# An examination of negative symptoms, traumatic life events and attachment style: A mixed methods investigation

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**Isabelle L Butcher**

**The School of Health Sciences**
**Division of Psychology and Mental Health**

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# List of Abbreviations

| | |
|---|---|
| AAI | Adult Attachment Interview |
| CAINS | The Clinical Assessment Interview for Negative Symptoms |
| CAPE | The Community Assessment of Psychic Experiences |
| CBT | Cognitive Behavorial Therapy |
| CDSS | Calgary Depression Scale for Schizophrenia |
| COREQ | Consolidated Criteria for Reporting Qualitative Research |
| CTQ | Childhood Trauma Questionnaire |
| GCP | Good Clinical Practice |
| HRA | Health Research Authority |
| MRC | Medical Research Council |
| NHS | National Health Service |
| NIHR | National Institute for Health Research |
| NIMH | National Institute of Mental Health |
| OPCRIT | Operational Criteria Checklist for Psychotic Illness and Affective Illness |

| | |
|---|---|
| PAM | Psychosis Attachment Measure |
| PANSS | Positive and Negative Syndrome Scale |
| PPI | Patient and Public Involvement |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PSYRATS | Psychotic Symptom Rating Scale |
| RSQ | Relationship Styles Questionnaire |
| SANS | Scale for the Assessment of Negative Symptoms |
| SENS | The Subjective Experience of Negative Symptoms Scale |
| SES | Service Engagement Scale |
| SPSS | Statistical Package for the Social Sciences |
| THQ | Trauma History Questionnaire |
| WHO | World Health Organisation |
| WPA | World Psychiatric Association |

# Abstract

**Background:** The thesis considers the impact of schizophrenia on an individual's quality of life and well-being, which has been highlighted to an extent through existing studies and research. Few studies have examined the potential relationship between traumatic life events, attachment style and negative symptoms. This thesis therefore investigates this relationship through the use of qualitative and quantitative studies.

**Methods:** The thesis is comprised of three separate studies. Each study, despite being a stand-alone paper, led from one to the next sequentially and logically. The first study was a systematic review, which sought to understand the association between traumatic life events and negative symptoms across the individual's life span. The second study was qualitative to examine the nature and experience of negative symptoms in those individuals who were experiencing these and who had a diagnosis of schizophrenia. The final study was a larger quantitative study that investigated the association between traumatic life events, attachment style and negative symptoms, with a larger sample of people from across the United Kingdom.

**Findings:** The systematic review revealed 34 studies that met the inclusion criteria, they investigated and reported on the association between traumatic life events and negative symptoms, these were conducted globally and of these, six revealed a positive significant association between childhood emotional neglect and negative symptoms. The qualitative study, from a sample of twenty individuals with a diagnosis of schizophrenia, revealed that those individuals who in addition experienced negative symptoms were able to articulate their feelings and experiences, as well as state what they believed were the reasons for those negative symptoms. The final study within the PhD was a quantitative study with a sample size of 85 individuals, of whom 71 completed the study through to the six months follow up point. Traumatic life events, attachment style and negative symptoms were assessed using a range of measures, and subsequently negative symptoms were reassessed at six months. There was no significant association discovered between traumatic life events and negative symptoms and there was no evidence for a mediation model between traumatic life events, attachment style and negative symptoms.

**Conclusion:** This PhD, through employing a mixed methods design, enabled a 'gap' in the literature to be explored in greater depth and revealed that there are few studies that research the association between traumatic life events and negative symptoms. This PhD also revealed that individuals who are experiencing negative symptoms do have insight into the reasons for those symptoms and are willing to articulate how they experience the symptoms. The final study revealed no association between trauma, attachment style and negative symptoms. Thus, this PhD highlights the paucity of research in this field.

## Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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## Acknowledgements

Firstly, a huge thanks to my parents, Karimah and David, and my sister Madeleine, for all their love and never ending support and patience over the last four years and for just being there no matter how many hundreds or thousands of miles we are away from one another. For all the care packages and for listening to me throughout the highs and lows!

Professor Gillian Haddock and Professor Katherine Berry - thank you both so much for supervising me and this entire project over the past four years.

There are so many people to thank I am sure I will miss someone out, so a huge thank you to all. To all those colleagues in the NHS Trusts who helped with recruitment, thank you. To all those friends who shared lunch, supper or endless cups of tea and cake with me over the past four years, you know who you are, so thank you.

Lastly, but by no means least, I wish to express my sincere gratitude and thanks to each person that participated in my research studies. Thank you for sharing your stories and lives with me. It has been a huge privilege and one I have immensely enjoyed.

This PhD is dedicated to my grandfather Gerald Arthur Champniss, OBE (1920-2018) who sadly passed away during the PhD but encouraged me throughout my life.


*There is a time for everything,*
*and a season for every activity under the heavens:*
*a time to be born and a time to die,*
*a time to plant and a time to uproot,*
*a time to kill and a time to heal,*
*a time to tear down and a time to build,*
*a time to weep and a time to laugh,*
*a time to mourn and a time to dance, a time to scatter stones and a time to gather them,*
*a time to embrace and a time to refrain from embracing,*
*a time to search and a time to give up,*
*a time to keep and a time to throw away, a time to tear and a time to mend, a time to be silent and a time to speak,*
*a time to love and a time to hate, a time for war and a time for peace.*

***(Ecclesiastes 3 : 1 -8, New International Version)***

## About the Author

I completed my BSc Psychology at Cardiff University, as part of my honours degree, this included a year on placement at the University of Manchester working in the Division of Clinical Psychology. During this placement year, I was awarded funding from the British Psychological Society (BPS), as part of their highly competitive summer undergraduate research assistantship scheme, where I conducted a case note review of violence and aggression within inpatient mental health wards.

In 2014, after undergraduate study, I undertook an MSc in Clinical Psychology at Leiden University in the Netherlands. This consisted of three elements: taught lectures in the Netherlands, an independent thesis on gluten free compliance in coeliac patients, and an assistant psychologist placement in an inpatient rehabilitation and recovery unit in Swansea.

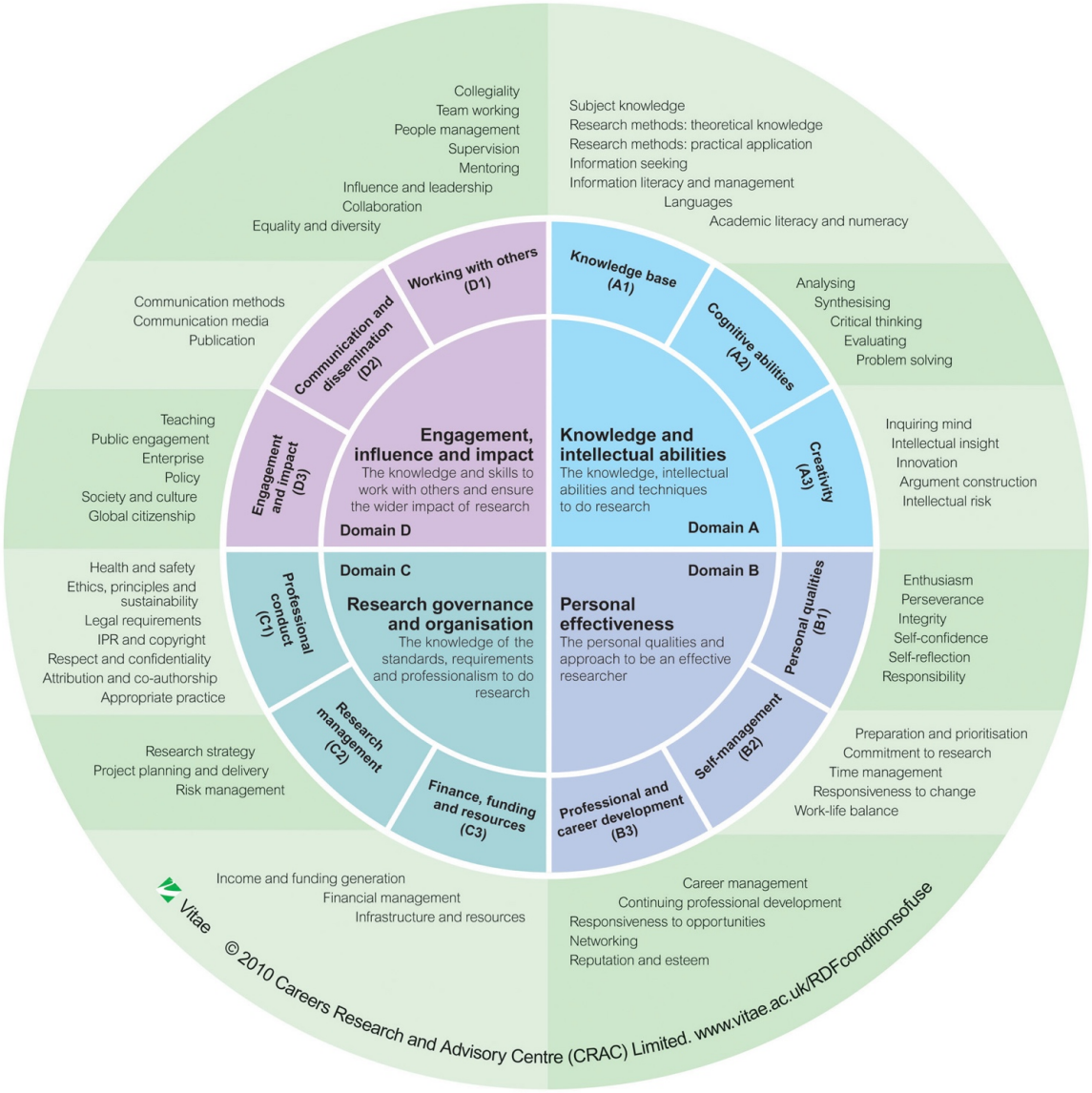
In October 2015, after successful completion of my Masters, I worked at Nottingham Trent University as a Psychology research assistant. In October 2016, I began work at the University of Manchester on a Medical Research Council-funded PhD studentship, which investigated trauma, attachment and psychotic symptoms with a specific emphasis on negative symptoms. I was subsequently awarded funding by the President's Doctoral Scholar Award, which gave me opportunities to present my findings at various events throughout the course of the PhD.

I appreciate that personal experiences, beliefs and views may have affected the aims of the thesis, data collection, interpretation and subsequently the write up. To work towards a bias free PhD, views were sought externally from my supervisors, members of the public who formed part of my Patient and Public Involvement group and also internal assessors at the University of Manchester. Where possible analysis of all data was conducted and supervised to reduce bias.

The attached diagram from Vitae succinctly represents my personal achievements during this PhD. Clearly some areas are stronger than others including those in Domain B while elements of Domain C such as finance and funding are currently limited. The diagram provides self-reflection and a plan for self-development.

During my final year of the PhD, and the current Covid restrictions, I have been offered a post-doctoral research fellowship at Aston University, which will explore the impact of working in a paediatric intensive care unit on staff wellbeing.

These achievements were despite being advised that I would not be able to attend mainstream school, which makes my academic awards more poignant, through overcoming adversity.

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## Rationale for Completing Thesis in Alternative Format

The alternative format for thesis submission was used as it was acknowledged that this was the most efficient way in which to disseminate the results from each study. Additionally, given the paucity of research into traumatic life events and, attachment style and negative symptoms, by writing the thesis in an alternative format this meant that the findings could contribute to the current research field more effectively when written as papers.

Paper 1 has been written for publication in Schizophrenia Bulletin, Paper 2 has been published in British Journal of Clinical Psychology and Paper 3 has been written and formatted for Schizophrenia Bulletin.

Across all studies within this PhD Isabelle Butcher designed, conducted , analysed and wrote up the findings for publications. Professor Gillian Haddock and Professor Katherine Berry supervised Isabelle both clinically and academically throughout the PhD.

## Rationale of the PhD

Schizophrenia is a psychotic disorder that affects 1% of individuals in the worldwide population (McGrath, Saha, Chant, & Welham, 2008). A diagnosis of schizophrenia is often associated with two types of symptoms, referred to as positive and negative symptoms. Positive symptoms are those things that occur in addition to a normal attribute; for example, hearing voices, and seeing things that other people do not. Negative symptoms refer to reductions in normal function and include what has been termed the five 'A's: affective flattening, alogia, anhedonia, asociality, and avolition (Andreasen, 1982). These negative symptoms are disabling, with very little conclusive evidence regarding the best treatment strategies.

The factors that contribute to the development of a diagnosis of schizophrenia have been widely studied. One area that has received much recent interest is the role of adverse life experience. Many individuals, during their lifetime, will experience events that may be deemed traumatic or adverse. These events may be intentional, such as acts that are done with the intention of causing harm to an individual; or non-intentional, for example, accidents or natural disasters. It is well-evidenced that the experience of traumatic life events can impact an individual's mental health, particularly with regard to positive psychotic symptoms (Bailey et al., 2018; Schäfer & Fisher, 2011; Varese et al., 2012). However, the relationship between traumatic life events and negative symptoms is under-researched, compared to the plethora of research showing a positive association between traumatic life events and positive symptoms.

One psychological mechanism that has been proposed to help explain the association between trauma and psychosis is insecure attachment style (Berry, Barrowclough, & Wearden, 2008; Gumley, Taylor, Schwannauer, & MacBeth, 2014). Research has shown that individuals with an insecure attachment style are more likely to display psychotic symptoms than individuals with secure attachment (Berry, Wearden, Barrowclough, & Liversidge, 2006; Carr, Hardy, & Fornells-Ambrojo, 2018). There are different types of insecure attachment, and there is evidence to suggest that individuals with an insecure avoidant attachment style, in particular, may experience and display more severe negative symptoms than individuals with other types of attachment style (Gumley et al., 2014).

This PhD examines the relationship between negative symptoms, trauma and insecure attachment styles in people with psychosis, in three studies. The first study is a systematic

review of the current literature to examine whether there is an association between adverse life events and negative symptoms, and, in particular, if certain types of traumatic event are directly correlated to negative symptoms. The second study examines how individuals subjectively experienced negative symptoms, and their views on the causes of symptoms, these are explored using qualitative methods. The third study uses quantitative methods to examine associations between trauma, attachment style and negative symptoms, in a large sample of individuals with a diagnosis of schizophrenia. This study measures experience of traumatic life events that were both deliberate (intentional) and non-deliberate (non-intentional), negative symptoms, and different types of attachment style. The study is cross-sectional and longitudinal, with measures administered at the baseline and six months later.

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# Chapter 1. An examination of negative symptoms, traumatic life events and attachment style: A mixed methods investigation

## 1.1. Introduction

This introduction provides an overview of the three constructs explored within the PhD: negative symptoms, traumatic life events and attachment style, and the relationships between them. Firstly, this introduction will describe negative symptoms, provide a historical overview, and review causes and treatments. Second, research investigating the role of traumatic life events in schizophrenia and psychosis will be described. Finally, the basic tenets of attachment theory will be described, along with the concept of insecure avoidant attachment and how this may play a role in explaining any association between traumatic life events and negative symptoms, for example, through engagement with services.

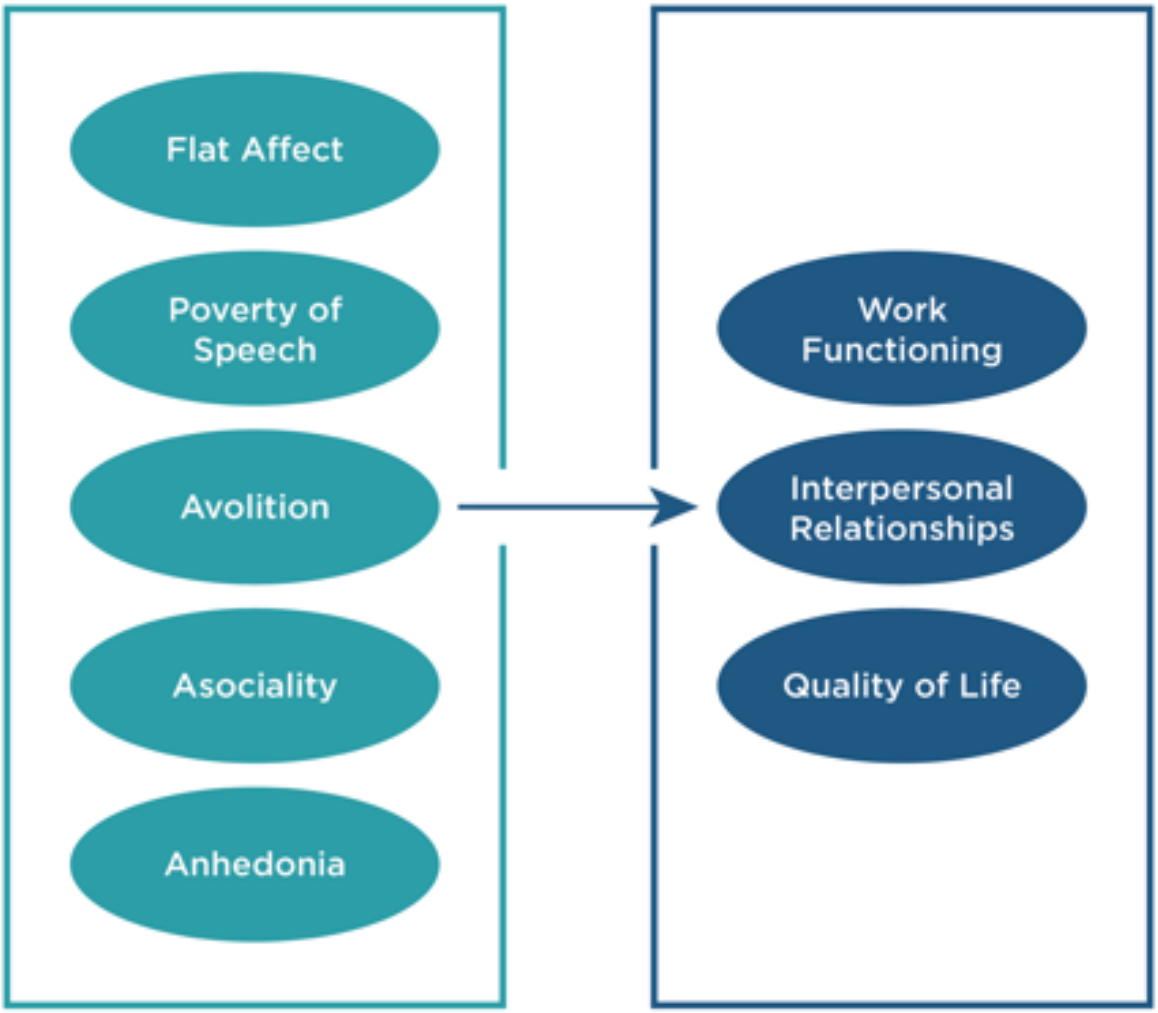
## 1.2. Negative symptoms

### 1.2.1. Description of negative symptoms

Negative symptoms have been termed as core symptoms of schizophrenia, and include affective flattening, alogia, anhedonia, asociality, and avolition (see Figure 1.1) (Kirkpatrick, Fenton, Carpenter, & Marder, 2006; Messinger et al., 2011). Negative symptoms have been described as falling into two sub-groups, relating to expressive or experiential deficits. Experiential deficits include the inability to experience pleasure from a wide range of activities, both work and socially (anhedonia), decreased motivation to interact with others (asociality), and lack of motivation to achieve goals in either a work or social setting (avolition). Expressive deficits are absences in expressing emotion, including reduced facial expressions or expressive gestures, or lack of intonation in voice (blunted affect), and poverty of speech (alogia).

Negative symptoms can change in their presentation over time. For example, negative symptoms may emerge in the initial prodromal stage of psychosis; however, as positive symptoms become more prominent, in an acute psychotic episode these may eclipse the negative symptoms. When positive symptoms are controlled by pharmacological treatment, negative symptoms may appear more prominent and worsen, sometimes leaving an individual unable to complete activities they once enjoyed (Möller, 2007).

*Figure 1.1. NIMH-MATRICS Consensus statement on negative symptoms; Messinger et al 2011*

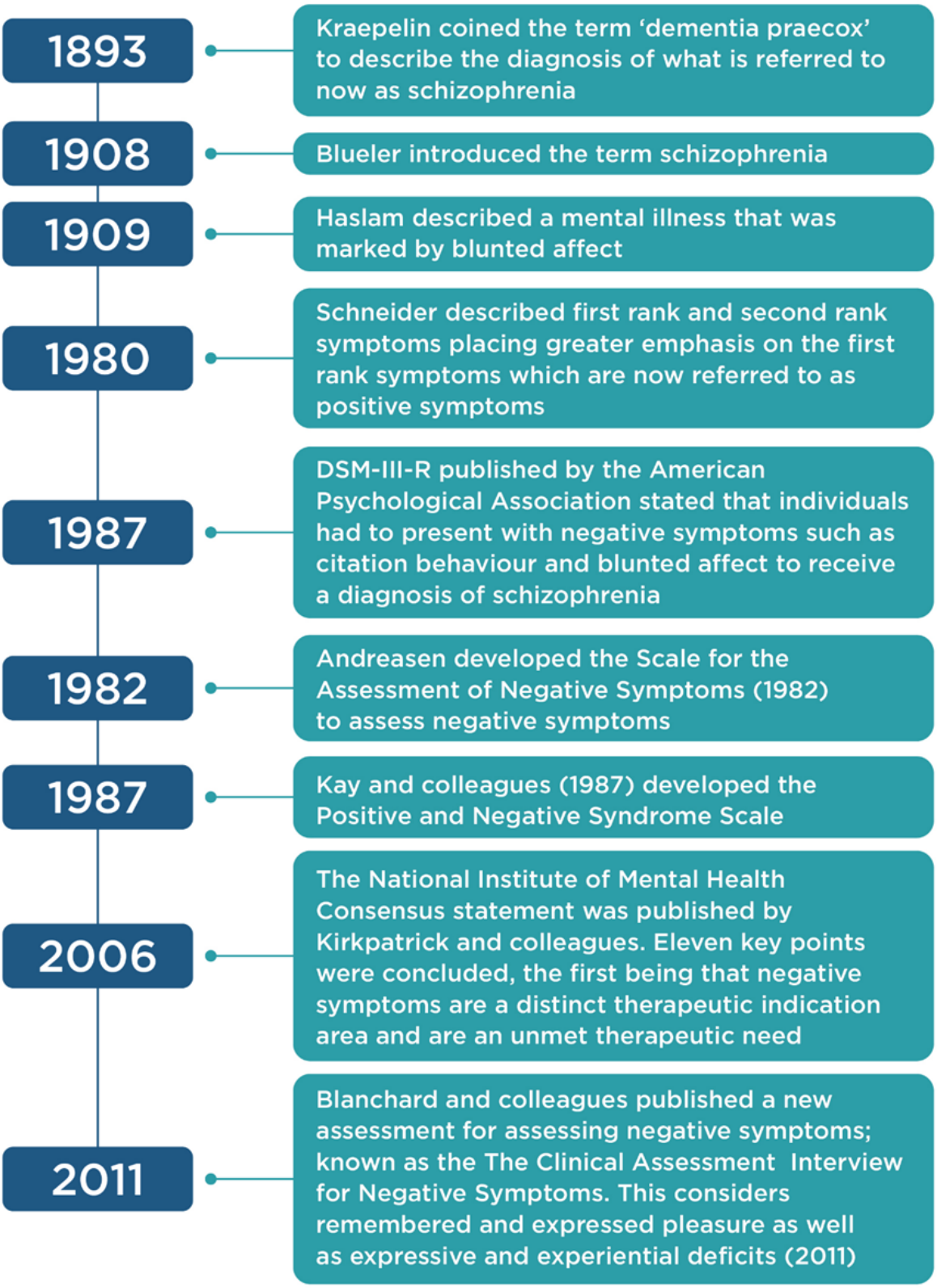



### 1.2.2. Historical overview of negative symptoms

In 1893, Kraepelin (Kraepelin, 1893) first coined the term *dementia praecox* to describe the now-known diagnosis of schizophrenia, describing individuals who were experiencing psychotic symptoms and cognitive decline. Kraepelin described negative symptom features as including indifference, emotional deficits, and lack of volition. Bleuler (Bleuler, 1908) unlike Kraepelin, was the first person to utilise the divisive term, *schizophrenia.* The term *schizophrenia* translates from Greek as 'splitting of the mind' and was used to convey the fragmented thinking of people with schizophrenia. Bleuler introduced the concept of primary and secondary symptoms associated with a diagnosis of schizophrenia. Bleuler (Bleuler, 1908) believed that there were four primary symptoms, known as the four 'A's: abnormal associations, autistic behaviour, abnormal affect and ambivalence. Bleuler stated that the central symptoms, key to a diagnosis of schizophrenia, were the loss of association between thought processes, emotion and behaviour.

Around the same time, Haslam (Haslam, 1809) also described what are now defined as negative symptoms. In his writings, Haslam described a mental illness that appeared to affect young people, which was marked by blunted and affective sensitivity (Haslam, 1809). Despite these early descriptions of the importance of negative symptoms, in the early twentieth century, there was a shift from consideration of negative symptoms to the importance of positive symptoms in the diagnostic criteria for schizophrenia (Schneider, 1959). Schneider separated the symptoms into 'first-rank symptoms' and 'second-rank symptoms'. First-rank symptoms are akin to key positive symptoms of psychosis, and include symptoms such as command hallucinations, and delusions; for example, feelings and actions controlled from outside the individual. Second-rank symptoms include non-auditory hallucinations and paranoid delusions. Both first-rank and second-rank symptoms are positive symptoms, and thus no emphasis is placed on negative symptoms in a diagnosis of schizophrenia. In the late 1980s, the publication of DSM-III-R by the American Psychological Association (DSM III & Association, 1987) stated that for a schizophrenia diagnosis to be met, individuals had to present with delusional ideas, auditory hallucinations and formal thought disorder as well as either catatonic behaviour or blunted inappropriate affect. This marked a shift towards a greater focus on negative symptoms. The late 1980s also saw the development of specific rating scales for the evaluation of negative symptoms; for example, the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1982) and the Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein, & Opler, 1987). Figure 1.2 outlines a historical overview of negative symptoms research.

*Figure 1.2. Negative Symptoms Research Timeline*



### 1.2.3. Treatment of negative symptoms

Negative symptoms are widely acknowledged, both amongst clinicians and across the literature, as difficult to treat; this is because negative symptoms do not respond as favourably to the pharmacological treatments traditionally used to target positive psychotic symptoms (Fusar-Poli et al., 2015). The National Institute for Health and Care Excellence (NICE) guidelines state that in the treatment of schizophrenia, cognitive behaviour therapy should be offered to assist in promoting recovery in individuals with persisting positive and negative symptoms ("National Institute for Health and Care Excellence: Clinical Guidelines," 2014). Family interventions should also be offered, with either a family member or with those who are closest to the individual who experiences the symptoms. According to the NICE guidelines, arts therapies should also be considered when promoting recovery, particularly in individuals with negative symptoms. Other possible psychological interventions to target negative symptoms include cognitive remediation therapy. A recent meta-analysis highlighted that cognitive remediation had a small-to-moderate effect on negative symptoms, which was maintained at follow-up (Cella, Preti, Edwards, Dow, & Wykes, 2017). In England, within the NICE guidelines, cognitive remediation is not stated as a recommended psychological intervention; however, it is in Scotland (Scotland, 2013). Despite negative symptoms being difficult to treat there has been some recent evidence that suggests that psychological interventions, such as cognitive-behavioural therapy and skills-based training, are useful in ameliorating some of negative symptoms observed in individuals who have a diagnosis of schizophrenia (Lutgens, Gariepy, & Malla, 2017). This review paper by Lutgens and colleagues suggests that despite the paucity of interventions available to treat negative symptoms, further research using cognitive-behavorial therapy needs to be conducted and assessed.

## 1.3. The link between trauma and negative symptoms

The causes of negative symptoms are not well understood, and little research has sought to identify and understand these symptoms. One variable that may play a role in the development of negative symptoms, which will be explored in this thesis, is the experience of traumatic life events. Social and emotional withdrawal are key aspects of negative symptoms, but are also mechanisms that individuals use to cope with traumatic life events (van der Kolk & Saporta, 1993). Stampfer (1990) posited that negative symptoms associated with a diagnosis of schizophrenia are manifestations of a stress response similar to that defined as numbing and withdrawal symptoms in post-traumatic stress disorder (PTSD).

### 1.3.1. Defining traumatic life events

There is much discussion on how to define traumatic life events, with some studies referring to these events as 'adversities' or 'adverse life events,' and others referring to them as 'traumatic life events.' For example, the widely cited Adverse Childhood Experiences (ACEs) Study by the Centers for Disease Control and Prevention (Felitti et al., 1998), used the term *adverse childhood experiences* to cover a wide range of unpleasant experiences in childhood, such as emotional and physical abuse, and household substance abuse. In this thesis, the terms *adverse life events* and *traumatic life events* will be used interchangeably, depending on context. The first study, the systematic review, refers to adverse life events, with the remaining studies within the PhD referring to these as traumatic life events. The term adverse life events was deemed more suitable to describe the wide range of unpleasant events that were captured in studies included in the systematic review. After conducting the qualitative study within this PhD, it emerged that individuals themselves referred to these unpleasant events they had experienced as traumatic life events rather than adverse life events. The term traumatic life events embodies a wide range of events that may occur across a lifespan, and these events can also be described as adverse life events.

Traumatic life events include events such as physical, sexual, emotional and psychological abuse, in addition to witnessing or being involved in events such as a natural disaster, accident, or experiencing a major illness. The impact of such events is subjective, varying from individual to individual; however, adverse childhood experiences can have a tremendous impact on future mental and physical health outcomes. Studies have evidenced that individuals who have experienced childhood trauma are more likely to suffer from obesity (Clark et al., 2007; Dube et al., 2001; Felitti et al., 2019) or engage in drug abuse (Tomassi et al., 2017) and alcohol abuse (Schneeberger et al., 2017) and to have received a diagnosis of a severe mental health problem (McGrath et al., 2017; Rauschenberg et al., 2017; Varese et al., 2012).

### 1.3.2. Traumatic life events and psychosis

The last ten years have seen a surge in evidence that supports the association between adverse childhood experiences and positive psychotic symptoms (Bailey et al., 2018; Varese et al., 2012). Research has suggested that there may be a positive association between the experience of childhood neglect and negative symptoms; however, evidence linking other types of trauma with negative symptoms is more limited (Bailey et al., 2018; Gallagher III & Jones, 2013). In particular, few studies have explored the impact of

parental loss, either through death or separation, and also the impact of events such as childhood bullying on negative symptoms. The omission of these events from the literature may be explained by the fact that key measures of trauma, such as the Childhood Trauma Questionnaire (CTQ; Bernstein, Fink, Handelsman, & Foote, 1998) and the Trauma History Questionnaire (THQ; Hooper, Stockton, Krupnick, & Green, 2011), do not explicitly ask about parental loss or bullying. In addition, relatively few studies have examined the mechanisms through which trauma may impact on negative symptoms. One such mechanism that would be worthy of further examination is the concept of insecure attachment.

## 1.4. Attachment

### 1.4.1. Attachment style

Bowlby's attachment theory states that to survive, infants must seek proximity to a primary caregiver who is protective, thus enabling the infants to feel safe and secure (Bowlby, 1969; Bowlby, 1973, 1979). When an infant is not provided with this safe haven and secure base, due to a caregiver being absent, ineffective or abusive, an insecure attachment style can develop. There are two main types of insecure attachment: anxious (sometimes referred to as ambivalent), and avoidant. An anxious attachment develops as a result of inconsistent and sporadic care from the primary caregiver, which results in an infant exaggerating their expression of emotions and seeking the attention of the caregiver in order to have their needs met. In adulthood, anxious attachment is observed as heightened emotional expression, poor self-efficacy, and overdependence on others. Avoidant attachment develops from infants experiencing rejection by caregivers, especially at points when they are distressed, and as a result, in adulthood, these individuals overregulate emotions and avoid experiences of close relationships.

In addition to these two main types of insecure attachment, there is another type of attachment pattern, which is termed *disorganised attachment* in the infant literature, and *fearful or unresolved attachment* in the adulthood literature. These typologies of attachment are thought to result from experiences of abuse by the caregiver and are associated with a dysregulated and inconsistent pattern of relating to others.

### 1.4.2. Attachment and psychosis

One meta-analysis and four systematic review papers have examined the association between attachment and psychosis (Berry, Barrowclough, & Wearden, 2007; Carr, Hardy, & Fornells-Ambrojo, 2018; Gumley, Taylor, Schwannauer, & MacBeth, 2014a; Korver-

Nieberg, Berry, Meijer, & de Haan, 2014). All four reviews highlight that insecure attachment is associated with symptoms of psychosis. Insecure attachment is also associated with earlier onset of illness, poor engagement with mental health services, and lower quality of life (Berry et al., 2007; Gumley et al., 2014a; Korver-Nieberg et al., 2014). The most recent meta-analysis by Carr et al. (2018) identified that an insecure attachment style was higher in psychosis samples than in non-clinical samples. This meta-analysis also reported that negative symptoms and attachment were significantly associated in non-clinical populations but not in clinical populations. The authors suggest that this could be explained by the paucity of research investigating attachment and negative symptoms. Additionally, the increased use of measures of schizotypy in non-clinical studies, which may have greater overlap with the concept of insecure attachment than measures of negative symptoms typically used with clinical samples, could explain the findings.

