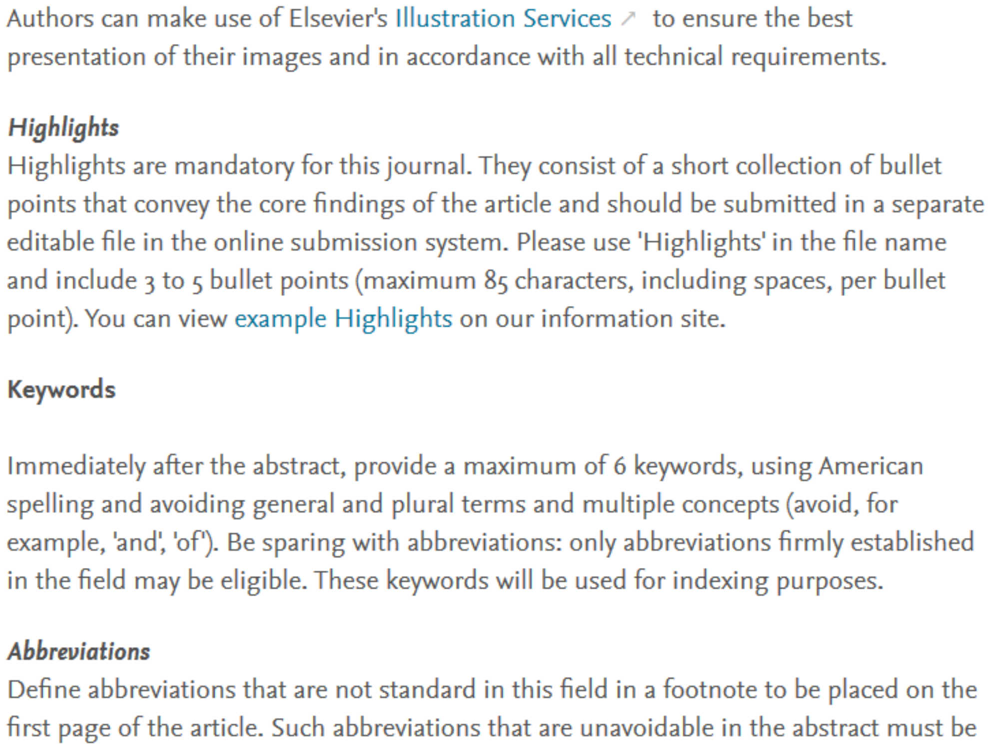


Abstract

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 Services ↗ to ensure the best presentation of their images and in accordance with all technical requirements.

Highlights

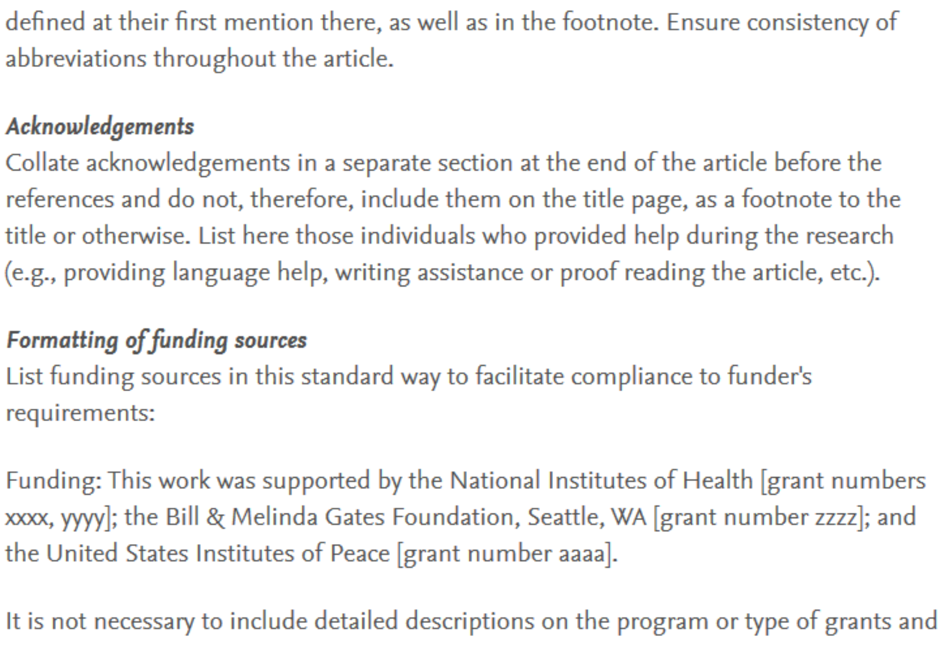
Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 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

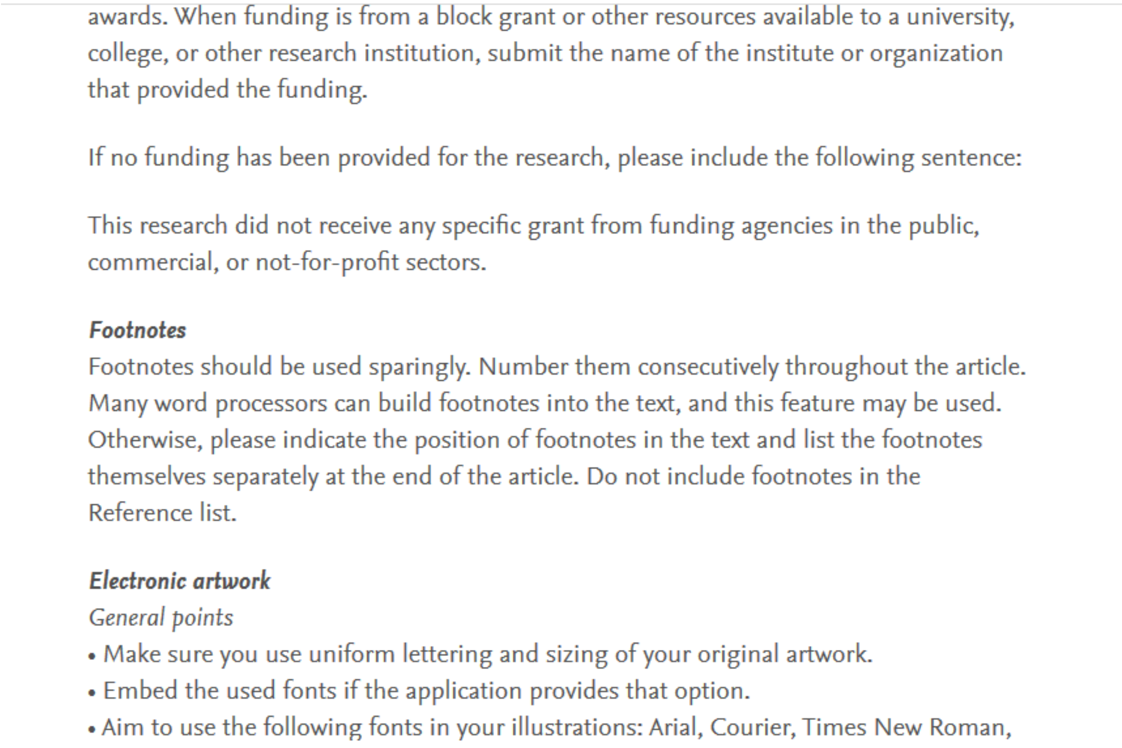
Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance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

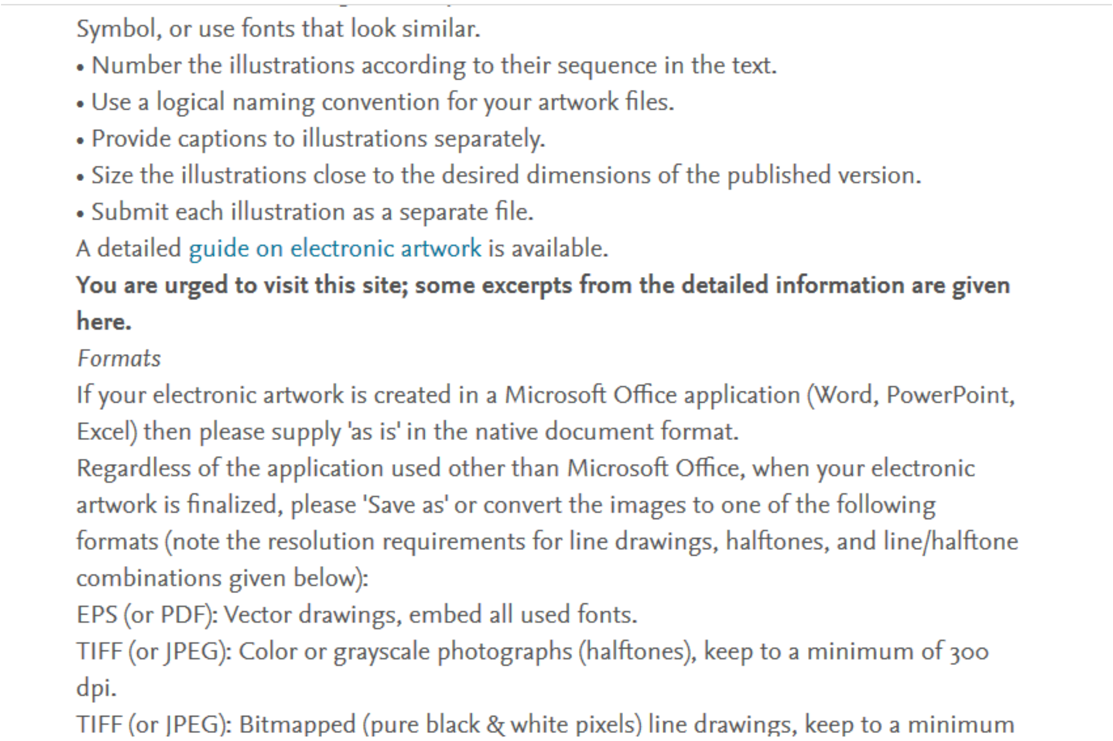
Footnotes

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

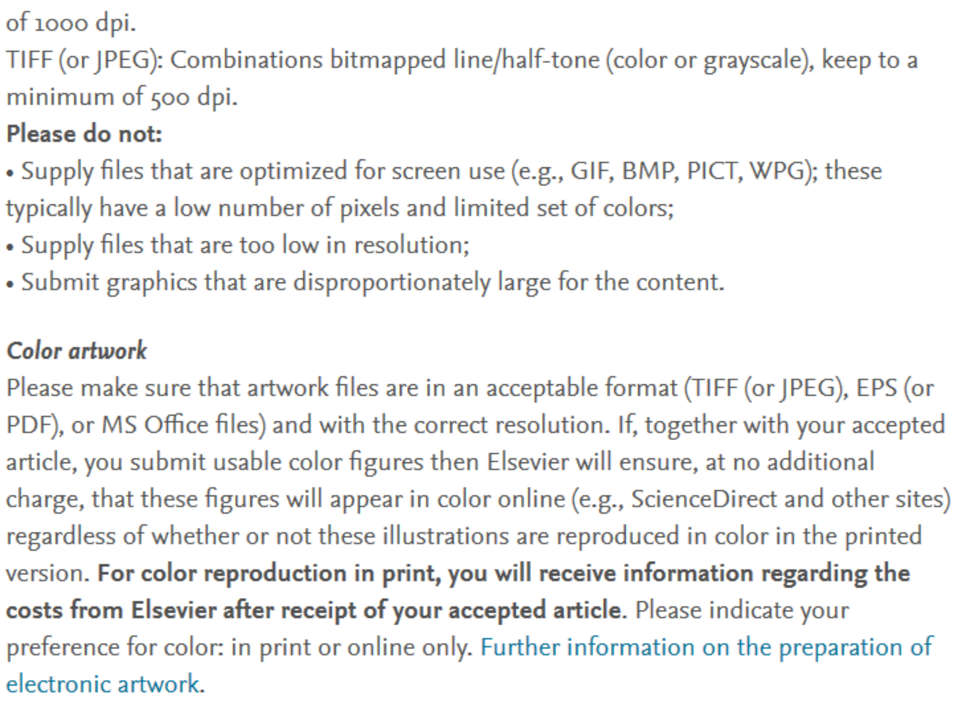
If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.

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.

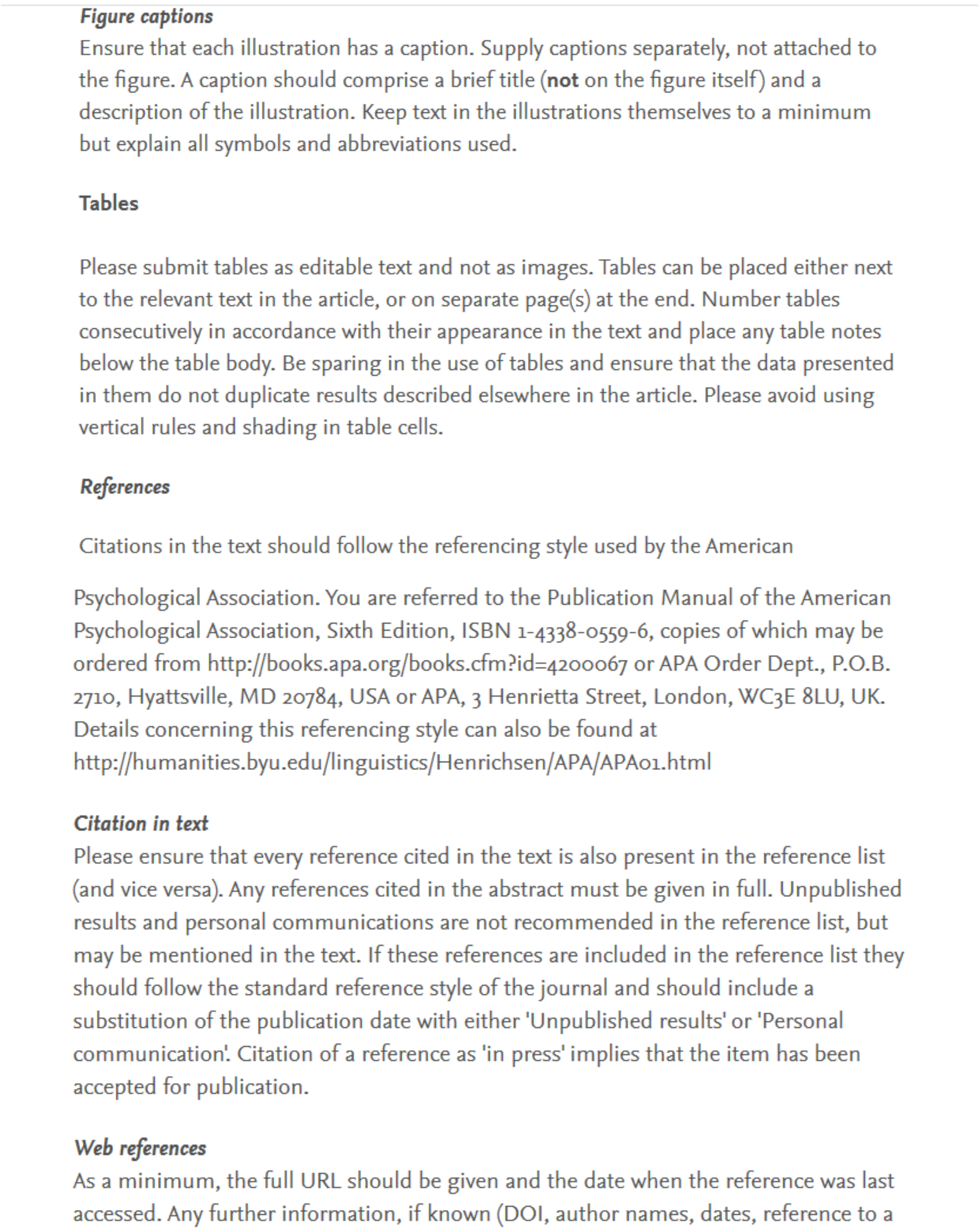


Figure captions

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 and shading in table cells.

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.