### 1.4.3. Attachment and negative symptoms

A relatively small number of studies have explored associations between insecure attachment and negative symptoms. Berry et al. (Berry, Barrowclough, & Wearden, 2008) found that negative symptom items on the PANSS were positively correlated with insecure avoidant attachment. Similarly, Ponizovsky,Nechamkin and Rosca (2007) reported that higher scores on the PANSS negative symptom items were associated with insecure avoidant attachment. However, Kvrgic (Kvrgic, 2011) found no association between avoidant attachment style and negative symptoms. The authors explain this result by suggesting the study had a small sample (n = 30), with a low prevalence of negative symptoms, in comparison to studies that report a positive association between avoidant attachment and negative symptoms. As reported by Korver-Nieberg, Berry, Meijer, de Haan and Ponizovsky (2015), attachment avoidance is not associated with overall negative symptom scores on the PANSS, although attachment avoidance is associated with negative symptom items of social and emotional withdrawal, suggesting that insecure attachment may be a better predictor of certain types of negative symptoms compared to others.

To date, all the studies on attachment and negative symptoms have utilised a cross-sectional research design, with very few being longitudinal. One exception is a 12-month longitudinal study by Gumley et al. (2014b), which sought to explore the relationship between insight, length of untreated psychosis, and recovery from negative and positive symptoms. The study investigated individuals (n = 68) in Scotland who had a diagnosis of first-episode psychosis. Attachment was measured by the Adult Attachment Interview

(AAI; George et al.,1996). Path analysis found a significant direct relationship between attachment and severity of negative symptoms at follow-up.

In summary, evidence suggests that there may be an association between insecure attachment style and negative symptoms. However, the evidence is limited due to the paucity of research overall, and particularly in relation to research conducted on attachment and negative symptoms that used longitudinal designs.

### 1.4.4. Attachment style, engagement with services and negative symptoms

Research has posited that attachment style has been associated with treatment compliance and engagement with services (Adams, Wrath, & Meng, 2018). Engagement with services cannot be easily defined, it is multi-faceted in that it draws upon different definitions. There is no one definition of engagement with services. The literature to date has focused on using clinician rated measures to assess patients' engagement with services (Tait, Birchwood, & Trower, 2002) primarily. The current measures of service engagement consider an individual's adherence to treatment and medication plans, and their engagement with mental health care professionals. Research to date has shown that a fearful attachment style can lead to individuals reporting higher levels of physical symptoms than individuals who have a secure attachment (Ciechanowski et al., 2006). Individuals who experience a higher severity of negative symptoms have been shown to have lower levels of engagement with services and additionally high levels of traumatic life events have been associated with low levels of engagement with services (Lecomte et al., 2008; MacBeth, Gumley, Schwannauer, & Fisher, 2013). Individuals with negative symptoms, as stated previously, typically withdrew from society and this included engagement with mental health care professionals. Glashan (McGlashan & Levy, 2019) noted in the 1970s the different ways in which an individual copes with the stress of an acute psychotic episode as 'sealing over' or 'integration'. Sealing over is a recovery style whereby an individual prefers to not remember the experience of psychosis, whereas integration is a process of reviewing the experience; both techniques can foster an individual's recovery. A study by Modestin, Soult and Malti (2004) reported a negative correlation between severity of negative symptoms and integration into society. There has been a dearth of research produced specifically on the impact of engagement with services and negative symptoms. The concept of service engagement is broad and as such there is no gold standard scientific measurement tool used to assess engagement with services. Studies have opted to assess individuals' engagement using the Service Engagement Scale

(Tait et al., 2002), the Active Engagement Scale (Frank & Gunderson, 1990) and the Working Alliance Inventory (Horvath & Greenberg, 1989).

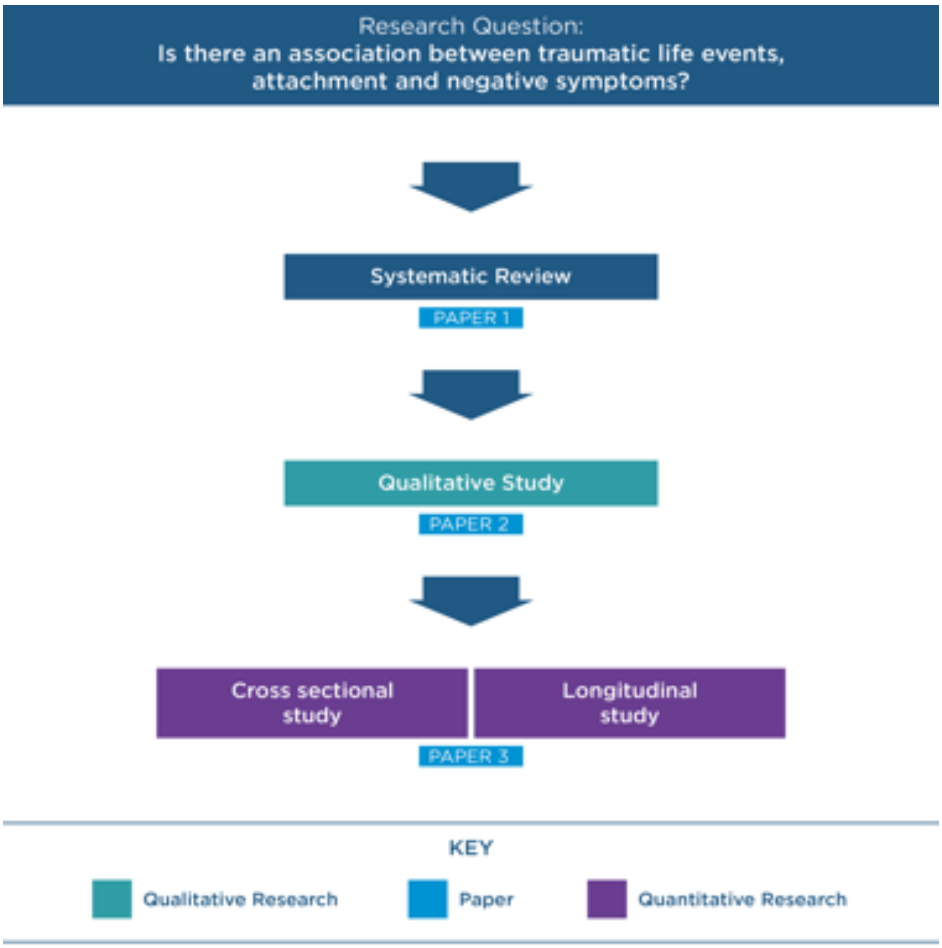
## 1.5. Negative symptoms, traumatic life events, and attachment style

This PhD aims to explore the association between negative symptoms, traumatic life events and attachment style, and using a cross-sectional and longitudinal methodology, to consider how these may interact. It was considered particularly pertinent to examine how the experience of trauma may lead to negative symptoms and the findings may serve to increase understanding of the factors that may lead to negative symptoms, which may, in turn, lead to potential treatments to help reduce the likelihood of developing those symptoms, and to treatments that may ameliorate them. Table 1.1. outlines the thesis and the five research questions that were addressed. Figure 1.3. highlights the different aspects of the PhD and the different research designs that have been utilised.

***Table 1.1. Thesis outline and the five research questions addressed***

| Question | Design of study to address the aim | Thesis chapter |
|---|---|---|
| 1. Are trauma and negative symptoms associated? | Systematic review<br>Cross-sectional study | Chapter 2<br>Chapter 5 |
| 2. Are specific types of trauma associated with particular symptoms? | Systematic review<br>Cross-sectional study | Chapter 2<br>Chapter 5 |
| 3. How do individuals subjectively experience negative symptoms? | Qualitative study | Chapter 4 |
| 4. What is the association between trauma, attachment style and negative symptoms? | Cross-sectional study | Chapter 5 |
| 5. Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six months? | Longitudinal study | Chapter 5 |

***Figure 1.3. Different aspects of the PhD and the different research designs utilised***



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## Preface to Chapter 2: Systematic Review

This paper seeks to investigate the association between distinct adverse life events and negative symptoms of schizophrenia, through a systematic review.

The paper has been formatted for submission to the Schizophrenia Bulletin journal which has previously published similar reviews. Some of the information presented will be submitted and shown as supplementary material in line with the journal guidelines. The paper will be submitted to the journal early in 2021.

Isabelle Butcher, Gillian Haddock and Katherine Berry made substantial contributions to the conception and design of the work, as well as the acquisition and interpretation of data. All were directly involved in the preparation of the manuscript for publication. Yasmine Alkotop contributed to the data extraction process and synthesis process. All authors will be involved in the final approval of the manuscript prior to publication.

# Chapter 2. Paper 1

## Is there a relationship between adverse life events and negative symptoms? A systematic review

*Running title: Adverse life events and negative symptoms*

Isabelle Butcher, [1] Katherine Berry, [1, 2] Yasmine Alkotob, [1] Gillian Haddock. [1, 2]

[1] Division of Psychology and Mental Health, School of Health Sciences, Faculty of Biology, Medicine and Health, Manchester Academic Health Sciences, The University of Manchester, UK

[2] Greater Manchester Mental Health NHS Foundation Trust, Manchester Academic Health Sciences , Manchester, UK

* Correspondence should be addressed to Gillian Haddock, Division of Psychology and Mental Health, University of Manchester, Manchester, M13 9PL, UK.

gillian.haddock@manchester.ac.uk

## 2.1. Abstract

### 2.1.1. Objective

Individuals with a diagnosis of schizophrenia present with positive symptoms such as hallucinations, delusions and negative symptoms which include social withdrawal, inattentiveness, and lack of motivation. It has been posited that adverse life events are associated with the development of positive psychotic symptoms; however, relatively little is known about the relationship between adverse life events and negative symptoms. This review investigates the questions:

i) Is there an association between adversity and the severity of negative symptoms?

ii) Is there a relationship between specific types of adversity and negative symptoms?

### 2.1.2. Method

A systematic search of the Ovid MEDLINE, Embase, PsycINFO, Web of Science, and PubMed databases was conducted using PRISMA guidelines. As part of the inclusion criteria, all studies had to report on the i) association between adverse life events and negative symptoms and ii) report on adverse life events and negative symptoms using validated measures.

### 2.1.3. Results

The findings from this systematic review are based on 34 studies that were primarily cross-sectional in design. Specifically, eight types of adverse life events were reported across these studies: childhood sexual abuse, childhood physical abuse, childhood emotional abuse, childhood physical neglect, childhood emotional neglect, parental separation, parental death, and parental loss. Of the 34 studies, nine reported a significant association between adverse life event(s) and negative symptoms. There were no significant relationships found between childhood sexual abuse and negative symptoms, childhood physical abuse and negative symptoms, childhood physical neglect and negative symptoms, or separation from parents and negative symptoms. Childhood emotional neglect was the most frequently reported event, with a significant association with negative symptoms.

### 2.1.4. Conclusion

Clinicians should pay greater attention to an individual's history of childhood emotional neglect in both assessing and formulating negative symptoms. In addition, the findings from this review suggest there needs to be more research into negative symptoms and their association with adverse life events using prospective designs.

**Keywords:** negative symptoms, adverse life events, schizophrenia, trauma.

## 2.2. Introduction

Negative symptoms have long been recognised as a central feature of the phenomenology of the diagnosis of schizophrenia, dating back to early descriptions by Bleuler and Kraepelin.[1] Negative symptoms, such as affect, alogia, apathy-avolition, anhedonia, and inattentiveness are thought to represent the absence or reduction of normal emotions and behaviours.[2] Negative symptoms can result in poor social functioning outcomes for individuals with psychosis[3] and contribute to the financial and emotional cost of schizophrenia, not only to the individual, but also to their carers and wider society.[4] Research on negative symptoms is relatively sparse compared to that on the positive symptoms of schizophrenia. As a result, there is a need to improve the understanding of negative symptoms in order to develop better treatment and prevention strategies. Reviews and meta-analyses have suggested that there is an association between the experience of adversity and the development of psychosis.[5, 6] However, these reviews have largely focused and reported on links between adverse events and positive symptoms, and, to date, no systematic review has specifically – and solely – examined the relationship between adverse life events and negative symptoms. However, it is possible that the experience of adverse events may be particularly important in contributing to negative symptoms. It has been suggested that negative symptoms may develop as a coping mechanism for dealing with the sequelae that arise from the experience of adverse life events, although these mechanisms may then become maladaptive over time.[7] For example, the emotional numbing and detachment that occurs as a way of coping with overwhelming emotions and adverse life events in individuals who have experienced adversity (e.g.,, combat-related post-traumatic stress disorder)[8] may serve a useful purpose, initially, as a way to cope with the trauma, but may later become a hindrance to subsequent interpersonal relationships and functioning.

In addition, if adverse life events impact on the subsequent development of negative symptoms, it is possible that some types of adverse life events may have a more significant impact on negative symptoms than others. Adverse life events can be categorised into two broad areas: intentional interpersonal events (e.g., sexual abuse, physical abuse, and bullying) and non-intentional interpersonal events (including experiences, such as parental loss through death or separation or witnessing a natural disaster or conflict). Additionally, adverse life events can also be categorised into those that involve an act of omission, such as physical and emotional neglect, and those that are more purposeful, such as sexual, physical, and emotional abuse.[9]

This review systematically examined the association between adverse life events (in general and by specific type of event) and negative symptoms in people with a diagnosis of schizophrenia in order to address 'the gap' that exists in the literature. The principal questions in this review were:

1. Is there an association between adversity and the severity of negative symptoms?
2. Is there a relationship between specific types of adversity and negative symptoms?

## 2.3. Method

This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting systematic reviews.[10] The protocol for the study can be found on PROSPERO (PROSPERO ID: CRD42017058047). Figure 2.1. depicts the PRISMA guidelines for this study.

### 2.3.1. Search strategy

The search process was conducted using the following electronic databases: Ovid MEDLINE, Embase, PsycINFO, Web of Science, and PubMed. Only articles published up to February 2020 were included. The search terms used are shown in Table 2.1. grouped under the three constructs being studied: negative symptoms, adverse life events and diagnosis of schizophrenia.

***Table 2.1. Search terms for systematic review***

| *Terms for negative symptoms* | *Terms for adverse life events* | *Terms for psychosis* |
|---|---|---|
| Negative symptom* | Child abuse | Schizo* |
| Anhedonia | Physical abuse | |
| Apath* | Sexual abuse | Psychotic symptom* |
| Avolition | Psychological abuse | Schizophren* |
| logia | Emotional abuse | Severe mental |
| Asociality | Neglect | Serious psychiatric |
| Inertia | Trauma* | Serious mental |
| Aloof | Advers* | Psychos* |
| Deficit syndrome* | Maltreat* | Psychotic* |
| Cognitive deficit | Bully* | |
| Blunted affect | Victim | |
| Emotional withdrawal | Expressed emotion | |
| Loss motivation | Communication deviance | |
| Flattening affect | Parental loss | |
| Poverty speech | Separat* | |
| | Discrimination | |

* Boolean operators, OR/and, were used to connect terms presented in any column and terms presented across columns, respectively.

### 2.3.2. Eligibility criteria

The inclusion criteria were studies that:

a) Included participants with a reported diagnosis of schizophrenia, schizophreniform disorder, or schizoaffective disorder, according to Diagnostic and Statistical Manual of Mental Disorders (DSM) or International Classification of Disease (ICD) criteria.

b) Reported findings from validated scales and structured interviews of negative symptoms; for example, the negative symptom subscale of the Positive and Negative Syndrome Scale (PANSS),[11] the Brief Psychiatric Rating Scale (BPRS),[12] and the Scale for the Assessment of Negative Symptoms (SANS).[13]

c) Reported findings from validated tools including interviews used to assess adverse life events; for example, the Childhood Trauma Questionnaire (CTQ) [14] or the Trauma History Questionnaire (THQ).[15]

d) Reported on an analysis of the statistical association between adverse life events and negative symptoms.

e) Reported findings in articles written in the English language.

f) Reported findings in peer-reviewed journals.

### 2.3.3. Exclusion criteria

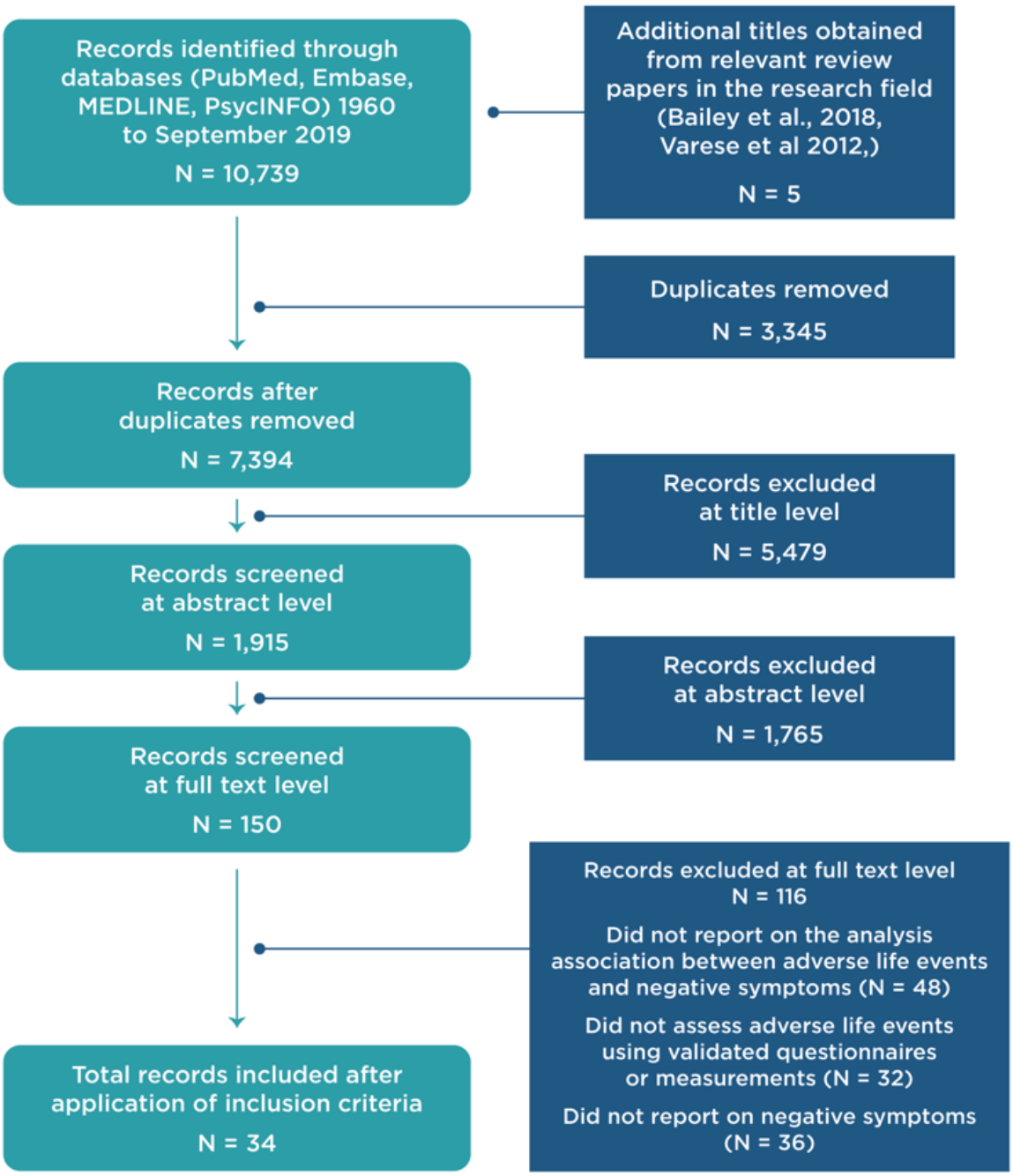
Exclusion criteria included: a) studies where the reported results included less than 50% of the sample with a diagnosis of schizophrenia or related psychotic disorders; b) review articles, posters, books, book chapters, abstracts, letters, commentaries, editorials, or dissertations; c) single-case studies, case series, or qualitative studies; and d) studies that assessed adversity solely using case notes or medical records because of the potentially unreliable nature of reporting adverse life events in clinical notes.[16]

### 2.3.4. Screening and data extraction

The first author (I.B.) screened the titles, abstracts, and full texts against the eligibility criteria. Twenty-five % of the records screened at an abstract level were also screened by an independent postgraduate researcher, and the level of agreement was 95%. When there were discrepancies, these were resolved by discussion with all the authors. This same independent postgraduate researcher also checked 25% of the full text against the eligibility criteria, and agreement was reached on 90% of articles. When there were uncertainties as to whether the paper should be included at the full text level, decisions were resolved with input from all the authors.

A review-specific data extraction form (Appendix 1) was used to collate study data from each paper included at the full-text level. Extracted information included: study setting, study population, participant demographics, measure of negative symptoms, measure of adverse life events, study methodology, findings, and the Appraisal tool for Cross-Sectional Studies (AXIS) risk tool of bias score.[17]

*Figure 2.1. Prisma diagram illustrating the systematic review process conducted*



### 2.3.5. Quality assessment

The AXIS tool[17] was used to assess the quality of each study. A proportion of the papers were selected at random by the thesis author and screened by the same independent postgraduate researcher who screened the titles, abstracts and full texts. The independent postgraduate screened 25% of the titles and 25% of the full text papers. Each item in the AXIS tool uses quality criteria similar to the Cochrane Collaboration Risk Bias Tool.[18] The AXIS tool consists of 20 *a priori* defined quality criteria that enable each article to be appraised critically by examining details of the study. The scores from the AXIS tool for the studies in this review can be seen in Table 2.2. Each item is coded as 'no,' 'unclear/don't know,' or 'yes.' The tool does not provide a total numerical scale for assessing the quality; thus, it enables all aspects of a study to be considered when ultimately reporting on its quality. If the responses to more than half of the questions were 'no,' or if they were not reported, the study was rated as 'poor quality.' Examples of items in the AXIS tool include assessing the appropriateness of study design for stated aims, sample size justification, the reliability of survey instruments, and evaluating whether the response rate raises concerns regarding non-response bias (Appendix 2).

## 2.4. Results

### 2.4.1. Study characteristics

Thirty-four studies (Table 2.3. and Table 2.4.) were identified for inclusion in this review. Sixteen were conducted in Europe, from nine European countries. Nine studies[19-27] were conducted in the United States, one in Canada,[28] four in Australia,[29-32] two studies in East Asia,[33, 34] (conducted in Japan and South Korea), as well as two studies from Africa, both from Egypt.[35, 36] Most of the studies included both males and females individuals in their samples, although two studies were conducted with female only participants [34, 37]. Across the 34 studies, a range of ethnicities was represented. The overall methodological quality of the included studies was rated to be sufficient in thirty -three out of the thirty-four studies. One study was rated as poor using the AXIS tool.

***Table 2.2. AXIS Quality assessment scores for each study***

| Study | Question 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | Overall AXIS quality tool outcome |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Alameda et al. (2016), Switzerland* | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Amr et al, (2012), Egypt* | Yes | Yes | Do not know | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Baudin et al, (2016), France* | Yes | Yes | No | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Bendall et al. (2013), Australia* | Yes | Yes | No | Yes | Yes | No | Do not know | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *De Rosse et al. (2014), U.S.A* | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Fawzi et al. (2013), Egypt* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | No | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Furukawa et al. (1998), Japan* | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Green et al. (2014), Australia* | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Hacioglu Yildirim (2014), Turkey* | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |

***Table 2.2. AXIS Quality assessment scores for each study***

| Study | Question 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | Overall AXIS quality tool outcome |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Heins et al. (2011), Belgium* | Yes | Yes | No | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Kelly et al, (2016), USA* | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Kim et al. (2006), South Korea* | Yes | Yes | No | Yes | Yes | Yes | Do not know | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Lysaker et al. (2001), USA* | Yes | Yes | No | Yes | Yes | Yes | Do not know | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Lysaker et a.l (2005), USA* | Yes | Yes | No | Yes | Yes | Yes | Do not know | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Lysaker and LaRocco (2008), USA* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Manuseto et al. (2019), the Netherlands* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *McCabe et al. (2012), Australia* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |

***Table 2.2. AXIS Quality assessment scores for each study***

| Study | Question 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | Overall AXIS quality tool outcome |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Misiak and Frydecka (2016), Poland* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Peleikis et al. 2013 Norway* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Prussner et al. 2019, Canada* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Ramsay et al.(2011) USA* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Ross, Anderson and Clark (1994), USA* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Poor |
| *Ruby et al.(2017), U.S.A* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Sahin et al. (2013), Turkey* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Sar et al (2010). Turkey* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Schalinski et al. (2015), Germany* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |

***Table 2.2. AXIS Quality assessment scores for each study***

| Study | Question 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | Overall AXIS quality tool outcome |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| *Schalinski et al. (2019), Germany* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Scheller-Gilkey et al. (2004), USA* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Seidenfaden et al. (2017), Denmark* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Shah et al. (2014), Australia* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Stain et al. 2014 Norway* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *Ucok and Bikmaz (2007), Turkey* | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *van Dam et al.(2014), the Netherlands* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |
| *van Dam et al. (2015), Netherlands* | Yes | Yes | No | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | No | Yes | Yes | Yes | Yes | No | Yes | Sufficient |

***Table 2.3. Study characteristics***

| Name | Population (m/f) | Design of Study | Diagnosis (FEP: First Episode Psychosis, MD: Major Depression, BP: Bipolar) | Measure of Trauma | Measure of Negative Symptoms |
|---|---|---|---|---|---|
| Alameda et al. (2016), Switzerland | 196 (139/57) | Prospective | Schizophrenia 60.2%<br>Schizophreniform 11.2%<br>Schizoaffective 9.2%<br>Major depression 4.6%<br>Bipolar disorder 5.6%<br>Others 9.2% | Extensive standardised questionnaire by clinicians which included type of traumatic life event, rated as present or absent. Trauma assessed included sexual abuse, physical abuse, emotional and physical neglect, emotional abuse & other types (not specified). | PANSS-NS |
| Amr et al. (2012), Egypt | 98 (61/37) | Cross-sectional | Schizophrenia 100% | TAA – briefed revised version | PANSS-NS |
| Baudin et al. (2016), France | 366 (274/92) | Cross-sectional | Schizophrenia 80.6%<br>Schizoaffective 19.4% | CTQ- French | PANSS-NS |
| Bendall et al. (2013), Australia | 28 (nr) | Cross-sectional | First episode psychosis 100% | CTQ | PANSS-NS |
| De Rosse et al. (2014),USA | 631 (299/332) | Cross-sectional | Schizophrenia or Schizoaffective 29.1%<br>Healthy controls 70.8% | CTQ | CAPE |
| Fawzi et al. (2013), Egypt | 74 (48/26) | Cross-sectional | Schizophrenia 100% | CTM | PANSS-NS |
| Furukawa et al. (1998), Japan | 377 (266/181) | Cross-sectional | Schizophrenia 59.7%<br>Control subjects 32.4% | PISA- section on loss | PISA |

***Table 2.3. Study characteristics***

| Name | Population (m/f) | Design of Study | Diagnosis (FEP: First Episode Psychosis, MD: Major Depression, BP: Bipolar) | Measure of Trauma | Measure of Negative Symptoms |
|---|---|---|---|---|---|
| Green et al. (2014), Australia | 1,276<br>(706, 570) | Cross-sectional | Schizophrenia 28.2%<br>Schizoaffective 5.4%<br>Healthy controls 60.3% | CAQ | DIP-NS |
| Hacioglu Yildirim (2014), Turkey | 70<br>(0/70) | Cross-sectional | Schizophrenia 100% | TEC | PANSS-NS |
| Heins et al. (2011), Belgium | 272<br>(189/83) | Cross-sectional | Schizophrenia 72%<br>Schizoaffective 11%<br>Psychotic disorder not 7% otherwise specified<br>other non-affective psychotic disorder 6%<br>Schizophreniform 3% | CTQ- Dutch S-F | PANSS-NS |
| Kelly et al. (2016), USA | 80<br>(56/24) | Cross-sectional | Schizophrenia 100% | CTQ | BPRS – NS |
| Kim et al. (2006), South Korea | 100<br>(0/100) | Cross-sectional | Schizophrenia 100% | CTS | PANSS - NS |
| Lysaker et al. (2001), USA | 43<br>(43/0) | Cross-sectional | Schizophrenia 72.1%<br>Schizoaffective 27.9% | Extensive Structured Interview | PANSS-NS |
| Lysaker et al. (2005), USA | 43<br>(43/0) | Prospective | Schizophrenia or Schizoaffective 100% | CEQ | PANSS-NS |

***Table 2.3. Study characteristics***

| Name | Population (m/f) | Design of Study | Diagnosis (FEP: First Episode Psychosis, MD: Major Depression, BP: Bipolar) | Measure of Trauma | Measure of Negative Symptoms |
|---|---|---|---|---|---|
| Lysaker and LaRocco (2008), USA | 68<br>(57/11) | Cross-sectional | Schizophrenia 51.4%<br>Schizoaffective 48.5% | TAA<br>TSI | PANSS-NS |
| Manuseto et al. (2019), the Netherlands | 757<br>(568/189) | Cross-sectional | Not reported figure but all individuals had to have a diagnosis of non-affective psychotic disorder | CTQ-SF Dutch | PANSS-NS |
| McCabe et al. (2012), Australia | 675<br>(384/291) | Cross-sectional | Schizophrenia 60.4%<br>Healthy controls 39.6% | CAQ | NS items Diagnostic Interview for Psychosis |
| Misiak and Frydecka (2016), Poland | 64<br>(32/32) | Cross-sectional | First episode psychosis 100% | Early Trauma Self Report Form | PANSS-NS |
| Peleikis et al. (2013), Norway | 292<br>(161/131) | Cross-sectional | Schizophrenia 77.1%<br>Schizophrenic 2.7 %<br>Schizoaffective 20.2 | M.I.N.I | PANSS-NS |
| Prussner et al. (2019), Canada | 210<br>(144/66) | Cross-sectional | First episode psychosis 100% | CTQ | BPRS |

***Table 2.3. Study characteristics***

| Name | Population (m/f) | Design of Study | Diagnosis (FEP: First Episode Psychosis, MD: Major Depression, BP: Bipolar) | Measure of Trauma | Measure of Negative Symptoms |
|---|---|---|---|---|---|
| Ramsay et al. (2011),USA | 61<br>(44/17) | Cross-sectional | Schizophrenia Paranoid type 32.8%<br>Schizophreniform 14.8%<br>Psychotic disorder not otherwise specified 14.8%<br>Schizophrenia, undifferentiated type 11.5%<br>Schizoaffective, depressive type 11.5%<br>Schizoaffective, bipolar type 4.9%<br>Schizophrenia disorganised type<br>Brief psychotic disorder<br>Delusional disorder 3.3% | CTQ-SF<br>Traumatic Experiences Checklist | SANS |
| Ross, Anderson and Clark (1994), USA | 83<br>(56/25) | Cross-sectional | All participants had stable DSM-III R diagnoses of schizophrenia. | DES | PANSS-NS |
| Ruby et al. (2017), USA | 28<br>(n/r) | Cross-sectional | All participants had schizophrenia and schizoaffective disorder | ETI | PANSS-NS |
| Sahin et al. (2013), Turkey | 124<br>(88/36) | Cross-sectional | First episode psychosis 66.9%<br>Ultra-high risk for psychosis 33.1% | CTQ | BPRS- negative symptom items, SANS |
| Sar et al. (2010), Turkey | 70<br>(32/38) | Cross-sectional | All individuals met the criteria for DSM-IV schizophrenic disorder. | CTQ | SANS |

***Table 2.3. Study characteristics***

| Name | Population (m/f) | Design of Study | Diagnosis (FEP: First Episode Psychosis, MD: Major Depression, BP: Bipolar) | Measure of Trauma | Measure of Negative Symptoms |
|---|---|---|---|---|---|
| Schalinski et al. (2015), Germany | 62 (43/19) | Prospective | Schizophrenia 77.4%<br>Schizoaffective disorder 16.1%<br>Acute polymorphic psychotic disorder 4.8% | MACE | PANSS-NS |
| Schalinski et al. (2017), Germany | 180 (123/57) | Cross-sectional | Schizophrenia 73%<br>Acute polymorph psychotic disorder 13.3%<br>Schizoaffective disorder 11.1%<br>Delusional disorder. 0.6% | LEC CHECKLIST MACE-German Version | PANSS-NS |
| Scheller-Gilkey et al. (2004), USA | 122 (75/47) | Cross-sectional | Schizophrenia 100% | CTE Scales | PANSS–NS |
| Seidenfaden et al. (2017), Denmark | 76 (37/39) | Cross-sectional | Schizophrenia or acute schizophreniform 100% | CATS | PANSS-NS |
| Shah et al. (2014), Australia | 1825 (1087/738) | Cross-sectional | Non-affective psychosis 70.2%<br>Affective psychosis 19.2%<br>Other 10.6% | Standardised Interview (Based on the Australian National Framework for defining the four types of childhood abuse – interview scoring done under the guidance of staff from the Western Australian department of Child Protection to ensure conformity to national guidelines). | DIP |

***Table 2.3. Study characteristics***

| Name | Population (m/f) | Design of Study | Diagnosis (FEP: First Episode Psychosis, MD: Major Depression, BP: Bipolar) | Measure of Trauma | Measure of Negative Symptoms |
|---|---|---|---|---|---|
| Stain et al. (2014), Norway | 233 (n/r) | Cross-sectional | Met the DSM-IV criteria for schizophrenia spectrum disorder or psychosis. | Brief Betrayal Trauma Survey | PANSS-NS |
| Ucok and Bikmaz (2007), Turkey | 57 (29/28) | Cross-sectional | First episode psychosis 100% | CTQ, CAQ | BPRS<br>SANS |
| van Dam et al. (2014), the Netherlands | 2765 (1603/1162) | Cross-sectional | DSM-IV Criteria for a non-affective psychotic disorder (schizophrenia, schizophreniform, schizoaffective, delusional disorder, psychotic disorder otherwise not specified) | Dutch CTQ-SF | PANSS-NS |
| van Dam et al. (2015), the Netherlands | 131 (110/21) | Prospective | Psychosis 100% | CTQ- SF Dutch | SANS |

## Key for study characteristics table

| BPRS | Brief Psychiatric Rating Scale |
|---|---|
| **CAG** | Childhood Adversity Questionnaire |
| **CEQ** | Childhood Experiences Questionnaire |
| **CTM** | Cumulative Trauma Measure |
| **CTQ** | Childhood Trauma Questionnaire |
| **CTQ-SF** | Childhood Trauma Questionnaire- Short Form |
| **CTS** | Conflict Tactics Scale |
| **DES** | Dissociative Experiences Scale |
| **DIP** | Diagnostic Interview for Psychoses |
| **ETI** | Early Trauma Inventory |
| **LEC** | Life Events Checklist |
| **PANSS-NS** | Positive and Negative Syndrome Scale – Negative Symptoms |
| **SANS** | Scale for the Assessment of Negative Symptoms- |
| **TAA** | Trauma Assessment for Adults |
| **TSI** | Trauma Symptom Inventory |

***Table 2.4. Associations between adverse life events and negative symptoms Key – NR = not reported, NE = not examined and * = significant association***

| Study Name | Measure of Adversity | Measure of Negative symptoms | Childhood Sexual Abuse | Childhood Physical Abuse | Childhood Emotional Abuse | Childhood Physical Neglect | Childhood Emotional Neglect | Parental Separation | Parental Death | Parental Loss | Total Childhood Trauma |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Alameda et al., (2016), Switzerland | Extensive Interview by TIPP program | PANSS | NR | NR | NR | NR | NR | NE | NE | NE | Significant |
| Amr et al., (2012), Egypt | TAA | PANSS | 0.644* | 0.614* | NE | NE | NE | NE | NE | NE | Significant |
| Baudin et al., (2016), France | CTQ-French | PANSS | 0.057* | NR | NR | NR | 0.093* | NE | NE | NE | Non-Significant |
| Bendall et al. (2013), Australia | CTQ | PANSS | 0.84* | NE | NE | NE | NE | NE | NE | NE | Non-Significant |
| De Rosse et al (2014), USA | CTQ | CAPE | 0.54 | 0.31 | 0.321* | 0.40 | 0.58* | NE | NE | NE | Significant |
| Fawzi et al. (2013), Egypt | Cumulative Trauma Measure | PANSS | 0.48* | 0.35* | 0.17 | 0.23 | 0.16 | 0.23 | NR | NE | Significant |
| Furukawa et al. (1998), Japan | Loss section on PISA | PISA interview | NE | NE | NE | NE | NE | NS | NR | 0.19* | Significant |

***Table 2.4. Associations between adverse life events and negative symptoms Key – NR = not reported, NE = not examined and * = significant association***

| Study Name | Measure of Adversity | Measure of Negative symptoms | Childhood Sexual Abuse | Childhood Physical Abuse | Childhood Emotional Abuse | Childhood Physical Neglect | Childhood Emotional Neglect | Parental Separation | Parental Death | Parental Loss | Total Childhood Trauma |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Green et al (2014), Australia | Childhood Adversity Questionnaire | DIP | NR | 0.290 | 0.660 | NR | 0.272* | NR | NR | NR | Significant |
| Hacioglu Yildirim (2014), Turkey | Traumatic Events Checklist | PANSS | 0.34 | 0.34 | 0.018* | NE | -1.09 | NE | NE | NE | Significant |
| Heins et al. (2011), Belgium | CTQ- Dutch | PANSS | 0.99 | 2.60 | 1.18 | 1.67 | 1.09 | NE | NE | NE | Non-significant |
| Kelly et al., (2016), USA | CTQ | BPRS | NR | 0.42 | NR | NR | NR | NE | NE | NE | Non-significant |
| Kim et al., (2006), South Korea | Conflict Tactics' Scale | PANSS | -0.75 | -0.35 | NE | NE | NE | NE | NE | NE | Non-significant |
| Lysaker et al (2001), USA | Extensive standardised interview | PANSS | 0.67 | NE | NE | NE | NE | NE | NE | NE | Non-significant |
| Lysaker et al (2005), USA | Childhood Experiences Questionnaire | PANSS | 1.92 | NE | NE | NE | NE | NE | NE | NE | Non-significant |

***Table 2.4. Associations between adverse life events and negative symptoms Key – NR = not reported, NE = not examined and * = significant association***

| Study Name | Measure of Adversity | Measure of Negative symptoms | Childhood Sexual Abuse | Childhood Physical Abuse | Childhood Emotional Abuse | Childhood Physical Neglect | Childhood Emotional Neglect | Parental Separation | Parental Death | Parental Loss | Total Childhood Trauma |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Lysaker and LaRocco (2008), USA | Trauma Symptoms Inventory | PANSS | NR | NR | 0.212 | NR | NR | NE | NE | NE | Non-significant |
| Manuseto et al (2019), the Netherlands | CTQ- short form Dutch | PANSS | 0.93 | 0.89 | 0.89 | 0.65 | 0.18* | NE | NE | NE | Non-significant |
| McCabe et al. (2012), Australia | Childhood Adversity Questionnaire | DIP | NE | 0.05 | 1.29 | 3.25 | 3.25 | NE | NE | NE | Non-significant |
| Misiak and Frydecka (2016), Poland | Early Trauma Self report form | PANSS | 0.014 | 0.016 | 0.139 | NE | NE | NE | NE | NE | Non-significant |
| Peleikis et al 2013 Norway | M.I.N. I | PANSS | NR | NR | NR | NR | NR | NR | NR | NR | Non-significant |
| Prussner et al 2019, Canada | CTQ | BPRS | .199 | .377 | .006 | .009 | 0.42* | NE | NE | NE | significant |
| Ramsay et al (2011) USA | CTQ-SF Trauma Events Checklist | SANS | -0.07 | 0.11 | 0.11 | 0.15 | 0.25* | NE | NE | NE | significant |

***Table 2.4. Associations between adverse life events and negative symptoms Key – NR = not reported, NE = not examined and * = significant association***

| Study Name | Measure of Adversity | Measure of Negative symptoms | Childhood Sexual Abuse | Childhood Physical Abuse | Childhood Emotional Abuse | Childhood Physical Neglect | Childhood Emotional Neglect | Parental Separation | Parental Death | Parental Loss | Total Childhood Trauma |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Ross, Anderson and Clark (1994), USA | Dissociative Disorders Interview Schedule | PANSS | NR | NR | N | NE | NE | NE | NE | NE | Non-significant |
| Ruby et al (2017), USA | Early Trauma I inventory | PANSS | 0.22 | 0.22 | 0.22 | NE | NE | NE | NE | NE | Non-significant |
| Sahin et al. (2013), Turkey | CTQ | BPRS | NR | NR | NR | NR | NR | NE | NE | NE | Non-significant |
| Sar et al (2010), Turkey | CTQ | SANS | NR | NE | NE | NE | NE | NE | NE | NE | Non-significant |
| Schalinski et al. (2015), Germany | MACE | PANSS | NR | NR | NR | NR | NR | NR | NR | NR | Non-significant |
| Schalinski et al. (2019), Germany | Life Events Checklist and MACE | PANSS | NE | 0.562 | 0.562 | 0.27 | 0.24 | NE | NE | NE | Non-significant |
| Scheller-Gilkey et al. (2004), USA | Childhood Trauma Events Scale | PANSS | NR | NR | NR | NR | NR | NR | NR | NR | Non-significant |

***Table 2.4. Associations between adverse life events and negative symptoms Key – NR = not reported, NE = not examined and * = significant association***

| Study Name | Measure of Adversity | Measure of Negative symptoms | Childhood Sexual Abuse | Childhood Physical Abuse | Childhood Emotional Abuse | Childhood Physical Neglect | Childhood Emotional Neglect | Parental Separation | Parental Death | Parental Loss | Total Childhood Trauma |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Seidenfaden et al. (2017), Denmark | Childhood Abuse and Trauma Scale | PANSS | NE | NE | NE | NE | NE | NE | NE | NE | Non-significant |
| Shah et al (2014), Australia | Standardised Interview based | DIP | NR | NR | NR | NR | NR | NR | NR | NR | Non-significant |
| Stain et al, 2014 Norway | Brief Betrayal Trauma Survey | PANSS | NE | NE | NE | NE | NE | NE | NE | NE | Non-significant |
| Ucok and Bikmaz (2007), Turkey | CTQ | BPRS-NS SANS | 0.067 | 0.69 | 0.67 | 0.67 | 0.67 | NE | NE | NE | Non-significant |
| Van Dam et al (2014), the Netherlands | CTQ-SF Dutch | PANSS | NR | NR | NR | NR | NR | NE | NE | NE | Significant |
| van Dam et al. (2015), Netherlands | CTQ-SF Dutch | SANS | -0.24 | -.010 | 0.03 | 0.10 | 0.10 | NE | NE | NE | Significant |

### 2.4.2. Measurements of adverse life events

Out of the 34 studies, the most frequently used tool to assess adverse life events, was the self-reported Childhood Trauma Questionnaire (CTQ)[14] which was used in 12 studies, either the full 28-item questionnaire or the short-form of the questionnaire (CTQ-SF) in either Dutch, French or the English language. However, four studies adopted a standardised validated interview to assess incidents of childhood adverse life events. These four studies included Shah et al.'s [32] study in Australia, which used the Australian National Framework for assessing abuse in childhood (a well validated interview used in clinical settings across Australia). Similarly, a Swiss study[38] used a structured clinical interview to assess adverse life events, which was a table that clinicians completed on an individual's history during their time at the Treatment and Early Intervention in Psychosis Program at a hospital in Switzerland. A Norwegian study[39] also utilised a validated clinical interview, the Mini International Neuropsychiatric Interview (M.I.N.I) [40] to assess incidents of adverse life events. A study in Egypt [33] used part of the validated interview measure Psychiatric Initial Screening for Affective Disorders (P.I.S.A) [41] to record the loss of a parent.

The remaining studies used other validated self-reported measures to retrospectively assess adverse life events, which included the Cumulative Trauma Measure (CTM),[42] the Childhood Experiences Questionnaire (CEQ)[43] the Trauma Assessment for Adults (TAA)[44], and the Trauma Symptom Inventory(TSI) [45] to assess adverse life events. These self-report questionnaires used to assess experiences of adversities in childhood all map onto items on the CTQ, which is often regarded as the 'gold standard' [14] for assessing childhood trauma. Some of the measures utilised in the studies focus solely on childhood adverse life events, such as the CTQ, whereas other measures utilised, such as the Brief Betrayal Trauma Survey (BBTS), assess traumatic life events across the life span.

### 2.4.3. Measurements of negative symptoms

The most widely used measure of negative symptoms was the Positive and Negative Syndrome Scale, negative symptoms Subscale (PANSS-NS)[11] which was used in 24 studies. The Scale for the Assessment of Negative Symptoms (SANS)[13] was used in five studies. Two studies [31, 32] used the negative symptoms items from the Diagnostic Interview for Psychoses (DIP).[46] Two studies used items from the Brief Psychiatric Rating Scale (BPRS).[12] The negative symptoms subscale of the Community Assessment of Psychic Experiences (CAPE)[47] was used in one study.

The measures of negative symptoms used across the 34 studies all assessed similar negative symptoms, such as anhedonia and apathy. Arguably, SANS is the most comprehensive measure of negative symptoms, as it expands upon the questions and items utilised in the PANSS-NS. The DIP negative symptoms items map onto the 90 diagnostic items that are used for the criteria checklist for psychotic and affective illness.[46] The CAPE is a self-report questionnaire that assesses sub-clinical positive, negative, and depressive symptoms.

## 2.5. Is there an association between adversity and the severity of negative symptoms?

All 34 studies were either purely cross-sectional in design or assessed changes in symptoms over relatively short periods of adverse life events prior to symptom onset using validated measures of adversity and negative symptoms.

Of the 34 studies in the review, nine studies[19, 24, 28, 30, 33, 37, 38, 48, 49] reported a significant relationship between adverse life events and negative symptoms. These nine studies assessed the association between adverse life event(s) and negative symptoms, using three different designs: i) comparison of people with and without a trauma history; ii) comparing people with a high versus low trauma; iii) a correlational design using a continuous measure of trauma. Due to the cross-sectional nature of these 34 studies and a one-time measurement of exposure and outcome it is not possible to infer causal relationships from these studies.

Of the remaining 25 studies, these similarly looked at people with, and without, a history of trauma and grouped individuals on the level of trauma experienced and reported as correlations. There were no clear differences in the measures used between the studies that identified significant findings and those that did not. Studies with both positive and null findings included first-episode samples and those with more established diagnoses, although a higher proportion of studies with first-episode samples found no significant relationship between trauma and negative symptoms. For example, five studies included first episode psychosis samples, and of these, four reported no significant association between adverse life events and negative symptoms. Sample sizes ranged from 28 to 2,765, and, not surprisingly, those studies with smaller samples were less likely to report significant associations, perhaps suggesting a problem in relation to the power of the study.

There were no clear differences in terms of geographical location between those that found significant results and those that did not.

In summary, the findings from this review indicate inconsistent evidence of a relationship between the presence or severity of adverse life events and the severity of negative symptoms, with no clear differences in characteristics between studies that showed a relationship and those that did not. To understand the literature further, it is also important to consider the association between specific adversities and negative symptoms.

## 2.6. Is there a relationship between specific types of adverse life events and negative symptoms?

Of the 34 studies, some examined more than one adverse life event. Sixteen examined the association between childhood sexual abuse and negative symptoms, and seventeen reported on the association between childhood physical abuse and negative symptoms. Fifteen studies reported on the association between childhood emotional abuse and negative symptoms. Twelve studies reported on the association between childhood physical neglect and negative symptoms, with 14 studies reporting on the association between childhood emotional neglect and negative symptoms. Four studies reported on loss and separation.

### 2.6.1. Childhood sexual abuse and negative symptoms

None of the 16 [19, 22-24, 28, 29, 34-37, 49-54] studies that examined the relationship between childhood sexual abuse and negative symptoms found a statistically significant association.

The studies included three first-episode sample[28, 29, 53] studies and a mix of inpatient and outpatient sample studies. There were group comparison studies comparing individuals with and without a history of sexual abuse, as well as correlational studies exploring associations between continuous measures. The majority of studies scored highly on the quality appraisal tool, using samples that were largely representative of the target population. They all used well validated measures of childhood abuse, such as the CTQ, CTQ-SF, and Maltreatment and Chronology of Exposure Scale (MACE), and well validated measures of negative symptoms, such as PANSS and BPRS, suggesting that the findings can be confidently relied upon.

### 2.6.2. Childhood physical abuse and negative symptoms

None of the 17 studies [19, 20, 24, 28, 30, 31, 34-37, 49-55] that examined the association between the presence of childhood physical abuse and negative symptoms found a statistically significant association. The quality of these studies was deemed good, with studies reporting on all aspects of the study design, and, in all 17 studies information on childhood physical abuse was elicited through questionnaires such as the CTQ and standardised interviews. All 17 studies used samples that were not representative of the target population. The studies were conducted across the world, and two had samples of individuals with first-episode psychosis. To conclude, based on the outcome of the 17 studies the findings regarding childhood physical abuse and negative symptoms can be trusted to confirm that there is no association between childhood physical abuse and negative symptoms.

### 2.6.3. Childhood emotional abuse and negative symptoms

Of the 15 studies[19, 24, 27, 28, 30, 31, 35, 37, 50, 51, 53, 56-59] examining the relationship between emotional abuse and negative symptoms, two reported a statistically significant association. These two studies utilised different measures of negative symptoms with, DeRosse[19] and colleagues using the PANSS-NS, and Yildrum[37] and colleagues using the CAPE. These two studies scored well on the quality appraisal tool. The two studies are niche and probably not representative of the target population. Yildrum's study was restricted to female individuals all of whom were inpatients at one hospital in Turkey. DeRosse's study used a larger study group but recruitment was restricted to outpatients from one hospital in the United States of America and included an exclusion criterion that patients must not have been hospitalised in a psychiatric unit in the preceding six months. Although both studies reported a statistically significant association it is important to consider the sample size. Yildrum's study was 70 and DeRosse's study 631. Whilst not discounting the evidence from these two studies, the findings from Yildrum's study could be explained by the use of the CAPE, which assesses subclinical (positive) and negative symptoms (no other study in the systematic review used the CAPE). DeRosse's study with a relatively larger sample size meant it would be more likely to pick up any smaller effects that were present. Data in both studies were adequately presented thus these studies on the quality assessment tool.

Of the remaining 13 studies that did not report a significant association, all utilised similar measures to assess childhood emotional abuse and mirrored the studies of Yildrum and

DeRosse's in regard to quality appraisal. All of these 13 studies were good at reporting the aim, data and results and had sample sizes ranging from 74 to 1,276. These 13 studies did not represent the target population of individuals with a diagnosis of schizophrenia, as in a number of these studies, the exclusion criteria included individuals with a history of substance abuse or hospital admission in the last six months. To conclude, there is limited evidence to support the association between childhood emotional abuse and negative symptoms.

### 2.6.4. Childhood physical neglect and negative symptoms

Of the 12 studies [19, 24, 28, 29, 31, 35, 49-52, 54, 55] reporting on the association between childhood physical neglect and negative symptoms, none reported a statistically significant association. These 12 studies reported on the association between the presence and severity of childhood physical neglect and negative symptoms. These individual studies were conducted in different countries. It is pertinent to note that three of these 12 studies utilised data that were collected from different phases of the multi-site Genetic Risk and Outcome of Psychosis (GROUP) study, with the same principal investigators overseeing the research, thus there may be bias not only in the investigation of childhood physical neglect but also other types of adverse life events that these studies examined. Sample sizes within these 12 studies ranged from 28 to 1,276. All scored well on the quality appraisal tool but, as with other findings within this review, the studies recruited a specific pre-defined sample group, for example, current inpatients or outpatients at specific clinics. Whilst this does not invalidate the findings from these studies it makes them less representative of individuals with a diagnosis of schizophrenia. Most of the studies used the CTQ, and four studies used the Traumatic Events Checklist, the Childhood Adversity Questionnaire, the Life Events Checklist, and the MACE scale. This systematic review gathered evidence from studies conducted across the world with a range of inclusion criteria applied. Notwithstanding these factors the findings stand; there is no significant association between childhood physical neglect and negative symptoms.

### 2.6.5. Childhood emotional neglect and negative symptoms

Of the 14 studies [19, 24, 28-31, 35, 37, 49-52, 54, 57] reporting on the association between childhood emotional neglect and negative symptoms, six found a statistically significant association. These six[19, 24, 28, 30, 49, 52] studies were conducted in the United States, Canada, Australia, and the Netherlands. All the studies used validated questionnaires to assess adverse life events, with five studies using the CTQ or the CTQ-SF. The sample sizes of these studies ranged

from 61 to 1,276. Of these six studies, three included samples of individuals with early psychosis, two included first episode psychosis samples and the remaining study a sample of individuals with a chronic schizophrenia diagnosis. Of these six studies, two excluded individuals with a history of substance abuse and dependence. These six studies scored well on the quality assessment tool in that all clearly stated the aim, target population and reported the data and results described.

The remaining eight studies[29, 31, 35, 37, 50, 51, 54, 57] all scored well on the quality assessment tool. These were conducted in France, Australia, Egypt, Turkey, Belgium, and Germany; four used the CTQ, with the remaining studies using well validated measures of adverse life events, such as the MACE scale and the Traumatic Events Checklist. The sample sizes of these eight studies ranged from 28 to 675. Of these eight studies, three included first episode psychosis samples, one included an early psychosis sample and the remaining studies used chronic samples. Two of these eight studies excluded individuals with a history of substance abuse.

Three studies [49, 51, 52] used data from the GROUP study[60] with two[49, 52] of these studies reporting a significant finding, and one reporting a non-significant finding[51]. Those that reported a significant finding had a larger sample size than those studies that did not and thus were more likely to pick up on small effects. Two other studies[30, 31] used the Australian Schizophrenia Research Bank, with Green and colleagues' study reporting a significant finding between childhood emotional neglect and negative symptoms, and one study reporting a non-significant association.[31] Green et al.'s sample size was larger than that of McCabe and thus was more likely to pick up small effect sizes. Furthermore, Green et al.'s study[30] employed a set of exclusion criteria that was not evident in the study by McCabe et al;[31] an inability to converse fluently in English, organic brain disorder, brain injury with greater than 24 hour post traumatic amnesia, mental retardation, movement disorders, and current diagnosis of substance dependence. Applying a stringent inclusion/exclusion criterion makes the sample in this study less representative of the target population, particularly considering the evidence of co-morbidity between psychosis and substance abuse.

To conclude, the association between childhood emotional neglect and negative symptoms is more striking in comparison to the other subtypes of adverse life events investigated. It should however be noted that those studies that reported a significant association applied

criteria that may have made them less representative of the target population. There remain inconsistent findings as to the association between childhood emotional neglect and negative symptoms, with a handful of studies reporting a significant association.

### 2.6.6. Separation from parents, parental death, and parental loss as one category

Four[28, 31, 33, 35] out of the 34 studies examined the association between separation from parents and negative symptoms. These studies were conducted in Egypt, Japan, Canada, and Australia. Samples sizes in these studies ranged from 74 to 377 individuals. In all four studies, there was no relationship between separation from parents and negative symptoms. These studies all scored well on the quality appraisal tool, however each of these studies had specific sample criteria and consequently were not representative of the target population. All assessed the experience of parental separation through the application of different measurement tools. For example, Furukawa and colleagues used the PISA to assess parental death and separation, and McCabe and colleagues utilised items on the Childhood Adversity Questionnaire (CAQ) to assess the loss of a parent and/or sibling. To conclude, the findings lack clarity.

Within these four studies, one study examined the association between parental death and negative symptoms and reported a significant association. This study was conducted in Japan[33] and included a mixed-gender sample of 377 individuals with schizophrenia and assessed the experience of parental death using a standardised interview. Although this study was of good quality as rated on the AXIS tool, the paucity of studies examining this phenomenon suggests that further exploration is needed from across a number of countries and cultures.

There is no consistent evidence supporting an association between the experience of parental loss either through death or separation, as one entity, and negative symptoms. Further research is therefore needed to investigate the impact of both parental death and parental separation in a clear and systematic manner using a validated measure to assess the impact of these two potentially traumatic life events.

## 2.7. Discussion

This review sought to understand the association between adverse life events and negative symptoms, including sexual abuse, physical abuse, emotional abuse, physical neglect, emotional neglect and parental loss through death or separation.

Thirty-four studies met the criteria for this review, and, of these, nine reported a significant association between the presence of adverse life events and negative symptoms, suggesting that there is a relationship between adversity and negative symptoms. In Bailey et al's review[5] and meta-analysis of childhood trauma and symptoms of schizophrenia, negative symptom severity was significantly associated with childhood neglect in eight out of the 28 studies included in their review. The findings from this review echoes that of Bailey and colleagues' 2018 review, positing that negative symptoms are associated with childhood neglect, but only in a minority of studies. As stated in the results section, six studies reported a significant association between childhood emotional neglect and negative symptoms.

The studies included in this review used a range of measures to assess similar adverse life events. Some measures focus on the presence or absence of an adverse life event, whereas others assess the frequency of such events. Additionally, some measures assess the impact of an event and elicit further qualitative information through an interview assessment; for example, the relationship to the abuser and the support received after the event, but this information was not included in the analysis of the association between adversities and negative symptoms. The CTQ[61] is the most widely used measure of assessing childhood maltreatment because of its reliability, validity, and the short amount of time it takes for an individual to complete it. The CTQ, unlike other measures of assessing childhood and adulthood maltreatment (e.g., MACE), does not record the age at which the adverse life event was experienced. There is some recent research suggesting that the age at which adversity occurs may be important in relation to negative symptoms that develop later in life.[62] The results from this review suggest that further research is warranted which examines the association between the age at which trauma is experienced and the experience of negative symptoms. Current research has noted that if trauma is experienced at a sensitive period in an individual's development it may lead to greater unwanted effects on an individual's mental health.[63] Additionally, there is evidence that the presence of other supportive figures in the environment can act as a 'buffer' on the effects of trauma on an individual's mental health in later life. The presence of supportive figures was not assessed in any of the thirty-four studies in this systematic review.

A key strength and a novel aspect of this review is that it includes types of adversity which were previously unaddressed in prior reviews of adverse life events and negative symptoms, such as the impact of parental loss and separation from parents. However, this

review found no strong, conclusive or significant association between these non-intentional interpersonal events and negative symptoms. It is also pertinent to consider the paucity of research that has sought to assess experiences of non-intentional adverse life events such as parental loss, these adversities are not included on widely used measures of adverse life events such as the CTQ.

A limitation of this extensive systematic review is that it is widely acknowledged that the field of trauma research is evolving and since the completion of this review, there may be studies published that would also warrant inclusion in this review. This systematic review therefore does not capture all the research on adverse life events and negative symptoms to date.

The finding that particular types of adverse life events may be associated with negative symptoms is not unique and builds upon research conducted by others suggesting that particular types of adverse life events may be more strongly associated with specific psychotic symptoms than others[5, 6]. This does suggest that there may be a pathway from experiencing specific events, for example emotional neglect, to experiencing specific negative symptoms and raises the question about which mechanism(s) explain the association between neglect and the presence of negative symptoms. One such mechanism could be an insecure attachment style or an insecure-avoidant attachment style. According to attachment theory, individuals who have experienced unresponsive caregiving as infants develop an insecure avoidant attachment style in adulthood.[64] Current research suggests that individuals who have an insecure avoidant attachment style and display reduced affective reactions are more likely to display negative symptoms in clinical and non-clinical populations.[65, 66] It could be hypothesised that in response to experiencing neglect, the individual develops an avoidant attachment style that increases vulnerability to developing negative symptoms in the face of later stressors, including life events or the occurrence of distressing positive symptoms.

Furthermore, this association between the experience of childhood neglect and the presence of negative symptoms can be understood through Rector and colleagues' model [67] of the role of cognitive expectancies in the production of negative symptoms. An individual may express a lack of interest in engaging in activities because they believe they will receive no pleasure from participating; this then leads to withdrawal from social activities and interaction with those around them and to exhibit avolition and alogia.

Emotional neglect refers to when the primary caregiver does not provide support for a child's psychological and emotional needs. If an individual has never experienced enjoyment from activities either with or without others, they do not know how to experience anticipatory pleasure from activities and therefore do not participate in activities, leading them to withdraw.

Stampfer [68]posited theoretically that key symptoms of Post-Traumatic Stress Disorder (PTSD), such as avoidance and numbing, are the same as negative symptoms and therefore cannot be disentangled from negative symptoms. Considering the findings from this extensive review, taken together with Stampfer's theory, it can be stated that neglect is more likely to evoke these symptoms of withdrawal and numbing in individuals as opposed to other types of adverse life events, such as sexual or physical abuse.

## 2.8. Conclusion

In conclusion, adverse life events impact not only positive psychotic symptoms, as has been previously reported [6] but, specifically, there is a suggestion that adversity, most likely in the form of neglect, shows some association with negative symptoms. There remains little research conducted on the association between adverse life events and negative symptoms, and even fewer studies have sought to investigate the possible association between specific adverse events (e.g., incidents of parental loss) and other key non-interpersonal events and negative symptoms. In addition, little research has been conducted on the associations between adult adverse life events and negative symptoms, with the focus having been on retrospective reporting of childhood adversity life events. Furthermore, there has been little research on adverse life events and negative symptoms that has been conducted prospectively, as indicated by the majority of the studies in this review being cross-sectional in nature. To conclude, this systematic review highlights the need that further research should be undertaken to consider the association between adverse life events and negative symptoms and whether specific types of adversities are related to negative symptoms.

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# Preface to Chapter 3: Methods

This chapter seeks to provide supplementary information on the methodology and methods used in each of the studies that are presented in Chapters 2, 4 and 5.

An overview of the thesis is first presented, and this is followed by a section on the methodology used in each paper. Each methodology used in the PhD will be described in greater depth.

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# Chapter 3. Methods

## 3.1. Introduction

The purpose of this chapter is to outline the different methodologies and methods that have been employed to investigate and answer the five research questions. This chapter elaborates on sections of each study which are not found within the papers; including the justification of the measures used and ethical procedures. Figure 3.1. outlines the structure of the thesis, which is also presented in Chapter 1. Table 3.1. gives an overview of the five research questions and the methodologies employed to answer each question. These questions are also presented in Chapter 1.

***Figure 3.1. Illustration of the thesis structure***

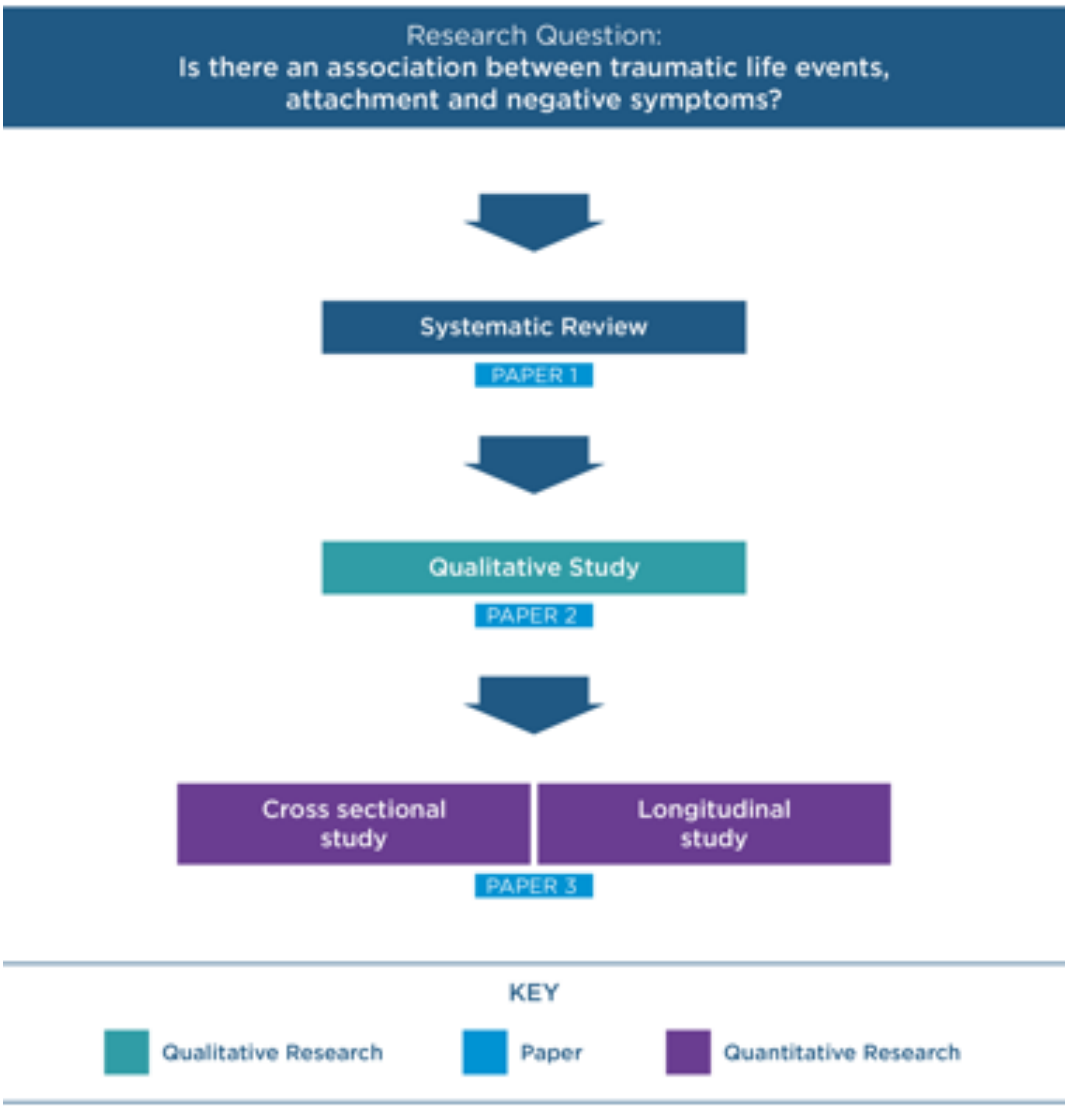


***Table 3.1. Thesis outline and the five research questions***

| Research Question | Design of study to address the aim | Thesis chapter |
|---|---|---|
| 1. Are trauma and negative symptoms associated? | Systematic review<br>Cross sectional | Chapter 2<br>Chapter 5 |
| 2. Are specific types of trauma associated with particular negative symptoms? | Systematic review<br>Cross sectional | Chapter 2<br>Chapter 5 |
| 3. How do individuals subjectively experience negative symptoms? | Qualitative study | Chapter 4 |
| 4. What is the association between trauma, attachment style and negative symptoms? | Cross-sectional study | Chapter 5 |
| 5. Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six months? | Longitudinal study | Chapter 5 |

## 3.2. Systematic review

Since the 1700s when James Lind (Lind, 1753) first conducted a systematic review to gather and examine the evidence related to scurvy, systematic reviews have continued to be used as a method of synthesising information in a clear, concise format. Thus, a systematic review was undertaken which asked the following questions:

i. Is there an association between adversity and severity of negative symptoms?
ii. Is there a relationship between specific types of adversity and negative symptoms?

The results of which answer the following thesis research questions:

1. Are trauma and negative symptoms associated?
2. Are specific types of trauma associated with particular negative symptoms?

To ensure that the systematic review was systematic and transparent, from initial conception to disseminating the results, the study was registered on the PROSPERO website (Booth et al., 2012)(ID: CRD: 2017058047).