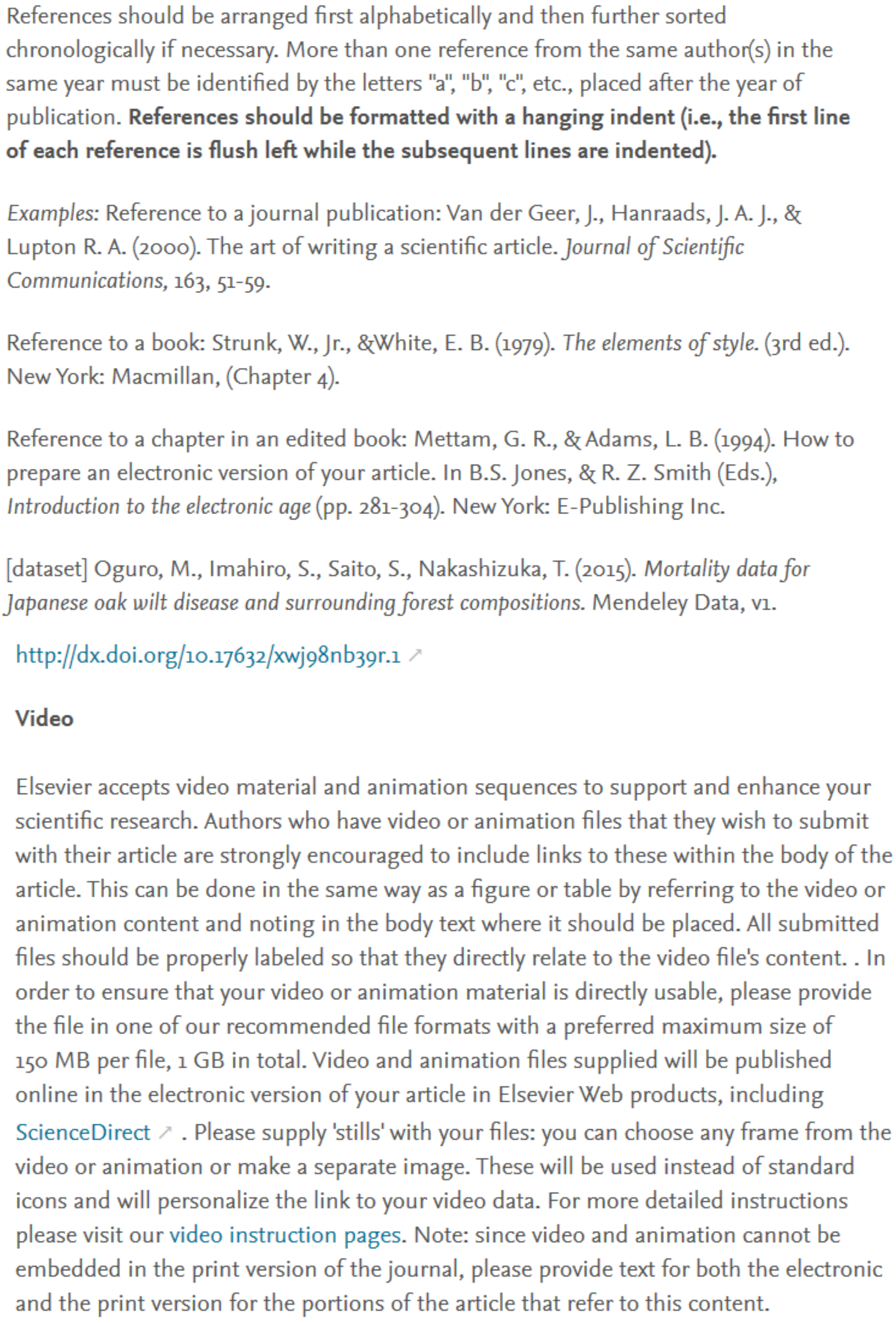
Data references
This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

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 ↗ . Using citation 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. If you use reference management software, please ensure that you remove all field codes before submitting the electronic manuscript. More information on how to remove field codes from different reference management software ↗ .

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 plug-ins 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).

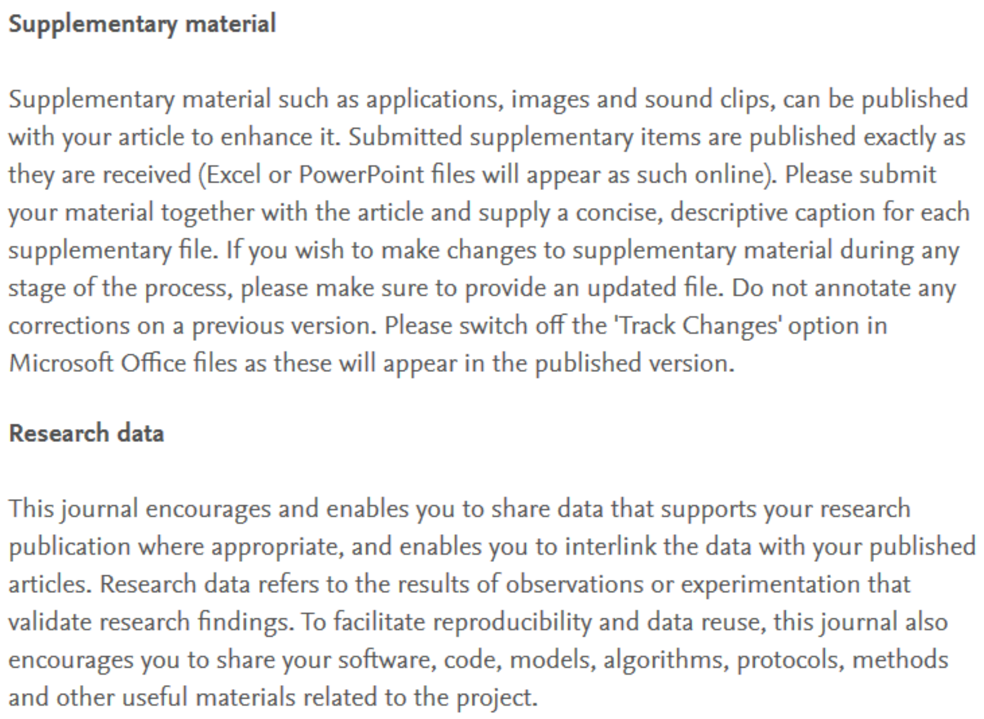
Reference to a chapter in an edited book: Mettam, G. R., & Adams, L. B. (1994). How to prepare an electronic version of your article. In B.S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281-304). New York: E-Publishing Inc.

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions.* Mendeley Data, v1.

http://dx.doi.org/10.17632/xwj98nb39r.1 ↗

Video

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. . In order to ensure that your video or animation material is directly usable, please provide the file in one of our recommended file formats with a preferred maximum size of 150 MB per file, 1 GB in total. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect ↗ . Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction pages. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

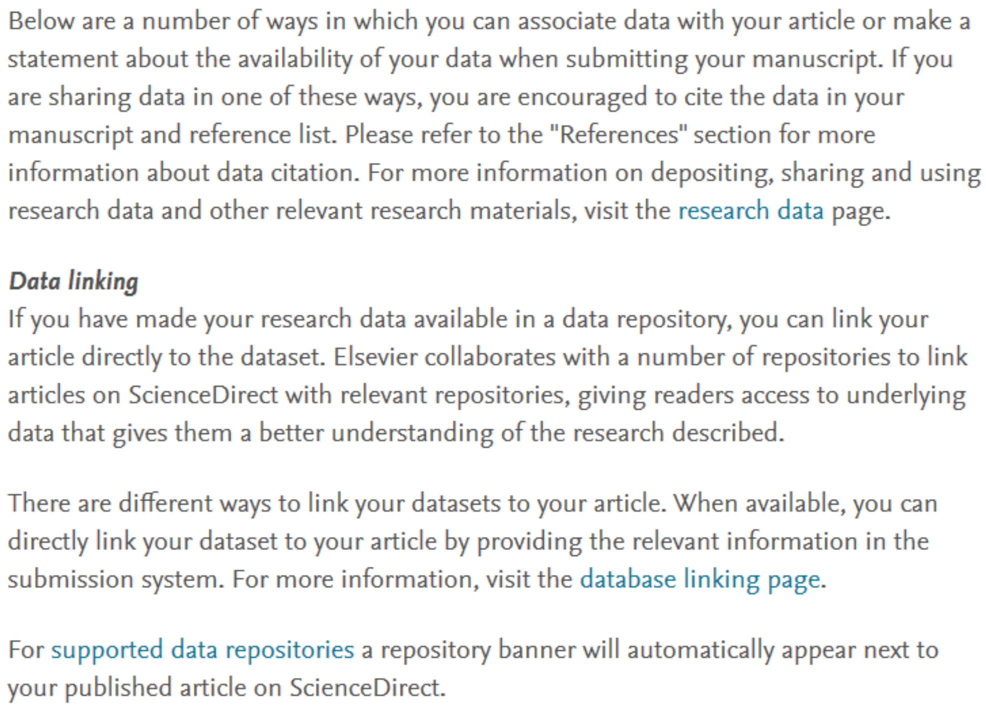


Supplementary material

Supplementary material such as applications, images and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file. Do not annotate any corrections on a previous version. Please switch off the 'Track Changes' option in Microsoft Office files as these will appear in the published version.

Research data

This journal encourages and enables you to share data that supports your research publication where appropriate, and enables you to interlink the data with your published articles. Research data refers to the results of observations or experimentation that validate research findings. To facilitate reproducibility and data reuse, this journal also encourages you to share your software, code, models, algorithms, protocols, methods and other useful materials related to the project.



Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

Data linking

If you have made your research data available in a data repository, you can link your article directly to the dataset. Elsevier collaborates with a number of repositories to link articles on ScienceDirect with relevant repositories, giving readers access to underlying data that gives them a better understanding of the research described.

There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page.

For supported data repositories a repository banner will automatically appear next to your published article on ScienceDirect.

In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

Mendeley Data

This journal supports Mendeley Data, enabling you to deposit any research data (including raw and processed data, video, code, software, algorithms, protocols, and methods) associated with your manuscript in a free-to-use, open access repository. During the submission process, after uploading your manuscript, you will have the opportunity to upload your relevant datasets directly to *Mendeley Data*. The datasets will be listed and directly accessible to readers next to your published article online.

For more information, visit the Mendeley Data for journals page.

Data statement

To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

After Acceptance

Online proof correction

Corresponding authors will receive an e-mail with a link to our online proofing system, allowing annotation and correction of proofs online. The environment is similar to MS Word: in addition to editing text, you can also comment on figures/tables and answer questions from the Copy Editor. Web-based proofing provides a faster and less error-prone process by allowing you to directly type your corrections, eliminating the potential introduction of errors.
If preferred, you can still choose to annotate and upload your edits on the PDF version. All instructions for proofing will be given in the e-mail we send to authors, including alternative methods to the online version and PDF.
We will do everything possible to get your article published quickly and accurately. Please use this proof only for checking the typesetting, editing, completeness and correctness of the text, tables and figures. Significant changes to the article as accepted

for publication will only be considered at this stage with permission from the Editor. It is important to ensure that all corrections are sent back to us in one communication. Please check carefully before replying, as inclusion of any subsequent corrections cannot be guaranteed. Proofreading is solely your responsibility.

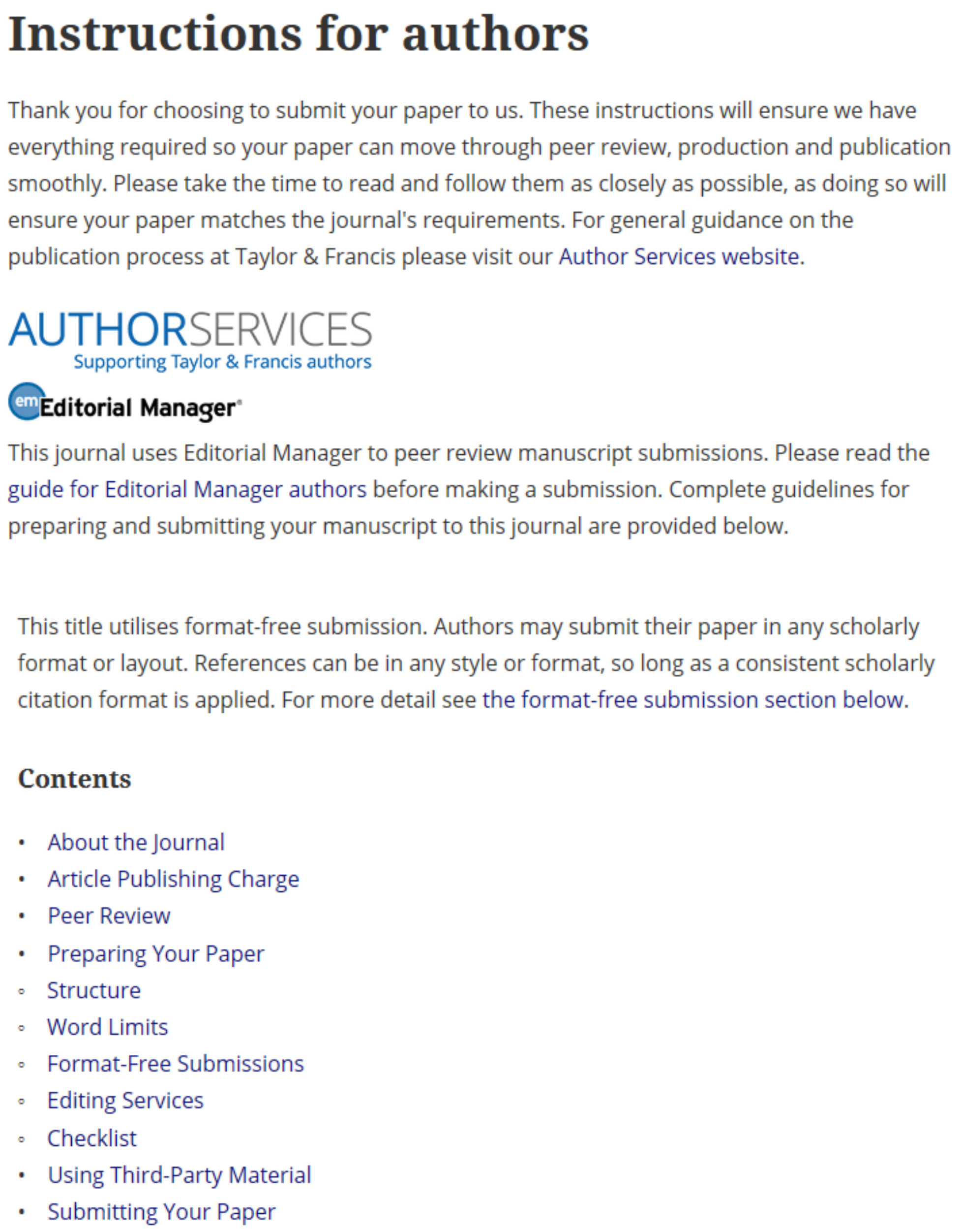
Offprints

The corresponding author will, at no cost, receive a customized Share Link providing 50 days free access to the final published version of the article on ScienceDirect ↗ . The Share Link can be used for sharing the article via any communication channel, including email and social media. For an extra charge, paper offprints can be ordered via the offprint order form which is sent once the article is accepted for publication. Both corresponding and co-authors may order offprints at any time via Elsevier's Webshop ↗ . Corresponding authors who have published their article gold open access do not receive a Share Link as their final published version of the article is available open access on ScienceDirect and can be shared through the article DOI link.

Author Inquiries

Visit the Elsevier Support Center ↗ to find the answers you need. Here you will find everything from Frequently Asked Questions to ways to get in touch.
You can also check the status of your submitted article ↗ or find out when your accepted article will be published ↗ .

Appendix B: Author Guidelines for International Journal of Qualitative Studies in Health and Well-being



Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

AUTHORSERVICES
Supporting Taylor & Francis authors

Editorial Manager

This journal uses Editorial Manager to peer review manuscript submissions. Please read the guide for Editorial Manager authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

This title utilises format-free submission. Authors may submit their paper in any scholarly format or layout. References can be in any style or format, so long as a consistent scholarly citation format is applied. For more detail see the format-free submission section below.

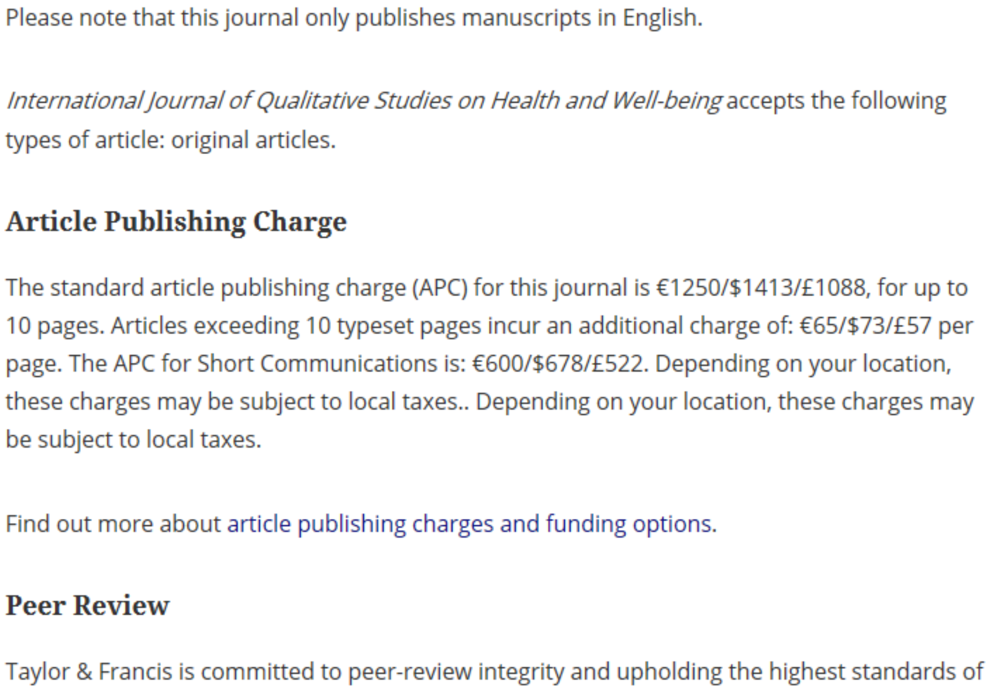
Contents

- Data Sharing Policy
- Publication Charges
- Copyright Options
- Complying with Funding Agencies
- My Authored Works
- Reprints

About the Journal

International Journal of Qualitative Studies on Health and Well-being is an Open Access international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Open Access means you can publish your research so it is free to access online as soon as it is published, meaning anyone can read (and cite) your work. Please see our guide to Open Access for more information. Many funders mandate publishing your research open access; you can check open access funder policies and mandates here.



Please note that this journal only publishes manuscripts in English.

International Journal of Qualitative Studies on Health and Well-being accepts the following types of article: original articles.