### 3.2.1. Justification for the research questions

This systematic review investigated the association between adverse life events and negative symptoms because research to date on adverse life events and psychotic symptoms has primarily focused on positive psychotic symptoms; for example, in Varese et al.'s (Varese et al., 2012) and Bailey et al.'s (Bailey et al., 2018) meta-analysis papers. However, research published in the literature does suggest that specific adversities may be associated with specific symptoms (Bailey et al., 2018); therefore, this review examined whether this association applied to adverse life events and negative symptoms.

### 3.2.2. Justification for completing a systematic review

As stated in section 3.1, a systematic review was chosen because the aim of a systematic review is to synthesise all the research on a particular topic and is conducted in an unbiased, reproducible way to provide evidence for practice, policymaking and identification of gaps in the research. PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & Group, 2009) were followed to ensure each step of the review, including the search process, was transparent. The benefits of a systematic review, compared to a solely narrative review, are that a systematic review includes comprehensive search terms and, often includes an assessment of quality of each study. A narrative review usually gives an overview of the research questions without a quality assessment tool and the discussion is limited to a conceptual overview of the topic. The author was not familiar with the topic of traumatic life events and negative symptoms at the beginning of the PhD when this review was conducted and so did not feel that a narrative review would fully capture all the research on traumatic life events and negative symptoms without using a framework such as PRISMA.

Meta-analyses (Haidich, 2010) are a subset of systematic reviews and attempt to combine the results of quantitative studies statistically to provide a clear quantitative output regarding the size of an association. A meta-analysis was ruled out because, as stated in Chapter 2, a wide range of measures exploring traumatic life events were used across the studies in the systematic review, and this would have made it difficult to conduct a meta-analysis. Furthermore Egger and colleagues (Egger & Smith, 1997) noted some key biases that are common when conducting meta-analyses which may affect the reliability of these studies; bias in provision of data and biased inclusion criteria. Bias in provision of data refers to the bias that may occur when researchers are not willing to share their datasets. Biased inclusion criteria refers to a researcher including papers that only support the finding(s) that they are looking for and ignoring other relevant information.

### 3.2.3. Justification for the search terms

The search terms utilised in this systematic review paper were chosen after examination of prior review papers and other relevant literature. This included previous empirical studies that had examined the possible association between traumatic life events and negative symptoms. Thorough examination of the literature in this manner allowed the thesis author to understand possible search terms that are used in the traumatic life events and negative symptoms research field. Additionally, the thesis author discussed the potential search terms with the thesis supervisors, who have a vast experience in the field of psychosis and traumatic life events (Johns, Sellwood, McGovern, & Haddock, 2002; Korver-Nieberg, Berry, Meijer, de Haan, & Ponizovsky, 2015; Williams, Bucci, Berry, & Varese, 2018). Varese et al. (2012) and Bailey et al. (2018) assessed the association between adversities and positive psychotic symptoms. However, they did not include search terms for non-intentional adversities, such as parental loss or parental discrimination. The thesis author's current systematic review included a broad range of adverse life events, which had not been included in previous reviews such as parental loss. It also included search terms for specific negative symptoms, such as anhedonia, apathy, emotional withdrawal and flattened affect. The thesis author chose the search terms based on the key negative symptoms; in particular, the '5' As of negative symptoms, which form the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1982) affective flattening or blunting, alogia, avolition-apathy, anhedonia-asociality and attention. Manuals for the diagnosis of schizophrenia were also used as potential sources, including the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (Association, 2013).

### 3.2.4. Justification for not including attachment in the systematic review

As stated in Chapter 2, attachment style was not captured in this systematic review. The author acknowledges that doing so may seem not to fit with the PhD title 'understanding traumatic life events, attachment style and negative symptoms' but the systematic review focused on traumatic life events and negative symptoms to allow a full investigation of these two areas. It is considered that this review provides an in-depth exploration of the literature on traumatic life events and negative symptoms. It complements other systematic reviews and meta-analyses that have examined attachment styles and positive and negative symptoms; for example, the extensive review by Carr et al (Carr, Hardy, & Fornells-Ambrojo, 2018) on attachment styles and positive and negative symptoms.

### 3.2.5. Justification for choice of using an additional independent postgraduate student in addition to the thesis author to screen papers for the systematic review

A proportion of the papers, 25% of the titles and 25% of the full text papers were selected by the thesis author at random (as stated in Chapter 2 of this thesis) and were screened by an independent postgraduate researcher within the same division as the thesis author. The purpose of this was to ensure that the thesis author screened reliably and that all relevant papers were captured and retained in the study. This specific individual was chosen as she was conducting a systematic review on a different topic, alexithymia, so was aware of the methods required to conduct a systematic review in this area of research.

### 3.2.6. Justification for the choice of the quality assessment and critical appraisal tool

Critical appraisal of each study is a key component of conducting a systematic review to rigorously assess the quality of each study. The Appraisal tool for Cross-Sectional Studies (AXIS tool) (Downes, Brennan, Williams, & Dean, 2016) was selected because it considers every element of a study. Other quality assessment tools considered were the Newcastle-Ottawa Scale (NOS) (Wells et al., 2011), and the Effective Public Health Practice Project (EPHPP) (Evans, Lasen, & Tsey, 2015); however, these tools 'score' each study in a crude manner by reducing the studies to a numerical rating in a reductionist approach. AXIS allows the user to conduct a subjective assessment that accounts for every aspect of the study, from study design to the methodology applied, hence why this specific tool was selected. AXIS was also chosen because it has been more recently developed than other tools and allowed the thesis author to gain training in the use of a new quality assessment tool. The thesis author received guidance on using the tool from the tool's authors and through the use of the supplementary material. Table 3.2. highlights a list of additional critical appraisal tools that can be used to critically appraise each tool depending on the design of each study.

*Table 3.2. A selection of quality assessment and critical appraisal tools*

| STUDY DESIGN | CRITICAL APPRAISAL AND QUALITY ASSESSMENT TOOL | STRENGTHS | WEAKNESSES |
|---|---|---|---|
| Clinical Practice Guidelines | GRADE (Guyatt et al 2011)<br>The Grading of Recommendations of Assessment, Development and Evaluation (GRADE) is a common, sensible and transparent approach to grading quality (or certainty) of evidence and strength of recommendations. | GRADE reproducible and transparent framework for grading certainty in evidence | There is a considerable amount of subjectivity required in reaching a decision. |
| Cohort Studies | Critical Appraisal Skills Program (CASP)<br>Cohort Studies is a methodological checklist which provides key criteria relevant to cohort studies. | CASP checklist. The CASP tool has been found to be a relatively good measure of transparency of research practice and reporting standards | It does not sensitively measure research design. |
| Observational Studies | STROBE (Von Elm et al 2007)<br>Observational studies in epidemiology (cohort, case-control studies and cross-sectional studies). | Assists authors when writing up analytical observational studies | Not developed as a tool for assessing the quality of published observational results |
| Qualitative Studies | Critical Appraisal Skills Program (CASP)<br>Qualitative Research is a methodological checklist which provides key criteria relevant to qualitative research studies. | The CASP tool has been found to be a relatively good measure of transparency of research practice and reporting standards | It does not sensitively measure research design. |
| Non-Randomized Control Trials | Ottawa-Newcastle Scale (Peterson et al 2011)<br>The Newcastle-Ottawa Scale (NOS) was developed to assess the quality of non-randomized studies with its design, content and ease of use directed to the task of incorporating the quality assessments in the interpretation of meta-analytic results. | Validated<br><br>Quick to use | Not validated for cross-sectional studies |
| Randomised Control Trials | CONSORT (Campbell et al 2004)<br>The Consolidated Standards of Reporting Trials (CONSORT) Statement is a detailed document which outlines an explanation and elaboration of the CONSORT statement for reporting randomized controlled trials.<br><br>Cochrane Risk Bias tool (Higgins et al 2011)<br>The Cochrane Risk of Bias Tool is used by the Cochrane Collaboration to assess the risk of bias for randomized controlled trials. Bias is assessed as a judgment (high, low, or other). | This checklist states the standards of how the trial was designed, analysed and interpreted.<br><br>Clear structured criteria to follow when assessing the risk of bias in randomised controlled trials | Close attention needs to be given to how coherent CONSORT checklist items and the characteristics of the assessed trial are.<br><br>Items relate primarily to randomised controlled trials. |
| Systematic Reviews | AMSTAR (Shea et al 2009)<br>Assessment of Multiple Systematic Reviews (AMSTAR) is a 37-item assessment tool used to assess the methodological quality of systematic reviews. | AMSTAR encompasses most of the key constructs that are relevant to the assessment of the methodological quality of systematic reviews; | It does not include an item which relates to the explicit and reproducible method for assessing the quality of the body of evidence for each important outcome |

## 3.3. Empirical studies: methodology design and methods used

A mixed-methods approach was used to answer the following thesis research questions:

3. How do individuals subjectively experience negative symptoms?
4. What is the association between trauma, attachment style and negative symptoms?
5. Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six months?

### 3.3.1. Rationale for mixed-methods design

Quantitative data collection enables an assessment of the strength of association between constructs that use prespecified criteria to determine significant relationships. In contrast, qualitative data enables individuals to describe their experiences, or views, in much greater detail. Qualitative data provides the researcher with a wide and informative body of data to analyse (Braun & Clarke, 2013).

Epistemological assumptions underpin all research. According to the Merriam-Webster dictionary (Dictionary, 2002), epistemology can be defined as 'relating to the study of the nature, origin, and limits of human knowledge'. Different epistemological assumptions often reinforce quantitative and qualitative research. Constructionism, which is more typically associated with qualitative approaches, argues that the knowledge of how things are is a product of how we come to understand them (Burr, 2006). Conversely, positivism, which is more typically associated with quantitative approaches, states that there is a linear relationship between the world and our perception of it (Kuhn, 2000).

The studies within this PhD took a constructionist stance. This approach was taken as it allows for the assimilation of new information into a previously existing framework. The theory states that knowledge should be discovered as a whole. Through investigating trauma, attachment style and negative symptoms, the thesis author recognised how these relate to one another in the appropriate cultural context.

The qualitative study took a constructionist approach by understanding how individuals experience negative symptoms of schizophrenia in their own lives. The thesis author learnt about negative symptoms through engaging in an active learning and discovering process, and through extensive interviewing of individuals about their experiences. Thus, the findings from the qualitative study are the result of a co-construction between the thesis author and the participants. However, despite these studies being constructionist, to a

certain extent the cross-sectional and longitudinal study took a positivist stance in that there is an objective reality that can be known to the researcher through the use of the appropriate methods.

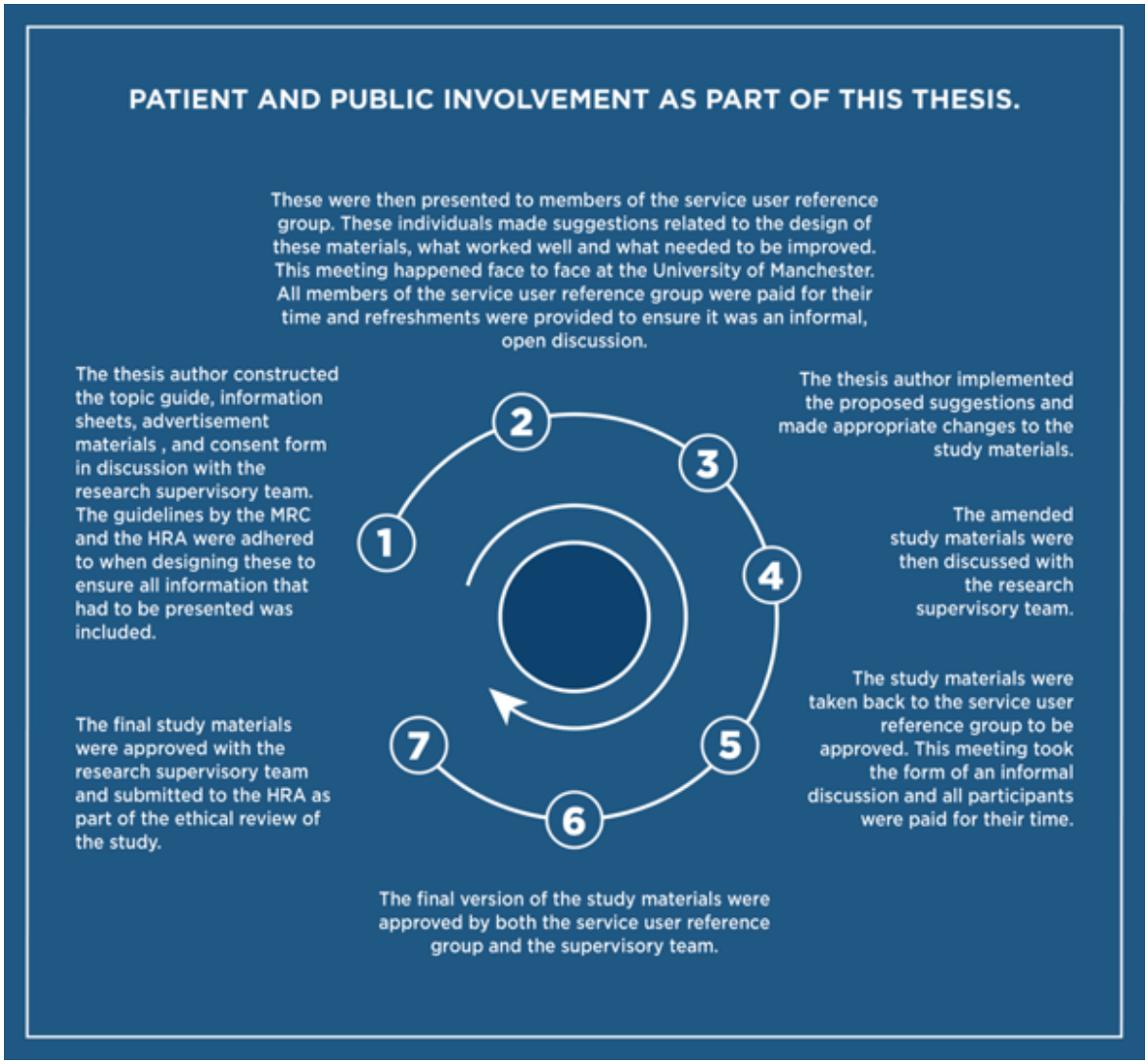
The issues that relate to ethics, patient and public involvement, advertisement of the study, inclusion and exclusion criteria, participant distress, participant risk, risk to the researcher in the field and confidentiality are common to both empirical studies. This section explores these issues before exploring the methodologies of each study in further depth.

### 3.3.2. Ethics

Ethical approval for these studies was obtained from the Health Research Authority and the NHS. All ethical guidelines given by the Declaration of Helsinki (Association, 2009) and Health Research Authority were adhered to throughout this study. Furthermore, to ensure that all current ethical guidelines were adhered to, the thesis author attended and completed a Good Clinical Practice (Vijayananthan & Nawawi, 2008) face-to-face training workshop at the beginning of the PhD, and this was updated two years later, as per the University of Manchester's guidelines. In addition to NHS ethical approval, both the qualitative and quantitative studies were externally peer reviewed (Appendix 3).

### 3.3.3. Patient and public involvement

*Figure 3.2. A pictorial description of the role of PPI*




Patient and Public Involvement (PPI) is recognised as an integral component of research with people. PPI is now a requirement for many research funding bodies. As the Medical Research Council supported this thesis, training and guidance on conducting PPI was completed in the first year of the PhD to enable the thesis author to involve patients and the public in these PhD studies.

The involvement of members of the public and patients in the conception of a study brings together different perspectives, and the consideration for a wide range of views and experiences. Design of research without PPI is to the detriment of the research, patients and the public (Domecq et al., 2014; Ennis & Wykes, 2013).

These studies were designed with the help of a service user reference group; this did not include the formulation of research questions and decisions about the methods used in the

study. Identifiable or demographic information was not captured on the members of the group, for confidentiality reasons. All had lived experience of mental health symptoms and were paid for their time, as per the guidelines set out by INVOLVE (Involve, 2016). These individuals helped with the design and format of the study materials, including, the advertisement and information sheets (Appendix 4).

It was hugely beneficial to involve members of the public in this research, as doing so gave greater insight into possible issues that were not immediately apparent to the thesis author; for example, one member commented that certain fonts are hard to read when on antipsychotic medication. Another member commented that it should be made clearer in the topic guide what negative symptoms are, as often, when an individual is experiencing symptoms, they do not perceive them as symptoms as they have to live with them.

In the quantitative study, the thesis author piloted the measures used in this large-scale empirical study with members of the service user reference group to estimate how long the battery of assessments would take. This information was needed so that the ethics committee could determine what was being asked of participants. It was also important to provide potential participants with an estimate of how long the study would take to complete (this being an ethical requirement and so participants were fully aware of what their participation entailed and were not misled). The members of the service user reference group also gave useful advice about the order in which the battery of measures should be administered to ensure minimal discomfort for the participants. On this recommendation, in the empirical studies, the questionnaire that assesses depression - the Calgary Depression Scale for schizophrenia (CDSS; Addington, Addington, & Schissel, 1990) - was asked in the middle of the battery of assessments and the last assessment was the PANSS, rather than asking about experiences of depression and hopelessness at the end of the assessment.

### 3.3.4. Advertisement

As stated in Chapter 5, the thesis author initially approached five NHS sites and a range of settings within these Trusts; these included community mental health teams, rehabilitation and recovery units, inpatient, and acute and forensic settings. The studies were presented at face-to-face meetings to several clinical multi-disciplinary teams and with patient-led community meetings on wards. Staff and potential participants were provided with an information sheet, a consent to contact form, and a poster that gave explicit information about the inclusion criteria for the study (Appendix 5). It was important that the study was presented in person by the thesis author in order that any questions about potential referrals could be addressed and to encourage rapport between the thesis author and the clinical teams within each Trust.

### 3.3.5. Inclusion criteria

In all studies, participants had to be 18 years of age or over, under the care of a mental health team or with a care coordinator or equivalent. Individuals were also required to meet the International Classification of Diseases (ICD-10) codes F20–F29 criteria for schizophrenia and related psychosis diagnosis (as judged by the thesis author from information provided by their care coordinator). In order to participate in the qualitative study, individuals had to have a score of at least three on two or more of the negative symptom items on the negative symptom subscale of the Positive and Negative Syndrome Scale (PANSS-NS). Individuals also had to be currently experiencing negative symptoms for the cross-sectional study, as defined by a score of at least three, on at least one of the PANSS negative syndrome subscale items, as assessed by the thesis author. This threshold was set after examination of the current literature on negative symptoms and negative symptom threshold scores used in other clinical studies (Patel et al., 2015; Santor, Ascher-Svanum, Lindenmayer, & Obenchain, 2007). This threshold was also set by examining the scores on the PANSS-NS and identifying what would constitute as an experience of negative symptoms, and, given that a score of three on the PANSS-NS is defined as ‘mild’, this was seen as the minimum required as scores below three are absent or minimal.

### 3.3.6. Exclusion criteria

It should be acknowledged that it was essential that all individuals could speak and understand the English language, as unfortunately, there were no finances to support the use of interpreters or translators. The thesis author acknowledges that this may have excluded some individuals who may have wanted to participate but their level of understanding of the English language was limited. The inclusion of such individuals could be a consideration for further studies. Additional exclusion criteria were applied, including individuals with an organic brain disorder implicated in the aetiology of symptoms and individuals with an intellectual disability that would impact their completion of written assessments, as evaluated by the care coordinator or thesis author. These criteria were applied as every individual must have the capacity to consent and understand the research in which they are participating.

### 3.3.7. Participant distress

It was anticipated that the interviews and questionnaires could elicit some sensitive information or lead to participant distress. It was therefore important that a distress protocol was in place; this stated that, if at any point in the study the participant was either uncomfortable or distressed, the interview or assessments would pause, and if necessary, stop. No interviews or assessments had to be stopped. Where concern was raised about an individual's mental health, the thesis author brought this to the attention of the clinical supervisors (Gillian Haddock and Katherine Berry) immediately after each interview and the appropriate course of action was taken. (Appendix 6). In order that participants did not feel distressed after completion of the interview, the thesis author debriefed each participant and explained the support available from a variety of specialist organisations. The information included the contact details of MIND and the Samaritans. After participation in the quantitative study, the information given also included details for ASSIST trauma care, which is a third-sector organisation that offers therapeutic programmes for adults and children who have been affected by a range of traumatic life experiences.

### 3.3.8. Risk assessment

Participant risk was managed through a risk assessment conducted by the thesis author in consultation with the participant's care coordinator or equivalent, with the agreement of the participant (Appendix 7); this assessment evaluated the individual's current risks in relation to mental health and any risks within their home environment. In cases where the care coordinator advised that the interview should take place in a public space, rather than in the individual's home, this was arranged at either a local General Practioners (GP) surgery, or in a meeting room at a community mental health team office. Individuals who were in an inpatient setting were risk-assessed by their ward manager, or relevant care professional, before the interview. Any necessary precautions were taken as advised by ward staff.

### 3.3.9. Risk to the researcher in the field

These studies involved the thesis author working alone in both inpatient and community settings. The University of Manchester lone worker policy was adhered to, and this ensured a limited risk for the thesis author; the policy stipulates that individuals adhere to a 'buddy system' by checking in with a staff member at the university when entering the participant's house/ward setting and state the duration and finish time of the interview. If the 'buddy' does not hear from the individual at the end of the allocated time, the 'buddy' must then take appropriate action, including informing the police, should the researcher be unreachable by telephone. Gillian Haddock and Katherine Berry supervised the thesis author in adhering to the lone worker policy throughout each of the studies in this PhD. (Appendix 8)

### 3.3.10. Confidentiality

All information for these studies was stored in accordance with the current data protection requirements, including the General Data Protection Regulation (GDPR) (Goddard, 2017) guidelines that came into force in the United Kingdom in 2018. All questionnaires were given a participant number, and no identifiable information was recorded on the questionnaires. All participant consent to contact forms, as well as participation consent forms, were kept separate from the questionnaires in a locked filing cabinet at the University of Manchester, which only the thesis author and the two supervisors could access. To further safeguard confidentiality, within the qualitative study, there was limited reporting of the demographics of the sample. It was discussed and agreed by the researcher and supervisors that some characteristics, such as the occupation of participants and gender could lead to some individuals being identified, particularly given the small sample size.

The remaining sections of this chapter explore the qualitative and quantitative studies respectively and the particular methods used in each study.

## 3.4. Understanding individuals' subjective experiences of negative symptoms of schizophrenia: a qualitative study

The aim of this study was to answer the following thesis research question:

3. How do individuals subjectively experience negative symptoms?

### 3.4.1. Design

Most studies on negative symptoms of schizophrenia have adopted a quantitative approach using clinician and observer-rated measures to assess negative symptoms. However, to gain a full picture, there is a need to understand negative symptoms from the viewpoint and experiences of the individual. The aim of this qualitative study was, therefore, to understand how individuals experience the negative symptoms of schizophrenia from their own perspective.

A qualitative research methodology with semi-structured interviews was used to elicit open-ended responses to questions informed by the existing literature. The topic guide provided the framework for the interviews but allowed participants to raise issues that were not pre-empted by the researcher. This approach was crucial as emerging thoughts and questions could be explored during the interview.

### 3.4.2. Justification for an interview-based study

Semi-structured interviews explored individuals' subjective experiences of living with, and experiencing, negative symptoms. This information could only have been elicited through this method, as it allowed participants to be open and freely share their experiences of life with negative symptoms. An interview study allowed individuals to articulate the experience of these symptoms without any prompting and to flow freely, without interruption. A written questionnaire that asked individuals to express their experience of each symptom may not have been easy for all participants; expressive writing has its benefits (Pennebaker, 1997) but it does not permit free-thinking and flow of conversation to the extent that talking face-to-face to someone allows.

Alternative approaches to collecting qualitative data were considered including unstructured interviews, focus groups and diaries (Braun & Clarke, 2013). However, structured interviews are the most common approach for qualitative research and is one of a group of methods that can be used to analyse interview data. As a result, a semi structured interview schedule was created, and semi structured interviews were adopted to elicit information for this study.

### 3.4.3. Recruitment and sampling frame

Individuals for this study were recruited from across the United Kingdom, and from a wide range of services, including inpatient rehabilitation recovery units and community settings. It was important to have a wide range of individuals, from a range of mental health settings, to explore the research questions fully. Thus, purposive sampling was adopted to ensure individuals from different ethnicities and age groups participated in the study. The study was included in the National Institute for Health Research (NIHR) portfolio, because the Medical Research Council funded the PhD; and this enabled the thesis author to have support from the Clinical Studies Officers in recruitment.

*3.4.3.1. Justification for choice of recruitment sites*

This study was conducted in two NHS Trusts, one in the North of England and one in the South of England; these two Trusts were chosen as, after an initial contact, they had expressed an interest in the study. Furthermore, in order to ensure that data saturation and data sufficiency (Saunders et al., 2018) was achieved in a short time frame (due to the time constraints of a PhD), the thesis author only approached these two Trusts. Recruitment across the United Kingdom ensured that should one Trust be recruiting participants for similar themed research projects and therefore unable to meet the recruitment target for this study, then participants could be sought from the other Trust. Consequently, access to two Trusts offered higher chances for the recruitment target to be met both quickly and efficiently.

### 3.4.4. Interview procedures

Each interview was conducted following the procedure(s) outlined in the main paper presented in Chapter 4.

### 3.4.5. Materials

(Appendix 9)

*3.4.5.1. Positive and Negative Syndrome Scale*

Prior to the interview, the thesis author captured individuals' current positive and negative symptoms through the use of PANSS (Kay, Fiszbein, & Opler, 1987) to ensure that all participants had current experience of negative symptoms of schizophrenia. Individuals had to have a score of at least three, on two or more of the negative symptom items on the PANSS.

*3.4.5.2. PANSS training*

In order to administer PANSS, the thesis author was fully trained in administering the PANSS, through the use of interactive and applied learning methods. The PANSS has complex features and thus requires an extensive training programme to become fully trained in the measure. These methods included the thesis author watching and scoring the PANSS on gold standard videos, which had been approved as part of the process to achieve reliability on the PANSS rating. The thesis author also role played the PANSS with peers, in the presence of research clinical psychologists who were fully trained in the PANSS. Furthermore, the thesis author had the opportunity to attend PANSS assessments with peers and observe the PANSS being conducted in 'real life' in 'real time.'

The thesis author attended monthly supervision meetings throughout the PhD with other researchers, who were also using the PANSS, whilst working on a large randomised controlled trial led by Katherine Berry and Gillian Haddock within the Division of Psychology and Mental Health at the University of Manchester; this approach to PANSS training allowed discussion of any ratings about which the thesis author was unsure.

The thesis author also adhered to the four core principles in the use of the PANSS (Opler, Yavorsky, & Daniel, 2017) throughout the PhD; i) read each item definition and all anchor points carefully and interpret each element as literally as possible, ii) always give the highest rating that applies, iii) always consider the reference period and time frame – reiterate that it is based on the past week and iv) use all available information for rating as long as it meets the basis for rating.

### 3.4.6. Demographic data

Demographic data was collected using a self-report questionnaire, which was based on the Operational Criteria Checklist for Psychotic Illness and Affective Illness (OPCRIT; McGuffin, Farmer, & Harvey, 1991). Age, gender, ethnicity, occupation and living status (living alone or with a partner) were recorded, as is stated in the paper. It was important to note this information because it enables a full view of the participant to be obtained and to ensure that people with a wide range of ethnicities and ages were captured in the study.

### 3.4.7. Data collection

Individuals who expressed an interest in participation in the study, either directly or via a clinical team, were contacted by the thesis author who provided further details of the study, confirmed that involvement was voluntary and explained that participants had a right to withdraw without any negative consequences for their care. All participants were given a further twenty-four hours before confirming their participation. Dependent on identified risks, interviews were either arranged with the participant electing the day, time and place or recommended by their care coordinator. All interviews either took place in a healthcare setting, including a General Practioners surgery, or in the participants' own homes or in a public space.

### 3.4.8. Transcription of interviews

The thesis author transcribed all interviews on a computer at the University of Manchester. All transcriptions were encrypted, and when typed up, each transcription had a password that only the thesis author knew. It is acknowledged that it may have been more time-efficient for a company or other individuals to transcribe the interviews; however, due to financial constraints and ethical approval, the author carried out all the transcriptions. Although this took time, it allowed the thesis author to immerse herself completely in the interviews. The transcription of the interviews was verbatim, which is also known as orthography. Transcribing verbatim focused on all words spoken, as well as sounds, such as laughing or crying, and recorded the words as they were said, including all the pauses and utterances. Subsequently, each interview was transcribed by adhering to the guidelines that Jefferson (Jefferson, 2004) produced for verbatim transcriptions. These are illustrated in Table 3.3.

*Table 3.3. Transcription notation system*

| Feature | Notation and explanation of use |
|---|---|
| The identity of the speakers turn-talking in talk | The speaker's name, followed by a colon signals the identity of a speaker; start a new line every time a new speaker enters the conversation, and start the first word of each new turn of talk with a capital letter. |
| Overlapping speech | Type ((in overlap)) before the start of the overlapping speech. |
| Spoken numbers | Spell out all numbers. |
| Inaudible speech | Use ((inaudible)) for speech and sounds that are completely inaudible. |
| Laughing, coughing etc. | ((laughs)) and ((coughs)) signals a speaker laughing or coughing during talking. |

### 3.4.9. Use of field notes

Field notes were maintained from the conception of the study to the final data analysis. The field notes contained useful information about the contextual environment of the interviews, preconceptions, notes to follow up and personal feelings. This information is vital as factors such as the environment, time of day, and weather can impact on the interview and the participant. For example, in one of the interviews conducted on a ward, a staff member came in and asked to see the patient and give medication. The interview was paused. The thesis author's notes highlight that, following the pause, the flow of the interview was negatively impacted demonstrated by a lack of flow of conversation between the thesis author and the participant. In another interview, in a hospital ward, the participant was keen to go outside and enjoy the sunshine. It was felt that the responses to questions were limited as being outside in the sunshine was more important to the participant than the interview.

In addition to the field notes, it was also beneficial to check the audio recording so any changes in flow or voice could be noted. It was important to put both the field notes and audio recording together when analysing the data so that the interview and its context could be accurately documented. To further ensure rigour, the thesis author followed the structures provided by Fook and Gardner (Fook & Gardner, 2007), which suggests that the researcher examine the field notes using a set of questions such as: i) what do these notes suggest regarding my beliefs and values about myself, my relationships with others and my

assumptions about knowledge, power and privilege and ii) how did my presence as an observer influence others around me?

### 3.4.10. Data analysis method

Thematic analysis was selected as the most appropriate method of examining and analysing the data because the aim of this study was to explore individuals' experiences and not to propose a theory to understand possible similarities in experiences of negative symptoms from a range of individuals. A six-step- approach to analysing the data from the study was used; the thesis author and all supervisors participated in steps 2 to 6, as outlined in Chapter 4.

### 3.4.11. Justification for thematic analysis

In qualitative research there are several different analytic approaches that can be applied to the data, for example, thematic analysis, interpretative phenomenological analysis, narrative analysis, discourse analysis, conversation analysis and grounded theory. Table 3.4. outlines some of the different analytic methods.

Thematic analysis was selected as the best possible methodology to answer the research question 'how do individuals subjectively experience negative symptoms?' because thematic analysis aims to broadly analyse an entire dataset of transcripts and generate an analysis by examining the dataset closely and in relation to the research question. The process is iterative and circular with themes continually being revisited between the theme that the researcher has noted and the dataset; it also considers how each theme fits with the wider research question. The type of thematic analysis used in this study (as explained in Chapter 4), was inductive as the analysis was based upon the data and not on an existing pre-determined theory that the thesis author had identified. It was also experiential in that it considered the participants' experiences and how they made sense of negative symptoms in their own lives. When thematic analysis is used, it is important that the research question is kept at the heart of the analysis to ensure that the question is being answered through the analytic process.

Interpretative Phenomenological Analysis (IPA; (Smith, Jarman, & Osborn, 1999; Smith & Shinebourne, 2012) is a form of qualitative analysis that is heavily influenced and underpinned by phenomenology and hermeneutics. Each participant is a 'case' in the analysis of IPA whereas in thematic analysis each individual is considered separately in the dataset; thus, it is not an iterative process to the extent that thematic analysis is. IPA, in

many ways, could have been used to explore this research question as it is concerned with how individuals make sense of their lived experiences; however, IPA would not have allowed for a broad set of themes to have emerged from across the dataset, which was the aim of this study.

Other potential qualitative designs include, but by no means are restricted to, narrative analysis, discourse analysis and conversation analysis. These methods focus on what the individual is saying, and how they narrate their own story. Grounded theory was not considered to be a good 'fit' for this research. Grounded theory aims to build a theory from the data obtained, similar to thematic analysis. It is cyclical and an exhaustive process in that it is an iterative process moving between the data collected and theory that is being developed simultaneously. This can lead to the researcher becoming embedded in the coding of data to the detriment of the focal research question(s). Grounded theory has a high potential for methodological error, amongst novice researchers, such as the adoption of a purposeful sampling technique instead of a theoretical sampling technique.

*Table 3.4. Overview of analytic methods used in qualitative research*

| METHOD | DESCRIPTION OF ANALYSIS | VARIETIES | DESCRIPTION | STRENGTHS | WEAKNESSES |
|---|---|---|---|---|---|
| Thematic Analysis | A broad method which is defined through the method of handling the data; a method of identifying patterns of meaning across a dataset in relation to a research question. | Inductive | Generates an analysis from the data up; thus, the analysis is not shaped by an existing theory (Braun and Clarke, 2006). | It is theoretically flexible and an accessible approach towards obtaining qualitative data. Allows for categories to evolve from data. Allows for social as well as psychological interpretations of data. | Thematic analysis might miss variating data.<br><br>Thematic analysis currently has no set analytic method. |
| | | Theoretical | Analysis is guided by an existing theory and theoretical concepts. | | |
| | | Experiential | This analysis focuses on the participant's experience of the world and how they make sense of it. | | |
| | | Constructionist | Constructionist TA focuses on how topics are constructed and also how accounts construct the world. | | |
| Interpretative phenomenological Analysis | A method that is influenced by the theoretical underpinnings of phenomenology and hermeneutics. It is idiographic in that analyses are conducted by examining each individual as a separate case rather than nomothetic which looks on a more generalised scale. | IPA | IPA can be conducted with one participant as is idiographic. It is also possible to have multiple participants but when analysing the data, you analyse the data from one individual before moving onto the next individual. IPA conveys the interplay between what the individual said, their reflections on their experiences and the analyst's interpretation(s) (Smith et al., 2009). | IPA allows the researcher to gain a phenomenological account of participant's experiences. Identifying their perceptions of their social world. These will be subjective and could be in-depth accounts. | Researchers may analyse data looking for specific themes that will support their research question. They may find it difficult to remain objective.<br><br>There is a danger that researchers may miss other relevant themes. How researchers interpret data will also be dependent on their own phenomenological worlds and experiences. |
| Narrative Analysis | Acknowledges that people create and use stories to make sense of the world for themselves. Thus, this analysis method focuses on what the individual (the storyteller) has decided to include in their story. | Narrative | It is not a fixed method and there are many ways in which narrative analysis can be structured. One way is using Labov's model of structural narrative analysis that focuses on the HOW of an event that is told and the organisation of the narrative. | Considers individuals' meaning and how they make sense of a situation whilst considering an individual's biography and history | Interviewing for narrative analysis requires narrative inducing questions to be asked |
| Discourse Analysis | Is a term used to describe a number of approaches that can be used to analyse talk and text. The main principle of discourse analysis is that it constructs rather than reflects reality. (Potter and Wetherell., 1987). | Thematic discourse analysis | Identified discursive themes and patterns in data. Identifies how themes construct reality in particular ways. | During analysis asks the three questions; what? How why? | The analysis encompasses a wide range of formats with varying approaches and perspectives |
| | | Interpretative repertoires | Understands how individuals talk ABOUT an object. | | |
| | | Critical discursive | Offers a 'synthetic' approach that focuses on the socially available and acceptable linguistic resources and language practices. | | |

*Table 3.4. Overview of analytic methods used in qualitative research*

| METHOD | DESCRIPTION OF ANALYSIS | VARIETIES | DESCRIPTION | STRENGTHS | WEAKNESSES |
|---|---|---|---|---|---|
| Conversation Analysis | This is the study of conversation yet the focus is not only on the content of the talk but on the methods people use to make sense of the world they are living in. | Conversation Analysis | Examination of the analysis done by the researcher asking three questions:<br><br>1. What do we have here?<br><br>2. What particular patterns can we identify?<br><br>3. What do people themselves do when engaged in talk with one another? | can be used in a wide range of settings from an everyday situation to more specific events that occur. | There is not a strict framework to follow when conducting the analysis |
| Grounded Theory | It was developed by Glaser and Strauss (Glaser & Strauss, 1967) with a range of different versions of grounded theory. It focuses on building theory from data whilst focusing on understanding social processes. | Grounded Theory-lite | Generates a range of categories with suggestions on possible relationships with concepts. | Rich data can be produce<br><br>Systematic data approach to data analysis | Limited generalisability<br><br>Exhaustive process |
| | | Full Grounded Theory | Aims to build a theory from the data (Glaser & Strauss,1967). | | |
| | | Positivist Grounded Theory | This analysis aims to represent reality (Glaser, 1978). | | |
| | | Constructionist Grounded Theory | This analysis considers the role of the researcher in the analysis process and Charmaz (2006) argues that in this analysis one 'true' reading of data is not obtained. | | |
| | | Constructionist Grounded Theory | This analysis gives close attention to the language used and there is emphasis on the discourses which shape the account. | | |

### 3.4.12. Quality in qualitative research

In qualitative research the process does not often appear transparent and so is sometimes critiqued for this (Leung, 2015). It is therefore important to consider the quality of such research to ensure that it is transparent and well conducted. The quality criteria that are often applied to qualitative research considers the following factors: reflexivity, transparency, coherence, value/contribution and rigor. Each of these five factors will be briefly examined in relation to this qualitative research study. Furthermore, to ensure that quality was adhered to and transparency was maintained throughout this qualitative study the COnsolidated criteria for REporting Qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007) was adhered to. The COREQ is a 32-item checklist that reports on key aspects of the study; for example, characteristics of the research study team, context of the study, analysis and interpretations (Appendix 10).

### 3.4.13. Reflexivity

Reflexivity refers to the process of critically reflecting on what, as an individual and as a researcher, one brings to the research and how the process and results may be influenced and impacted by one's own behaviours. Reflexivity is crucial when conducting qualitative research (Finlay & Gough, 2008). There are two types of reflexivity: functional reflexivity, which considers how the formulated questionnaires and interview topic guides may impact the findings; and personal reflexivity, which considers the role of researchers and their influence on the study.

Open questions in this qualitative study allowed individuals to express themselves with little prompting by the thesis author. Interestingly, because of the thesis author's absence of personal experience of negative symptoms, many of the participants were keen to share details of their experiences. Arguably, the thesis author's lack of personal experience of negative symptoms was an asset, because her interpretations were less likely to be coloured by past experiences. The insight gained into the impact of negative symptoms on the daily lives of participants who experience anhedonia or apathy over a long period meant that when the thesis author came to analyse the data, personal perspective of negative symptoms had altered since the design of the study. As the study progressed the thesis author was more acutely aware of how persistent these negative symptoms can be for many individuals who experience them.

In terms of personal reflexivity, the thesis author has stated in the 'about the author' section of the thesis, that she has no experience of negative symptoms or no personal

experience of the mental health system as a service user. The thesis author is a White British woman with past experiences of working alongside individuals who experienced psychosis in inpatient settings. Additionally, the thesis author had past experience of the recruitment of individuals with these diagnoses to take part in clinical trials. The thesis author, from her prior experiences, understood and believed that every individual in society has a story to tell and recognised from her clinical work how disabling negative symptoms can be.

### 3.4.14. Transparency

Transparency acknowledges that as much information as possible has been clearly provided to ensure each step of the process is clear and may be replicated. For example, researchers should state what has been done and by whom and why this method of transcription was chosen. Transparency also means that transcripts, fields notes and other comments relating to the research process are available. An exemplar extract from an interview transcript can be seen in Appendix 11 The notion of transparency can be highlighted in the prior section on reflexivity, which highlights the thesis author's position and gives insight into the lens through which she undertook the research.

### 3.4.15. Coherence

Demuth (Demuth, 2013) states that coherence is the degree to which the study is internally consistent, comprehensive and persuasive as a whole. Coherence is the thread which joins the theoretical approach, the research question and the methodological approach and interpretation. Coherence was achieved in this qualitative study by ensuring that a clear rationale for each decision made in each step of the qualitative study was provided and the consequences and benefits of each decision was considered. Examples of this include: the reason for opting for thematic analysis over other methodologies, the reason for using two NHS Trusts as opposed to just one NHS site, and the reason for the thesis author transcribing all the interviews verbatim. This method of questioning and justifying each decision in a rational and logical manner ensures that no decision is made for arbitrary reasons and therefore it optimises the coherence of the study and ultimately the quality of this research.

### 3.4.16. Value and contribution of the research

Yardley (Yardley, 2008) states that there is no point in conducting research unless the findings can contribute to society. Furthermore, the Research Excellence Framework (Sousa & Brennan, 2014) within the United Kingdom states that the research has to have

an impact outside of academia, for example, the general public. This particular factor was considered at the conception of this qualitative study by the thesis author, who realised that very little qualitative research had been produced on how individuals qualitatively experience severe negative symptoms. One other group of authors (Gee et al., 2019) conducted a similar study which used qualitative methods to understand individuals' experiences of negative symptoms, but Gee's sample only included individuals with a first episode psychosis diagnosis. The thesis author's study focused on individuals with both early schizophrenia or chronic schizophrenia diagnoses and thus took a different perspective to Gee and colleagues' study. The thesis author's rationale for conducting this qualitative study was because negative symptoms are acknowledged to be disabling to individuals, but there is a lack of knowledge as to how they are disabling and how these symptoms manifest in an individual's life. Therefore, this study answered these questions and gives further insight for clinicians, carers and researchers into the experiences of negative symptoms in a more comprehensive way than an observer rated instrument such as the PANSS could reveal.

### 3.4.17. Rigour

Rigour ensures the qualitative study has been conducted thoroughly and systematically to guarantee that the research is of a high standard. Some qualitative researchers disagree with the term 'rigour' when applied in qualitative research, because they state it implies that there is a 'right way' of conducting qualitative research that does not allow for the multiple interpretations which can be correct, yet all different (Willig, 2013). Rigour therefore means that the research must be systematically undertaken with clear justified processes. However, where the methodology allows there should be flexibility to allow for an iterative process which provides valid and trustworthy data, and the outcomes contribute to the area(s) of research.

### 3.4.18. Trustworthiness

Trustworthiness reflects the transparency of the research process from conception to publication and is achieved by following each of the factors explored in this section of the thesis. Compliance with all these factors allows the readers to see that a clear and systematic process has been achieved and the findings are plausible and are justified by the data produced.

### 3.4.19. Data collection dates

The data was collected between April 2017 and July 2018.

## 3.5. Traumatic life events, attachment style, and negative symptoms: a cross-sectional study and a six-month follow-up study

The aim of this study was to answer the following thesis research questions:

4. What is the association between trauma, attachment style and negative symptoms?

5. Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six months?

### 3.5.1. Design

This large study was called LEANS, which stands for Life experiences, Engagement with services, Attachment style and Negative Symptoms. This can be seen on the study information documentation. The logo is a hand holding a plant symbolising how, as individuals, we grow and develop over time with the help of those around us.

This study used solely quantitative methods and sought to understand and investigate the association between traumatic life events, attachment style and negative symptoms. Service engagement was also examined in this study. As stated by O'Brien (O'Brien, Fahmy, & Singh, 2009):

> *"Engagement is not a simple construct and is rarely explicitly defined."*
>
> *(O'Brien et al., 2009)*

Disengagement from services is, however, a serious problem which needs to be considered in psychosis research. Those individuals with a diagnosis of schizophrenia who drop out of research often have greater social needs and are more unwell than those individuals who actively engage with services both in inpatient and outpatient settings (Killaspy, Banerjee, King, & Lloyd, 2000). Within psychosis research, it has been evidenced that poorer servicer engagement is associated with greater severity of negative symptoms (MacBeth, Gumley, Schwannauer, & Fisher, 2013).

The study was a cross-sectional study examining the association between traumatic life events, attachment style and negative symptoms at one time point and a longitudinal study in that negative symptoms were assessed six months later.

### 3.5.2. Recruitment and sampling frame

Recruitment was conducted across England in five different NHS sites so that there was a diverse sample in terms of diagnoses, with some individuals having early psychosis and some more chronic symptoms of schizophrenia.

#### *3.5.2.1. Justification for the sample size*

The sample size was calculated by the thesis author using G Power (Erdfelder, Faul, & Buchner, 1996); a sample size of 82 participants was estimated to provide 80% power to detect, a coefficient of .3 at the 0.05 alpha level. Eight five, participants participated in the study in total.

#### *3.5.2.2. Justification for choice of recruitment sites*

This study recruited from across five NHS Trust sites within England. The reason for this number of sites was to ensure that the target sample size was reached. Recruiting across sites enabled a larger number of people to be involved. The number of sites was selected after the thesis author liaised with the local NIHR clinical research network. As this study was externally funded, it meant that it could be on NIHR's clinical portfolio and thus have the assistance of clinical research officers. Prior to setting up the five sites, the thesis author liaised with the clinical research officers in the local Trusts to gain an understanding of the estimates of eligible participants, and what target they perceived was achievable from their own Trust. Some Trusts stated they had more potential eligible participants than other Trusts, hence the use of five Trusts spread across England (Appendix 12).

### 3.5.3. Study procedure

The procedure adhered to while conducting this study is outlined in the full paper, which is presented in Chapter 5. The thesis author conducted all aspects of the study and, as stated in sections 3.4.2 and 3.4.8, the thesis author was clinically supervised by Katherine Berry and Gillian Haddock throughout the PhD to manage risk to both the participant and to the thesis author.

### 3.5.4. Materials

*3.5.4.1. Measures of traumatic life events - Justification for using three different measures of traumatic life events*

Trauma was assessed using three different validated questionnaires. The reason for utilising three different assessments of traumatic life events was that there is, to date, no single questionnaire that measures all possible traumatic life events that an individual might experience.

The Childhood Trauma Questionnaire (CTQ) (Bernstein et al., 1994) is a commonly used measure to assess childhood trauma retrospectively. It assesses five different types of childhood maltreatment (DiLillo et al., 2006) : emotional abuse, physical abuse, sexual abuse, emotional neglect, physical neglect and has a scale for minimisation/denial. CTQ has been well validated and shown to demonstrate good test-retest reliability over a two- to six-month period (Bernstein, Fink, Handelsman, & Foote, 1998).

However, CTQ does not assess the presence or absence of events occurring in adulthood. It also does not assess the presence of non-intentional traumatic life events occurring in childhood, such as the loss of parents through death or natural disaster. Importantly, CTQ also does not assess the presence or absence of childhood bullying. Childhood traumatic events are now well-documented and evidenced to impact an individual's mental health (Bailey et al., 2018; Varese et al., 2012).

The Trauma History Questionnaire (THQ) (Hooper, Stockton, Krupnick, & Green, 2011) was used in addition to the CTQ, because it assesses trauma in depth by asking individuals to state the age at which event(s) occurred and to identify the perpetrator. It also records events occurring in adults and distinguishes between events occurring in childhood and adulthood. This approach is particularly pertinent as recent research by Schalinksi and colleagues (Schalinski et al., 2019) has indicated that the timing of environmental adversities may be crucial in knowing if individuals will go on to develop severe mental health needs.

The THQ is a 24-item- checklist that covers events that fall into the subscale categories of crime, general disaster, physical abuse, and sexual experiences (Appendix 13). The questionnaire assesses exposure to each event through 'yes' or 'no' responses, and frequency is assessed by asking participants to report the number of times an event has occurred. The THQ has been validated in clinical and non-clinical samples. Mueser and

colleagues (Mueser et al., 2001) found moderate to high test-retest reliability for a range of traumatic events experienced over a lifetime in a psychometric evaluation of the measure in individuals with severe mental illness.

Together, CTQ and THQ assess traumatic life events that may have occurred from childhood to adulthood. However, neither CTQ nor THQ explicitly asks individuals about incidents of bullying, possibly because the measures are 20 years old and, at that time when these measures were constructed and validated, bullying was not as widely reported in this literature as other types of trauma. As the aim of this study was to assess the association between traumatic life events and negative symptoms it was necessary to assess bullying, as the current literature surrounding childhood adversities and psychotic symptoms has shown that bullying may lead to the development of psychotic phenomena (Trotta et al., 2013; Varese et al., 2012). Thus, four validated questions from Olweus' (Olweus, 1996) measure were selected to assess bullying alongside the use of CTQ and THQ. These four validated questions are: i*) I was called mean names, was made fun of or teased in a hurtful way, ii) other students left me out of things on purpose, excluded me from their group of friends or completely ignored me, iii) I was hit, kicked, pushed, shoved around or locked indoors and iv) other students told lies or spread false rumours about me and tried to make others dislike me*. Each question is answered on a five-item- scale ranging from: *did not happen to me, only once or twice a week, two or three times a month, about once a week and several times a week*. Olweus (Olweus, Limber, & Mihalic, 1999) found evidence to support the construct validity of the Bullying Victimisation Questionnaire through extensive testing and retesting of the measure in different populations. Olweus (Olweus, 1994) found correlations in the .60 – .70 range between class-aggregated student ratings of bullies and victims, and class-aggregated estimates of self-report ratings suggesting that the scores are robust.

*3.5.4.2. Measure of attachment style – Justification for using the Psychosis Attachment Measure*

To assess attachment, the Psychosis Attachment Measure (PAM(Berry, Wearden, Barrowclough, & Liversidge, 2006)) was used (Appendix 14) PAM is a 16-item self-report questionnaire that assesses anxious and avoidant attachment styles, with questions relating to thoughts and feelings in close interpersonal relationships. It has been widely used in psychosis populations and thus, it was agreed, by the thesis author and supervisors, to be the most appropriate tool. Each item on PAM is rated on a 4-point Likert scale, from 'not at all' to 'very much'. PAM has been demonstrated to have good validity and good internal

consistency in clinical samples (Berry, Barrowclough, & Wearden, 2008). The PAM was chosen over other measures of attachment style because it is time efficient, it has been used with similar populations before and it is not fixated on a particular type of relationship – it encompasses all types of relationships, friendships and romantic relationships. The PAM is a questionnaire which also has advantages over interview measures, such as the Adult Attachment Interview (AAI)(George, Kaplan, & Main, 1996), which are time consuming to administer and score. Furthermore, to implement and use the AAI measure, it requires extensive training. In this specific study, the thesis author felt that asking the participants to take part in another interview, in addition to the PANSS, the CAINS, the PSYRATS and the CDSS, would be too onerous particularly when reliable information on attachment styles can be obtained from the PAM whilst still enabling the research questions of this thesis author to be examined (refer to Appendix 11).

Table 3.5 highlights the other measures of attachment that have been utilised in psychosis studies, and are widely validated to assess attachment style in psychosis population, and as identified in Gumley et al.'s extensive 2014 (Gumley, Taylor, Schwannauer, & MacBeth, 2014) systematic review paper.

*Table 3.5. Measures of attachment*

| MEASURE | DESCRIPTION | STRENGTHS | WEAKNESSES |
|---|---|---|---|
| AAI<br>AdultAttachment Interview<br>(Kaplan & Main, 1985) | The AAI is a semi structured interview which has twenty questions and allows the interviewer to categorise an adult's attachment style through questions about their childhood and relationships. | It uncovers traumatic experiences and important losses in a systematic manner whilst assessing attachment style. The 20 questions create an interview schedule that is standardised. Can be analysed in two ways using the Q-sort method or the narrative approach. | Requires extensive training led by a therapist who is trained in AAI.<br>Time consuming for both the interviewer and the interviewee. |
| AAQ<br>Adult Attachment Questionnaire<br>(Simpson, 1990) | The AAQ is a measure of psychological and emotional closeness in relationships by focusing on insecure, avoidant, anxious/ambivalent attachment style. Individuals read three short descriptions and indicate which one best describes their feeling regarding relationships. Participants are also asked to rate how much each description relates to general relationships style. | The AAQ yields continuous measures of three attachment styles in romantic relationships - secure, avoidant and anxious. | Only focus on three types of attachment.<br><br>Focused on romantic and/ dating partners. |
| ASQ<br>Attachment Style Questionnaire (Feeney, Noller, & Hanrahan, 1994) | The ASQ is a self-report measure used to assess an individual's internal working model of relationships generally. | Relationships in general rather than romantic or close relationships with five subscales that cover a wide range of emotional states; confidence, discomfort with closeness, relationships as secondary need for approval and preoccupation with relationships. Used as,a continuous measure of attachment security or can be used to divide participants into four groups; autonomous, avoidant, preoccupied and ambivalent. | It asks implicitly rather than explicitly about relationships in general and so does not focus on romantic or close relationships |
| PAM<br>Psychosis Attachment Measure (Berry et al 2006) | A 16-item questionnaire that asks individuals to rate each item on a four-point Likert scale to the extent to which each statement describes how they relate to key people in their life currently. The PAM assesses two dimensions of anxious and avoidant attachment. PAM items were derived from previous self-report attachment measures. | Self-report questionnaire. Asks about attachment in relation to any individual not just romantic relationships. | Items are broad and not specific questions on particular romantic relationships. Likert scale is not numerical but is holistic with items related from not at all , a little, quite a bit to very much and focuses on two dimensions of anxious and avoidant attachment. |
| RAAS<br>Revised Adult Attachment Scale<br>(Collins & Read, 1990) | The RAAS is a self-report measure of adult attachment based on the descriptions given in the aforementioned AAQ. The three subscales are; closeness, dependence and anxiety. | Three attachment styles (secure, avoidant, and anxious-ambivalent) in the context of romantic relationships.<br>Dimensional scores are converted into four categories. Secure, occupied, dismissing and fearful. | Captures all relationships not just romantic relationships. |
| RQ<br>Relationships Questionnaire<br>(Bartholomew and Horowitz, 1991) | The RQ is a brief self-report questionnaire that is an adaption of the AAQ and categorise attachment styles as adults through the use of four statements and individuals are asked to state the statement which most describes their friendship pattern. Individuals are also asked to rate how much each description corresponds to their general relationships. This questionnaire focuses on the four attachment styles' secure, fearful/avoidant, preoccupied and dismissive/avoidant. | Dimensions related to one's model of self (dependence) and model of others (avoid- ance) can also be generated from this instrument however, its primary aim was to classify into one of four prototype | Primarily focused on friendships rather than romantic or other relationships. |

*3.5.4.3. Justification for only assessing attachment style at baseline*

Attachment style was recorded at baseline only. The current literature was examined, and it was evident that attachment style in adults does not change substantially over a six-month-period. Bowlby stated that 'whatever expectations are developed during those [childhood] years tend to persist relatively unchanged throughout the rest of life'(Bowlby, 1973); this suggests that in a six-month timeframe, an adult's attachment style is not going to alter significantly (Chopik, Edelstein, & Grimm, 2019; Consedine & Magai, 2003). Furthermore, the aim of this study was not to explore the changing nature of attachment style but rather the nature of the negative symptoms over a six-month- period.

### 3.5.5. Measures of positive and negative symptoms

*3.5.5.1. Justification for using the Positive and Negative Syndrome Scale*

Symptomatology was assessed at baseline and at a six-month follow-up using PANSS; this 30-item semi-structured interview has been extensively used and has good psychometric properties. Seven items relate to positive symptoms, seven to negative symptoms and 16 to general psychopathology; each item is scored on a 1-7 scale (with 1 being 'absent' and 7 being the highest). The thesis author acknowledges that there are a number of measures that could be administered to assess negative symptoms but the PANSS is widely used in mental health research and has high internal consistency in samples of people with a diagnosis of schizophrenia ($\alpha$-.71;(Esfahlani, Sayama, Visser, & Strauss, 2017). Another measure that was considered was the Brief Negative Symptom Scale (BNSS; (Kirkpatrick et al., 2011) which includes 13 items that fit onto six subscales and these subscales are anhedonia, distress, asociality, avolition, blunted affect and alogia. All the items are rated on a scale of 0 to 6 with 0 being absent and 6 being severe. However, the thesis author acknowledges that although the PANSS has not been modified since it was conceptualised thirty years ago and so does not address all of the five current domains of negative symptoms that the BNSS does, the PANSS does offer a comprehensive understanding of an individuals' symptoms. The PANSS focuses on the positive and negative symptoms over the past seven days. Weaknesses of the BNSS are similar to those criticisms of the SANS (Andreasen, 1982), that it is too restrictive i.e., it focuses on a specific set of predefined negative symptoms. The strengths and weaknesses of measures of negative symptoms are illustrated in Table 3.6.

***Table 3.6. Overview of measures of negative symptoms***

| Instrument (Author, Year) | **Administration time** | **Type of measure** | **Number of items** | **Strengths** | **Weakness** | **General Utility** |
|---|---|---|---|---|---|---|
| Brief Negative Symptoms Scale (BNSS; Kirkpatrick 2011) | 15 minutes | Clinician rated. Measures negative symptom. It assesses distress in addition to the negative symptoms domain that is included in the CAINS. | 13 items with 6 subscales that are<br>• Anhedonia<br>• Distress<br>• Asociality<br>• Avoliton<br>• Blunted Affect<br>• Alogia | BNSS scores are highly correlated with SANS and PANSS negative symptom scores. | Not clear whether BNSS is sensitive to change, so not evident whether it can be used in clinical trials. | BNSS was developed out of recommendation by the NIMH-sponsored Consensus Development Conference on Negative Symptoms that suggested that a scale based on recent developments into negative symptoms should be constructed. (Kirkpatrick, Fenton, Carpenter, & Marder, 2006) |
| Clinical Assessment Interview for Negative Symptoms (CAINS; (Kring, Gur, Blanchard, Horan, & Reise, 2013) | Cannot be measured - it varies | Clinician rated. Comprised of two scales that are scored separately: motivation and pleasure with nine and four items respectively. | Total of 13 items that assess presence and severity of negative symptoms. All items are scored on a five-point scale from 0 (no impairment) to 4 (severe deficit). | Brief yet comprehensive scale and can be used in clinical and research contexts.<br>Assesses remembered and anticipated pleasure.<br>Greater convergent validity than the BPRS and the SANS for assessing negative symptoms (Kring et al., 2013) | CAINS scales are not strongly related to depression, or positive symptoms (Kring et al., 2013) yet this could also be considered a strength. | Novel approach to assessing negative symptoms and has yielded promising results in clinical and research settings. |

***Table 3.6. Overview of measures of negative symptoms***

| Instrument (Author, Year) | **Administration time** | **Type of measure** | **Number of items** | **Strengths** | **Weakness** | **General Utility** |
|---|---|---|---|---|---|---|
| Positive and Negative Syndrome Scale (PANSS; Kay et al.,1997) | 45-50 minutes | Clinician rated | Total of 30 items. 7 items on positive scale and 7 on negative scale. 16 items on the general psychopathology scale. | Sensitive to change – therefore a gold standard in treatment studies.<br>It is not restricted to negative symptoms exclusively but also assesses the assessment of overall psychopathology. | Criticised because it includes items that measure cognitive functioning such as abstract thinking that have been recognised as distinct from negative symptoms (Harvey et al 2006) | Most widely used rating scale both in academic and pharmaceutical trials. |
| Scale for Assessment of Negative Symptoms (SANS; (Andreasen, 1989) | Varies, no specific time frame. | Clinician rated | Originally consisted of 25 items but now has 19 items that map onto 5 scales.<br>• Affective flattening<br>• Alogia<br>• Avolition-apathy<br>• Anhedonia-asociality<br>• Attention | Separates negative symptoms from positive symptoms and depression. | Cannot be conducted without the Scale for Assessment of Positive Symptoms (SAPS; Andreasen et al 1984). | One of the most commonly used rating scales, and widely used in academic and pharmaceutical trials. |

*3.5.5.2. Justification for using The Psychotic Symptom Rating Scales*

The Psychotic Symptom Rating Scales (PSYRATS) (Haddock, McCarron, Tarrier, & Faragher, 1999) comprise two scales measuring hallucinations and delusions on an 11 and 6 item scale respectively; each item is rated zero to five. The tests were administered at baseline and six months. PSYRATS has been shown to have good reliability and validity for individuals with psychosis (Haddock et al., 1999). PSYRATS was used in this study to obtain a clear understanding of an individual's symptoms and provide a more detailed description of the sample at both time points.

*3.5.5.3. Justification for using The Clinical Assessment Interview for Negative Symptoms*

The Clinical Assessment Interview for Negative Symptoms (CAINS) (Horan, Kring, Gur, Reise, & Blanchard, 2011) was conducted with fifty out of the eighty-five study participants at baseline and all seventy one participants at six months completed the CAINS. (Appendix 15). The decision was made by the thesis author in discussion with the supervisors to introduce these measures part-way through the recruitment phase of the study, because the items on CAINS are not fully captured by PANSS; specifically, the PANSS does not capture experiential and expressive deficits which the CAINS does. It became apparent to the thesis author that, after seeing the first participants, these individuals lacked the ability to think of an activity that they had enjoyed in the last week or so. The PANSS-NS does not seek information on remembered and anticipated pleasure. CAINS assesses remembered pleasure and anticipated pleasure from work, school, and recreational activities in addition to examining expressive deficits such as lack of facial expressions. The inclusion of the CAINS was therefore crucial because it could be that these scores on remembered pleasure and anticipated pleasure on the CAINS may be associated with traumatic life events. It has been hypothesised that individuals who have experienced traumatic life events may experience numbing and withdrawal as a way of coping with the traumatic event (Stampfer, 1990). The CAINS measure has good psychometric properties in psychosis samples (Horan et al., 2011; Strauss & Gold, 2016). One may consider it 'odd' to include two measures of negative symptoms and more onerous to add another measure of negative symptomology to this study for participants. The information gained from asking individuals to complete the CAINS short interview was, however, pertinent to understanding the research question and hypotheses explored in this study. The unique aspect of the CAINS is that it clearly and explicitly asks individuals to state experiences of remembered pleasure in the previous seven days and to state anticipated moments of pleasure in the upcoming seven days – the PANSS-NS does not

ask this of individuals in such an explicit and probing manner. It is of great importance to ask individuals these questions because the experience of negative symptoms is greater than simply experiencing pleasure or happiness from an activity, and thus, by tapping into remembered pleasure and anticipated pleasure, researchers gain greater insight into the depth of negative symptoms. Studies have illustrated that individuals with negative symptoms experience a reduced capacity to anticipate pleasure (Raffard, Esposito, Boulenger, & Van der Linden, 2013). In this specific study, the thesis author, having conducted the systematic review on traumatic life events and negative symptoms, identified that perhaps if an individual has experienced a traumatic life event of any degree, they may be less able to experience and anticipate pleasurable events in their lives.

*3.5.5.4. Training on CAINS*

The CAINS is a relatively new measure of assessing the experiential and expressive deficits of negative symptoms, and training in it is only available through the CAINS research website (Forbes et al., 2010). The thesis author gained an insight into CAINS by scoring sample videos from the research website to assess her own reliability on administering this measure. The thesis author was also provided with manuals from the CAINS authors to ensure that she was proficient in its administration. Additionally, the thesis author had the opportunity to role-play CAINS, under supervision, to familiarise herself with the measurement tool and, for example, to understand how to introduce each question and set the scene so the interview was delivered in a manner that was clear for the participants.

A group of researchers in the United States developed the CAINS (Forbes et al., 2010) to allow individuals to rate the amount of pleasure they have experienced and whether they anticipated future pleasure. Some minor modifications pertaining to the language used in the questions on the CAINS scale had to be made by the thesis author to ensure that the interview could be administered, and each item was understood. This was seen by the fact that individuals found it difficult to understand what was meant by ‘pleasure’ and thus, the word ‘enjoyment’ was used, as well as ‘pleasure,’ to assist individuals with the intention of the questions. The thesis author contacted researchers in Germany and Scotland who also had to use alternative words for ‘pleasure’ or ‘pleasurable.’ The reason for this is that in the United Kingdom and Germany perhaps individuals associate the word pleasurable with sexual activities rather than enjoyment of activities, such as seeing friends or playing sport

with friends; the Lexico Oxford Dictionary defines pleasure as ‘sensual gratification’, and, as a verb, is used as ‘giving sexual enjoyment or pleasure to’.

#### *3.5.5.5. Measures of depressive symptoms*

*Justification for using the Calgary Depression Scale for Schizophrenia*

The Calgary Depression Scale for Schizophrenia (CDSS; Addington et al., 1990) was administered as a control for depression in the analysis, due to the overlap in the phenomena between depressive symptoms and negative symptoms (Krynicki, Upthegrove, Deakin, & Barnes, 2018). CDSS was used at baseline and the six-month follow-up. CDSS features nine items, and each item is scored from 0 to 3, with 0 being ‘absent’ and 3 being ‘severe’. CDSS has been shown to be reliable and has good congruent validity with a self-report scale of depression in people with a diagnosis of schizophrenia. In further research, CDSS has been shown to have good specificity for depression and showed no correlation with scales of extrapyramidal symptoms and negative symptoms (Addington, Addington, & Maticka-Tyndale, 1994).

#### *3.5.5.6. Measures of engagement with services*

*Justification for using the Service Engagement Scale*

The care coordinator completed the Service Engagement Scale (SES;Tait, Birchwood, & Trower, 2002), at baseline and six months with the thesis author over the telephone. The SES asks questions concerning an individual’s engagement during the previous two weeks. The scale is a 14-item- inventory completed by the clinician or individual’s key worker or care coordinator. Each item is rated on a scale of 0 to 3, with 0 meaning ‘not at all’, or ‘rarely’, and 3 meaning ‘most of the time’. Higher scores reflect a greater level of difficulty of engagement with services. The scale covers four key areas of engagement: availability, collaboration, help-seeking and treatment adherence and a total score is obtained. The SES has been demonstrated to have good test-retest reliability across populations.

### 3.5.6. Demographic data

Demographic data were collected through means of a self-report questionnaire, which was based on the OPCRIT criteria (McGuffin et al., 1991). Age, gender, ethnicity, occupation and living status (living alone or with a partner) were recorded. Individuals completed the demographic questionnaire at the first visit only.

### 3.5.7. Data analysis method

The analysis of the data for this study involved five steps to test each of the five hypotheses in turn, in a systematic manner.

1. Initially to understand and immerse oneself in the dataset the thesis author conducted descriptive statistics to describe each of the variables used in the quantitative study. This allowed the thesis author to understand the mean, standard deviation and skewness of the data, through examining the kurtosis level. Parallel to running the descriptive statistics, the thesis author explored the distribution of each variable in the study through the completion of histograms using SPSS. This provided clear visual data (Appendix 16).