Article Publishing Charge

The standard article publishing charge (APC) for this journal is €1250/$1413/£1088, for up to 10 pages. Articles exceeding 10 typeset pages incur an additional charge of: €65/$73/£57 per page. The APC for Short Communications is: €600/$678/£522. Depending on your location, these charges may be subject to local taxes.. Depending on your location, these charges may be subject to local taxes.

Find out more about article publishing charges and funding options.

Peer Review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

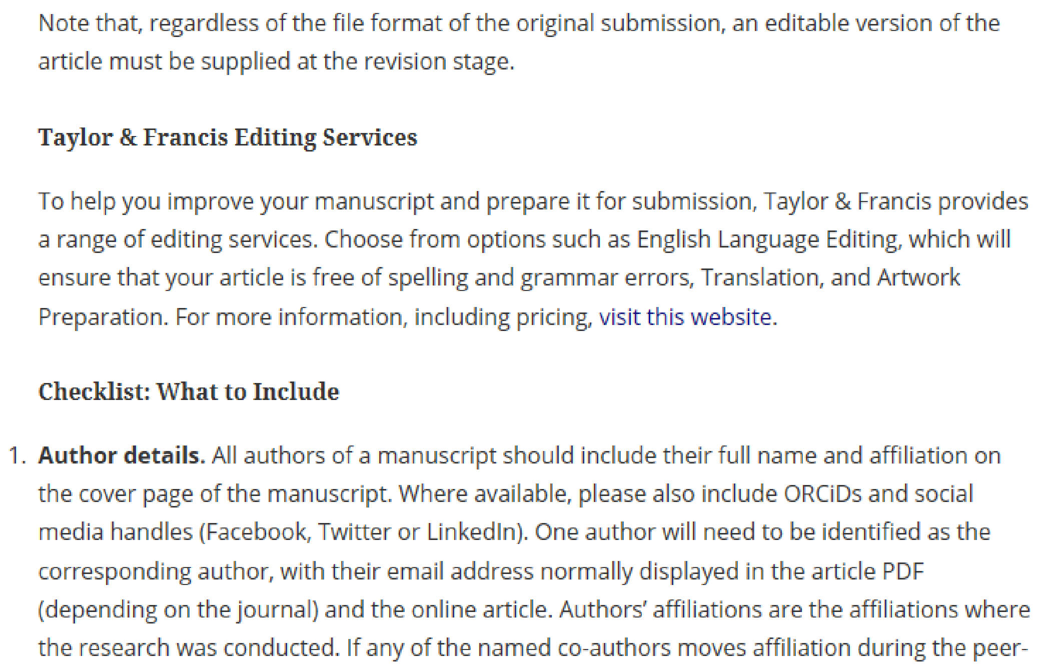
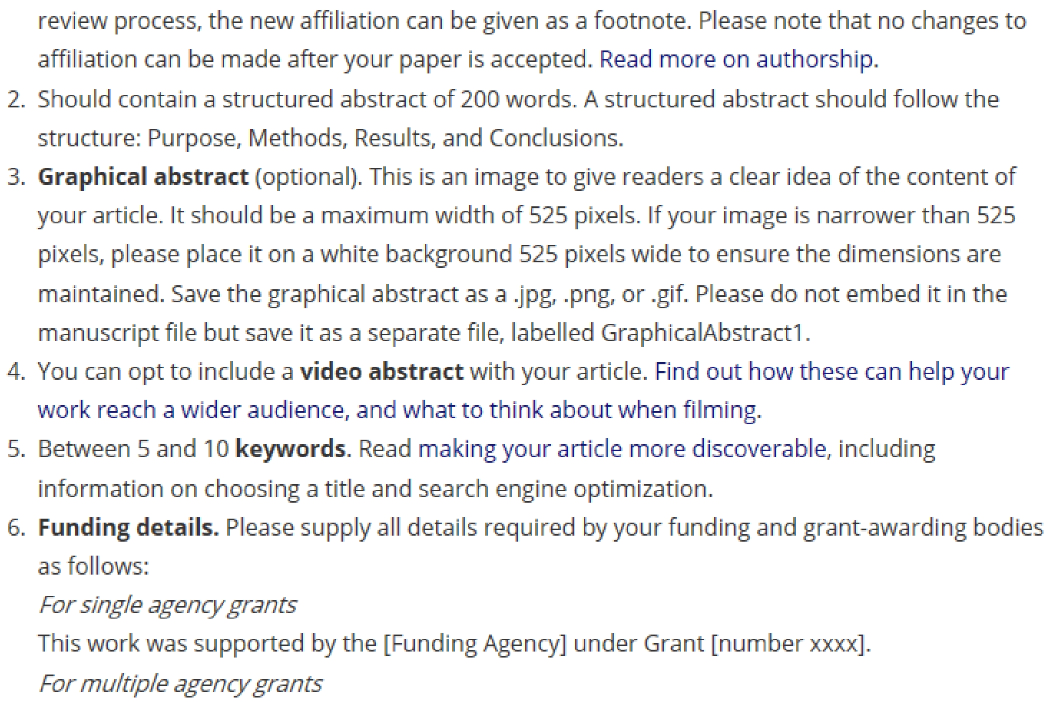
Word Limits

Please include a word count for your paper. There are no word limits for papers in this journal.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), or PDF files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a consistent scholarly citation format is applied. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

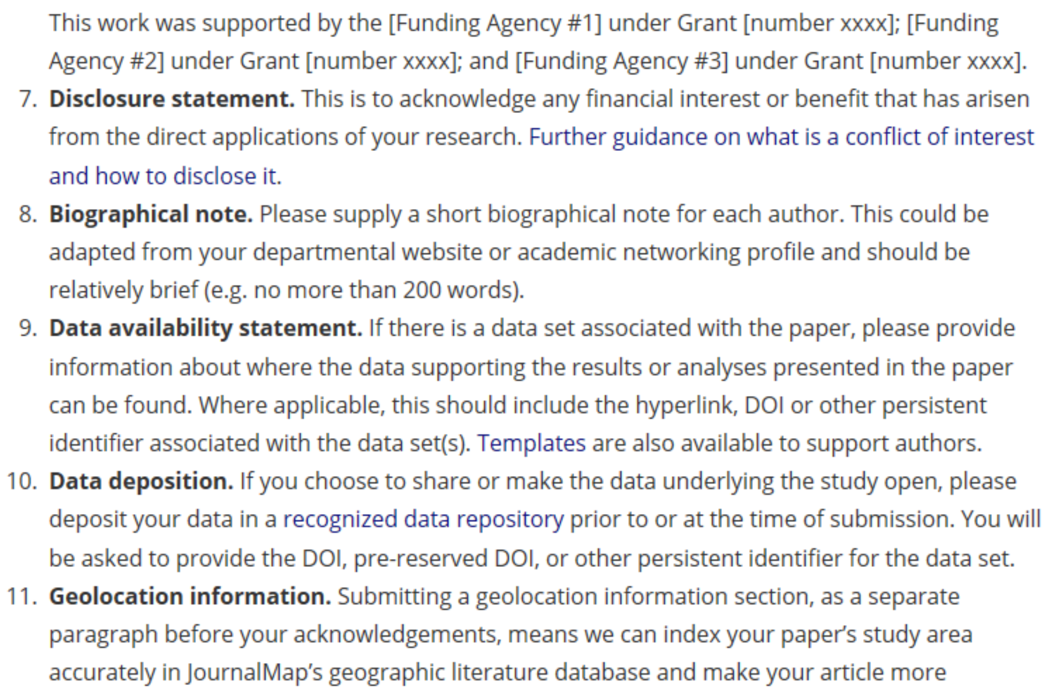
Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

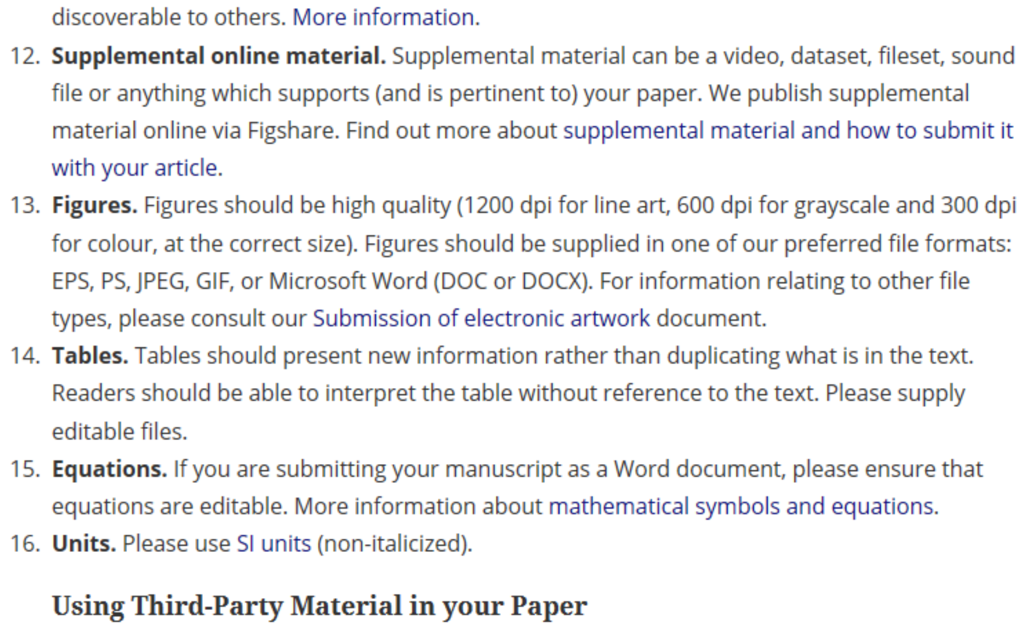
Checklist: What to Include

1. **Author details.** All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. Should contain a structured abstract of 200 words. A structured abstract should follow the structure: Purpose, Methods, Results, and Conclusions.
3. **Graphical abstract** (optional). This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are maintained. Save the graphical abstract as a .jpg, .png, or .gif. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.
4. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
5. Between 5 and 10 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
6. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants



This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

7. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.
8. **Biographical note.** Please supply a short biographical note for each author. This could be adapted from your departmental website or academic networking profile and should be relatively brief (e.g. no more than 200 words).
9. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
10. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
11. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.



12. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
13. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our Submission of electronic artwork document.
14. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
15. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
16. **Units.** Please use SI units (non-italicized).

Using Third-Party Material in your Paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Submitting Your Paper

This journal uses Editorial Manager to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in Editorial Manager. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

Please note that *International Journal of Qualitative Studies on Health and Well-being* uses Crossref™ to screen papers for unoriginal material. By submitting your paper to *International Journal of Qualitative Studies on Health and Well-being* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on

publishing agreements.

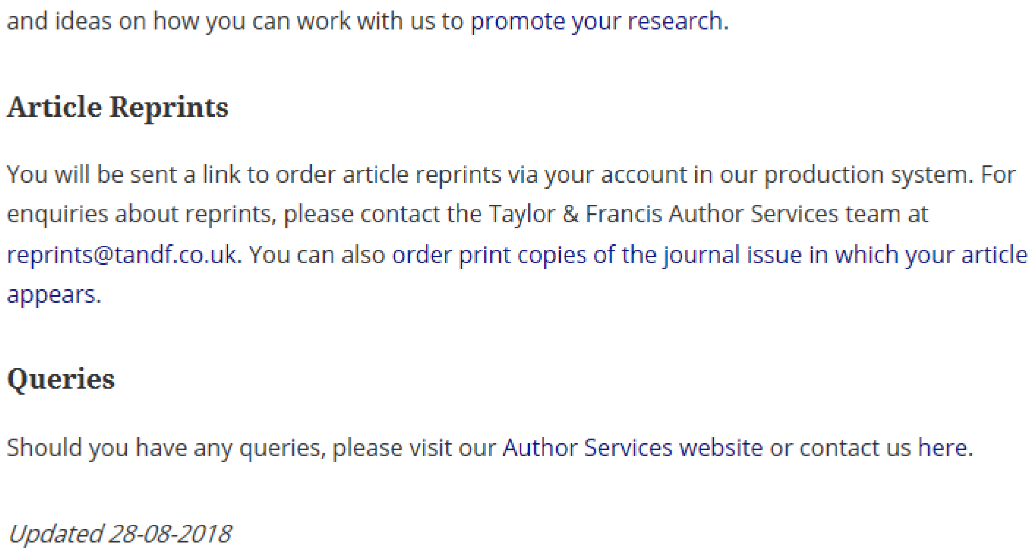
Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips



and ideas on how you can work with us to promote your research.

Article Reprints

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact the Taylor & Francis Author Services team at reprints@tandf.co.uk. You can also order print copies of the journal issue in which your article appears.

Queries

Should you have any queries, please visit our Author Services website or contact us here.

Updated 28-08-2018

Appendix C: Search Strategy for systematic review

PsycINFO (January 1980 – October 2018)

01. Borderline personality disorder
02. BPD
03. Emotionally unstable personality disorder
04. EUPD
05. Psychotic symptoms
06. Psychotic-like experiences
07. Psychosis
08. Hallucination
09. Dissociation
10. Delusion
11. Psychological risk factor
12. Trauma
13. Childhood trauma
14. Physical abuse
15. Sexual abuse
16. Emotional abuse
17. Neglect
18. Stressful life event
19. Comorbidity
20. Mood disorders
21. Anxiety disorders
22. Post-traumatic stress disorder
23. PTSD
24. Complex trauma
25. Substance abuse
26. Substance use dependence
27. SUD
28. 1 or 2 or 3 or 4
29. 5 or 6 or 7 or 8 or 9 or 10
30. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
31. 28 and 29 and 30

PubMED (January 1980 – October 2018)

01. Borderline personality disorder
02. BPD
03. Emotionally unstable personality disorder
04. EUPD
05. Psychotic symptoms
06. Psychotic-like experiences
07. Psychosis
08. Hallucination
09. Dissociation
10. Delusion
11. Psychological risk factor
12. Trauma

13. Childhood trauma
14. Physical abuse
15. Sexual abuse
16. Emotional abuse
17. Neglect
18. Stressful life event
19. Comorbidity
20. Mood disorders
21. Anxiety disorders
22. Post-traumatic stress disorder
23. PTSD
24. Complex trauma
25. Substance abuse
26. Substance use dependence
27. SUD
28. 1 or 2 or 3 or 4
29. 5 or 6 or 7 or 8 or 9 or 10
30. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
31. 28 and 29 and 30

GoogleScholar (January 1980 – October 2018)

01. Borderline personality disorder
02. BPD
03. Psychotic Symptoms
04. Psychotic-like experiences
05. Psychosis
06. Hallucination
07. Dissociation
08. Delusion
09. Psychological risk factors
10. Comorbidity
11. 1 or 2
12. 3 or 4 or 5 or 6 or 7 or 8
13. 9 or 10
14. 11 and 12 and 13

Scopus (January 1980 – October 2018)

01. Borderline personality disorder
02. BPD
03. Psychotic symptoms
04. Psychotic-like experiences
05. Psychosis
06. Hallucination
07. Dissociation
08. Delusion

09. 1 or 2
10. 3 or 4 or 5 or 6 or 7 or 8
11. 9 and 10

Appendix D: The QATSDD tool

Table 1 Quality assessment tool and scoring guidance notes

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test–retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

Appendix E: NHS Health Research Authority Approval

NHS
Health Research Authority

Mrs Aisya Musa
Trainee Clinical Psychologist
University of East Anglia
Norwich Medical School
Faculty of Medicine and Health Sciences
University of East Anglia, Norwich
NR4 7TJ

Email: hra.approval@nhs.net

19 March 2018

Dear Mrs Musa

Letter of HRA Approval

Study title:	**Psychotic-Like Experiences in Help Seeking Young People with Borderline Personality Traits: An Interpretative Phenomenological Analysis of Experiences**
IRAS project ID:	**237619**
REC reference:	**18/SW/0046**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further from the HRA.

How should I continue to work with participating NHS organisations in England?
You should now provide a copy of this letter to all participating NHS organisations in England, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of HRA assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland, Scotland and Wales?
HRA Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland, Scotland and Wales.

If you indicated in your IRAS form that you do have participating organisations in one or more devolved administration, the HRA has sent the final document set and the study wide governance report (including this letter) to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with Northern Ireland, Scotland and Wales.

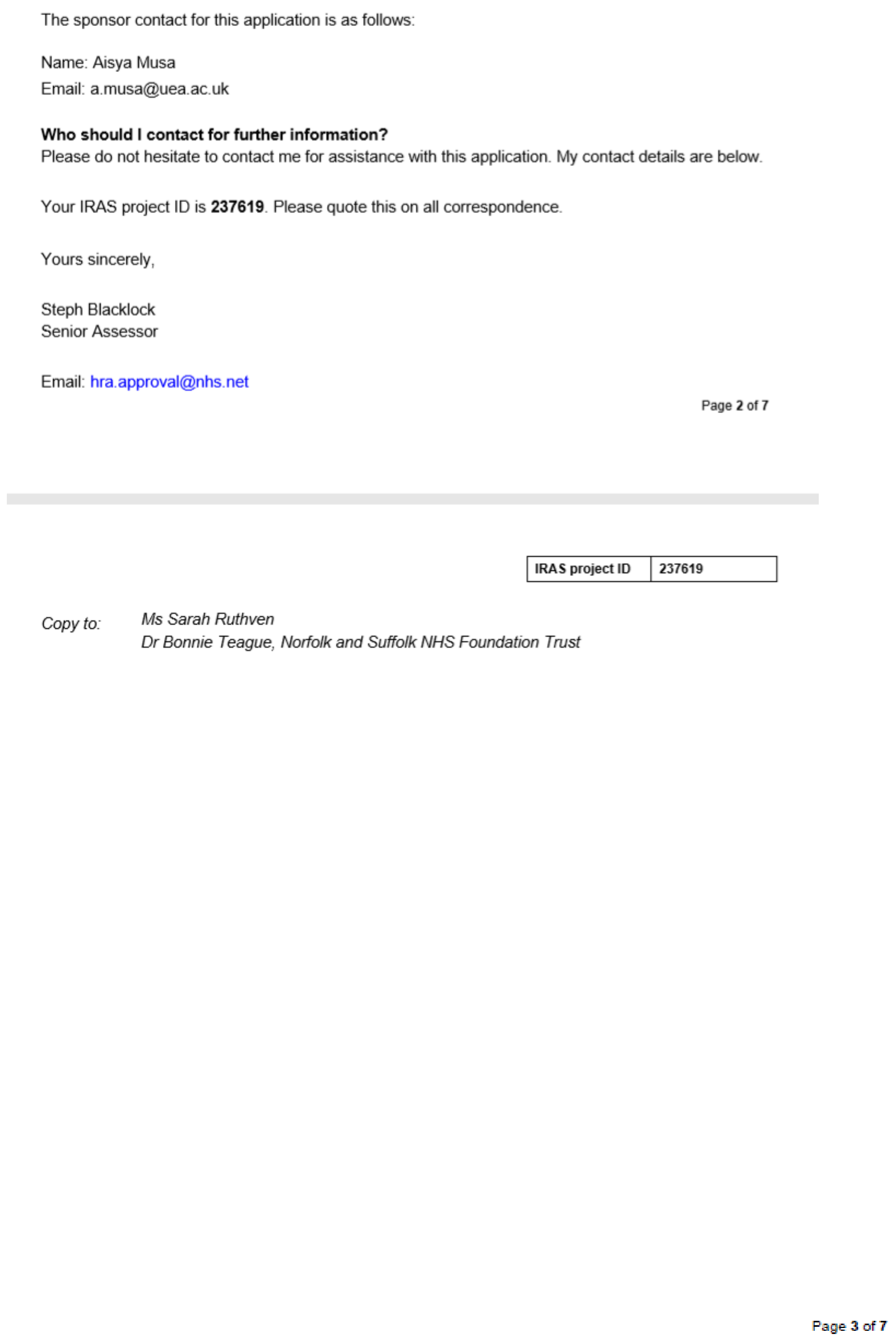
How should I work with participating non-NHS organisations?
HRA Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.



The sponsor contact for this application is as follows:

Name: Aisya Musa
Email: a.musa@uea.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **237619**. Please quote this on all correspondence.

Yours sincerely,

Steph Blacklock
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Sarah Ruthven*
Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust

List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Research Poster]	1	23 January 2018
Covering letter on headed paper [Coversheet for REN]	8	01 January 2012
GP/consultant information sheets or letters [Clinician Information Sheet]	2	20 February 2018
Interview schedules or topic guides for participants [Topic Guide]	1	23 January 2018
IRAS Application Form [IRAS_Form_23012018]		23 January 2018
Letter from sponsor [Letter from Sponsor]	1	16 January 2018
Non-validated questionnaire [Socio-demographic questionnaire]	1	23 January 2018
Other [UEA Checklist for Sponsor]		27 November 2017
Other [Secondary Supervisor CV]		
Other [Study Collaborator CV]		27 November 2017
Other [Consent to Contact Form]	1	23 January 2018
Other [The Youth Mental Health Service Referral Checklist]	1	23 January 2018
Other [Letter to Gatekeeper]	1	23 January 2018
Other [Participant receipt form]	1	23 January 2018
Other [Validated Questionnaire - Borderline Personality Questionnaire]	1	23 January 2018
Other [Thesis Budget Form]		
Other [Study Timeline]	1	23 January 2018
Other [Possible Systematic Review Topics]	1	23 January 2018
Other [Debrief Form]	2	20 February 2018
Other [Validated Questionnaire: HYPE Screen]	2	20 February 2018
Other [Amendment Letter to REC]	1	26 February 2018
Participant consent form [Participant consent form]	3	08 March 2018
Participant information sheet (PIS) [Participant Information Sheet]	3	08 March 2018
Research protocol or project proposal [Thesis Proposal]	1	23 January 2018
Summary CV for Chief Investigator (CI) [Trainee_CV]		
Summary CV for student [Trainee CV]		
Summary CV for supervisor (student research) [Primary Supervisor CV]		
Validated questionnaire [Prodromal Questionnaire]		
Statement of Activities	1	19 March 2018
Schedule of Events	1	19 March 2018

Summary of HRA assessment

The following information provides assurance to you, the sponsor and the NHS in England that the study, as assessed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing, arranging and confirming capacity and capability.

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Applicant has provided a Statement of Activities and Schedule of Events.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	No funds available to participating NHS organisations.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments

Section	HRA Assessment Criteria	Compliant with Standards	Comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a student, questionnaire/interview study with one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

As per the Statement of Activities a Principal Investigator is expected to be in place at each participating NHS organisation.

GCP training is not a generic training expectation, in line with the HRA/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
It is unlikely that letters of access or honorary research contracts will be applicable, except where local staff employed by another Trust (or University) are involved (and then it is likely that arrangements are already in place). Where arrangements are not already in place, such staff (or similar) undertaking any of the research activities listed in the IRAS form, would be expected to obtain a Letter of Access on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

NHS
Health Research Authority
South West - Frenchay Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead,
Bristol BS1 2NT
Email: nrescommittee.southwest-frenchay@nhs.net

Telephone: 0207 104 8041

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

14 March 2018

Mrs Aisya Musa
Trainee Clinical Psychologist
University of East Anglia
Norwich Medical School
Faculty of Medicine and Health Sciences
University of East Anglia, Norwich
NR4 7TJ

Dear Mrs Musa

Study title:	**Psychotic-Like Experiences in Help Seeking Young People with Borderline Personality Traits: An Interpretative Phenomenological Analysis of Experiences**
REC reference:	**18/SW/0046**
IRAS project ID:	**237619**

Thank you for your letter of 8 March 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

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

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

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

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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

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

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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

Ethical review of research sites

NHS sites

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

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Research Poster]	1	23 January 2018
Covering letter on headed paper [Coversheet for REN]	8	01 January 2012
GP/consultant information sheets or letters [Clinician Information Sheet]	2	20 February 2018
Interview schedules or topic guides for participants [Topic Guide]	1	23 January 2018
IRAS Application Form [IRAS_Form_23012018]		23 January 2018
IRAS Checklist XML [Checklist_08032018]		08 March 2018
Letter from sponsor [Letter from Sponsor]	1	16 January 2018
Non-validated questionnaire [Socio-demographic questionnaire]	1	23 January 2018
Other [UEA Checklist for Sponsor]		27 November 2017
Other [Secondary Supervisor CV]		
Other [Study Collaborator CV]		27 November 2017
Other [Consent to Contact Form]	1	23 January 2018
Other [The Youth Mental Health Service Referral Checklist]	1	23 January 2018
Other [Letter to Gatekeeper]	1	23 January 2018
Other [Participant receipt form]	1	23 January 2018
Other [Validated Questionnaire - Borderline Personality Questionnaire]	1	23 January 2018
Other [Thesis Budget Form]		
Other [Study Timeline]	1	23 January 2018
Other [Possible Systematic Review Topics]	1	23 January 2018
Other [Debrief Form]	2	20 February 2018

Other [Validated Questionnaire: HYPE Screen]	2	20 February 2018
Other [Amendment Letter to REC]	1	26 February 2018
Participant consent form [Participant consent form]	3	08 March 2018
Participant information sheet (PIS) [Participant Information Sheet]	3	08 March 2018
Research protocol or project proposal [Thesis Proposal]	1	23 January 2018
Summary CV for Chief Investigator (CI) [Trainee_CV]		
Summary CV for student [Trainee CV]		
Summary CV for supervisor (student research) [Primary Supervisor CV]		
Validated questionnaire [Prodromal Questionnaire]		

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

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

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

Yours sincerely

pp.

Mr Stephen Draper
Chair

Email:nrescommittee.southwest-frenchay@nhs.net

Enclosures:	"After ethical review – guidance for researchers"
Copy to:	*Ms Sarah Ruthven* *Dr Bonnie Teague, Norfolk and Suffolk NHS Foundation Trust*

Appendix F: 16-item Prodromal Questionnaire (PQ-16)

1. I feel uninterested in the things I used to enjoy.
  [ ] True
  [ ] False
1.1. If True: how much distress did you experience?
  [ ] 0 No
  [ ] 1 Mild
  [ ] 2 Moderate
  [ ] 3 Severe

2. I often seem to live through events exactly as they happened before (déjà vu.)
  [ ] True
  [ ] False
2.1. If True: how much distress did you experience?
  [ ] 0 No
  [ ] 1 Mild
  [ ] 2 Moderate
  [ ] 3 Severe

3. I sometimes smell or taste things that other people can’t smell or taste.
  [ ] True
  [ ] False
3.1. If True: how much distress did you experience?
  [ ] 0 No
  [ ] 1 Mild
  [ ] 2 Moderate
  [ ] 3 Severe

4. I often hear unusual sounds like banging, clicking, hissing, clapping or ringing in my ears.
  [ ] True
  [ ] False
4.1. If True: how much distress did you experience?
  [ ] 0 No
  [ ] 1 Mild
  [ ] 2 Moderate
  [ ] 3 Severe

5. I have been confused at times whether something I experienced was real or imaginary.
  [ ] True
  [ ] False

5.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

6. When I look at a person, or look at myself in a mirror, I have seen the face change right before my eyes.
[ ] True
[ ] False
6.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

7. I get extremely anxious when meeting people for the first time.
[ ] True
[ ] False
7.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

8. I have seen things that other people apparently can’t see.
[ ] True
[ ] False
8.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe
9. My thoughts are sometimes so strong that I can almost hear them.
[ ] True
[ ] False
9.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

10. I sometimes see special meanings in advertisements, shop windows, or in the way things are arranged around me.
[ ] True
[ ] False
10.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

11. Sometimes I have felt that I'm not in control of my own ideas or thoughts.
[ ] True
[ ] False
11.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

12. Sometimes I feel suddenly distracted by distant sounds that I am not normally aware of.
[ ] True
[ ] False
12.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

13. I have heard things other people can't hear like voices of people whispering or talking.
[ ] True
[ ] False
13.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

14. I often feel that others have it in for me.
[ ] True
[ ] False
14.1. If True: how much distress did you experience?
[ ] 0 No

[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

15. I have had the sense that some person or force is around me, even though I could not see anyone.
[ ] True
[ ] False
15.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

16. I feel that parts of my body have changed in some way, or that parts of my body are working differently than before.
[ ] True
[ ] False
16.1. If True: how much distress did you experience?
[ ] 0 No
[ ] 1 Mild
[ ] 2 Moderate
[ ] 3 Severe

Document Version: 1
Document Date: 23/01/2018

Appendix G: Helping Young People Early **(**HYPE) Screen

Participant ID: ________________________

Date: ___________________________

These questions are about the kind of person you generally are – that is, how you have usually felt or behaved over the past several years. Circle "YES" if the question completely or mostly applies to you, or circle "NO" if it does not apply to you. If you do not understand a questions or are not sure of your answer, leave it blank.

Tick One

1. Have you often become frantic when you thought that someone you really cared about was going to leave you?

   ☐ Yes

   ☐ No

2. Do your relationships with people you really care about have lots of extreme ups and downs?

   ☐ Yes

   ☐ No

3. Have you all of a sudden changed your sense of who you are and where you are headed?

   ☐ Yes

   ☐ No

4. Does your sense of who you are often change dramatically?

   ☐ Yes

   ☐ No

5. Are you different with different people or in different situations, so that you sometimes don't know who you really are?

   ☐ Yes

   ☐ No
6. Have there been lots of sudden changes in your goals, career plans, religious beliefs, and so on?

☐ Yes

☐ No

7. Have you often done things impulsively?

   ☐ Yes

   ☐ No

8. Have you tried to hurt or kill yourself or threatened to do so?

   ☐ Yes

   ☐ No

9. Have you ever cut, burned, or scratched yourself on purpose?

   ☐ Yes

   ☐ No

10. Do you have a lot of sudden mood changes?

    ☐ Yes

    ☐ No

11. Do you feel empty inside?

    ☐ Yes

    ☐ No

12. Do you often have temper outbursts or get so angry that you lose control?

    ☐ Yes

    ☐ No

13. Do you hit people or throw things when you get angry?

    ☐ Yes

    ☐ No

14. Do even little things get you very angry?

    ☐ Yes

☐ No

15. When you are under a lot of stress, do you get suspicious of other people or feel especially spaced out?
    ☐ Yes
    ☐ No

Document Version: 2
Document Date: 20/02/2018

Appendix H: Socio-demographic Questionnaire

Participant ID: ____________________
Date: ________________

Demographics Questionnaire

1. What is your age? ___________

2. What is your gender?
   - ☐ Female
   - ☐ Male

3. Are you fluent in the English language?
   - ☐ Yes
   - ☐ No

4. What is your ethnicity?
   - ☐ White
   - ☐ Mixed/Multiple Ethnic Groups
   - ☐ Asian/Asian British: Indian
   - ☐ Asian/Asian British: Pakistani
   - ☐ Asian/Asian British: Bangladeshi
   - ☐ Asian/Asian British: Chinese
   - ☐ Asian/Asian British: Other Asian
   - ☐ Black/African/ Carribean/ Black British
   - ☐ Other Ethnic Group

5. How long have you utilised the mental health service you are currently receiving care?

____

Document Version: 1
Document Date: 23/01/2018

Appendix I: AANEX-inventory probe questions

A1 Thought transmission:

a) Have you had the experience of your thoughts being read or picked up by other people?
   Yes No
b) Have you ever had the experience of people reacting to thoughts you have had, so that you wonder if they are aware of what you are thinking?
   Yes No

A2 Receptivity:

a) Have you had the experience of feeling emotions or thinking thoughts that were actually those of other people?
   Yes No
b) Have you ever thought that other people or agencies were putting thoughts in your head, or making you feel certain things?
   Yes No
c) Have you had the experience of picking up on other people's thoughts?
   Yes No

A3 Thought withdrawal:

a) Have you ever experienced your thoughts being taken out of your mind, blocked or stopped by something or someone else?
   Yes No

A4 Controlled actions:

a) Have you ever experienced your bodily movements being controlled by someone or something outside of you?
   Yes No

A5 Passivity (other):

a) Have you ever had an experience of having your thoughts, feelings or movements influenced by other people? Through their thoughts, or gestures alone?
   Yes No
b) Have you ever had an experience in which you felt your body moving automatically, or felt urges to move into certain postures or make certain movements, when you didn't seem to be controlling this?
   Yes No

A6 Reference experiences:

a) Have you had experiences in which things you read or heard people say seemed to reflect or resonate with your own thoughts?
   Yes No
b) Have you had experiences in which things in the world around you seemed to contain messages or hints, perhaps in a metaphorical or symbolic way?
   Yes No

c) Have you had the experience of people seeming to be communicating with you in a special way, like with double meanings or significant words or hints?
   Yes No
d) Have you had the experience of feeling as though events in your environment, such as the actions or comments of other people, are in reference to you, or are directed at you, even though you know that this is unlikely?