2. Before hypothesis testing the impact of demographic factors was investigated.

3. The thesis author then conducted correlations to test the hypotheses where this was applicable. Given the non-normal distribution of the data, Spearman's bivariate correlation was used. This allowed the thesis author to understand whether there was an association between trauma and negative symptoms. Furthermore, correlations between attachment style and negative symptoms were also conducted.

4. Where it was deemed appropriate mediation analysis following Baron and Kenny (Baron & Kenny, 1986) rules for conducting mediation analyses were employed.

5. The thesis author also planned additional exploratory analyses to further understand the association between trauma and negative symptoms any relationships.

The in-depth analyses applied can be seen in Chapter 5, where the quantitative paper is presented.

#### *3.5.7.1. Data standardisation procedures*

In the linear regression models, both unstandardised (B) and standardised coefficients (Beta) were reported in the analysis. When several predictors are significant and have different measurements, it is necessary to use the standardised coefficients to make the different predictors more comparable by avoiding different units of measurement. In this study, as no significant predictor was found, standardisation becomes redundant to be commented on.

*3.5.7.2. Missing data*

As stated earlier in this chapter, the full sample of the study included 85 participants. However, only 51completed the CAINS at baseline. This was due to the thesis author introducing this measure halfway through. At six months, fourteen participants (16.5%) declined to participate in the study reducing the sample. For these participants no answers were provided to any questionnaires in the second stage of the research. As the pattern of missing data could be classified as 'missing not at random' (MNAR) (Fielding et al., 2008), no multiple or single imputation method was used to replace the missing data. There was no missing data for any of the items on the questionnaires and measures other than those participants that did not complete the CAINS at baseline or did not complete the 6 months follow up period.

### 3.5.8. Data collection dates

Data collection occurred between March 2018 and March 2019. All data were collected by the thesis author, under the supervision of Katherine Berry and Gillian Haddock.

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# Preface to Chapter 4: Qualitative study

After completion of an extensive systematic review which examined the possible associations between adverse life events and negative symptoms, it was deemed important to conduct a qualitative study. Little prior research has been conducted that has sought to qualitatively understand and explore individuals' subjective views of negative symptoms.

This qualitative study aimed to understand individuals' subjective experiences of these disabling negative symptoms.

The more frequent approach is that of a large empirical study without fully understanding or exploring the concepts that are being examined. As the lead author, I felt that, by asking individuals how they perceived their negative symptoms, this would elicit not only useful and interesting information for possible further research but, for this thesis, it would enable me to have a greater understanding of what exactly, in their own words, it is that the individual experiences in relation to, for example, apathy and anhedonia amongst other negative symptoms.

In order to achieve the inclusion of individuals with a wide range of experiences in this study, the study was conducted in the North West of England and South London.

Isabelle Butcher, Katherine Berry, and Gillian Haddock made substantial contribution to the conception and design of the study. Isabelle Butcher completed and conducted all interviews under the clinical and academic supervision of Katherine Berry and Gillian Haddock. All three authors were directly involved in the analysis and interpretation of the data. All three authors were also directly involved in the preparation of the manuscript submitted for publication. All three authors were involved in the final approval of the manuscript in the British Journal of Clinical Psychology.

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# Chapter 4. Paper 2

# Understanding individuals' subjective experiences of negative symptoms of schizophrenia: a qualitative study

**Short title: Understanding negative symptoms**

**Isabelle Butcher[1,2], Katherine Berry[1,2], and Gillian Haddock[1,2,]**

[1]Division of Psychology and Mental Health, School of Health Sciences, Faculty of Biology, Medicine and Health, Manchester Academic Health Sciences Centre, The University of Manchester, UK

[2]Greater Manchester Mental Health NHS Foundation Trust, Manchester Academic Health Sciences Centre, UK

*Corresponding author: Correspondence should be addressed to Professor Gillian Haddock, Division of Psychology and Mental Health, School of Health Sciences, Faculty of Biology, Medicine and Health, Manchester Academic Health Science Centre, The University of Manchester, 2nd Floor Zochonis Building, Brunswick Street, Manchester M13 9PL, UK (email: gillian.haddock@manchester.ac.uk)

## 4.1. Abstract

*Objectives*: Individuals with a diagnosis of schizophrenia often experience both positive and negative symptoms. Negative symptoms can be disabling and have a serious impact on everyday functioning. Despite the range of clinician-rated measurement tools used to assess negative symptoms, very little is known about how individuals subjectively experience these symptoms. This study sought to examine, using qualitative methods, how people living with a diagnosis of schizophrenia subjectively experience negative symptoms.

*Design*: Qualitative study.

*Method*: Semi-structured interviews were carried out with individuals with a diagnosis of schizophrenia who were experiencing negative symptoms. The sample was recruited from community and inpatient National Health Service mental health settings in the United Kingdom. Interviews were analysed using thematic analysis.

*Results*: Twenty individuals took part. Individuals highlighted the persistent and enduring nature of their negative symptoms. Two central themes were identified: what it is like to experience negative symptoms, and where have my negative symptoms come from? Within the first theme, four sub-themes emerged: loss of concentration, loss of motivation, withdrawal, and 'feeling but not feeling.' Within the second theme, four sub-themes emerged related to the causes of negative symptoms: impact of traumatic life events, positive psychotic symptoms, impact of social network, and recreational and prescribed drug use.

*Conclusion*: Individuals, who experience negative symptoms were able to articulate the persistent and disabling nature of negative symptoms and clearly described factors which they believed contributed to the onset, exacerbation and amelioration of the experiences.

**Keywords:** Schizophrenia, negative symptoms, qualitative

### 4.1.1. Data availability statement

Research data are not shared.

### 4.1.2. Acknowledgements

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### 4.1.3. Practitioner points

- Negative symptoms for people diagnosed with schizophrenia are persistent and enduring and impact an individual's life.
- There has been little research conducted qualitatively on individuals' subjective experiences of negative symptoms.
- Individuals who experience negative symptoms attribute these to a number of factors, including adverse life events, recreational and prescribed drug use, an absence of social support, and positive psychotic symptoms.
- Understanding negative symptoms is important for services, clinicians and family members, where misattributions made about negative symptoms can lead to such experiences being dismissed.

## 4.2. Introduction

Negative symptoms have been recognised as a central feature of the diagnosis of schizophrenia dating back to early descriptions by Kraepelin (Kraepelin, Barclay, & Robertson, 1919) and Bleuler (1911). Negative symptoms have been defined as an absence of behaviours and include, for example, lack of motivation, flattened affect, anhedonia and alogia (Andreasen, 1982). These symptoms have been noted to be some of the most disabling symptoms for people with a diagnosis of schizophrenia, resulting in significant adverse effects on longitudinal, social, and occupational functional outcomes (Ferhava, Foussias, Agid, & Remington, 2014). Such symptoms have an impact not only on the individual but also on their family and wider society, emotionally and economically. In the last decade, there has been considerable interest in how best to understand negative symptoms (Cella, Preti, Edwards, Dow, & Wykes, 2016).

Research has suggested that positive symptoms of schizophrenia, such as hallucinations and delusions, may be linked to stressful early life events, including childhood abuse and neglect (Gallagher & Jones, 2013; Gallagher, Jones, & Pardes, 2016; Read, van Os,

Morrison, & Ross, 2005; Varese, Barkus, & Bentall, 2012). Little research, however, has been conducted on whether there is a link between traumatic life events and negative symptoms. Nevertheless, it has been noted that negative symptoms can be similar to the symptoms that individuals display in response to experiencing adverse life events; for example, numbness and emotional shutdown (Beichtman et al., 1992), suggesting that exploration of the potential links between negative symptoms and early life adversity is warranted.

In terms of treatment, there has been a particular surge in research in the last twenty years (Remington et al., 2016; Stahl & Buckley, 2007). Studies include evaluations of pharmacological interventions, such as the use of antipsychotics and antidepressants (Harvey, James, & Shields, 2016; Kraus et al., 2018), as well as psychosocial-based therapies such as cognitive behavioural therapy (Staring, ter Huurne, & van der Gaag, 2013) and art therapy (Johnson et al., 2009; Rohricht & Priebe, 2006). Despite this increased attention, there is currently no treatment that unequivocally reduces negative symptoms.

Traditionally, different aspects of negative symptoms have been identified through the use of observer or clinician-rated instruments, such as the Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein, & Opfer, 1987), the Scale for the Assessment of Negative Symptoms (SANS) (Andreasen, 1982), and the Clinical Assessment Interview for Negative Symptoms (CAINS) (Kring, Gur, Blanchard, Joran, & Reise, 2013). An example of a self-report measure is the Subjective Experience of Negative Symptoms (SENS) scale (Selten, Silben, van den Bosch, Omloo-Visser, & Warmerdam, 1993), which is designed to assess and measure subjective aspects of negative symptoms, including the experiencer's awareness of them and their related disruption and distress. SENS has been shown to have good psychometric properties, including test re-test reliability (Selten, Silben, van den Bosch, Omloo-Visser, & Warmerdam, 1993), but it does not allow for a full understanding of the individual's perspectives on the symptoms.

Most of the research on negative symptoms has not been carried out involving people experiencing the symptoms. However, there is evidence that highlights the importance of involving in research those who have lived experience of a mental health condition in order to fully understand the experience and to develop treatments and services which will meet their needs (Faulkner et al., 2019). Research has been conducted into how individuals

experience symptoms of psychosis (Tanskanen et al., 2011), yet little research has been carried out into the subjective experience of negative symptoms (Selten et al., 1998) using a qualitative methodology. One exception is a study carried out by Gee et al. (2018) which explored the lived experiences of 24 individuals experiencing first-episode psychosis, all of whom presented with negative symptoms. Reduced facial expression, motivation and sociability featured commonly in the participants' accounts. Participants tended to attribute their negative symptom experiences to lack of confidence and medication side-effects. The study was carried out with individuals who had experienced recent-onset psychosis, and there is a paucity of research examining experiences of negative symptoms in people with more longstanding diagnoses of schizophrenia. The paper also constituted a secondary analysis of a nested qualitative study within a trial of psychological therapy for psychosis, with the potential risk that pertinent themes to the question of subjective experiences were not followed up by interviewers.

Given this gap in the literature, the present study aimed to identify and understand how individuals, who vary in the time since the onset of psychosis, subjectively experience negative symptoms. Qualitative methods were considered to be the most appropriate for gaining a detailed understanding of individuals' experiences of negative symptoms. Ultimately, obtaining a more in-depth understanding of the subjective experiences of negative symptoms through qualitative research may help us pinpoint potential underlying mechanisms and develop effective and appropriate treatments.

## 4.3. Method

### 4.3.1. Design

This study was a qualitative study that was conducted with individuals, all of whom were currently experiencing negative symptoms associated with a diagnosis of schizophrenia. All individuals were living in the United Kingdom. All interviews were conducted by the first author, and a semi structured interview guide was adhered to, to elicit information on the experience(s) of individuals. This study received ethical approval from the National Health Service Research Ethics Committee and throughout the study the Declaration of Helsinki was adhered to, ensuring that all participants were protected from harm.

### 4.3.2. Sample

In order to ensure that purposive sampling was achieved rather than convenience sampling, recruitment was from four large NHS Trusts across the United Kingdom. The approach of purposive sampling was taken to obtain a sample of individuals that was diverse in relation to age, gender and ethnicity. These four large NHS Trusts differ with regards to the demographics of their service users; one Trust primarily has service users from minority ethnic groups and the other Trusts are predominantly white British service users. As recruitment for the study progressed, the sample was continually examined to ensure that it was diverse with regards to these three characteristics of age, gender and ethnicity. Eligible participants were English speakers aged 18 and over who were either mental health inpatients or outpatients under the care of a Community Mental Health Team in National Health Service Trusts in the UK. Individuals had to have a score of at least three on two or more of the negative symptom items on PANSS, as assessed by the first author. Individuals were also required to have a DSM IV or DSM V diagnosis of schizophrenia, schizophreniform disorder, schizoaffective disorder, or delusional disorder. Finally, individuals were required to consent to having the study interview audio recorded.

*4.3.2.1. Procedure*

This study was reviewed by a North West Ethics Committee and was carried out, from April 2017 to July 2018. Four NHS trusts were used as sites for this project.

Participants were recruited from inpatient mental health settings and community mental health teams. Care co-ordinators and other clinicians were approached by the lead author to identify people who potentially met the inclusion criteria for the study. Potential participants were given information about the study and completed a 'consent to contact' form with their contact details. The lead author, IB, then approached each individual's clinical care team to obtain risk information. Participants were then contacted and given an information sheet. If they were willing to take part, they signed a consent form. Participants were seen in either their home or a hospital setting. The lead author conducted the PANSS interview with each individual to ensure they met this inclusion criterion, and, if they met the criterion, the lead author conducted the qualitative interview. It is important to note that individuals may have also been experiencing positive symptoms associated with a diagnosis of schizophrenia, for example auditory hallucinations and command hallucinations.

Semi-structured interviews were conducted by the first author face-to-face and covered a range of pre-specified topics (Appendix 17) regarding participants' experiences of their negative symptoms, such as their effect on functioning and relationships with others, and their thoughts on what may have contributed to the development of their symptoms. The topic guide was derived from the literature on negative symptoms and refined through discussion amongst the authors (a postgraduate psychology researcher and experienced clinical psychologists who have worked with people with psychosis for many years). Individuals with experience of psychosis were consulted in the design of the study and helped inform the researchers with regard to the design of the topic guide.

Individuals were debriefed after the interview and given information about relevant organisations that could be contacted for further information and support if necessary. If any risk issues were raised during the interview, these were dealt with by the lead author who fed back to the clinical team and members of the research team. Recruitment ceased once data saturation had been reached. All interviews were recorded on an encrypted device and any identifiable information was minimised.

Each interview was transcribed verbatim by the lead author with all data anonymised as much as possible, and all data were kept confidential and stored securely.

### 4.3.3. Demographic information

Self-report information on the following demographic variables was obtained: age, gender, ethnicity, marital status, current accommodation type, living status, employment status, date of first contact with mental health services, and current service use. The diagnosis was obtained from case notes by the individual's key worker.

### 4.3.4. Thematic data analysis

Thematic data analysis was chosen as it is a flexible process which enables the exploration of rich data in an efficient method. Furthermore, this study did not seek to build upon theory; rather, it sought to understand individuals' subjective experiences of negative symptoms. Thematic analysis is not tied to a specific epistemological approach (Norris, Nowell, White & Moules, 2017) but is a systematic inductive approach, in which patterns and common themes are identified to describe a dataset and to understand a given phenomenon (Braun & Clarke, 2006). An inductive approach was taken to analyse the data in that the codes and themes were led by the content that emerged from the interviews. A six-step approach to analysing the data was used, as outlined below. All the authors took part in steps 2 to 6 of the analysis process.

1. Data were transcribed verbatim by the lead author.
2. The transcripts were read and re-read by members of the research team to enable familiarisation with the data. Interviews were electronically placed into NVivo11 qualitative analysis software to enable the data to be organised and stored systematically.
3. Systematic line-by-line coding was conducted separately by all three authors in order to identify common emergent themes in the data.
4. The themes were discussed to identify key common emergent themes across the interviews enabling a thematic map to be established. Any differences in themes were discussed amongst the authors.
5. The themes were defined, and names generated.
6. The final themes were checked with all members of the research team.

### 4.3.5. Quality and rigour

This study was conducted in a rigorous and high-quality manner. Reading and discussion of each transcript by the research team ensured that the process was iterative and transparent. It is acknowledged that each author's experiences inevitably shape data analysis (Willig, 2008). The lead author, IB, is a White British woman psychology postgraduate researcher with experience in interviewing individuals with psychosis. GH and KB are both White British women who are senior clinical academics and honorary clinical psychologists in the NHS, experienced in working with people with psychosis. Rigour was also achieved by recruiting and interviewing individuals until data saturation had been reached. Field notes were taken during each interview by the lead author, which also helped ensure the context of each interview was considered.

## 4.4. Results

Of the 23 individuals approached about the study, three declined to participate. Twenty individuals participated: 17 males and 3 females. Individuals were from a range of settings: inpatient acute wards (n=7), community mental health teams (n=9), and rehabilitation and recovery wards (n=4). Of the participants included in this study, eight identified themselves as Black African, and the remaining individuals (n=12) were White British. Age ranged from 35 to 62; with the mean age range being 52 years. Out of the 20 participants, 18 were unemployed and two were in full-time employment. The positive and negative symptoms total scale scores for each individual are in Table 4.1.

Each interview lasted between thirty-five minutes and one hour; the mean duration of the interviews was thirty-nine minutes. A total of 65 initial codes were generated and collated into groups, and these were organised into 30 codes, which comprised two main themes. These 30 codes then allowed a condensed overview of the main points and common meanings to be portrayed.

Two main themes were identified: *What is it like to experience negative symptoms?* and *Where have my negative symptoms come from?* The emerging themes highlighted the enduring nature of negative symptoms. The subjective experience of the negative symptoms appeared relentless as opposed to sporadic and impacted many aspects of individuals' lives. As a caveat, it is important to recognise that some of these individuals were experiencing positive symptoms and so when the interviewer, the lead author, felt that positive symptoms were being explained, the individuals were led back to negative

symptoms through subtle cues to ensure that it was indeed the negative symptoms they were describing. The main and sub-themes are illustrated in Figure 4.1. As can be seen in Figure 4.1. the four themes presented in the yellow inner circles are the sub themes that fall under main theme 1: *what is it like to experience negative symptoms*? The four purple circles indicate the sub themes of main theme 2*: Where have my negative symptoms come from?*

*Table 4.1. Positive and negative symptoms scale scores*

| Participant ID number | Total score on Positive Scale on Positive and Negative Syndrome Scale | Total score on Negative scale on Positive and Negative Syndrome Scale |
|---|---|---|
| 001 | 7 | 21 |
| 002 | 10 | 26 |
| 003 | 15 | 17 |
| 004 | 7 | 20 |
| 005 | 12 | 25 |
| 006 | 20 | 23 |
| 007 | 7 | 14 |
| 008 | 21 | 15 |
| 009 | 18 | 18 |
| 010 | 21 | 21 |
| 011 | 7 | 28 |
| 012 | 40 | 14 |
| 013 | 20 | 24 |
| 014 | 25 | 22 |
| 015 | 10 | 25 |
| 016 | 18 | 28 |
| 017 | 7 | 19 |
| 018 | 18 | 20 |
| 019 | 16 | 24 |
| 020 | 22 | 20 |

*Figure 4.1. Main and sub themes of the qualitative study*


**Key to Figure 4.1.**

- Yellow circles – sub themes of main theme 1: *What is it like to experience negative symptoms?*
- Purple circles - sub themes of main theme 2: *Where have my negative symptoms come from?*

### 4.4.1. Main theme 1: What is it like to experience negative symptoms?

Individuals described their experiences in rich detail, highlighting the pervasive and disabling nature of the experience. Four sub-themes were evident within this overarching theme that related to how individuals experienced their symptoms: loss of concentration, loss of motivation, withdrawal, and 'feeling but not feeling'.

#### *4.4.1.1. Loss of concentration*

Participants reported that even seemingly small daily tasks required a large amount of concentration, and this had a huge consequent effect on their lives. Individuals said that because their concentration was often affected, they were unable to participate in recreational activities or even something as seemingly undemanding as watching television or reading.

> *Um ... it's, it's not about picking up a book, it's about concentrating and understanding the book ... (Participant 1005)*

> *Like, er like, see somebody was looking at teletext earlier on the tv and I had problems reading 'cause generally I read the first couple of lines and I forget what it is that I've read and have to go back to the beginning 'cause my mind keeps on collapsing. (Participant 1015)*

> *Concentration ... dreadful ... absolutely dreadful. Couldn't watch TV programme; couldn't listen to the radio couldn't even listen to music. (Participant 1007)*

#### *4.4.1.2. II. Loss of motivation*

Participants frequently said that they lacked the 'get-up-and-go' to complete a task, or simply to function on an everyday basis. Small tasks were perceived as larger tasks that required an amount of energy the individual did not possess, and thus the task was seen as unattainable. This lack of motivation was described as persistent over time and did not appear to come and go. Participants clearly stated that this was a physical experience which was independent and subjectively different from their feelings or mood.

> *... brushing teeth felt like climbing the biggest mountain and I just couldn't be bothered to … no motivation ever … (Participant 1018)*

> *It's like a nightmare… living in a nightmare...you can't, you try and push yourself, but you can't ... you cannot do It ... Summat holding you back all time … and it feels like I'm being pulled back … you're not going forward or anywhere like that. (Participant 1020)*

#### *4.4.1.3. III. Withdrawal*

Individuals said they often preferred spending time on their own, and that being around other people was difficult. Individuals expressed problems in initiating conversations, reporting that they lacked the desire to do so. Withdrawal was both emotional and social, with individuals often choosing to be on their own with their thoughts rather than participating in social activities or interacting with others. It was evident that some participants experienced substantial social disconnection as a result of isolating themselves.

> *I'd rather just chill out all on my own … until I am feeling more energetic. (Participant 1003)*

> *Erm, like … I like my own company. I love me own company ... (Participant 1004)*

#### *4.4.1.4. IV. 'Feeling but not feeling'*

Some individuals said that they were acutely aware of their feelings. In particular, participants highlighted that they specifically experienced 'feelings' of numbness and emptiness. Others reported that this was evident to others through their lack of ability to illustrate their feelings with, for example, their facial expressions.

> *I used to feel numb sometimes. I just feel like no-one is listening to me sometimes. It just makes me feel empty… 'specially if I am trying to get my point across… all empty inside.* (Participant 1003)

> *About something; it just feels like I am not getting through … that's what makes me numb and, er, obviously I, er, er, er, I control my temper and … but just trying to get my point across makes me feel numb.* (Participant 1004)

> *I do feel numb … I just feel that no-one's listening to me sometimes.* (Participant 1017)

> *Facial expressions? I haven't got many expressions…* (*Participant 1003*)

### 4.4.2. Main Theme 2: Where have my negative symptoms come from?

The second theme that emerged was participants' attributions about what had contributed to the development of their symptoms or where they believed their symptoms had come from. Individuals had strong beliefs about where their experiences of negative symptoms had arisen from and made clear links between life experiences and their current problems.

#### *4.4.2.1. I. Impact of traumatic life events*

Participants said that adverse life events, such as the experience of abuse or loss, had contributed to their negative symptoms. The adverse life events expressed tended to be those described as 'intentional interpersonal events'; that is, events carried out by other people with the deliberate intention of inflicting harm. The most frequently mentioned adverse life events included sexual abuse, emotional abuse, and bullying (by peers). These events could have been experienced some years previously but were still considered to have had an impact. All adverse life events occurred prior to adulthood. Each interviewee was asked what they thought had contributed, or led, to their negative symptoms.

> *It's because you've been abused in the past, that's all… I've been abused in* the *past… have those emotions within in me; um, perhaps they are there… and so you end up withdrawing from people, and you know, life.* (Participant 1011)

> *Like I say, erm, being bullied at school ... by three girls. My mum and dad take 'em to court, so that went to court; I were only eleven. Then twelve, I were nearly raped. Only stopped it because he knew me brother. He worked with me brother… and I told him, 'what d'ya think (K) gonna do to you?' and 'what about your job?' Er, I don't think that helped I don't want to be with people. I just can't, you know, go out and meet people, and I feel nothingness, you know.* (Participant 1020)

> *Well, I seen a lot of people die; a lot of friends die from doing drugs, in my lifetime. Er, recently I've been clean a couple of years, but a friend lost his arm. Cannot be bothered with life … and doing anything, and yeah, don't want to do anything…* (Participant 1005)

#### *4.4.2.2. II. Positive symptoms as a root cause of negative symptoms*

Participants particularly mentioned the presence of auditory hallucinations as key factors which contributed to their experience of negative symptoms. They described the impact as exhausting, leaving them feeling enervated and unable to function. The voices appeared, in some cases, to be relentless, only stopping when individuals slept, and resulted in their feeling mentally and physically lethargic. In addition to auditory hallucinations, individuals also stated that feelings of paranoia led to negative symptoms. A belief that they were being followed or persecuted created difficulties in functioning and interacting with others, subsequently leading to withdrawal socially and emotionally from those around them.

> *The voices just make me tired all the time, they never stop, only when I go to sleep.* (Participant 1015)

> *I could hear voices; they always seemed to be like external by the sound they had, and it made me exhausted you know.* (Participant 1007)

> *I don't know, because, you know, I think I am being chased when I go outta the house, and yeah I just stay in here with TV and, you know…* (Participant 1016)

> *Yeah, I don't wanna talk to people because, you know, it's just you never know what they are saying 'bout me … they talk, you know… about me being a loser* (Participant 1019)

#### *4.4.2.3. III. Impact of social network*

Participants described difficult life circumstances, such as lack of money, that they believed had contributed to their negative symptoms. However, it was support from their loved ones that had pulled them through.

> *If I didn't have the support of my family, I would be nailed against the wall… I was on the street in debt pretty much. If you don't have any money you can't do anything. I had long sleeps. I definitely overslept.* (Participant 1002)

A small minority also referred to pet ownership and dependants as having a positive influence on their motivation to get up and be active. Having children and pets to look after gave them a sense of meaning and direction, enabling them to function.

> *Having a pet helps because I have to feed her and let it out yeah, that's a good thing.* (Participant 1020)

> *Having to look after the children and my partner helped because I had to get up, I couldn't lie down all day and do nothing.* (Participant 1015)

#### *4.4.2.4. IV. The influence of prescribed and recreational drug use*

Individuals particularly said that the use of cannabis might have contributed to their negative symptoms. Individuals referred to past use of cannabis drugs in terms of the effect on their mental health symptoms. Smoking cannabis was particularly reported by individuals as contributing to feeling unmotivated.

> *Like I said, I was smoking lots of skunk weed; I think it must have triggered the symptoms, you know.* (Participant 1003)

> *I smoked a lot of cannabis, you know, and it's easy to get, so I felt unmotivated to do anything after a smoke, you know*. (Participant 1015)

> *It started with the smoking cannabis, which was quite all-consuming and made me feel like s*** … Yeah cannabis, the reflective journal was good, it helped motivate me … the cannabis didn't and had the opposite effect.* (Participant 1011)

Additionally, individuals voiced concern about their prescribed medication, which they perceived as contributing to their negative symptoms.

> *Well it's the olanzapine ... you know, makes me feel drugged up and s***.* (Participant 1020)

> *Meds, all they give me, PRN, ''''ing sh*** ... I don't want to get out the bed.* (Participant 1017)

> *I dunno though, I mean it could be… but I think its aripiprazole, well but I just don't wanna talk, or do anything I feel ... tired, ya know.* (Participant 1006)

## 4.5. Discussion

### 4.5.1. Summary of findings

The study investigated subjective experiences of negative symptoms in people with a diagnosis of schizophrenia, in a diverse sample from across the United Kingdom. Individuals described the huge impact that experiencing negative symptoms presented to them, with poor concentration and motivation, which subsequently made it difficult to engage in 'normal' activities and often resulted in withdrawal. Individuals also described 'feeling but not feeling', whereby a feeling of numbness was the pervasive emotional experience. Furthermore, individuals highlighted the factors that they perceived and believed had influenced the occurrence of their negative symptoms. These factors included adverse life events, positive psychotic symptoms, and social networks, as well as recreational and prescribed drugs, with particular reference to cannabis and antipsychotic medication. Across all the interviews, negative symptoms were perceived as persistent, prolonged and enduring; this was an overarching theme that underpinned all the themes, as illustrated in Figure 1.

These findings have similarities with those found by Gee et al. (2018), who sought to identify individuals' experiences of negative symptoms in a sample of individuals with a first-episode psychosis diagnosis. Both studies found that feelings of numbness and withdrawal, as well as poor concentration, attention and motivation were predominant in participants' accounts of their experiences. The findings suggest that these symptoms are hallmark negative symptoms that exist throughout the course of life for someone who receives a diagnosis of schizophrenia.

Individuals identified key contributing factors to their negative symptoms. Despite this study being unable to infer causality, it is of interest to reflect on those factors that individuals attributed as being important in the occurrence of their negative symptoms. Trauma was identified as a key factor. Arguably, the experience of trauma, and interpersonal trauma in particular, may be so overwhelming that it causes individuals to withdraw mentally and physically from the world around them. In support of this view, studies by Gallagher and Jones (Gallagher & Jones, 2013; Gallagher, Jones, & Pardes, 2016) showed an association between traumatic life events as assessed by a case note review, and negative symptoms as measured by PANSS and SANS. The authors also found that associations between specific life events and specific negative psychotic symptoms were associated with neglect experienced in childhood. Individuals who

reported neglect presented with greater negative symptoms than those who experienced physical abuse.

Individuals also reported that they believed that their positive symptoms contributed to their negative symptoms, with voice-hearing and paranoia being highlighted as particularly pertinent. Previous theoretical accounts of negative symptoms have similarly conceptualised negative symptoms, such as withdrawal, as coping strategies in relation to stressful and overstimulating positive symptoms (Stampfer, 1990).

The finding that social environments contributed both positively and negatively to negative symptoms is also consistent with early psychosocial theories of schizophrenia, such as the stress vulnerability model, which posits that social stressors and social buffers influence relapse (Zubin & Spring, 1977). Findings here suggest that these social factors may be just as important for the course of negative symptoms as positive symptoms. Previous studies have identified that pets can benefit an individual's mental health in a positive manner (Brooks, Rushton, Walker, Lovell, & Rogers, 2016); therefore, it is interesting to note that in this study, having dependants in the form of children or pets was identified as being helpful with their experiences of negative symptoms.

Participants described prescribed and recreational drugs as having a negative consequence. Literature dating back to the late 19$^{th}$ century has consistently shown that there is a link between cannabis and motivation, and specifically that heavy cannabis use is linked to apathy (Kalant, 1972; Pacheco-Colón, Ramirez, & Gonzalez, 2019). In more recent years, the link has been evidenced, with findings in a laboratory setting, showing that reduced motivation for reward-related behaviour is more evident in cannabis users than in healthy controls (Lane, Cherek, Pietras, & Steinberg, 2005). Similarly, research has also identified links between antipsychotic medication and a lack of energy; antipsychotic medications are evidenced to have sedating effects. The degree of lack of energy is often related to the dosage of medication that an individual is given (Miller, 2004).

Overall, the findings of the present study suggest that the impact of adversity and environmental factors need to be considered in understanding negative symptoms and, these need to be taken into account when developing treatments and services for people with such symptoms.

### 4.5.2. Clinical implications

Understanding the experience of negative symptoms and what individuals consider contributes to their occurrence is important for clinicians, researchers and service planners to enable the design and delivery of effective treatment. This understanding may help to facilitate the development of idiosyncratic formulations and treatment approaches, enabling a cause-specific approach to 'tackling' negative symptoms to be utilised. If individuals identify that the impact of a traumatic life event contributes to their experience of negative symptoms, then this could be addressed clinically through interventions such as trauma-focused CBT. This has been shown to be effective in the treatment of PTSD and psychosis more generally and has recently been adapted to focus on complex childhood trauma (Cohen, Deblinger, & Mannarino, 2004). If individuals state that it is the positive psychotic symptoms that led to their negative symptoms, delivering CBT by targeting voices or paranoia may be of greater benefit to the individual. If an individual identified that it is lack of social support which resulted in negative symptoms, then family therapy or peer support approaches may help to maximise the social support available to them. However, if an individual identifies that they perceived that recreational drug use led to negative symptoms, then this could be targeted by delivering a motivational interviewing approach to therapy, which has been shown to be effective in reducing substance misuse in the context of psychosis (Barrowclough et al., 2010). Where the medication is thought to be the cause, considering a treatment plan that involves changing dosage may increase an individual's motivation and energy levels. It is acknowledged that these treatment opportunities will take time to implement within clinical settings but in doing so, can serve to enable recovery from negative symptoms.

### 4.5.3. Strengths and limitations

A key strength is that this study differs from much of the literature on negative symptoms, which has focused on assessing individuals' experiences of negative symptoms through a questionnaire or clinician-rated instrument. Individuals are also not often asked what they think might contribute to the occurrence of their symptoms.

The sample was diverse, in that individuals from a range of settings and geographic locations participated. There was a range of ethnicities, reflecting the diagnosis of schizophrenia in the wider population. There was a limited number of females; however, this reflects the gender imbalance of schizophrenia in the population (Braun & Clarke, 2006). The participants also all had longstanding diagnoses of schizophrenia, whereas previous research has focused on those with first episodes of psychosis (Gee et al., 2018).

An additional limitation of this study is that its aim and focus were on individuals' subjective experiences of negative symptoms. Therefore, from this study, we cannot identify any causal mechanisms from the results; the data illustrated and generated from this study merely highlights individuals' subjective experience of negative symptoms and perceived contributing factors.

### 4.5.4. Future research

This study signposts researchers and clinicians towards conducting further work on the psychological mechanisms underpinning negative symptoms in order to aid an individual's recovery and improve functional outcomes across a range of domains whilst acknowledging the impact that positive psychotic symptoms can have on negative symptoms. The study emphasises that there needs to be greater work conducted qualitatively on the causes of individuals' negative symptoms; this should involve a broader and larger sample, with people recruited from those presenting in Early Intervention Services at the prodromal stage to those with more longstanding diagnoses of schizophrenia. Further qualitative research could explore longitudinally how an individual's experiences of negative symptoms change and develop. Additionally, this study highlights the need for quantitative research that explores the themes evidenced in relation to the causes of the negative symptoms.

## 4.6. Conclusion

Negative symptoms are a key aspect of the experience in people who have a diagnosis of schizophrenia (Andreasen, 1982). However, these symptoms are often overlooked by clinicians and researchers due to the difficulty in distinguishing negative symptoms from low mood and the side-effects of medication (Bailey et al., 2018). This study shows that individuals with a diagnosis of schizophrenia are able to describe their experiences of negative symptoms. This study also demonstrates the importance of asking individuals about their negative symptoms and their potential causes, and of understanding the individual's social environments. Individuals do have insight into what may be contributing to their negative symptoms. Recognising that these experiences are extremely debilitating and persistent is important not only for services and clinicians, but also for families and carers, where misattributions can be made about negative symptoms, leading to conflict or to such experiences being dismissed (Horan, Brown, & Blanchard, 2007).

A copy of this paper in its published form is available in Appendix 18.

# References for Chapter 4


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## Preface to Chapter 5: A Cross-Sectional and Longitudinal Study

The third study in the PhD was a large cross-sectional study with a longitudinal aspect. This study brings together all three components of the PhD thesis: traumatic life events, attachment style and negative symptoms.

This study was conducted after the completion of the systematic review and the qualitative review; the outcomes of which suggested that there may be certain types of traumatic life events that are associated with specific psychotic symptoms. In addition to the findings of the systematic review and qualitative study, the question of links between traumatic events and symptoms was raised by clinicians during the recruitment process for qualitative study.

To explore these theories, this study assessed attachment style, the experience of traumatic life events and positive and negative symptoms. Traumatic life events and attachment style were assessed at baseline and symptoms were assessed at baseline and six months.

This study recruited individuals with a diagnosis of schizophrenia from across the United Kingdom to ensure a range of individuals were included in the study.

Isabelle Butcher, Katherine Berry and Gillian Haddock made substantial contributions to the conception and design of the study. Isabelle Butcher completed and conducted all assessments under the clinical and academic supervision of Katherine Berry and Gillian Haddock. All three authors were directly involved in the analysis and interpretation of the data. All three authors were directly involved in the preparation of the manuscript for publication and all three authors will be directly involved in the final approval of manuscript prior to publication.

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# Chapter 5. Paper 3

# Traumatic life events, attachment style, and negative symptoms: a cross-sectional and a six-month follow up study

**Short title: Trauma, attachment and negative symptoms**

**Isabelle Butcher [1], Katherine Berry[1,2], Gillian Haddock[1,2*]**

[1]Division of Psychology and Mental Health, School of Health Sciences, Faculty of Biology, Medicine and Health, Manchester Academic Health Sciences Centre, The University of Manchester, UK

[2]Greater Manchester Mental Health NHS Foundation Trust, Manchester Academic Health Sciences Centre, UK

*Corresponding author: Correspondence should be addressed to Professor Gillian Haddock, Division of Psychology and Mental Health, School of Health Sciences, Faculty of Biology, Medicine and Health, Manchester Academic Health Science Centre, The University of Manchester, 2nd Floor Zochonis Building, Brunswick Street, Manchester M13 9PL, UK (email: gillian.haddock@manchester.ac.uk)

## 5.1. Abstract

Previous studies have explored the association between experiences of traumatic life events and the development of positive psychotic symptoms, but few have explored the link between experiences of traumatic life events, attachment and negative symptoms. This study aimed to investigate the association between the experience of traumatic life events, attachment and negative symptoms, whilst considering the role of service engagement. The paper investigated how negative symptoms relate with trauma and how their relation is mediated by attachment style. The sample of eighty-five participants diagnosed with schizophrenia were recruited from mental health services across the United Kingdom. Negative symptoms were measured at baseline and six months. The presence of traumatic life events was assessed at baseline. Attachment was assessed at baseline; service engagement was assessed at both baseline and six months. Findings using the Trauma History Questionnaire, the Childhood Trauma Questionnaire, the Psychosis Attachment Measure, the Positive and Negative Symptoms Scale and the Clinical Assessment for Negative Symptoms identified no statistically significant association between experiences of traumatic life events (across the life span), attachment and negative symptoms cross sectionally and over six months. Difficulty in engaging with services was found to be associated with higher negative symptoms when measured using the Clinical Assessment for Negative Symptoms but not when using Positive and Negative Syndrome Scale at six months. There was no evidence to assess the mediation role of attachment between trauma and negative symptoms. The findings from this study provide evidence that when considering the aetiology of negative symptoms attention should be paid to factors including the presence of trauma and an individual's level of engagement with services.

**Key words**: schizophrenia, trauma, adversities, negative symptoms, attachment.

## 5.2. Introduction

Individuals with a diagnosis of schizophrenia experience both positive and negative symptoms[1]. Positive symptoms are those attributes that are present, in addition to normal functioning, and include delusions and hallucinations. Negative symptoms are an absence of an attribute that 'so called' healthy individuals possess and include lack of motivation, apathy, avolition and social withdrawal[1]. Individuals who experience these negative symptoms can find it difficult to engage with family, friends and health services [2].

Negative symptoms are often viewed as the most disabling symptoms of schizophrenia [3, 4]. The symptoms may be separated into two subdomains: i) expressive deficits, and ii) experiential deficits. Expressive deficits are related to an inability to express emotions and include poverty of speech and blunted affect; experiential deficits are the ability to experience events and include symptoms of apathy and anhedonia [4]. Furthermore, individuals who experience negative symptoms associated with a diagnosis of schizophrenia can find it challenging to remember and anticipate pleasurable events. Beck and Rector's model of negative symptoms[5] proposes that individuals with prominent negative symptoms anticipate that an event that requires energy and motivation will be unpleasant. More recent measures of negative symptoms such as the Clinical Assessment of Negative Symptoms (CAINS)[6] assess these two aspects through observer rated measures, whereas the Positive and Negative Syndrome Scale[7] does not quantify or ask individuals explicitly about remembered and anticipated pleasurable events.

Individuals with a diagnosis of depression have reported experiences of low mood and anhedonia, and research has documented that there are symptoms of depression which are negative symptoms for schizophrenia[8, 9]. In order to distinguish depressive symptoms from negative symptoms Addington and colleagues[10] constructed the Calgary Depression Scale for Schizophrenia (CDSS) which enables researchers and clinicians to assess and differentiate negative symptoms from depressive symptoms.

Traumatic life events can be described as either non-intentional or intentional. Non-intentional events include loss of a parent, through death or separation, as well as witnessing or being involved in a natural disaster, whereas intentional events include sexual abuse, psychological abuse or physical abuse [11]. In a meta-analysis of 41 studies, Varese et al.[12] reported that individuals with psychosis were 2.72 times more likely to have reported childhood adversity (including sexual abuse and bullying in childhood) than the

control population who did not have a diagnosis of psychosis. However, Varese et al.[12] did not examine the impact of childhood adversity on negative symptoms, and search terms that included negative symptoms were not included in the search process. More recently, Bailey and colleagues[13] conducted a meta-analysis on the association between childhood trauma and psychosis. The results from 29 studies revealed that exposure to childhood adversity was overall related to positive symptoms, but not to negative symptoms; however, there was evidence from eight studies of a relationship between childhood neglect and severity of negative symptoms.

There has also been evidence to date that has suggested that there are similarities in the symptoms observed in individuals with a diagnosis of schizophrenia and the symptoms that are associated with a diagnosis of borderline personality disorder. In a study by Kingdon et al [14] which included individuals with diagnoses of schizophrenia or borderline personality disorder. Results identified that those individuals with a diagnosis of borderline and those who had a diagnosis of comorbidity with schizophrenia both independently reported significantly greater experience of trauma overall than those with a diagnosis of schizophrenia only. Results identify that the types of childhood trauma as assessed on the Childhood Trauma Questionnaire[15] were significantly higher for those with a diagnosis of borderline personality disorder and borderline personality disorder and schizophrenia compared to the group of individuals who had a diagnosis of schizophrenia only. Thus, the experience of childhood trauma is not only associated with a diagnosis of schizophrenia but also borderline personality disorder.

In a recent systematic review of 37 papers, Williams et al.[16] examined the roles of several explanatory mediators between childhood adversity and the development of psychosis; it indicated that there are several potential groups of mediators, including post-traumatic symptoms, affective disturbances, cognitive processes and appraisal of stressors. There was substantial support for the potential mediating role of 'post-traumatic sequelae' such as dissociation, cognitive factors, and negative beliefs about self and an individual's social world. Additionally, one of the psychological mechanisms considered in the review by Williams et al.[16] was attachment style. Six studies in Williams et al's[16] review investigated attachment and its role as a mediator in the association between trauma and psychosis[17-21]. The studies all indicated that anxiety and avoidance attachment styles both mediated the relationship between childhood trauma and positive psychotic symptoms. However, the evidence supporting the mediating role of avoidant attachment was weaker. Only one

study[19] looked at the relationship between attachment and negative symptoms and found that avoidant or anxious attachment style mediated this relationship, but solely in siblings of individuals who had psychosis. Research consistently suggests that insecure attachment styles are over-represented in samples with a diagnosis of psychosis and that specific attachment styles are linked to particular psychotic phenomena [22-24].

There are different types of insecure attachment described in the psychological literature, most commonly, the concepts of anxious and avoidant attachment [25]. Avoidant attachment is characterised by fear of intimate relationships and a consequent avoidance of close relationships. Individuals with avoidant attachment tend to overly control their emotions and do not appear to experience or communicate strong emotions. Anxious attachment style is characterised by a poor self-image and high dependence on others, with a strong need for constant reciprocation and validation. Additionally, individuals who have an anxious attachment style experience extreme emotional highs and lows and have difficulty regulating affect[26].

Gumley et al.'s [27] extensive review found a positive association between attachment styles, and positive and negative symptoms. For example, individuals with an anxious attachment style displayed more severe positive psychotic characteristics, such as paranoia and hallucinations, whereas individuals with avoidant attachment styles demonstrated more severe negative symptoms, such as social anhedonia. The review also found that insecure attachment styles were associated with a number of other important psychosocial outcomes including difficulties in engaging in treatment.

Gumley et al.[22] found that insecure attachment styles predicted recovery from negative symptoms over a 12-month period in a sample of 68 people with first-episode psychosis. The study by Gumley et al.[22] is important as it examined associations between attachment and negative symptoms using a longitudinal design in a sample of individuals with first episode psychosis. The majority of studies investigating attachment and symptoms have cross- sectional designs, meaning that it is not possible to infer the direction of causal relationships between insecure attachment and symptoms.

Individuals with a diagnosis of schizophrenia can find it hard to engage with services. This is an issue that the healthcare system and wider society is impacted by. Engagement is a complex concept which is dependent on a number of factors as noted in an extensive review by O'Brien and colleagues [28] such as; sociodemographic factors, socioeconomic

factors, forensic history, clinical factors and satisfaction with services. To date there are few measures of engagement that are rated by the individual, most measures of engagement such as the Service Engagement Scale (SES)[29] are clinician rated. In a paper by O'Brien [30] an important point raised is that a clinician's interpretation of engagement may be interpreted by the individual patient as coercive and the individual patient may have valid for reasons for not engaging with services. Research[31] [32]has provided evidence that poor clinician-rated engagement is associated with greater negative symptoms yet the research into negative symptoms and engagement with services remains limited with the research primarily focusing on engaging with services and first episode psychosis and positive symptomology. Service engagement is also associated with specific attachment styles as highlighted in Gumley et al's study [22] in which insecure attachment style was related to the duration of untreated psychosis. The authors in Gumley et al [22] argued that the duration of untreated psychosis despite not measuring engagement with services, may be a proxy measure for service engagement.

Taken together, these findings suggest further research is warranted to understand the potential relationships between trauma, attachment style and negative symptoms, specifically in a clinical population. The current study examined the association between traumatic life events, attachment style and negative symptoms in a cross-sectional study of individuals with a diagnosis within the schizophrenia spectrum, and over a follow-up period on negative symptoms over six months whilst controlling for depression.

The following hypotheses were tested in this study:

**Hypothesis 1. There will be a relationship between the presence of traumatic life events and severity of negative symptoms at baseline.**

**Hypothesis 2. There will be a positive association between subtypes of traumatic life events, specifically severity of neglect and negative symptoms at baseline.**

**Hypothesis 3. There will be a positive association between insecure attachment style and severity of negative symptoms at baseline.**

**Hypothesis 4. There will be a relationship between the presence of traumatic life events and the change in negative symptoms from baseline to six months.**

**Hypothesis 5. Any association between trauma and negative symptoms will be mediated by insecure attachment style.**

**Hypothesis 6. There will be a relationship between the level of engagement with services at baseline and severity of negative symptoms at baseline.**

## 5.3. Method

### 5.3.1. Design

An observation repeated-design study was performed to understand the impact of traumatic life events and attachment style on negative symptoms for a group of individuals diagnosed with schizophrenia. At baseline, participants completed a group of assessments that examined the presence of traumatic life events, adult attachment style and negative symptoms. At six months, participants were invited to complete a set of measures that assessed negative symptoms. Ethical approval was obtained for this study from the National Health Service Research Ethics Committee.

### 5.3.2. Participants

A total of 85 participants were recruited between March 2018 and March 2019, from five NHS Trusts across the United Kingdom. Recruitment involved the first author giving a brief verbal summary of the study and its rationale to clinicians, then asking clinicians to share this information with potentially eligible participants within their caseload. Clinicians then referred eligible participants to the research team via a 'Consent to Contact' form, which provided potential participants' contact details.

At the six-month follow-up point, a total of 71 (of 85) participants were re-assessed. A number of participants (n = 7) were no longer contactable due to a change in services and another 7 participants declined further contact with the study.

### 5.3.3. Sample size

When selecting the sample, the researcher aimed to obtain a coefficient and a small to medium effect size of 0.3. Using G Power[33], the thesis author estimated that a sample size of 82 participants would provide 80% power to detect a correlation coefficient of .3 at the 0.05 alpha level. The same level of power is provided for the multiple regression models. Finally, 85 participants were completed the baseline time-point of this study

### 5.3.4. Inclusion criteria

Participants had to be 18 years of age or over, under the care of a mental health team, with a care coordinator or equivalent. Individuals were also required to meet the International Classification of Diseases (ICD -10) codes F20–F29 criteria for schizophrenia and related psychosis diagnosis, which was established from the case notes by the first author. Furthermore, individuals were required to be experiencing negative symptoms, as defined by a score of at least three, on at least one of the Positive and Negative Syndrome Scale (PANSS) [34] negative symptom subscale items as assessed by IB (the first author).

### 5.3.5. Exclusion criteria

The following exclusion criteria were applied: individuals with an organic brain disorder implicated in the aetiology of symptoms; an insufficient English language ability to understand and complete assessments, or an intellectual disability impacting on participants' ability to complete assessments, as evaluated by the care coordinator or first author.

## 5.4. Measures

### 5.4.1. Trauma assessment

The Trauma History Questionnaire (THQ)[35] was utilised to assess traumatic life events. The THQ is a 24-item checklist that covers events that fall into the subscale categories of: crime, general disaster, physical abuse and sexual experiences. The questionnaire assesses exposure to each event through 'yes' or 'no' responses, and frequency is assessed by asking participants to report on the number of times an event has occurred. The participant is also asked to rate the age at which the event, or events occurred. The THQ has been validated in clinical and non-clinical samples. Mueser and colleagues[36] found moderate to high test-retest reliability for a range of traumatic events experienced over a lifetime in a psychometric evaluation of the measure in individuals with severe mental illness.

In addition to the THQ, the Childhood Trauma Questionnaire (CTQ) [37]was used as it measures childhood traumatic events not covered on the THQ; for example, incidents of childhood neglect. The CTQ is a commonly used measure to retrospectively measure childhood trauma, and it assesses five different types of childhood maltreatment[38]. These are emotional abuse, physical abuse, sexual abuse, emotional neglect, physical neglect and also a scale on minimization/denial. The CTQ has been well validated and shown to demonstrate good test-retest reliability over a two to six-month period [37].

Furthermore, as the THQ and the CTQ do not explicitly assess incidences of bullying, an adapted version of Olweus et al.'s [39] bullying and victimisation questionnaire was used, which involved asking individuals four questions to assess overt and covert measures of bullying at school. The four questions used in this study focused on verbal and physical bullying, as well as exclusion; the questions had been validated in previous studies. The four questions are i*) I was called mean names, was made fun of or teased in a hurtful way, ii) other students left me out of things on purpose, excluded me from their group of friends or completely ignored me, iii) I was hit, kicked, pushed, shoved around or locked indoors and iv) Other students told lies or spread false rumours about me and tried to make others dislike me*. For each of these four questions there are five possible answers for the participant to tick; *did not happen to me, only once or twice, 2 or 3 times a month, about once a week or several times a week*. All measures of traumatic life events were completed at baseline only.

### 5.4.2. Attachment measure

In order to assess attachment, the Psychosis Attachment Measure (PAM) was used. The PAM is a 16-item self-report questionnaire that assesses anxious and avoidant attachment styles, with questions about thoughts and feelings in close interpersonal relationships. Each item on the PAM is rated on a 4-point Likert scale, from 'not at all' to 'very much'. The PAM has been demonstrated to have good validity and good internal consistency in clinical samples with a severe mental illness[40].

Attachment style was recorded at baseline only.

### 5.4.3. Measure of service engagement

Engagement with services was recorded using the Service Engagement Scale (SES)[41] at baseline and six months follow up, which aims to assess the level of client engagement with services. The care coordinator completed the SES, in relation to the patient's engagement during the previous two weeks. The scale is a 14-item inventory completed by the clinician or individual's key worker or care coordinator. Each item is rated on a scale of 0 to 3, with 0 meaning 'not at all', or 'rarely', and 3 meaning 'most of the time'. The subscales are scored so that higher scores reflect an individual's greater level of difficulty of engagement with services. The scale covers four key areas of engagement: availability, collaboration, help-seeking and treatment adherence. The SES has been demonstrated to have good test-retest reliability in samples including individuals diagnosed with schizophrenia.[41]

### 5.4.4. Symptom assessment

Current symptomatology was assessed at baseline and at a six-months follow up using the Positive and Negative Syndrome Scale (PANSS)[34]. This 30-item semi-structured interview has been extensively used and has good psychometric properties. Seven items relate to positive symptoms, seven to negative symptoms and sixteen items relate to general psychopathology; each item is scored on a 1-7 scale (with 1 being 'absent' and 7 being the highest).

The Psychotic Symptom Rating Scales (PSYRATS)[42] comprise two scales measuring hallucinations and delusions on an 11 and 6 item scale respectively; each item is rated on a zero to four scale. They were administered at baseline and six months. PSYRATS has been shown to have good reliability and validity for individuals with psychosis[42]. The PSYRATS was used in this study to obtain a more detailed description of participants' current symptoms.

Depression was measured using the Calgary Depression Scale for Schizophrenia (CDSS) [10] at baseline and six -months- follow up. The CDSS was administered to control for depression in the analysis due to the potential overlap of depression and negative symptoms. The CDSS features nine items, each item is scored from 0 to 3, with 0 being 'absent' and 3 being 'severe'. CDSS has been shown to be reliable and has good congruent validity with a self-report scale of depression in people with a diagnosis of schizophrenia.

In further research, CDSS has been shown to have good specificity for depression and showed no correlation with scales of extrapyramidal symptoms and negative symptoms[43].

The Clinical Assessment Interview for Negative Symptoms (CAINS)[44] was conducted with 51 out of the 85 study participants. The CAINS measure assesses remembered pleasure and anticipated pleasure from work, school, and recreational activities in addition to examining expressive deficits such as lack of facial expressions. The former items are not captured by the PANSS, so the decision was made to include an additional measure of negative symptoms. This decision was made part way through the recruitment phase of the study so not all the participants had ratings on the CAINS. The CAINS measure has good psychometric properties in psychosis samples[45, 46]. This was important in the design of this study because of Beck and Rector's aforementioned model of negative symptoms[5] which proposes that individuals with prominent negative symptoms anticipate that an event that requires energy and motivation will be unpleasant. This negative anticipation from an event serves as an impetus for the activation of other forms of anticipated pleasure; for example, if an individual anticipates a lack of energy from engaging in an activity then they are more likely to not enjoy the activity and will appear as lacking in motivation to those they are engaging with. Therefore, the authors considered that if individuals had experienced a traumatic life event, this could dampen their ability to anticipate pleasure and thus these individuals would have a greater severity of negative symptoms than those who had experienced fewer traumas in their lifetime.

## 5.5. Reliability analysis

The Cronbach's alphas test can be seen in Table 5.1. Reliability analysis was assessed using Cronbach's alphas test. This was conducted for each scale utilised in this study, for baseline and at six months, where the measure was used at both time points. Conducting Cronbach's alpha is an important part of assessing the internal consistency of a questionnaire[47]. Low value of alphas, that is below 0.70 can be due to a low number of questions and/or poor relatedness between individual items. For this study, all Cronbach's alpha were approximately at the 0.6 level except PANSS General Symptom score at baseline and six months.

***Table 5.1. Cronbach's alphas***

| | Cronbach's Alpha | Number of Items |
|---|---|---|
| CTQ | **0.815** | **28** |
| THQ | **0.713** | **24** |
| PAM | **0.908** | **16** |
| PANSS-PS baseline | **0.752** | **7** |
| PANSS-NS baseline | **0.853** | **7** |
| PANSS-GS baseline | **0.594** | **16** |
| CAINS total baseline | **0.906** | **13** |
| CDSS Total baseline | **0.878** | **13** |
| SES Total baseline | **0.697** | **14** |
| PANSS-PS 6 months | **0.843** | **7** |
| PANSS-NS 6 months | **0.944** | **7** |
| PANSS-GS 6 months | **0.388** | **16** |
| CAINS total 6 months | **0.755** | **13** |
| CDSS Total 6 months | **0.878** | **9** |

## 5.6. Demographic data

Demographic data was collected through a self-report questionnaire that was based on the Operational Criteria Checklist for Psychotic Illness and Affective Illness criteria (OPCRIT; [48]). Age, gender, ethnicity, occupation and living status (living alone or with a partner) were recorded. Individuals completed the questionnaire in the presence of the first author at the time of the initial visit.

## 5.7. Procedure

The first author approached the participants, either by telephone or face-to-face, once they had expressed an interest in taking part. They were then given a participant information sheet about the study. Individuals were given at least 24 hours to decide whether they wished to take part. If an individual wished to participate, written consent was obtained and the first author sought their permission to speak with the individual's care coordinator, to seek information on the individual's risk, diagnosis and medication. Once a participant completed the assessments, they received £10 as a thank you for their time.

Six months later the first author contacted the participant to ask if they wished to take part in the second, 6-month follow up time point. If they agreed, the first author contacted the individual's care coordinator to assess risk, and then once this was obtained the individual arranged with the participant to meet in a convenient place. At this second time point, the PANSS, PSYRATS, CDSS, CAINS were administered after which participants were given £10 as a token of thanks for participating.

## 5.8. Data analysis

The analysis was conducted using Statistical Product and Service Solutions (SPSS) version 27. The visual inspection of histograms and Shapiro-Wilk tests were used to assess whether the data were normally distributed. Descriptive statistics were used to describe all variables. Prior to conducting the data analysis; a five step data analysis procedure was conducted which took account of the aims and outcomes of the study; i) the exploration of the descriptive statistics and examining the skewness and distribution of the data, ii) as the normality of variables was violated Spearman's rho correlations were conducted to test the hypothesis regarding the association between traumatic life events, attachment style and negative symptoms iii) multiple regression models were performed to test hypothesis regarding the association between trauma and attachment style. iv) Correlations and multiple regressions were used to assess relationship between continuous variables. v) T tests and one-way ANOVA were used to assess whether there was a difference between trauma and no trauma groups, gender and marital status difference in variables of interest.

## 5.9. Results

### 5.9.1. Sample characteristics

The sample consists of 85 individuals recruited from across five NHS Trusts within the United Kingdom. The characteristics of the participants' demographic characteristics are summarised in Table 5.2.

***Table 5.2. Socio-demographic characteristics of the sample as assessed using the OPCRIT criteria***

| | | Frequency | Percent |
|---|---|---|---|
| Ethnicity | **White British** | 68 | 80.0 |
| | **White and Black African** | 2 | 2.4 |
| | **Pakistani** | 1 | 1.2 |
| | **Black African** | 8 | 9.4 |
| | **Other mixed** | 1 | 1.2 |
| | **Black Caribbean** | 1 | 1.2 |
| | **Any other ethnic group** | 4 | 4.7 |
| Gender | **Male** | 68 | 80.0 |
| | **Female** | 17 | 20.0 |
| Marital status | **Single** | 70 | 82.4 |
| | **Married/Civil Partnership** | 10 | 11.8 |
| | **Divorced** | 4 | 4.7 |
| | **Separated** | 1 | 1.2 |
| Employment status | **Unemployed** | 76 | 89.4 |
| | **Employed** | 4 | 4.7 |
| | **Volunteer work** | 2 | 2.4 |
| | **Student** | 1 | 1.2 |
| | **Employment stated as Other** | 2 | 2.4 |
| Current service | **Inpatient Rehab** | 26 | 30.6 |
| | **Inpatient Forensic** | 10 | 11.8 |
| | **Community mental health team** | 49 | 57.6 |
| Age of respondent | **39.65 years ± 12.16** | 85 | |
| Age of onset of mental health problem | **24.8 years ± 10.04** | 85 | |

### 5.9.2. Descriptive statistics of main variables

Means and SDs on all key variables are shown in Table 5.3.

***Table 5.3. Descriptive statistics of trauma measures, attachment style, negative symptoms, depression at baseline and negative symptoms and depression at six months***

**Descriptive Statistics**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| **Trauma measures** | | | | | |
| Total score on Childhood Trauma Questionnaire | 85 | 32 | 95 | 61.2 | 15.3 |
| Emotional abuse total | 85 | 5 | 22 | 10.9 | 4.3 |
| Physical abuse total | 85 | 5 | 22 | 9.0 | 4.2 |
| Sexual abuse total | 85 | 5 | 25 | 9.9 | 6.2 |
| Emotional neglect total | 85 | 5 | 25 | 13.8 | 5.5 |
| Physical neglect total | 85 | 5 | 21 | 10.4 | 3.8 |
| Total score on Trauma History Questionnaire | 85 | 0 | 14 | 3.4 | 3.6 |
| Total crime related score | 85 | 0 | 4 | 0.7 | 1.0 |
| Total score general disaster and trauma | 85 | 0 | 8 | 1.3 | 1.7 |
| Total score for physical and sexual experiences | 85 | 0 | 7 | 1.2 | 1.6 |
| Total score bullying | 85 | 0 | 16 | 3.3 | 4.0 |
| **Attachment measure** | | | | | |
| Total anxiety subscale | 85 | 0 | 21 | 8.9 | 5.8 |
| Total avoidance subscale | 85 | 0 | 21 | 10.6 | 5.3 |
| **Negative symptoms baseline** | | | | | |
| Negative symptoms total baseline PANSS | 85 | 10 | 28 | 21.0 | 4.3 |
| Total score on CAINS baseline | 51 | 22 | 52 | 32.1 | 6.8 |
| Motivation and Pleasure Total score | 51 | 13 | 36 | 23.6 | 5.3 |
| Expression total score | 51 | 4 | 16 | 8.5 | 3.0 |
| **Depression at baseline** | | | | | |
| Total score on Calgary Depression Scale (CDS) baseline | 85 | 0 | 18 | 4.0 | 4.0 |
| **Service Engagement Scale baseline** | | | | | |
| Total Service Engagement Scale | 82 | 2 | 30 | 18.9 | 6.4 |
| **Negative symptoms and depression at 6 month** | | | | | |
| Negative symptoms total score 6 month PANSS | 71 | 13 | 32 | 21.9 | 4.2 |
| Total Score on CAINS 6 month | 71 | 8 | 47 | 36.6 | 5.3 |
| Motivation and Pleasure Total score 6 month | 71 | 0 | 36 | 25.6 | 4.1 |
| Expression total score total 6 month score | 71 | 7 | 16 | 10.9 | 2.0 |
| **Depression at 6 month** | | | | | |
| Total score on Calgary Depression Scale (CDS) 6 month | 71 | 0 | 9 | 1.8 | 2.0 |
| **Service Engagement Scale at 6 month** | | | | | |
| Total Service Engagement Scale | 71 | 9 | 37 | 17.3 | 4.0 |

In order to examine potential confounding variables, independent sample t-tests were performed to identify if there was any difference between men and women for any of the variables: PANSS negative baseline, PANSS negative six months, CAINS baseline, CAINS six months. No gender differences were identified.

The potential confounding effect generated by marital status were assessed using different one-way ANOVA models to identify if there was a difference between participants who are either married, divorced, single and widowed in terms of negative symptoms. The performed F tests suggest there are no significant difference between marital status groups in PANSS baseline, PANSS six months, CAINS baseline, CAINS six months. The confounding effect of age was assessed using bivariate correlation. As not significant correlation was identified it was not included in the further steps of the analysis. Using independent sample t-test the confounding effect of ethnicity (white British vs other) was assessed. No significant difference was identified so it was not included in the further steps of the analysis.

Following the observations from Table 5.3. the scores for individual items in PANSS baseline and 6 months are presented in Table 5.4. By observing their average scores, it can be concluded that each individual item is stable over time. Blunted affect (M = 2.67, SD = 0.93 at baseline, M = 3.0, SD = 0.77 at 6 months) and stereotype thinking (M = 2.85, SD = 0.92 at baseline, M = 3.18, SD = 0.78 at 6 months) as assessed in the PANSS seem to reveal an observable increase.

***Table 5.4. Scores for individual items on the PANSS at baseline and 6 months***

**Descriptive Statistics**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| **PANSS Negative Symptoms Baseline** | | | | | |
| Blunted affect | 85 | 1 | 4 | 2.67 | 0.93 |
| Emotional withdrawal | 85 | 1 | 4 | 3.02 | 0.86 |
| Poor rapport | 85 | 1 | 5 | 2.98 | 0.86 |
| Passive/apathetic social withdrawal | 85 | 1 | 4 | 3.18 | 0.74 |
| Difficulty in abstract thinking | 85 | 1 | 5 | 3.13 | 0.87 |
| Lack of spontaneity amd flow of conversation | 85 | 1 | 4 | 3.19 | 0.73 |
| Stereotyped thinking | 85 | 1 | 5 | 2.85 | 0.92 |
| **PANSS Negative Symptoms 6 Months** | | | | | |
| Blunted affect | 71 | 1 | 5 | 3.00 | 0.77 |
| Emotional withdrawal | 71 | 2 | 5 | 3.00 | 0.76 |
| Poor rapport | 71 | 2 | 5 | 3.11 | 0.78 |
| Passive/apathetic social withdrawal | 71 | 1 | 4 | 3.18 | 0.76 |
| Difficulty in abstract thinking | 71 | 2 | 5 | 3.21 | 0.75 |
| Lack of spontaneity amd flow of conversation | 71 | 2 | 5 | 3.23 | 0.72 |
| Stereotyped thinking | 71 | 1 | 5 | 3.18 | 0.78 |

Table 5.5. below reveal the same aspects for CAINS. Comparing the average scores of individual items from baseline to 6 months it is observed that sizable differences for Motivation for school and work activities, expected pleasurable school and work activities, frequency of expected school and work activities. Facial expression as measured on

CAINS improved even stronger at 6 months (from 2.12 (SD = 0.77) to 2.85 (SD = 0.8)). The same is seen for expressive gestures (from 2.14 (SD = 0.83) to 2.79 (SD = 0.72)) and quantity of speech (from 2.02 (SD = 0.84) to 2.76 (SD = 0.73)).

***Table 5.5. Scores for individual items on the CAINS at baseline and 6 months***

**Descriptive Statistics**

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| **CAINS Motivation and Pleasure Items Baseline** | | | | | |
| Motivation for close family/spouse/partner relationships | 51 | 1 | 4 | 2.51 | 0.76 |
| Motivation for close friendships/romantic relationships | 51 | 1 | 4 | 2.61 | 0.70 |
| Frequency of pleasurable social activities (past week) | 51 | 1 | 4 | 2.59 | 0.70 |
| Frequency of expected pleasurable social activities (Next week) | 51 | 1 | 4 | 2.59 | 0.75 |
| Motivation for work and school activities | 51 | 1 | 4 | 2.73 | 0.72 |
| Expected pleasurable work and school acitivities | 51 | 1 | 4 | 2.75 | 0.66 |
| Motivation for recreational activities | 51 | 0 | 4 | 2.55 | 0.88 |
| Frequency of pleasurable recreational activities | 51 | 1 | 4 | 2.69 | 0.68 |
| Frequency of expected pleasure from recreational activities | 51 | 0 | 4 | 2.61 | 0.83 |
| **CAINS Expression items Baseline** | | | | | |
| Facial expression | 51 | 1 | 4 | 2.12 | 0.77 |
| Vocal Expression | 51 | 1 | 4 | 2.20 | 0.83 |
| Expressive Gestures | 51 | 1 | 4 | 2.14 | 0.83 |
| Quantity of Speech | 51 | 1 | 4 | 2.02 | 0.84 |

| | N | Minimum | Maximum | Mean | Std. Deviation |
|---|---|---|---|---|---|
| **CAINS Motivation and Pleasure Items 6 Months** | | | | | |
| Motivation for close family/spouse/partner relationships | 71 | 0 | 4 | 2.58 | 0.89 |
| Motivation for close friendships/romantic relationships | 71 | 0 | 4 | 2.42 | 0.86 |
| Frequency of pleasurable social activities (past week) | 71 | 0 | 4 | 2.77 | 0.85 |
| Frequency of expected pleasurable social activities (Next week) | 71 | 0 | 4 | 2.77 | 0.81 |
| Motivation for work and school activities | 71 | 0 | 4 | 3.20 | 0.69 |
| Expected pleasurable work and school acitivities | 71 | 0 | 4 | 3.15 | 0.82 |
| Motivation for recreational activities | 71 | 0 | 4 | 2.77 | 0.94 |
| Frequency of pleasurable recreational activities | 71 | 0 | 4 | 2.96 | 0.80 |
| Frequency of expected pleasure from recreational activities | 71 | 0 | 4 | 3.00 | 0.79 |
| **CAINS Expression items 6 Months** | | | | | |
| Facial expression | 71 | 1 | 4 | 2.85 | 0.80 |
| Vocal Expression | 71 | 1 | 4 | 2.56 | 0.81 |
| Expressive Gestures | 71 | 1 | 4 | 2.79 | 0.72 |
| Quantity of Speech | 71 | 1 | 4 | 2.76 | 0.73 |

## 5.10. Hypotheses testing baseline

**Hypothesis 1. There will be a relationship between the frequency of traumatic life events and severity of negative symptoms at baseline**

**Hypothesis 2. There will be a positive association between subtypes of traumatic life events, specifically severity of neglect and negative symptom at baseline**

**Hypothesis 3. There will be a positive association between attachment style and severity of negative symptoms at baseline**

To investigate hypotheses 1 and 2, Spearman's bivariate correlation were conducted (Table 5.6 and 5.7). There was no significant association between traumatic life events and negative symptoms at baseline, additionally no association was observed between type of traumatic life events and negative symptoms. For hypothesis 3, once again there was no statistically significant association between insecure avoidant attachment and severity of negative symptoms.