Yes No

A7 Activity:

a) Have you had the experience of influencing or controlling people with your thoughts or gestures?
Yes No
b) Have you had the experience of watching something happen and feeling as though you had caused it with your mind?
Yes No
c) Have you had the experience of causing things to happen by thinking about it, when the effect happened some time later?
Yes No

A8 Loud thoughts:

a) Have you ever experienced your own thoughts being very loud, so that you could hear them being spoken in your head?
Yes No

*A9 Voice experiences***:**

a) Have you ever had the experience of hearing things, like voices talking, or music playing, when there hasn't been anyone around?
Yes No

*B1 Depersonalisation***:**

a) Have you had the experience of feeling alienated or at a distance from yourself, so that your actions and movements seem impersonal and automatic, or it feels as though you are listening to yourself speaking when you talk?
Yes No

*B2 Derealisation***:**

a) Have you had the experience of the world seeming altered in a strange way, so that it didn't seem as real and familiar as usual, but perhaps looked flat or artificial?
Yes No
b) Have you had the experience of the world seeming different or new, so that it seemed less solid, and more perfect or 'glowing' somehow?
Yes No

B3 Visual anomalies (global):

a) Have you had the experience of alterations in your vision, so that for example colours look different, you are more sensitive to light, things seem to move when you look at them, or people's faces look strange?
Yes No

*B4 Visual anomalies (hallucinations***):**

a) Have you had ever had the experience of seeing something that other people couldn’t see, or that you later found out was not there?
   Yes No
b) Have you had the experience of seeing someone’s aura, or other manifestations of energy?
   Yes No

B5 Auditory anomalies:

a) Have you had the experience of changes in your hearing, so that for example noises seem louder and more intrusive, or speech or music seem to sound different, peculiar or distorted?
   Yes No

B6 Oversensitivity:

a) Have you had the experience of feeling as though you have a ‘thinner skin’, because sounds or visual stimuli can’t be filtered out, and seem to flood or overwhelm you?
   Yes No

B7 Somatic anomalies:

a) Have you ever had experiences of unusual sensations in your body, not created by any obvious physical cause, for example of heat or cold, energy moving, or something entering or passing through your body?
   Yes No

B8 Lost automatic skills:

a) Have you experienced the loss of automatic skills, so that things you could normally do easily and without really thinking suddenly require all your attention and have be taken one step at a time?
   Yes No

B8b *Can’t divide attention:*

a) Have you noticed that it is more difficult than it used to be to do two things at the same time? E.g. to talk to someone and do some cooking at the same time?
   Yes No

B9 *Language Disturbance:*

a) Have you experienced being in a state in which it is difficult to follow a conversation or understand what someone is saying, because the words seem to stand on their own and don’t make sense?
   Yes No

B9b *Concretism:*

a) Have you noticed yourself misunderstanding what people say because they've used a metaphor or an expression that you've taken literally?
Yes No

C1 Distractability:

a) Have you had the experience of being unusually distractible, so that your attention is constantly caught by anything in your environment, and you can't control or direct your attention purposefully at one thing?
Yes No

C1b *Thought interference:*

a) Have you noticed that irrelevant or intrusive thoughts or images interrupt your thinking when you are trying to concentrate? Has this happened more than usual in any period of time? E.g. when trying to concentrate on a conversation or to some work or a book?
Yes No

C1c *Thought blockages:*

a) Have you noticed ever that your thoughts seem to suddenly stop or fade out, so that you lose your train of thought much more often than usual?
Yes No

C1d) *Captivation/fixation:*

a) Have you noticed ever that your attention gets caught by something you can see, and you find yourself looking at it without really wanting to? Like you get fixed at staring at something, or somehow something in your environment seems to stand out from everything else, so you're drawn to look at it?
Yes No

C2 Time distortion:

a) Have you had the experience of an alteration in the sense of time, so that past and future seem to disappear into an experience of the present moment?
Yes No

b) Have you ever experienced difficulties with your memory, so that it is very difficult to remember what you have done or what has happened yesterday, or earlier in the day, or even a few minutes before?
Yes No

c) Have you ever experienced difficulties with thinking about the future, so that it becomes very hard to plan out what you have to do, or envisage what might happen later on?
Yes No

C3 Disorientation:

a) Have you had the experience of feeling disorientated in space, so that it is unusually difficult to get a sense of direction, or to find your way somewhere, even if you know the way quite well?
   Yes No

C4 Insight experiences:

a) Have you had the experience of having 'insights' or sudden revelations come into your mind, for example about the nature of divine or cosmic principles, or the functioning of society, or other fundamental issues?
   Yes No

C5 Thought pressure:

a) Have you had the experience of thoughts rushing very rapidly through your mind, so that one idea after another comes into your head and the thoughts seem to whirl around beyond your control?
   Yes No

C6 Mission experiences:

a) Have you had the experience of some kind of 'mission' or duty being revealed to you, and knowing that you have to fulfill this mission, or feeling compelled to do so?
   Yes No

D1 Spiritual elation:

a) Have you ever had an experience like a state of 'grace', in which you felt extremely content and peaceful, or released from all responsibilities, or very light and full of energy and love, which has been unlike your normal fluctuations of mood?
   Yes No

D2 Monitored:

a) Have you had the experience of feeling monitored or watched, or otherwise the subject of external attention, when there is no obvious cause for this?
   Yes No

*D3 Doom***:**

a) Have you ever experienced feelings of doom, or impending catastrophe that you couldn't explain?
   Yes No
b) or heaviness and lack of energy that might have made you feel as if you were dying, dead or dissolving, without any obvious cause?
   Yes No

D4 Mixed/unknown emotions:

a) Have you experienced states in which it has been difficult to distinguish what emotions you are feeling, as if they are all mixed up and impossible to identify, or all seem equally unpleasant and intense?
Yes No

D5 Emotional reactivity:

a) Have you experienced states when you are much more emotionally reactive than usual, so that little things agitate you more than usual, and things like music, books, or news footage have the power to 'move' you intensely?
Yes No

D6 Loss of emotions:

a) Have you had the experience of feeling as though your emotions have disappeared, so that you feel numb, or as if something is missing inside?
Yes No

E1 Precognition:

a) Have you had the experience of knowing what is going to happen a fraction of a second before it happens?
Yes No
b) Have you had experiences of precognition when you foresee an event that happens later?
Yes No

E2 Out of body experiences:

a) Have you ever had an out-of-body experience, in which you were actually able to look at your body from outside?
Yes No

F1 Loss of boundary:

a) Have you experienced being in a state in which there seemed to be no clear boundary or difference between yourself and things around you?
Yes No
b) Have you had an experience of a loss of your individual identity and a sense of being part of some greater whole that extends far beyond you?
Yes No

F2 Subjective isolation:

a) Have you experienced being in a state in which you felt cut off or isolated from things and people around you, perhaps as if there were some invisible barrier around you that prevented a normal connection?
Yes No

Appendix J: Topic Guide

Introduction: Thank you for taking part in this interview, I am going to ask you a few questions relating to the unusual experiences you have, and how you understand, interpret and respond to them. Please let me know if you feel uncomfortable about any of the questions or if you wish to stop the interview. Are you okay to continue?

1. (Set scene) I was wondering if you could tell me a bit more about the experiences you have.
   Prompt: Have you had this experience more than once, or was it an isolated event? Do you still experience this (from time to time)? How long has the experience lasted for? Did this experience occur in the context of an 'altered state'?
2. How long have you had these experiences for?
   Prompt: Which of the experiences that you've told me about came first? Have there been periods of time in which you haven't had any unusual experiences?
3. What was your life like when you first had the experiences?
   Prompt: Were there any particularly event (be it difficult or exciting) happening to you then?

4. How did you make sense of the experiences at the time?
   Prompt: What were you thinking when you first had the experience? Was the experience beneficial or a bad sign? Was the experience dangerous or harmless? Was the experience caused by changes in you, or something outside of you?

5. How did you feel when the experiences first started?
   Prompt: *Did you have any worries or fears? Did you have any good feelings? Were you distressed by the experience?*
6. What did you do when the experiences first started?
   Prompt: Did you seek reassurance from yourself and/or others? Did you act in accordance to the experience (i.e. voice hearing) or did you try to resist them? Did you make changes to your daily activities?

7. What effect did the experiences have on how you saw yourself?
   Prompt: Did you see yourself differently after the experiences started? How has your sense of self changed?

8. How have others acted with you after the experiences started?
   Prompt: Did you feel your experiences are understood by the people around you, or did you feel you needed to keep quiet about it?

9. When you started to have these experiences, how much control did you feel you had over the experience?
   Prompt: Could you stop the experience when you wanted to? Could you deliberately elicit the experience?

10. What do you think about these experiences?
    Prompt: Do you think many people have experiences that are similar to the experiences you have spoken about?

11. How have you coped with your experiences?

Prompt: What has helped you to cope or come to terms with these experiences? What have others done to help you cope with these experiences?

12. Are there any other aspects of your experience which you feel are important and that you would like to tell me?

Document Version: 1
Document Date: 23/01/2018

Appendix K: Consent to Contact Form

Norfolk and Suffolk NHS
NHS Foundation Trust

UEA
University of East Anglia

Consent to Contact Form

STUDY TITLE: How Do Help-Seeking Young people Within Secondary Mental Health Services Make Sense of, and Respond to, Unusual Experiences?

NAME AND CONTACT DETAILS

Please initial box if you agree:

I confirm that I am potentially interested in taking part in the above study and give consent to the researcher to contact me using the following details to discuss further: ☐

Name: ________________________________

Preferred method of contact (please tick):

☐ Tel. number: ________________________

☐ Email: ______________________________

______________________________ Signature

______________________________ Date

Document Version: 1
Document Date: 23/01/2018

Appendix L: Participant Information Sheet (PIS)

Participant Information Sheet

Norfolk and Suffolk NHS
NHS Foundation Trust

UEA
University of East Anglia

Norwich Medical School
Postgraduate Research Office 2.30
Elizabeth Fry Building
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ
Email: clinpsyd@uea.ac.uk
Tel: +44 (0) 1603 593076
Fax: +44 (0) 1603 591132
Web: www.uea.ac.uk

Study title

How do help-seeking young people within secondary mental health services make sense of, and respond to, unusual experiences?

Invitation

We would like to invite you to take part in a research study. Before you decide if you would like to take part or not, please read this information sheet that explains what the study is about and how you will be involved. If you have any questions about the study then please contact the researcher directly who will try to answer them for you. The details of the researcher can be found at the end of this information sheet. Please take your time to read the information sheet. There is no need to make a decision right away as to whether you would like to take part in it, or not.

What is the purpose of this study?

We are interested in speaking to young people, between the age of 16 to 25, who have unusual experiences. Research has shown that it is very common for individuals to describe experiences such as seeing or hearing things that others cannot, altered patterns of thinking, and spiritual experiences. Like any other experience, these unusual experiences can be interpreted and responded to in different ways. For some individuals, these experiences may have a negative impact on their life and for others, these experiences can be positive and enrich their lives. We are conducting this study on one site within _____, so that we may be able to talk to young people who are currently receiving mental health care. This research will attempt to explore how young people understand and respond to their unusual experiences. We are particularly interested in what these experiences are like for people who have particular kinds of personality traits, e.g. individuals who experience a lot of ups and downs with their mood or who may experience difficulties in their relationships. We hope a better psychological understanding of these types of experiences will, in the long term, help people to feel less distressed and more able to cope with them.

Do I have to take part?

It is up to you if you would like to take part in the study. Whether you do decide to take part or not will have no effect on the care you are currently receiving. If you are not sure, we can try to answer any questions you may have before you make a decision. If you agree to take part in this study you will be asked to sign a consent form.

What would taking part involve?

Should you express interest in the study, you will be contacted by the researcher to discuss a time for a meeting which is convenient for you. The meeting may be conducted in the service where you usually attend appointments or within your own home. During the meeting, you will be asked to complete one questionnaire and an interview. The questionnaire will be used to attain socio-demographic information. We will then ask you to take part in an interview discussing these unusual experiences, including how often they happen and how distressing they find them, how you make sense of these experiences and what you do to cope with them. The questionnaire will take less than 5 minutes to complete, and the interview will approximately take 1 hour and 30 minutes to complete. The total time to complete the study is approximately 1 hour and 30 minutes. Breaks will be provided should you like one.

What are the possible benefits of taking part?

By taking part in this study, you will be helping us to understand how young people who utilise mental health services understand and respond to their unusual experiences. This information will help inform future research on unusual experiences and could help make treatments for help-seeking young people be more helpful. Furthermore, you will receive a £5 Amazon voucher as part of your participation.

What are the possible disadvantages and risks of taking part?

The questionnaire and interview contain detailed questions on unusual experiences which some individuals may find anxiety-provoking. You do not have to answer all the questions if you do not want to. If you do experience any distress then we can stop the interview at any time and discuss the source of this distress and you can decide whether you would like to continue or not. There is also further information in the debrief form about who you can contact should you wish to.

What if there is a problem?

If you have any concerns about any aspects of this study, you should speak to the researcher directly who will try to answer your questions. You can also discuss this with the Project supervisor Professor Sian Coker. If you remain unhappy, you can make a formal complaint and contact Professor Richard Meiser-Stedman, R.Meiser-stedman@uea.ac.uk, University of East Anglia, School of Medicine, Elizabeth Fry Building, NR4 7TJ.

What happens if I don’t want to carry on with the study?

You are free to withdraw from the study at any time without giving a reason. Your withdrawal will have no effect on the care you are currently receiving. If you decide that you would like to withdraw, you can contact the researcher on the details provided below. We would ask that you do this before September 2018 when the data will be analysed. Up to this point, if you withdraw from the study any information that you provide will be destroyed.

How will information be kept confidential?

All information relating to the study will be confidential. You will be given a study ID number that will be used on all of your research questionnaires to ensure that all the answers you provide are entirely anonymous. All personally identifiable information will be stored in a locked filing cabinet or on secure computer systems at UEA which are only accessible by the research team. At the end of the study, a fully anonymised electronic copy of the study data will be stored at UEA and may be used in future research projects to understand more about unusual experiences. Your identity will be protected at all times.

Only the study researchers will have access to the study data and all will be asked to agree to preserve the confidentiality of the information collected in this study. Circumstances in which confidentiality might be breached may include any disclosure of risk made during the study. Disclosure of risk may include providing information that may indicate risk to self, and/or risk to others.

What will happen to the results of the study?

We intend to publish the results of this study in a journal. There will be no personal details used in this. We will also give a brief summary of the results to the mental health services involved in the study as well as yourself if you wish to see the results.

Who is organising and funding this study?

This study is being organised by Mrs Aisya Musa (Trainee Clinical Psychologist) under the supervision of Professor Sian Coker, Dr Joanna Semlyen, and Dr Paul Fisher, and is being funded by the University of East Anglia.

Who has reviewed this study?

The research is being supervised by the Department of Clinical Psychology at the University of East Anglia. All research in a healthcare setting is reviewed by an Ethics Committee to protect the interests of service users.

Further information and contact details

If you have any questions, I can be contacted via the following:

Mrs Aisya Musa
Department of Clinical Psychology
Norwich Medical School
Faculty of Medicine and Health Sciences
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ
Email: A.Musa@uea.ac.uk

Mobile number: 07 480 314652

Alternatively, please contact my supervisor via email or telephone: S.Coker@uea.ac.uk, Tel: 01603 593544.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact:

Professor Richard Meiser-Stedman
Professor of Clinical Psychology
Department of Clinical Psychology
Norwich Medical School
Elizabeth Fry Building
Chancellor's Drive
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
Email: R.Meiser-stedman@uea.ac.uk
Tel: 01603 593601

Document Version: 4
Document Date: 25/10/2018

Appendix M: Written Consent Form

Written Consent Form
(Form to be on headed paper)
IRAS ID: 237619
Centre Number _____
Study Number ______

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

Insert local site logo here

Participant Consent Form

Study Title: How Do Young People accessing Mental Health Services Make Sense of, and Respond to, Unusual Experiences?

Researcher: Aisya Musa

Please tick or delete the following in the box provided:

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

2. I understand that my participation is entirely voluntary and that I may withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the Sponsor, regulatory authorities, or from the NHS organisation, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. I also understand that the researcher will not have access to my medical records through the course of the study. ☐

4. I understand that confidentiality of information provided in this study will be upheld. Circumstances in which confidentiality might be breached may include any disclosure of risk to self and/or risk to others made during the study. ☐

5. I agree to the interview session between the researcher and myself to be audio-recorded. I understand that all audio-recordings will be anonymised, and stored securely within NHS premises. ☐

6. I agree to the researcher to use quotes from the interview in verbatim as part of the write-up of the above study. ☐

7. I agree to take part in the above study. ☐

______________________________	______________	________________________
Name of Participant	Date	Signature
______________________________	______________	________________________
Name of the Person taking Consent	Date	Signature

**When completed: 1 copy for Researcher, 1 copy for Participant, original kept in medical note*

Document Version: 3
Document Date: 08/03/2018

Appendix N: Clinician Information Sheet

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

Clinician Information Sheet

Sample: 12 young people with borderline personality traits between the age of 16 to 25 years reporting unusual experiences are being recruited from secondary mental health services

The following **<u>inclusion</u>** criteria will be applied:

- Aged 16 to 25, accessing secondary mental health services
- Reporting symptoms of borderline personality traits such as difficulties with emotion regulation and interpersonal relationships, scoring 11 and above on the

HYPE Screen, and currently receiving support within the BPD traits treatment pathway

- Reporting unusual or psychotic-like experiences (e.g. seeing or hearing things others cannot) scoring above 6 on the PQ-16.
- Fluent in the English language

The following **exclusion** criteria will be applied:

- Young people with learning disabilities
- Young people with formal diagnosis of psychosis
- Young people whose primary diagnosis is organic brain injury, epilepsy and substance use dependence
- Insufficient fluency in the English language

Study design: Young people with borderline personality traits (score of 11 and above on the HYPE Screen) who report psychotic-like experiences (score 6 or above on the Prodromal Questionnaire) are eligible to proceed with the study. If participants are eligible for the study and are interested in taking part, the researcher will arrange to meet with them at the service where they usually receive care or in their own homes. This will include an interview exploring the nature of their unusual experiences (approximately 90 minutes) and answering a questionnaire on socio-demographic characteristics (approximately 5 minutes). Participants may withdraw at any time without providing a reason, and without it affecting their care.

Referring to the study: Please contact the researcher if you identify potential participants who are under your care using the contact details below. If your client has given consent to be contacted by a researcher, they will get in touch to arrange a meeting and discuss the project in more detail. The researcher will also send out an information sheet to potential participants so that they receive it 48 hours before meeting to allow them time to read the information.

Timescale: Recruitment of participants will begin in February 2018.

Contacts: Please get in touch if you have any questions on the following email: Aisya.Musa@nsft.nhs.uk or A.Musa@uea.ac.uk, Tel: 07 480 314652 or Professor Sian Coker, Email: S.Coker@uea.ac.uk, Tel: 01603 593544.

If you would like to make a complaint about any area of the research you can contact Professor Richard Meiser-Stedman. Tel: 01603 593601 Email: R.Meiser-stedman@uea.ac.uk

Many Thanks

Document Version: 3
Document Date: 25/10/2018

Appendix O: Participant Receipt Form

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

Participant Receipt:
Study on how help-seeking young people within secondary mental health services make sense of, and respond to, unusual experiences

I confirm that I have received a £5 Amazon gift voucher.

For participant
Name of Participant: ___________________________________
Signature ________________________________ Date: ________________

For researcher
Name of Researcher: _________________________________
Signature ________________________________ Date: ________________

Document Version: 1
Document Date: 23/01/2018

Appendix P: Letter to Gatekeeper

University of East Anglia

Aisya Musa
Department of Clinical Psychology
Elizabeth Fry Building
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ
Email: clinpsyd@uea.ac.uk
Tel: +44 (0) 1603 593076
Fax: +44 (0) 1603 591132
Web: www.uea.ac.uk

Name and address block

Dear xxx

I am writing to ask your permission to conduct research within your service for a study entitled ‘How Do Young People accessing Mental Health Services Make Sense of, and Respond to, Unusual Experiences?’, which has been given ethical clearance under reference xxx. This research is being conducted by Aisya Musa from University of East Anglia as part of her Doctoral Programme in Clinical Psychology thesis. The study has been approved by NHS ethical review and has gained Health Research Authority approval.

The aim of this study is to explore the nature of unusual experiences in help-seeking young people borderline personality traits (more details can be found in the attached Clinical Information Sheet and Participant Information Sheet, respectively). The overall goal of this study is to improve our understanding of unusual experiences in these young people, and to inform future psychological intervention within this group. The project consists of an interview and one self-report questionnaire. Overall, the study will last about 1 hour and 30 minutes. If you would like to be involved, I would be really keen to come and meet with you to discuss the study further.

I look forward to hearing from you.

Best wishes

Mrs Aisya Musa
Trainee Clinical Psychologist

Document Version: 1
Document Date: 23/01/2018

Appendix Q: Research Poster

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

Research Participants Needed!

Study Title: How Do Help-Seeking Young people Within Secondary Mental Health Services Make Sense of, and Respond to, Unusual Experiences?

Would you like to take part in research?
We are interested in contacting and interviewing young people have unusual experiences (e.g., seeing or hearing things others cannot) to understand more about how they understand and make sense of them.

What does the study involve?
Filling in a questionnaire, and an interview with a researcher about these experiences
The study can take place at the service you usually attend or within your own home. The study will take approximately 1 hour and 30 minutes to complete. Refreshment breaks will be provided.

How do I get involved?
If you are aged between 16- 25 years and have unusual experiences, and is interested in the study, please contact the researcher with the contact details given below. Alternatively, you can speak to your case manager and they can get in touch with the researcher.

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Researcher: Aisya Musa
Email:
A.Musa@uea.ac.uk

Document
Version: 1
Document Date: 23/01/2018

Appendix R: Study Debrief Form

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

Debriefing for a study on how help-seeking young people within secondary mental health services make sense of, and respond to, unusual experiences

This study was looking at exploring how young people with mental health problems understand, interpret and respond to unusual experiences (e.g. seeing or hearing things others cannot). Unusual experiences are frequently reported by individuals in the general population, and those experiencing mental health problems. Research has shown that young people with mental health problems who have unusual experiences may find them distressing. They may have had these unusual experiences for years, and often report how these experiences can interfere with their day-to-day life. Furthermore, research has shown that young people with mental health problems who also have unusual experiences may be more likely to experience other difficulties, including struggling with very strong and changeable emotions, and finding relationships with other people difficult. It would be useful to know more about how best to help young people with these experiences.

The present study aims to explore the nature of these unusual experiences, and how young people with mental health conditions understand and respond to then. By conducting this study, we hope to broaden our understanding of unusual experiences, and also help develop interventions which might help reduce distress associated with them.

If you would like any further information regarding this study please get in touch with: Aisya Musa. Tel: 07 480 314652, Email: A.Musa@uea.ac.uk, or Professor Sian Coker: Tel: 01603 593544, Email: S.Coker@uea.ac.uk

Sources of Support

If you feel distressed, please refer to your individualised care plan. Your care plan should contain a detailed plan in times of crisis. Alternatively, if you would like to talk to someone, please get in touch with your case manager or GP.

Thank you for taking part in the study

Document Version: 3
Document Date: 28/10/2018

Appendix S: Example of initial analysis: coding and emergent themes (for Paul)

Emerging Themes	**Transcript**	**Exploring Comments (Descriptive, Linguistic, Conceptual)**
The trauma from parents splitting	Paul: My parents split up when I was about 13 and I’ve just never been the same since really it was weird yes I used to be like such an innocent like just head down kind of guy you know	Traumatic or triggering event when a child – parents split up at 13 Never been the same? Who was he prior to the split? Repeated word ‘weird’ – is weird a word/term he uses for feelings of uncertainty?
	and I can remember my parents split up and it wasn’t like the trauma itself like I still see both parents like both my parents get on now I mean obviously we’re seven years down the line but it was how it went about	Cannot remember parents splitting? Is this due to a need to avoid/block out what had happened in the past?
Lack of understanding towards parents splitting	like I moved with my dad and like my sister moved with my mum and it was I was too young to understand how I was feeling	A lack of understanding the situation of parents splitting A theme of uncertainty in his life?
Uncertainty led to ‘chaotic’ emotions	so it was like embracing emotions rather than like now I have the skills I need to be able to sit there and accept how I feel and then rationalise why I’m feeling like that so yes it just turned my life into chaos like I went from being and this is the start of what made me think I had something with mental health you know that I always thought as a kid and yes I just went from being like a normal lad to just being chaotic	Uncertainty of the situation led to a need to embrace chaotic emotions for the first time Chaos/Chaotic – Seen as bad? Words used to symbolise the difficulty of the situation and his emotions which led me to wonder if he’s had anyone to sooth his feelings before. Is this the consequence of uncertainty? Is this connected to his fear of his emotions and sense of paranoia?
Changes, uncertainty led to a change in persona	just I was just always angry all the time and things I liked changed over night things I didn’t like changed over night and	Changes happened too quickly, changes he didn’t like

	like my reactions to things in general changed over night I went from being really good at school to getting kicked out of two different schools getting suspended 12 times like just fighting being arrested while I was at high school and stuff and it never really changed throughout there and obviously it was dealing with other things I mean a lot obviously a lot of people have had to go through that and there's people that are in worse situations than what I was	Change in who he was Became angry all the time Uncertainty of the situation leading to lack of safety, fear? Change in self, Getting into fights, arrested at high school *There's people that are in worse situations than I was* – Could this be a way of minimising his situation?
Difficulties with emotions leading to BPD Importance on BPD, a sense of solace	but yes I didn't how to deal with my emotions and I personally think that's why I had BPD the way	Difficulties in dealing with emotions leading to BPD Is his diagnosis of BPD his go to explanation of why he is the way he is? He almost speaks of it with a sense of solace? Is his BPD a way to explain his unusual experiences?
	cos they do says it's down to like child trauma and abuse isn't it so I think it's something along them lines personally	Trauma and abuse leads to BPD Who is 'they'?
	Interviewer: I'm sorry that happened to you Paul: that's absolutely fine thank you Interviewer: And you went through all of that in your early teen years and then suddenly you started feeling a bit more paranoid after that?	
A sense of isolation	Paul: well I went on to I went when I lived with my dad my dad is very chilled out he's the kind of dad that he gives you space to do what you want to do like we're more friends than we are father and son and I don't think that helped my mental health	'He gives you space' – ignoring/avoiding the situation? 'More friends than we are father and son' – no one to turn to?

		No one to talk to at the time – a sense of isolation?
A need to avoid the situation	cos I mean no one knew I had mental health even I didn’t know but I used to react to things and lose my temper and stuff and	No one knew he had mental health difficulties ‘Even I didn’t know’ – a need to avoid the issue? Temper and stuff – a sense of frustration at the situation?
A cry for help	everyone just thought I was a bit like problematic but really I think looking back it was my way of trying to get the attention I needed	‘Attention’ – a need to be heard by others? A cry for help?
Aggression, violence and anger	but obviously when you’re at that age like you don’t think do you and I started building my own impulses to like react to certain things and I started getting about the age of 15 16 I started getting like really aggressive very violent I didn’t really have any other emotion other than violence or anger to be honest	Didn’t know how to react to what was going on inside him. Uncertainty towards the situation? Situation unsafe? Lack of others helping him to process his emotions? Led to further aggression, anger and violence
	Interviewer: what you mean by violence and anger and…?	
Life ruled by anger	Paul: It just ruled my life I was angry 24/7. I’d wake up angry go to school and misbehave and fight and that would be the same after school as well it was it was my only way	‘Ruled my life’ to mean the lack of control of what he felt at the time?
Anger as a way of coping	I felt like I was dealing with something was by letting out the anger if you know what I mean	Anger as a way of coping through his experiences. The repeated use of ‘if you know what I mean’ as an invitation for validation or as a way of transferring the onus of meaning-making onto

		me. Is this another way of hinting at an avoidance to reflect on his experiences?
	Interviewer: yes with your paranoia is there one significant event that you remember that happened where the paranoia or paranoia thoughts just happened?	
	Paul: there's been a few events I can remember living with my dad right my dad he's not like he's a great guy but he's not he's not an angel if you know what I mean	It's interesting here that rather than answering the question, he goes on to elaborate about other things that's happened in his past. Could he be avoiding talking about his experiences? Contradictory language - Dad not an angel, a great guy? Again repetition of the term if you know what I mean
Tumultuous childhood	and where I used to live as well he used to always be getting into fights and getting arrested and stuff like that and I think watching it from a young age you don't see the damage it does to yourself until you get there	Tumultuous childhood. Dad always gets into fights. Damage is such a strong word, does he see himself as damaged?

Appendix T: Master table of themes for the group

Theme 1: Description of experiences
Hearing and seeing things that others do not Thomas: ‘it's weird like, I was sitting up on myself and it feels like sometimes I'm sitting in a room. And not now, not I am for ages but I'm sitting in a room and I think that there's group of other people next door and I can hear em.’ Paul: ‘I used to finished work and I’d sit at home and then I’d sit in silence I’d have all my lights off and no noise on at all like I’d unplug refrigerators and stuff like that just so it would be dead silent and I could like I could hear people outside my house talking and if I opened the door and went outside there would be no one there’/ ‘I think it was about half eleven one night and I wasn’t even asleep but I was half way there and this might sound weird right but I can close my eyes and I can visualise what I was thinking in my own head and I could do a picture of it in my own head so it was like sitting in front of a TV screen like I could remember I was thinking of a place and like a chair and seating and I could see it in my brain like I could see it in my head which sounds completely weird and I wasn’t under the influence of any drugs or anything’ Richard: ‘So I’ll hear voices usually my own voice or I’ll hear random noises like I’ll hear a ticking or something like a clock or for example I can hear the walls breathing… and then that will sort of heighten up and quite derogatory things like affect me like you’re worthless you should go and kill yourself um yes quite a lot of personal attacks and stuff’ Alex: ‘Well, it's a bit-it's it's odd. I can be really really really stressed out and they'd [voices] be like 'You alright?' I-I'd be like 'No I'm not' and then they'd be like "Breathe, calm down" like they'd be like walking me through it like if I'm having a panic attack. So like on one hand I could be having a panic attack, and they'd be like "Haha you deserve this" like making it worse but like occasionally like it's not often but it's quite nice when it happens.’ Susan: ‘About three or four years ago…I just tried to ligature and I was in hospital and I started thinking that people were putting them thoughts in my head…to kill myself’/ ‘I saw like little they weren’t little bit they were like black people like figures…that’s when I first started hearing voices as well’ Mary: ‘it’s quite distressing as in I know they’re not real but they’re so there but it seems like they’re real and they almost get on my nerves and if I don’t do what they’re saying I find that they don’t go away…to kill myself or telling me that I’m useless’

Laura: 'Um when I was 16, I had friends staying over in mum's house with me and um we stayed up till four in the morning in the living room and then he fell asleep and then I can't remember how it got to it but I remember waking him up and being like I feel like there's something in the room and he was like he went and got my mom as well and I was just really like inconsolable and I don't really know where that came from but my mum's always said that I was so adamant that there was a um black figure in the corner but I don't remember seeing it I don't remember uh I don't really remember which is strange my memory's really bad'.

A sense of paranoia

Thomas: 'Yeah, I mean it's just like that's your bit of body language, do you know what I mean? When you're thinking stuff, some people might decide your body language what you can pick up on their thoughts. Even though you saying nothing, you can just look at their body language and you can tell they're about to do something or - do you know what I mean? Or they just angry or, I don't read people quite well.'

Paul: '…A lot of it comes from like violence so I'm worried about like someone committing an act towards me or bumping into someone that I don't get on with and being in a situation like a volatile situation and stuff like that so um like I went through a stage before I come here and started getting therapy and that I went through a stage of like carrying round knives to make myself feel safer without any intention of using it obviously but it was just something I used to make myself feel safer like a step I put in place to do'

Richard: 'I was sharing a room with my brother at the time so I was laying in bed and I could hear it and I just started screaming and my mum came rushing into the room and I could hear it and I could see her face start to like change and like I was screaming at her to go away cos I thought she was trying to kill me and stuff'

Alex: 'But I was like sitting in bed and like she was like kissing me and like usually it's fine but then I just said like 'Get off' and then she was like 'Why?' I'm like 'Get off' and she was like 'Why?' And I'm like pointing to my head and she was like 'What's up? What are you seeing?' I was like 'I'm imagining you and I'm imagining him and it's not it's not a great thing' Like imagining your girlfriend having sex with someone else especially when that person is a cis male'

Susan: 'like when I have negative thoughts to like hurt and stuff I feel like someone or something has put them in my head and they're not mine…just I feel like people are just putting things in my mind and stuff'

Mary: 'well like for example I think people are judging me when they're not or I feel like from peoples expressions that I can I judge what I think they're thinking at the time'

Laura: 'I wanna go out later how am i gonna be asked to tell him or whatever like and like cause my brain's always thinking i find that i'm always thinking thinking thinking i remember the amount of times i'd sit down and please don't keep thinking cause you know you feel like your thoughts are loud but that yeah just i did worry i yeah'

Feelings of numbness and being out of touch with reality.

Paul: '…um I also used to have something as well before I got diagnosed called it was like dissociative amnesia where I used to experience blackouts a lot like as I was about to kick off and the medic and I spoke about this and he said it's like a reaction my body has created that when it goes into like a when I go into what we used to call it like an episode but when I used to go towards that way my body would just shut down' Richard: 'Basically I change into a different person almost um one of which is called Sam um quite aggressive and derogative towards me and it usually leads with me hurting myself and running off somewhere so I usually get lost quite easily yes'/'um it's usually so much of like what the voices say like he's like he's worthless doesn't need to be in this life like everyone around him is out to get him he needs to end it.' Alex: 'I get distracted quite easily I guess? But like sometimes I just won't feel like myself. And it stays like that a lot-like I isolate myself. Cause I'm like...and I feel like a nuisance. I'm just like... No, like I could be with somebody talking like - they'll be talking at me like, to me like, in front of me, and then I'll like snap back into it and I'll be like 'What?' and they'll be like 'Alex I've been talking to you for 30 minutes' I'm like I didn't get a word of it and it had gone by in like 3 seconds like I kinda zone out a bit. Like it's not all the time but like when I'm like when there's a lot on my mind I think. So when I'm like more stressed or whatever, it happens more often'. Susan: 'well I started talking about it after because it's like I couldn't I knew what happened that like I felt I wasn't there and like everything was a dream and I spoke to my mum and we told my case worker and we just spoke about it for a bit and stuff but it only seems to happened when I was quite stressed' Mary: '…because it [voices] was distressing me too much that I'd go into shutdown mode almost and just focus on the voices and shut down from what's happening in reality' Laura: 'um like uh pretty hard to explain i guess it's like you can't pinpoint it's just nothing you just feel like inadequate as well…i used to spend a lot of time in bed like i used to get like that i used to just sleep and try to make myself as like as insignificant as possible cause that's how i felt and just like a weight comes down'
Theme 2. Making sense of the experiences
The enduring presence of the experiences. Thomas: 'When I got older, I started feeling in the end, it's like bad, but it happen all the time, it's spontaneous; happened all the time.' Paul: 'What was overwhelming was like where they come from like how come I can hear this conversation and no one else can and then like opening the door and there not actually being anyone there and then I've been to bed a couple of times from sitting up and having a joint and you sort of take the voices with you so like you get in bed and they'd sort of be there' Richard: "Um well I usually remember about ten or twenty minutes of it like give or take but I can be down for I can be down for like hours at a time."

Alex: So the worst times I've ever have like ever have images is imagining either people who I am with with other people…Because it's not fun, it's not great and then or like people I care about being hurt by other people...images like that they distress me. Because I could be fine and then I'll like I will see it and I would just be like 'No' and like I don't know how I get rid of it…I manage it eventually but images they last for a while.

Susan: 'They'd stop of a little bit but there's always like come back'

Mary: 'The fact they were there they didn't go away they um were just constant'

Laura: 'um well yeah when I was with my son's dad i sort of come to terms with a lot of it was trying to you know I was just paranoid of him and still to this day like I work in Yarmouth and i'm still paranoid I'm always looking for him somewhere and before that I just I don't know I just a bit of a wrecking ball'

The role of trauma and stressful life experiences

Thomas: 'Yeah, reading their body language; reading their thoughts obviously of course I'd been through quite a lot of traumatic event. I have to, I have to do that for my own precaution to read someone's body language and know what they're about. Like, you know what I mean? I don't like people standing behind me. And that after having traumatic events, I've been stabbed twice. Once my neck, once my back. I got attacked not that long ago, an ashtray to my arm. I got hammers and screwdrivers stabbed in my legs.

Paul: 'My parents split up when I was about 13 and I've just never been the same since really it was weird yes I used to be like such an innocent like just head down kind of guy you know and I can remember my parents split up and it wasn't like the trauma itself like I still see both parents like both my parents get on now I mean obviously we're seven years down the line but it was how it went about like I moved with my dad and like my sister moved with my mum and it was I was too young to understand how I was feeling so it was like embracing emotions rather than like now I have the skills I need to be able to sit there and accept how I feel and then rationalise why I'm feeling like that so yes it just turned my life into chaos like I went from being and this is the start of what made me think I had something with mental health you know that I always thought as a kid and yes I just went from being like a normal lad to just being chaotic'

Richard: '…um well basically I'd been bullied throughout all of my school life and I went home to my dad or my mum who were constantly arguing and sort of escalated physically I guess and I was getting stuff thrown at me I was getting like beaten with a belt hit um I was locked up in a room the bathroom for hours and hours on end I was getting ice cold water poured on me like if I slept in for too long or getting hit if I slept in for too long or pulled out of bed uh glasses smashed in my face…'/ 'It's usually stress related…it could be like I can't get to sleep and it starts stressing me out or it could be an argument or someone starts getting aggressive towards me or if I think like something physical is going to escalate it tends to ramp up very quickly'

Alex: ‘I don't think my experiences are the cause of them. Like distress and stuff I think maybe but like not the experiences. Like if someone says 'Oh they're cheating on you' I'll be like 'Oh no they're not' like it's a joke. But then my head will go through all of the scenario and then I'll start seeing things. Like I would physically see that person with like someone else who they'd said they're cheating with and I will see it replay over and over and over and over again in my head with them like doing stuff that I'm just like 'It's not great'. So like the experiences itself can impact what it is but like I don't think it caused them.’

Susan: ‘I’d been bullied I’d been assaulted and I was feeling quite low about myself and stuff so I think that’s what like started it’

Mary: ‘It started when I was at a really low point in life and I was quite suicidal and the voices told me to go and jump off a bridge so I tried…it might have been a bit more than six months but um my boyfriend split up with me cos my brother was in prison and I didn’t take it too well’ ‘um I can be really emotionally low or something has happened that’s really upset me so I’m quite vulnerable as in like it’s hard to explain it um…… it’s like anything will get to me at that point in time so therefore I’m more susceptible to getting the voices and feeling distressed and I'm in a really low place’

Laura: ’…well i kind of boil it all down to my childhood um i got adopted at six and before that a lot of bad things happened um which growing up i never really cared about but like i started thinking about it again i was like fourteen or fifteen cause i went and searched for my birth mother and all that and yeah so found out a lot of stuff then and as the years went by just felt worse and worse about it think’/ ‘um through difficult times so more than likely it'll come about but then sometimes it does come up when i'm doing well like for example when i lost my job at the start of the year i was doing so well I've been like a year and a half full time longest job i'd ever had and then i started getting really panicky and i didn't like working nights and they kept putting me on nights and i don't know i couldn't control it even when things were going well within two weeks i'd deteriorate so bad i just i can't come in and then even when they sacked me they sack me to my face and i was just crying and crying in batches i was like look i don't even care i can't even control this so yeah’

Self-stigma: ‘Experiences mean I am crazy’.

Thomas: ‘I'm not fucking schizo. It don't tell me what to do. I'd kill myself if I did. I would - fuck - If I heard voices telling me to hurt people and tell me to make sacrifices and shit like that. That means, it's time for me leave this earth. I won't do it. That's messed up.’

Paul: ‘It makes you feel abnormal it makes you feel like like the stigma around mental health has always been crap you know like people have always perceived people with mental health as like nutters or you know whatever their words are now you don’t with the media of today as well you don’t mean to but you take on these opinions you know you know you shouldn’t but you take on the opinions of what the democracy have so it’s like you find out you’re hearing voices yourself and it’s like you’re convincing yourself you’re nuts like I’m crazy’

Richard: ‘I feel like they’re dangerous quite a lot of the time to be honest like when I’m sort of getting to the latter end like I know for a fact usually something bad is going to happen’

Alex: ‘And then um like my girlfriend, we had a bit of an argument. And we hadn't been great but we had a bit of an argument and then she like left and then she like broke up with me over the phone. And then I sat on like my friend's bed just like crying and then like rocking back and forth and I was like 'Ow, oh crap'. And then I was like 'My head better not get to the place where it has been'...when she broke up with me I did go a bit off the rail’/‘I mean I-I don't I can't recall having voices before year 8. I think they were there but I can't actually like physically recall it because I kinda just like push it to the back of my mind.’

Susan: ‘I felt like it was normal for me but I felt like I was still crazy if that makes sense I don’t really know if that makes sense’/‘I would try to ignore them as much as I could’

Mary: ‘It wasn’t distressing but it was like it was just normal to experience it but time’s gone on it’s more I know it’s more abnormal…because they’re still saying the same sort of things and if it was normal then that wouldn’t be happening on a regular basis I think I’ve just understood more that it’s not real’

Laura: ‘I did talk to the doctor about it then because my mom took me to the doctor and he said something about how when he get a bit stressed tired or upset um like you can just see things out of the corner of your eye and i was like okay so i just brushed it off um but my mom never let that lie (laughs) she was like schizophrenia so yeah i don't know i'm i wouldn't say i got schizophrenia but yeah i've always been really scared i've always felt like this fine line between how i am and then like how like i could go if that makes sense like i always worry that i could get ill or crazy or but yeah like my worst fears is getting sanctioned like it's just scary.’/’Um apart from my counsellors not really no no my partner just said to me it's like your brain goes off in one is what he says he's like you're just going off in one like focus back on the point about of what we're talking about so i think he's aware that i'm very my thoughts are everywhere but I don't see the need in sitting down and talking about it but maybe like my fellow peers in psychology.’

Theme 3: Deterioration of sense of self and well-being

A change in sense of self.

Paul: ‘I used to I used to be just like a normal person like I just wanted to get on with my life I had ambitions and goals I’d set myself that I wanted to achieve’

Richard: ‘yes confidence wise yes…to a massive degree like I felt quite unsafe to be around other people cos I didn’t want to be a burden on them and it kind of shot my confidence especially with like the body weight stuff like the voice and the stuff that really did affect it and I just left a bit like a bit worthless to be honest like not being in control of my own life…um I’ve never been happy quite a lot…I mean I did have depression at the time at the time that it started but I would say I was more considerably happy back then and had a lot more motivation that what I did like prior to that’

Alex: ‘I want to be a cis male but I'm like very clearly not so stuff like that is a bit upsetting. Like knowing that I'm not. And I was like I was thinking...and like the other day we were on facetime and um I was just sitting there and then she was like 'Are you alright?' and I was like 'Yea, yea I'm good I'm good' and then it just like happened and I started imagining it again. And like if I closed my eyes it was there and if I opened my eyes it was there.’

Susan: ‘that’s the thing like I don’t know who like she’s the complete opposite of me really…she was always going out she had lots of friends she was confident and I just feel like that isn’t me now it’s weird to think about it’/ ‘I think I definitely don’t obviously like it and it’s scary and stuff but I think it’s helped me in a way to help other people…I just think in general if I see anybody struggling I’ll just straight away message them and just try and do whatever I can to help them’

Mary: ‘I haven’t got my confidence any more I have lost sort of my passions and my goals have become further apart…I was confident um and life was going well and things were really positive and now it’s almost the opposite things aren’t going so well things are more negative’

Laura: ‘I get really angry at myself and I get like like I feel weak um try to get motivation after to push away from it but yeah at the time oh my god I'm so stupid it's really annoying because it's like I'm aware of what's going on but i can't control it so yeah it does it changes how I see myself because I get really angry’

Deterioration of control

Thomas: ‘Well it's in my head, innit? What can I do? Well, I can't really carve my - carve my brain out, do you know what I mean? To stop it. You know what I mean? So, can't control it.’

Paul: ‘I could control it but like I said I’ve had moments before where I’ve felt like something has took over which sounds weird doesn’t it but I’ve had a few moments where something took over and it feels like I’m being controlled but I feel like someone else is inside me dictating movements and stuff’

Richard: ‘um it usually always tend to eventually I mean like I’ve tried to ground some techniques and mindfulness and stuff but usually when it starts when it hits like the start of the visuals like it’s too far gone for me usually’

Alex: ‘But like the other night, I was like pulling at my hair and I was like hitting my head to make like-sometimes I physically punch myself in the head just to make it stop. And like I'd bang my head on walls and people will be like "Alex stop" and I'm like 'No because this is not stopping'. And I look like a mad man but I physically cannot get it to stop any other way than just hitting myself in the head.’

Susan: ‘it’s just like it’s like they tell me to like get a brick and smash it against my head or hang myself or overdose stab myself and they’d go over and over and over until I do something’

Mary: I tried to tell the voices to go away and they tend to get stronger and more makes me more distressed than what I already am…yes more intense…occasionally I can get on top of them by telling them to go away and then sometimes they do just go away, at other times they get more intense when I try and tell them to go away

Laura: ‘If I keep myself busy like busy busy brush off my feet and don't get time to think but then as soon as I get home and sit down it'll come over me seeing as I have five minutes to relax which is you know I feel like huh can't control it and when I get upset and if I start crying I don't know how long it's gonna be until I stop cause i'll be so like overwhelmed yeah’

Fear, despair and isolation.

Thomas: ‘No, I ain't really got friends now. They all disappeared. But when I did have some good friends, they were all intimidated by me, yeah. They were, yeah. Definitely. Cause they know what sort of person they seeing; they hang around me, they knew what I was like.’

Paul: ‘I knew I had something wrong with me but when you don’t know what it is there could be so many possibilities like it’s just something you keep to yourself and hope that you can overcome but it was one of them things’

Richard: ‘I got a bit more used to it but still it’s distressing like it affects my emotions like incredibly like I start crying and like just become like flustered with everything it just becomes overwhelming like in the later parts of it’

Alex: ‘At the beginning, like a 100% like no doubt about it, it affected me like badly. But now I'm just like 'Yea I know, yup yup alright alright I get it shut up' Like...So it's not as bad as it used to be because I-as I said I like fake confidence. So now I can just kinda shrug it off and be like 'You're wrong because a few years ago, you might have been right because I didn't really have any friends but now I have all these friends and like that' So you're wrong. But like sometimes I'm like I can't see you today and they're like 'Why not?' 'Because I really don't feel great so I'll see you tomorrow'. And they're like 'Alright' They understand. ’

Susan: ‘It could be like seeing like people or hearing things and then I’ll start to get really panicky and then yes’

Mary: ‘I tend to disengage with society and go off on my own when they happen’

Laura: ‘Cause my brain's always thinking i find that i'm always thinking thinking thinking i remember the amount of times i'd sit down and please don't keep thinking cause you know you feel like your thoughts are loud but that yeah just i did worry i yeah’

Theme 4: Managing and finding respite

Seeking relief from the experiences.

Thomas: ‘that's why I smoke cannabis to try and like, do you know what i mean? self-medicate. in a way, self-medicate and like uh i seeing go two ways. i've smoke cannabis since i'm twenty-three now, i started when i was thirteen. that's ten years. that's enough time to have a kid and watch it grow up in school do you know what i mean - that's quite a long time. but it just seems... I don't know. probably. i don't really get the same effects of it like i used to. my mood system, my tolerance is obviously gone up.'

Paul: 'Cannabis for me had a really good effect on me cos it used to do what prescription tablets couldn't and just calm you down it used to take my temper away take my paranoia away it used to just chill me out but I'm not stupid I wouldn't sit here and condone using it'

Richard: 'Um it usually always tend to eventually I mean like I've tried to ground some techniques and mindfulness and stuff but usually when it starts when it hits like the start of the visuals like it's too far gone for me usually'/'yes I'd usually like self inflict pain or something they'd usually help me snap out of that sort of frame of mind'

Alex: 'It depends how bad it is. Sometimes it's there and I can see it but it's like faded and like I could put it off and I'd play a game and it'd be gone. But like the other night, I was like pulling at my hair and I was like hitting my head to make like-sometimes I physically punch myself in the head just to make it stop. And like I'd bang my head on walls and people will be like "Alex stop" and I'm like 'No because this is not stopping'. And I look like a mad man but I physically cannot get it to stop any other way than just hitting myself in the head. And-or I'll just like sit there and I hope it'll leave so it depends how severe it is. So I could go from just being like distracting myself or listening to music those two are like things that are common that that ones are alright. But listening to music is my go to when I'm proper freaked out. To like literally hitting-like I might cut myself because of my visions. Because it's all in my head so my solutions is to like just like hit my head on things rather than like cutting myself. Which I guess it is self-harm but it's not like scaring. But I did concussed myself the other day to like I hit my head on the wall.'

Susan: 'It would always like depend on what was going on but normally about half an hour or so and then I'd take some medicine and I'd just like try and I can't remember what it's called where I just think about where I am and like stuff like ground myself'

Mary: 'no they just I just take my clonazepam when they happen to try and relax me cos I get quite stressed up when the voices are there (I: ok and does the medication help at all?) yes it just helps to try and relax my muscles…they're (voices) still there but because I feel more relaxed I can cope with them a bit better

Laura: 'I used to just drink and take drugs I used to take whatever was there more so like cocaine and ecstasy things like that I could find as well'

Having supportive relationships is important.

Thomas: 'Yeah. Having a relationship, you know what i mean? Sounds corny innit, sounds fucking gay, yeah i need to be fair - i'm in a relatrionship. When you was by yourself, and you got no partner or anything, do you know what i mean - it's a bit depressing. To make your - you know what i mean? I ain't got a girlfriend or anything. I hadn't for awhile, so, do you know what i mean? makes you a bit lonely, but that's why - you know what i mean? i compensate. and i have four dogs, they're like my babies. (I: Okay, alright) do you know what i mean?

Paul: ‘not just the people as well the place itself it’s like a safe haven as soon as I walk on site I feel safe I feel like I’m surrounded by people that know how to deal with me if you know what I mean I know I can come here in a bad state in a good state and people they just know how to deal with me you know I’m surrounded by people who’s job is to look after people like me so that’s why it’s like when I spoke to you I always like coming to here for an appointment rather than at home cos I come to a place in which I feel comfortable I have no paranoia or anxiety and that for me is really important but all the staff I’ve dealt with here over my time in the year and a half have all been amazing and I think that’s what I appreciate I appreciate how they they get to know you and work around what’s best for you like they know I’m like when I first come in I didn’t really like getting told something I didn’t like hearing and they worked around that you know and I sit here now and after like 11 weeks of therapy classes and stuff like that like they’ve changed so much like I’m so much more calmer now and and I have that rational response where I can react to stuff now after I’ve accepted how I feel and realise why I feel certain ways and whereas beforehand I never really had that it was always just like I feel this emotion I need to react to it. whereas now I’m starting to getting insight into my illness’

Richard: ‘…if someone is there I’ll tend to seek reassurance but I’m a bit weird about strangers touching me but I’ve been in a lot of relationships where people have been quite understanding about it. I tend to seek reassurance from them…usually I’ll just I’ll just end up like breaking down and just like running up to them and like just holding onto them I guess’

Alex: ‘Luckily I have like support of people and like I've said to my friend I was like 'If I'm really bad to the point where you could tell I'm bad and I ask you to go out and do anything, make sure I don't.' So I have the support of friends, stuff like that.’

Mary: ‘One of my friends knows…they were fine about it they were just like it’s just one of those things and tried to reassure me by explaining that they’re [voices] not real that they’ll go away they’re not there forever.

Susan: ‘My mum or dad…they’ve stuck by me a lot and I think the biggest thing is that they’ve just done everything they could to try and understand like they’ve researched everything and stuff like that cause I know a lot of people that their parents don’t really accept it and stuff.

Laura: Recently everyone's been quite supportive so I've been so open um in the past I'd always get called a mess you know sort out people used to assume that i was a bit of a slob um things like that they'd assume bad things of me…and it wasn't until I met my current partner that I've managed to understand like what like emotional niceness is.’

Acceptance in overcoming experiences.

Thomas: ‘I don't know, really. I just think that's a part of life. What part of it, I got to go through? Do you know what I mean? To come where I am now. Do you know what I mean? I don't know many twenty-three year olds that got four dogs, just got, do you know what I mean, a flat, just got - do you know what I mean? You move, move from one bedroom flat to a three-bedroom house. Three-bedroom house, do you know what I mean? I got it. Do you know what I mean? It's in the motion. I'm moving into a three-bedroom house. Got a driveway. Got a garage. Got my four dogs so I can have kennels. Don't really know many twenty-three so I feel quite positive, to be fair.’

Paul: ‘It’s like you find out you’re hearing voices yourself and it’s like you’re convincing yourself you’re nuts like I’m crazy why am I hearing voices when it took them a couple of months to convince me like it’s quite a common thing actually and a lot of people experience it and once you get your head round that I think the acceptance is the biggest thing once you accept it then you can focus on actually dealing with it’

Richard: ‘I just see it as part of me and part of my personality I‘ve had to learn to deal with it although it’s something that’s prevalent I mean you’ve got to learn to deal with these things I guess if not it will destroy you’

Susan: ‘I think now I have accepted more and I realise that there are other people that it is it’s not normal but it’s not like I’m not crazy although I do feel like that I’m struggling a lot logically I can think that I’m not and I think that’s helped’

Laura: ‘I see my doctor a lot at the time trying to get into a counselling or something um i just spoke with her and mainly and my partner i went into wellbeing groups as well and society groups and i don't really talk out with them but it was nice to understand that it's not just me making all these things appear in my head like it is a thing where they come back and you know i think um i'm quite interested in like psychology anyway so i think that's what's always helped me but i do my reading and be like this is normal like yeah (laughs) so that's how i cope especially now like studying and going back to college has really helped me so.’

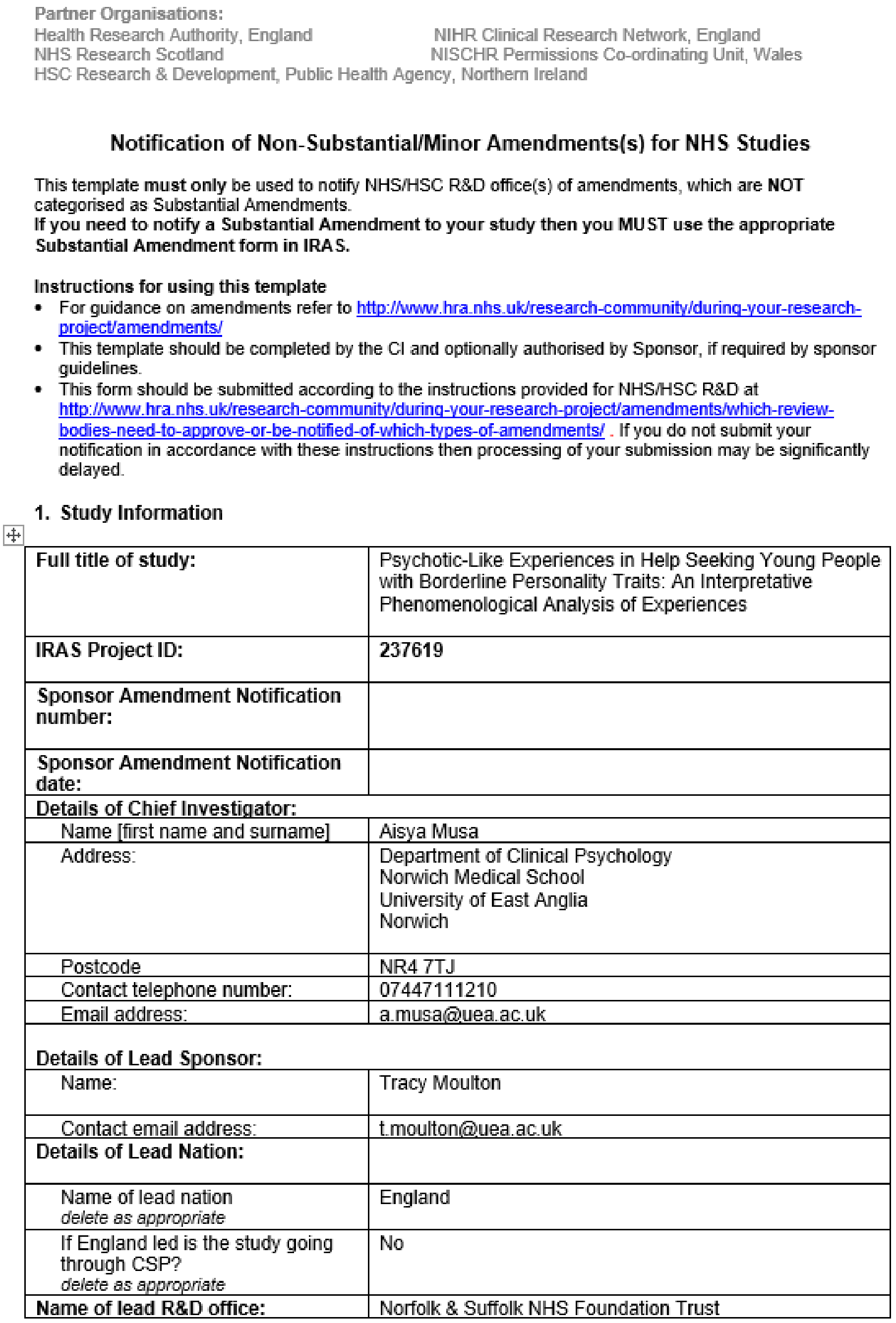
Appendix U: Occurrence of Themes across Participants

	Descriptions of experiences			Making sense of the experiences			Deterioration of senses of self and well-being			Managing and Finding Respite		
Participants	Hearing and seeing things	A sense of paranoia	Feelings of numbness and	The enduring presence of	The role of trauma and stressful life	Self-stigma: ‘Experiences mean I am crazy’	A change in	Deterioration of control	Fear, despair and	Seeking relief from the	Having supportive relationship	Acceptance in overcoming

	that others don’t		being out of touch with reality	experiences	experiences		sense of self		isolation	experiences	s is important	experiences
Thomas	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓
Paul	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Richard	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Alex	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Susan	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Mary	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Laura	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Appendix V: Non-Substantial Amendments for Supervisory Change (in Progress)

As I had a recent supervisor change (January 31st, 2019), I am in the midst of requesting for non-substantial amendments. As of the time of writing, the non-substantial amendments form is currently being reviewed by the Research Sponsor (see e-mail exchange below)



Partner Organisations:
Health Research Authority, England
NIHR Clinical Research Network, England
NHS Research Scotland
NISCHR Permissions Co-ordinating Unit, Wales
HSC Research & Development, Public Health Agency, Northern Ireland

Notification of Non-Substantial/Minor Amendments(s) for NHS Studies

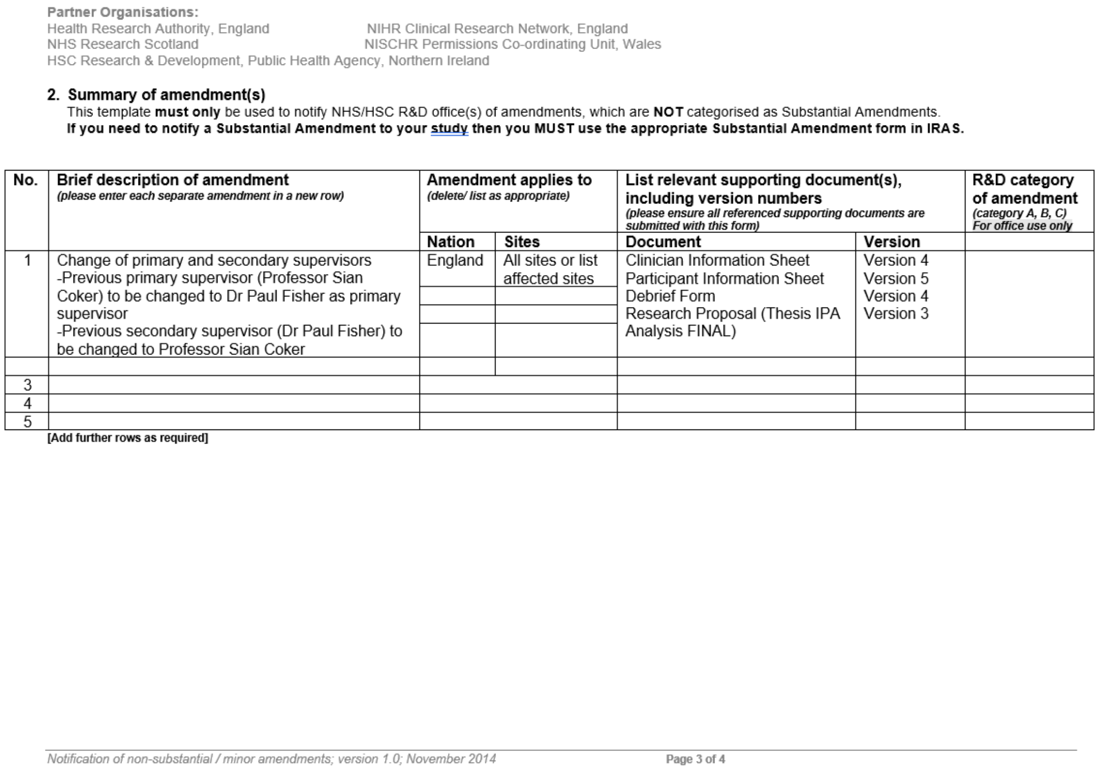
This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.
If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

Instructions for using this template

- For guidance on amendments refer to http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/
- This template should be completed by the CI and optionally authorised by Sponsor, if required by sponsor guidelines.
- This form should be submitted according to the instructions provided for NHS/HSC R&D at http://www.hra.nhs.uk/research-community/during-your-research-project/amendments/which-review-bodies-need-to-approve-or-be-notified-of-which-types-of-amendments/ . If you do not submit your notification in accordance with these instructions then processing of your submission may be significantly delayed.

1. Study Information

Full title of study:	Psychotic-Like Experiences in Help Seeking Young People with Borderline Personality Traits: An Interpretative Phenomenological Analysis of Experiences
IRAS Project ID:	**237619**
Sponsor Amendment Notification number:	
Sponsor Amendment Notification date:	
Details of Chief Investigator:	
Name [first name and surname]	Aisya Musa
Address:	Department of Clinical Psychology Norwich Medical School University of East Anglia Norwich
Postcode	NR4 7TJ
Contact telephone number:	07447111210
Email address:	a.musa@uea.ac.uk
Details of Lead Sponsor:	
Name:	Tracy Moulton
Contact email address:	t.moulton@uea.ac.uk
Details of Lead Nation:	
Name of lead nation *delete as appropriate*	England
If England led is the study going through CSP? *delete as appropriate*	No
Name of lead R&D office:	Norfolk & Suffolk NHS Foundation Trust



Partner Organisations:
Health Research Authority, England NIHR Clinical Research Network, England
NHS Research Scotland NISCHR Permissions Co-ordinating Unit, Wales
HSC Research & Development, Public Health Agency, Northern Ireland

2. Summary of amendment(s)

This template **must only** be used to notify NHS/HSC R&D office(s) of amendments, which are **NOT** categorised as Substantial Amendments.
If you need to notify a Substantial Amendment to your study then you MUST use the appropriate Substantial Amendment form in IRAS.

No.	**Brief description of amendment** *(please enter each separate amendment in a new row)*	**Amendment applies to** *(delete/ list as appropriate)*		**List relevant supporting document(s), including version numbers** *(please ensure all referenced supporting documents are submitted with this form)*		**R&D category of amendment** *(category A, B, C)* *For office use only*
		Nation	**Sites**	**Document**	**Version**	
1	Change of primary and secondary supervisors -Previous primary supervisor (Professor Sian Coker) to be changed to Dr Paul Fisher as primary supervisor -Previous secondary supervisor (Dr Paul Fisher) to be changed to Professor Sian Coker	England	All sites or list affected sites	Clinician Information Sheet Participant Information Sheet Debrief Form Research Proposal (Thesis IPA Analysis FINAL)	Version 4 Version 5 Version 4 Version 3	
3						
4						
5						

[Add further rows as required]

Notification of non-substantial / minor amendments; version 1.0; November 2014 **Page 3 of 4**

3. Declaration(s)

Declaration by Chief Investigator

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
- I consider that it would be reasonable for the proposed amendment(s) to be implemented.

Signature of Chief Investigator:

Print name: Aisya Musa

Date: 16.01.2019

Optional Declaration by the Sponsor's Representative (as per Sponsor Guidelines)

The sponsor of an approved study is responsible for all amendments made during its conduct.

The person authorising the declaration should be authorised to do so. There is no requirement for a particular level of seniority; the sponsor's rules on delegated authority should be adhered to.

- I confirm the sponsor's support for the amendment(s) in this notification.

Signature of sponsor's representative: ……………………………………

Print name:……………………………………

Post: ……………………………………

Organisation:……………………………………

Date:……………………………………

From: Aisya Musa (MED - Postgraduate Researcher)
Sent: 01 March 2019 09:40
To: Basia Brown (RIN - Staff)
Subject: Re: Regarding non-substantial amendment for study (IRAS no 237619)

Dear Basia,

Attached is the amended amendment form

Best wishes
Aisya

From: Basia Brown (RIN - Staff)
Sent: 27 February 2019 14:40:46
To: Aisya Musa (MED - Postgraduate Researcher)
Subject: RE: Regarding non-substantial amendment for study (IRAS no 237619)

Hi Aisya

Sorry for being a pain. Are you able to update the form as requested in my email:

- “In amendment form could you please indicate names of previous supervisors and who they are being replaced by”

Basia Brown
Project Officer
Research & Innovation Services, Registry, Room 1.14
University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, UK
+44 (0)1603 593713
basia.brown@uea.ac.uk

University of East Anglia

From: Aisya Musa (MED - Postgraduate Researcher) <A.Musa@uea.ac.uk>
Sent: 27 February 2019 13:13
To: Basia Brown (RIN - Staff) <Basia.Brown@uea.ac.uk>
Subject: Re: Regarding non-substantial amendment for study (IRAS no 237619)

Hi there,

Attached is the amendment form. Hope all is in order.

Best wishes
Aisya

From: Basia Brown (RIN - Staff)
Sent: 27 February 2019 12:34:06
To: Aisya Musa (MED - Postgraduate Researcher)
Cc: Tracy Moulton (RIN - Staff)
Subject: RE: Regarding non-substantial amendment for study (IRAS no 237619)

Hi Aisya

No worries at all

Could I also ask for the amendment form?

All the best

Basia

Basia Brown
Project Officer
Research & Innovation Services, Registry, Room 1.14
University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, UK
+44 (0)1603 593713
basia.brown@uea.ac.uk

University of East Anglia

From: Aisya Musa (MED - Postgraduate Researcher) <A.Musa@uea.ac.uk>
Sent: 25 February 2019 10:15
To: Basia Brown (RIN - Staff) <Basia.Brown@uea.ac.uk>

Cc: Tracy Moulton (RIN - Staff) <T.Moulton@uea.ac.uk>
Subject: Re: Regarding non-substantial amendment for study (IRAS no 237619)

Dear Basia,

Apologies for the late response. I hadn't realise that the e-mail extends from your e-mail that the previous message has bounced back (it was hidden in the ...). Attached are all the amended documents as per requested. Hope all is in order.

Many thanks
Aisya

From: Basia Brown (RIN - Staff)
Sent: 14 February 2019 16:45
To: Aisya Musa (MED - Postgraduate Researcher)
Subject: FW: Regarding non-substantial amendment for study (IRAS no 237619)

Apologies original email bounced back.

Please see below.

Basia

Basia Brown
Project Officer
Research & Innovation Services, Registry, Room 1.14
University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, UK
+44 (0)1603 593713
basia.brown@uea.ac.uk

Gold (Teaching Excellence Framework 2017-2020)
UK Top 15 (The Times/Sunday Times 2019 and Complete University Guide 2019)
World Top 200 (Times Higher Education World University Rankings 2019)

From: Basia Brown (RIN - Staff)
Sent: 14 February 2019 16:39
To: 'A.Musa@uea.ac.uk:' <A.Musa@uea.ac.uk:>

Cc: Tracy Moulton (RIN - Staff) <T.Moulton@uea.ac.uk>; Research Sponsor <researchsponsor@uea.ac.uk>
Subject: FW: Regarding non-substantial amendment for study (IRAS no 237619)

Dear Aisya

Thank you very much for your email and apologies for late reply.

There are some minor changes that I would like you implement before we authorise the amendment:

- In amendment form could you please indicate names of previous supervisors and who they are being replaced by
- In attached documents:
    - Could you please use tracked changes to amend names of supervisors and update version and dates of each document
    - Where there is indication of your contact number, could you please provide a your phone number rather than "XXXXX". Please note that the number provided on any research project should be a professional number (e.g. work mobile or landline) rather than your personal number.

When the above changes are completed could you please email updated docs and Amendment form to Tracy (cc-ed) who will be able to sing the form for you.

All the best

Basia

Basia Brown

Project Officer

Research & Innovation Services, Registry, Room 1.14

University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, UK

+44 (0)1603 593713

basia.brown@uea.ac.uk

From: Aisya Musa (MED - Postgraduate Researcher) <A.Musa@uea.ac.uk>
Sent: 30 January 2019 10:39
To: Research Sponsor <researchsponsor@uea.ac.uk>; Tracy Moulton (RIN - Staff) <T.Moulton@uea.ac.uk>
Subject: Re: Regarding non-substantial amendment for study (IRAS no 237619)

Hi there,

A couple of weeks ago I'd sent an email about a non-substantial amendments, I was wondering if my request has already been looked at?

Many thanks
Aisya

From: Aisya Musa (MED - Postgraduate Researcher) <A.Musa@uea.ac.uk>
Sent: 30 January 2019 10:39
To: Research Sponsor <researchsponsor@uea.ac.uk>; Tracy Moulton (RIN - Staff) <T.Moulton@uea.ac.uk>
Subject: Re: Regarding non-substantial amendment for study (IRAS no 237619)

Hi there,

A couple of weeks ago I'd sent an email about a non-substantial amendments, I was wondering if my request has already been looked at?

Many thanks
Aisya

From: Aisya Musa (MED - Postgraduate Researcher)
Sent: 20 January 2019 22:29
To: Research Sponsor; Tracy Moulton (RIN - Staff)
Subject: Regarding non-substantial amendment for study (IRAS no 237619)

Hi there,

Please find attached a notification of a non-substantial amendment relating to the change in my primary and supervisor, as well as independent point of contact.
I have recently had another change of supervisors and was notified that I needed to make a non-substantial amendment again to reflect this change. I have updated the research proposal, clinician information sheet, debrief form and participant information sheet to reflect these changes. Let me know if there's anything else I need to edit/change.

Thank you.

Best wishes,

Aisya Musa
Trainee Clinical Psychologist
University of East Anglia