*Table 5.6. Bivariate correlation coefficients between trauma, trauma subtypes, attachment style and negative symptoms at baseline*

| | PANSS-NS baseline | CAINS baseline | Expression total score | Motivation and Pleasure total score |
|---|---|---|---|---|
| | (N = 85) | (N = 51) | (N = 51) | (N = 51) |
| **Total score on THQ** | -0.09 | -0.01 | -0.01 | 0.03 |
| **Sig** | 0.43 | 0.92 | 0.96 | 0.84 |
| **Total score bullying** | 0.07 | 0.08 | -0.07 | 0.15 |
| **Sig** | 0.52 | 0.57 | 0.62 | 0.29 |
| **Total score on CTQ** | 0.09 | 0.04 | 0.18 | -0.03 |
| **Sig** | 0.43 | 0.79 | 0.21 | 0.84 |
| **Emotional abuse total** | 0.06 | -0.02 | 0.22 | -0.10 |
| **Sig** | 0.58 | 0.87 | 0.12 | 0.50 |
| **Physical abuse total** | 0.15 | -0.09 | 0.17 | -0.17 |
| **Sig** | 0.18 | 0.55 | 0.25 | 0.23 |
| **Sexual abuse total** | -0.06 | 0.18 | -0.02 | 0.22 |
| **Sig** | 0.59 | 0.21 | 0.91 | 0.12 |
| **Emotional neglect total** | 0.05 | -0.05 | 0.03 | -0.08 |
| **Sig** | 0.64 | 0.74 | 0.83 | 0.57 |
| **Physical neglect total** | 0.16 | -0.06 | 0.08 | -0.12 |
| **Sig** | 0.14 | 0.66 | 0.57 | 0.40 |
| **Total score for physical and sexual experiences** | -0.07 | 0.15 | 0.07 | 0.15 |
| **Sig** | 0.55 | 0.29 | 0.65 | 0.29 |
| **Total crime related score** | -0.16 | -0.13 | -0.15 | -0.01 |
| **Sig** | 0.14 | 0.38 | 0.28 | 0.93 |
| **Total score general disaster and trauma** | -0.06 | -0.03 | -0.04 | 0.02 |
| **Sig** | 0.56 | 0.85 | 0.81 | 0.87 |
| **Total anxiety subscale** | -0.04 | -0.09 | -0.15 | -0.03 |
| **Sig** | 0.73 | 0.51 | 0.30 | 0.84 |
| **Total avoidance subscale** | -0.14 | 0.05 | -0.10 | 0.13 |
| **Sig** | 0.22 | 0.73 | 0.49 | 0.36 |
| **Total score** | -0.06 | -0.03 | -0.17 | 0.07 |
| **Sig** | 0.58 | 0.86 | 0.24 | 0.65 |

*Table 5.7. Bivariate correlation coefficients between trauma, trauma subtypes, attachment style and negative symptoms at six months*

| | PANSS-NS 6 months | CAINS 6 months | Expression total score | Motivation and Pleasure total score |
|---|---|---|---|---|
| | (N = 85) | (N = 51) | (N = 51) | (N = 51) |
| **Total score on THQ** | 0.11 | 0.16 | 0.19 | 0.08 |
| **Sig** | 0.32 | 0.14 | 0.08 | 0.47 |
| **Total score bullying** | 0.17 | 0.02 | -0.07 | 0.07 |
| **Sig** | 0.13 | 0.89 | 0.50 | 0.54 |
| **Total score on CTQ** | 0.01 | 0.06 | -0.04 | 0.10 |
| **Sig** | 0.93 | 0.61 | 0.71 | 0.37 |
| **Emotional abuse total** | 0.14 | 0.05 | -0.07 | 0.12 |
| **Sig** | 0.20 | 0.64 | 0.55 | 0.28 |
| **Physical abuse total** | -0.11 | 0.02 | -0.12 | 0.16 |
| **Sig** | 0.31 | 0.84 | 0.27 | 0.14 |
| **Sexual abuse total** | -0.13 | -0.03 | -0.17 | 0.05 |
| **Sig** | 0.26 | 0.78 | 0.12 | 0.65 |
| **Emotional neglect total** | 0.05 | 0.08 | 0.06 | 0.02 |
| **Sig** | 0.66 | 0.49 | 0.61 | 0.88 |
| **Physical neglect total** | 0.08 | 0.15 | 0.01 | 0.19 |
| **Sig** | 0.45 | 0.16 | 0.93 | 0.09 |
| **Total score for physical and sexual experiences** | 0.08 | 0.15 | 0.18 | 0.11 |
| **Sig** | 0.47 | 0.18 | 0.09 | 0.32 |
| **Total crime related score** | 0.02 | 0.07 | 0.16 | 0.01 |
| **Sig** | 0.83 | 0.52 | 0.13 | 0.97 |
| **Total score general disaster and trauma** | 0.07 | 0.15 | 0.21 | 0.05 |
| **Sig** | 0.51 | 0.18 | 0.05 | 0.67 |
| **Total anxiety subscale** | -0.10 | 0.18 | -0.03 | 0.20 |
| **Sig** | 0.39 | 0.10 | 0.76 | 0.07 |
| **Total avoidance subscale** | 0.04 | 0.02 | 0.03 | -0.03 |
| **Sig** | 0.73 | 0.86 | 0.76 | 0.78 |
| **Total score** | -0.07 | 0.13 | -0.02 | 0.13 |
| **Sig** | 0.50 | 0.25 | 0.87 | 0.25 |

### 5.10.1. Hypotheses testing: six months

**Hypothesis 4. There will be a relationship between the frequency of traumatic life events and the change in negative symptoms from baseline to six months**

A multiple regression model was performed to test Hypothesis 4. Negative symptoms at baseline as measured by the PANSS negative symptoms subscale, total score on CTQ, total attachment anxiety subscale, total attachment avoidance subscale. Total score on trauma history questionnaire, total score on Olweus' bullying items, and total score on THQ were used as predictor of negative symptoms at six months. As observed in Table 5.6, the model is statistically significant ($R^2 = 0.198$, $F(7, 77) = 2.71$, $p = 0.014$) indicating that our predictors account for 20% of negative symptoms at six months. Negative symptoms baseline (B = -.215*), bullying (B = -.320**), anxiety (B = .232*) and avoidance (B = -.285*) were the only significant predictors this indicates that there is support to accept hypothesis 4 that traumatic events measures as total score on Olweus' bullying items are associated with negative symptoms at six months when attachment style, other traumatic events and depression are controlled for.

***Table 5.8. Multiple regression model 1. PANSS at six months is used as dependent variable***

| | Model 1 |
|---|---|
| Negative symptoms total baseline PANSS | -.215 * |
| Total score on THQ | .125 |
| Total score on CDS | -.098 |
| Total Score on CTQ | -.031 |
| Total score on Bullying | -.320 ** |
| Total anxiety subscale | .232 * |
| Total avoidance subscale | -.285 * |
| $R^2$ | .198 |
| Sig | < 0.05 |

Sig: *** "< 0.001", ** "< 0.01", * "< 0.05"

Unstandardised coefficients are reported in Table 5.8.

A multiple regression was performed to determine if total attachment avoidance subscale, total attachment anxiety subscale, CAINS baseline, total score on THQ, total score on

CTQ and total score on Olweus' bullying items are significant predictors of CAINS at six months. The model was not statistically significant ($R^2$ = .102, $F$(7, 43) = .701, $p$ = .671) indicating that no baseline predictors have an impact on the CAINS at six months.

As CAINS scale contains two sub-scales (Motivation and Pleasure Total score, Expression total score) the author created another model which included these as predictors instead of CAINS baseline. Model 3 overall ($R^2$ = .144, $F$(8, 42) = .886, $p$ = .536) and none of its predictors are significant indicating they have no impact on CAINS at six months.

Following the previous two regression models the thesis author concluded that there is some enough empirical evidence to accept Hypothesis 4 when either only when PANSS (baseline) are used as predictors of PANSS at six months. In this model the total bullying score on Olweus' bullying items are the only trauma which significantly predicts PANSS.

***Table 5.9. Multiple regression model 2 and 3. CAINS at six months is used as dependent variable***

| | Model 2 | Model 3 |
|---|---|---|
| CAINS baseline | .012 | |
| Total score on THQ | .110 | .104 |
| Total score on CTQ | -.026 | -.012 |
| Total score on Bullying | -.096 | -.156 |
| Total anxiety subscale | .214 | .194 |
| Total avoidance subscale | .016 | .003 |
| Total score on CDS | -.082 | -.114 |
| Motivation and Pleasure Total score | | .154 |
| Expression total score | | -.317 |
| $R^2$ | .102 | .144 |
| Sig | > 0.05 | > 0.05 |

Sig: *** "< 0.001", ** "< 0.01", * "< 0.05"

Unstandardised coefficients are reported in Table 5.9.

**Hypothesis 5. Any association between trauma and negative symptoms will be mediated by attachment style**

Mediation was not investigated as none of the univariate correlations between trauma, negative symptoms and attachment at any time point were statistically significant. Consequently, there is not enough empirical support to accept Hypothesis 5.

**Hypothesis 6. There will be a relationship between the level of engagement with services at baseline and severity of negative symptoms at baseline**

A multiple regression (Model 4) was performed to determine if total score on service engagement scale and total score on CDS baseline are significant predictors of PANSS at six months. The model is not statistically significant ($R^2$ = .007, $F$ (2, 79) = .279, $p$ = .757) indicating that no baseline variables/predictor impact the PANSS at six months. A multiple regression (Model 5) was performed to determine if total score on SES and total score on CDS baseline are significant predictors of CAINS at six months. The model is statistically significant ($R^2$ = .013, $F$ (2, 79) = 5.889, $p$ = 0.004) indicating that 13% of CAINS at six months is accounted by SES and CDS baseline. Total Score on SES is a significant predictor (B = 0.317, p = 0.001) suggesting that for each one unit increase in engagement with the service we can expect the CAINS to be higher by 0.317. This indicates those participants who have difficulties to engage with the service have higher negative symptom scores on the CAINS.

Following the results in this model as observed in Table 5.10. the first author concluded that there is not enough empirical evidence to accept Hypothesis 6 when the PANSS is used to assess negative symptoms but is signficant when the CAINS is used.

***Table 5.10. Multiple regression model 4 and 5. PANSS at six months is used as dependent variable in Model 4 and CAINS at six months in Model 5***

| | Model 4 | Model 5 |
|---|---|---|
| Total score on Service Engagement Scale | -.057 | .317*** |
| Total score on CDSS | .001 | 0.069 |
| $R^2$ | 0.007 | .130 |
| Sig | >0.05 | < 0.05 |

Sig: *** "< 0.001", ** "< 0.01", * "< 0.05"

Unstandardised coefficients are reported in Table 5.10.

## 5.11. Discussion

This study explored the association between traumatic life events, attachment style and negative symptoms at baseline and at six months. It was concluded that only PANSS baseline is a significant predictor of negative symptoms at six months. Additionally, this study explored whether attachment style mediates the association between traumatic life events and negative symptoms. This study also considered the role of depression and engagement with services.

The findings revealed that there was no significant association between the frequency of traumatic life events, and severity of negative symptoms at baseline. There was no positive observation observed between the subtypes of traumatic life events, specifically neglect and. negative symptoms at baseline. Thirdly, no positive association was observed between attachment style and severity of negative symptoms at baseline. These hypotheses were conducted using both the PANSS and the CAINS to assess negative symptomology. When examining the fourth hypothesis, the results indicated that the total bullying score, predicted PANSS score at six months. The proposed mediation model between trauma, attachment style and negative symptoms was not examined due to none of the univariate correlations being statistically significant. The final finding from this study revealed that there is a statistically significant association between the level of engagement with services and severity of negative symptoms on the CAINS.

The hypotheses were based on the current literature which suggests that specific traumas may be associated with negative symptoms [49, 50]. A previous study conducted in the United Kingdom revealed an association between attachment style and negative symptom severity[22] in a sample of 68 individuals with a diagnosis of first- episode psychosis. Trauma was not assessed in Gumley's study[22]. Gumley's [22] findings were from a sample of sixty eight individuals with a diagnosis of first episode psychosis whereas this current study recruited sample of individuals experiencing negative symptoms or those that had either an 'early schizophrenia or chronic schizophrenia' diagnoses.

Findings from the current study found no statistically significant association between traumatic life events and negative symptoms. This null finding between traumatic life events and negative symptoms is indeed contrary to previous literature suggesting that there is an association between specific traumatic life events and negative symptoms[19, 49, 50].

Yet, in light of this perhaps surprising null finding, it is interesting and pertinent to report these null findings because it suggests that there is a need for further research into negative symptoms specifically. Research to date exploring the impact of adversities and diagnosis of schizophrenia has been primarily associated with positive psychotic phenomena[12, 51] . Whilst positive psychotic symptoms can be unpleasant, the disabling and persistent nature of negative symptoms should not be forgotten. The impact that negative symptoms can have on an individual's life was evident in the study through the finding that poorer level of engagement with services was associated with greater scores on the CAINS. This finding is similar to the finding that MacBeth[31] and colleagues reported in a sample of individuals with first episode psychosis, suggesting that the association between engagement with services and negative symptoms warrants further consideration.

When considering the findings from this study it is important to recognise that there may have been e a diversity of psychosis presentations with some individual's psychosis the result of perhaps substance misuse. Other individuals may have experienced psychosis as a result of childhood trauma. It is important to state that the specific causes of each of the eight five participants was not recorded and so it must be acknowledged that these individuals may have experienced a range of life events that led to a diagnosis of psychosis.

Interestingly and in line with the current literature, difficulty in service engagement was associated with higher negative symptoms; thus, evidencing that individuals with negative symptoms find engaging with services and other individuals harder. This finding was only evidenced using the CAINS scores (Model 1) but not the PANSS-NS score (Model 2 and 3). This study sheds further light into negative symptoms, and it is interesting to note that CAINS baseline did not predict CAINS at six months.

The null findings of this study are however in line with the findings obtained in previous systematic reviews and meta-analyses [12, 13], as well as previous cross-sectional studies that have reported no significant associations between traumatic life events and negative symptoms in similar populations, There is a paucity of research published on traumatic life events with studies, adopting a range of designs, a range of measures to assess the presence of trauma and range of measures to assess negative symptomology. The studies that have been conducted are primarily cross sectional in nature with fairly small sample sizes.

## 5.12. Limitations

This study reported a null finding between traumatic life events and negative symptoms which some may consider a limitation. The sample consisted of 85 individuals at baseline and 71 at six months. This might not be regarded as large; however, the power analysis criteria were met. Additionally, all individuals had to meet specific inclusion criteria and consequently, individuals who did not meet the threshold for negative symptoms were excluded. There may have been an association between those individuals excluded from the study but due to the inclusion criteria these findings are only generalisable to individuals who met the negative symptoms threshold for this study.

Furthermore, negative symptoms scores on the CAINS were not checked for interrater reliability as the first author conducted all assessments. The thesis author did however receive online training on the CAINS from the authors who designed and validated the CAINS.

A third limitation of this study is that this study used retrospective self-report items to assess presence or absence and severity of traumatic life events, and these are subject to recall bias. Some events may be more easily recalled than other events.

The analysis of this extensive study did not include the age at which trauma was experienced; this can be recorded on the THQ and so further extraction of the dataset

would elicit this information. However, for this study due to incomplete data on the age at which events occurred, this aspect of the THQ was not used in this analysis. The age at which adversities are experienced is an area of research which researchers have identified as may be worth investigating because research has suggested that there are prominent sensitive periods in an individual's life whereby if experienced at the time point, they are at increased likelihood of going on to experience several mental health symptoms later in life.[52]

A limitation of this study was that to assess an individual's level of engagement with services; reports from clinicans and staff were relied upon. The individuals who participated were not asked to score their experience of engaging with services. As indicated by other reserachers[29, 30] it may be that this score is therefore not wholly representative of an individual's level of engagement. Future research may consider asking individuals to score their engagement with services through the use of a self-report measure such as the Singh O'Brien Level of Engagement Scale.[30]

Furthermore, a limitation of this study is that trauma has been crudely scored which does not account for the subjective experience of trauma differing from person to person. To categorise and group the traumas as has been done in this study by the number of traumas experienced, may not be accurate as several traumas could be less traumatic than one single traumatic life event.

## 5.13. Strengths

Although a non-significant positive association was identified between traumatic life events and negative symptoms, this study clearly identifies that individuals with a diagnosis of schizophrenia may have experienced traumatic life events across their life span and thus it is crucial that these are explored clinically with an individual.

A further key strength of this study is that it utilised a range of measures to assess traumatic life events, in addition to those on the CTQ; which the majority of studies to date have focused on using. The measures in this study included occurrences of bullying as well as instances of natural disasters and parental loss all of which are not items on the CTQ. This study therefore focused on traumatic life events across the life span with a large sample size.

An additional strength of this study is that two different measures of negative symptoms were adopted in this study which encompasses all aspects of negative symptoms domains: expressive and experiential deficits. This ensured that all aspects of negative symptoms were included and thus obtained a detailed overview of an individual and their current experiencing.

A strength of this study is that the sample was recruited from across the United Kingdom from a range of settings; thus, the findings from this study are generalisable to a range of clinical settings. To date, negative symptoms research has primarily focused on large inpatient settings and thus not generalisable to those individuals with a diagnosis of schizophrenia and experiencing negative symptoms who reside in their own homes or community settings.

## 5.14. Conclusion

This study offers further insight into the association(s) between traumatic life events, attachment style and negative symptoms; it is of interest that this study assessed traumatic life events across the life span, as previous research has focused primarily on traumatic life events that happened in childhood. The study included participants from a wide range of mental health settings; thus, building upon current literature that examined negative symptoms and their course in individuals with first-episode psychosis. By utilising the CAINS measure to assess negative symptoms it enabled further understanding of the association between experiential and expressive deficits and traumatic life events. This study reported no significant association between traumatic life events and negative symptoms, and that there was no association between traumatic life events and attachment style. However as reported by Kingdon and Turkington [53] the first author supports their view that a "case specific" approach is beneficial in understanding cause and factors of negative symptoms. Service engagement, as reported by a participant's key worker was associated with greater severity of negative symptoms when the CAINS was used. To conclude, despite the null findings from this study, traumatic life events, attachment and negative symptoms is an area of research that warrants further attention.

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# Preface to Chapter 6: General Discussion

This PhD sought to delve deeper into the impact and experiences of individuals with negative symptoms of schizophrenia for two reasons; i) these symptoms are disabling and ii) there is no known pharmacological or psychological intervention that can successfully 'treat' these symptoms. It is challenging for an individual who does not experience symptoms such as anhedonia, to imagine what it must be like to be unable to experience pleasure and enjoyment from daily life activities.

There has been, in recent years, an increase in research to evaluate experiences of traumatic life events and positive psychotic symptoms. This must be applauded. However there now needs to be further research into negative symptoms from a similar perspective. Within the last twenty years there has been a 'shift' into what constitutes a traumatic life event and the measures have been appropriately updated to explicitly include such events as bullying.

Attachment and its importance to individuals has been researched for decades and is well documented. There is consistent evidence that demonstrates certain attachment types are more likely to be associated with specific psychotic symptoms, both positive and negative symptoms. It remains unclear whether attachment style may impact on negative symptoms. However, results from the qualitative study in chapter 4 indicate that negative symptoms do have an impact on an individual's relationships with those around them.

As I write this, we are living in uncertain times with people reporting that COVID19 is a traumatic life event and that it will leave people with mental health needs that were unknown prior to the global pandemic. So perhaps now more than ever before it is important that as researchers, we identify the impact of different traumatic life events on symptoms associated with severe mental health illnesses.

**This discussion chapter aims to answer the key research questions of this PhD:**

1) Are trauma and negative symptoms associated?

2) Are specific types of trauma associated with particular symptoms?

3) How do individuals subjectively experience negative symptoms?

4)What is the association between trauma, attachment style and negative symptoms?

5) Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six months?

# Chapter 6. General Discussion: An examination of negative symptoms, traumatic life events and attachment style: A mixed methods investigation

## 6.1. Overview

In Chapter 1 of this thesis, the aims of the PhD were described through five research questions.

This chapter provides a summary of the findings of each research question contained within this thesis, then considers how these findings relate to the wider literature and their implications for the field, as well as for clinical practice. After this, the strengths and limitations of the studies within this thesis are discussed prior to further directions for research and final conclusions. This general discussion chapter is structured through an exploration of the findings from each research question in numerical order, as given in Chapter 1.

## 6.2. Summary of aims

This thesis explored the association between traumatic life events, attachment style and negative symptoms in individuals with a diagnosis of schizophrenia, located across the United Kingdom. The project title at the beginning of this MRC-funded PhD, four years ago, was 'trauma, attachment and psychosis.' After an initial scoping search, the thesis author was made aware of an extensive narrative review conducted by Gibson et al. (Gibson, Alloy, & Ellman, 2016), which succinctly synthesized all literature to date on traumatic life events and psychotic spectrum disorders. This review highlighted the paucity of research conducted on traumatic life events and negative symptoms. Consequently, the thesis author, in discussion with the supervisory team, chose to focus on trauma, attachment and negative symptoms of schizophrenia. Additionally, the author's experience of working in an inpatient rehabilitation and recovery unit highlighted the disabling nature of negative symptoms and how individuals' who experience negative symptoms find it hard to engage with services. Individuals who experience negative symptoms often do not participate in group activities within a hospital environment and thus it became apparent to the thesis author that there may be a possible association between the presence/absence of negative symptoms and the level of engagement with services.

The thesis research aimed to identify and explore whether there is a link between traumatic life events, attachment style and negative symptoms through an exploration of the following five key research questions. It also considered the impact of negative symptoms on an individual's engagement with services.

The five key research questions are:

1. Is there an association between trauma and negative symptoms?
2. Are specific types of trauma associated with negative symptoms?
3. How do individuals experience negative symptoms?
4. What is the association between trauma, attachment style and negative symptoms?
5. Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six months?

The thesis consists of three progressive studies; each study led to the development of the next study, thus providing a coherent and cohesive story that ties each study to the next. The mixed methods design of this PhD provided a rich insight into the experience of negative symptoms, as well as the nature of the association between traumatic life events and negative symptoms.

The thesis author acknowledges that there will be a commonality of literature highlighted with each of the research questions. It is important to acknowledge the research that has already been completed, with regard to each specific research question.

## 6.3. Research question 1 and 2 findings

1. **Is there an association between trauma and negative symptoms?**
2. **Are specific types of trauma associated with negative symptoms?**

To date there has been a plethora of research, which explores the association between traumatic life events and positive psychotic symptoms, such as voice hearing (Bailey et al., 2018; Varese et al., 2012). This research has been primarily conducted over the past ten years, through the use of a range of study designs that have included observational studies, longitudinal studies, qualitative studies and more recently epidemiological studies. The vast majority of studies agree that there is a positive association between the experience of traumatic life events and positive symptoms (Bailey et al., 2018; Longden, Madill, & Waterman, 2012; Varese et al., 2012). This is particularly relevant for all researchers and clinicians who work with individuals that experience these symptoms and it has led clinicians to re-evaluate treatment programmes for people who experience psychosis. An example is the Trauma-Integrated Psychotherapy for Psychosis (TRIPP; (Bendall, 2014) programme, which involves integration of the principles of trauma-informed care into routine clinical care. As part of this approach, individuals are asked to describe major events that have occurred over the course of their life, and their reactions to those events, during the TRIPP programme; these are illustrated on a timeline and explored over the course of the programme. This approach differs from traditional medical model approaches, which conceptualise severe mental health illness, such as schizophrenia as 'brain diseases' that require pharmacological treatments to target biological abnormalities.

George Engel (Engel, 1977) described the biomedical model as:

> *"The dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes diseases to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioural dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behaviour, but it also demands that behavioural aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes" (p. 130).*

Whilst this shift in thinking and research is no doubt positive, it highlights the gap in research. There has been little research that explores the causes of negative symptoms. This is pertinent because negative symptoms, whilst not always apparent, are disabling.

Furthermore, negative symptoms, have been evidenced to prevent recovery from psychosis (Austin et al., 2015; Hodgekins et al., 2015; Wunderink et al., 2020). This lack of research into negative symptoms is concerning, as there is, to date, no medication that successfully targets and treats negative symptoms. There have been several investigations into potential drug treatments but with few positive results (Deakin et al., 2019; Downs et al., 2019). Whilst the research into the cause of positive psychotic symptoms moves forward in 'leaps and bounds,' research into the causes of negative symptomology is left behind, therefore it is crucial that researchers pay heed to negative symptoms.

The first two questions of this PhD were examined through a systematic review, which revealed a total of 34 studies that met the inclusion criteria, of these, only nine demonstrated a statistically significant association between the experience of trauma and negative symptoms. The thesis author, through registering the systematic review on PROSPERO, was aware that Bailey and colleagues (Bailey et al., 2018) were in the process of conducting a similar systematic review and meta-analysis of the literature. Unlike Bailey et al. and Varese et al.'s meta-analyses, the current review by the thesis author included specific search terms for negative symptoms and through the inclusion of these additional search terms this resulted in supplementary studies that were not in Bailey's original meta-analysis. The thesis author chose to use specific negative symptoms as search terms such as 'alogia' and 'avolition.' This ensured that this systematic review contributed to the research field rather than simply replicating what Bailey and colleagues and Varese et al. had already reviewed.

This systematic review by the thesis author revealed that there was no conclusive evidence as to the association between traumatic life events and negative symptoms, yet nine out of thirty-four studies reported a significant relationship. This review also examined the following types of traumatic life events: emotional abuse, physical abuse, sexual abuse, emotional neglect, physical neglect, parental loss and parental separation.

Childhood emotional neglect was the type of trauma that was most consistently associated with negative symptoms in this systematic review. Of the thirty-four studies included in this extensive systematic review, fourteen studies reported on childhood emotional neglect and negative symptoms. Of these fourteen studies, six reported a statistically significant association between childhood emotional neglect and negative symptoms. This finding was

particularly pertinent given that, the National Society for the Prevention of Cruelty to Children (NSPCC) reported that:

> *"Neglect is the most common cause for being subject to a child protection plan (CPP) or on a child protection register (CPR) in all nations." (NSPCC, 2014)*

One possible theory to explain an association between emotional neglect and negative symptoms is that the experience of emotional neglect could lead to emotional numbing, as a way of coping, but at some point in an individual's life this becomes maladaptive, and leads individuals to withdraw, both emotionally and socially, from the world around them and thus displaying negative symptoms (Stampfer, 1990; Van der Kolk, 1987).

The thesis author's systematic review highlighted that there is a lack of published research that has been conducted on traumatic life events and negative symptoms both cross-sectionally and longitudinally. There have been limited studies that use longitudinal methodologies (DeRosse, Nitzburg, Kompancaril, & Malhotra, 2014; Heins et al., 2011; Van Dam, Korver-Nieberg, Velthorst, Meijer, & de Haan, 2014) but none of these were conducted in the United Kingdom. The sample characteristics of the thirty-four studies in the thesis author's systematic review included studies that focussed on first-episode psychosis samples, and studies that included individuals with chronic schizophrenia diagnoses. The lack of longitudinal research, found in the thesis author's systematic review, emphasises the point made by Veena Kumari (Kumari, 2020) in a recent publication in which the author of the publication suggests that there needs to be more multimodal research conducted into the mechanisms underlying emotional abuse, emotional neglect and poor mental health outcomes.

Furthermore, this systematic review provided not only insight into the possible association between traumatic life events and negative symptoms, but also insight into the types of studies that have been conducted into trauma and negative symptoms. This review also further highlighted the lack of studies that report on the association between trauma and negative symptoms. It became apparent, during the completion of this extensive systematic review, that many studies reported on the association between trauma and positive symptoms but did not meet the inclusion criteria for this review because they did not report on associations between trauma and negative symptoms. A proportion of studies excluded from this extensive systematic review included measures of negative symptoms such as the PANSS but did not report the negative symptom data in the paper. Thus, there is

potentially lots of 'missing' data in the research on traumatic life events and negative symptoms, through lack of reporting. A limitation of the systematic review conducted as part of thesis is that it excluded any research that had been published in grey literature such as conference abstracts, posters and unpublished theses. The exclusion of these sources meant that some potential research on the association between adverse life events and negative symptoms may have not been included. Furthermore, recently studies that explored the impact of adverse life events on an individual's mental health have assessed the experiences through qualitative methods, the systematic review conducted as part of this PhD excluded those studies that assessed the presence/absence of adverse life events solely through interview-based methods.

After completion of a systematic review, an empirical quantitative study was designed to investigate the same two research questions:

i) is there an association between trauma and negative symptoms?

ii) are specific types of trauma associated with negative symptoms?

The impetus for the empirical study was the systematic review, because it highlighted that there may be some association between certain types of traumatic life events and negative symptoms, specifically, emotional neglect. A further catalyst for the empirical study, in this thesis, was a well-conducted study by Gumley and colleagues (Gumley et al., 2014b) that explored associations between attachment style and positive and negative symptoms in a sample of 68 individuals who had a diagnosis of first-episode psychosis and the role of insight, attachment and duration of untreated psychosis in predicting negative symptoms at a 12-month-follow up. This empirical study by the thesis author was designed to assess attachment styles and negative symptoms, similar to Gumley et al.'s study, but it also assessed the presence or absence of trauma experienced by an individual.

Through utilisation of quantitative methods of data collection and analysis, a sample of 85 people with a diagnosis of schizophrenia were recruited in both inpatient and outpatient settings in order to examine the first two these research questions, as stated previously.

This study found that there was no association between traumatic life events and severity of negative symptoms. The correlations observed could be described as weak, with distributions on each of the subscales of trauma on the CTQ being abnormally distributed.

The overall CTQ total mean score obtained was 96 (out of a possible 140), thus indicating that the individuals who participated in this study did not report a high presence of childhood traumatic life events. The null findings in the quantitative study could be explained by the inclusion criteria of the sample; all individuals had to meet a set threshold of negative symptoms, but the presence or absence of trauma was not a criterion. It may well be that some of these individuals had not experienced any events that they themselves deemed as traumatic. Indeed, one may consider that if the sample in the thesis author's quantitative study had included individuals with a diagnosis of post-traumatic stress disorder (PTSD) then all the participants in this study would have experienced a traumatic life event. Nevertheless, in the light of rejecting all the hypotheses in this cross-sectional study, this does not counteract the notion that the experience of traumatic life events may lead to a diagnosis of schizophrenia. The findings from this cross-sectional study emphasise that there needs to be further investigation into negative symptoms and their aetiology given the null findings from this thesis author's quantitative study, as observed in Chapter 5.

## 6.4. Research question 3 findings

**How do individuals experience negative symptoms?**

The thesis author felt it integral to the PhD to be able to empathise with how individuals experienced negative symptoms in order to more fully understand the experiences of debilitating negative symptoms. Research has mainly focused on using quantitative methodologies to explore and further understand the association between traumatic life events and negative symptoms (Gallagher III & Jones, 2013; Mansueto et al., 2019; Ramsay, Flanagan, Gantt, Broussard, & Compton, 2011). Quantitative data provides clear objective results to answer a research question but does not allow for people's subjective experiences to be captured and explored. Qualitative data allows for the individual to express their own feelings and emotions without being tied to a framework or suggested responses in a questionnaire.

This question "how do individuals experience negative symptoms?" was explored using in-depth, semi-structured interviews that were completed by 20 individuals who had a diagnosis of schizophrenia and were currently experiencing negative symptoms. This study used a qualitative methodology by the thesis author to gather the data from across two NHS Trusts within the United Kingdom. This data was then analysed using thematic

analysis (Braun & Clarke, 2013). Responses from the interviewees to the question - how do individuals experience negative symptoms? - provided common themes across the 20 interviews. Two main themes emerged: what it is like to experience negative symptoms, and, where have my negative symptoms come from? The former theme explored how individuals experienced negative symptoms and four sub-themes emerged: loss of concentration, loss of motivation, withdrawal, and 'feeling but not feeling.' These describe how negative symptoms are debilitating and provided rich data on individuals' experiences. Within the second theme, four sub-themes emerged, related to the causes of negative symptoms: impact of traumatic life events, positive psychotic symptoms, impact of social network, and recreational and prescribed drug use. In order to gain further insight into individual's experiences of negative symptoms individuals were prompted with the question 'what do you think led to these experiences?' and the question was asked in a sensitive manner, which reassured participants that no particular answer was expected or considered correct.

The results of this study have parallels with the findings of Gee and colleagues (Gee et al., 2019), which investigated individuals with a diagnosis of First Episode Psychosis (FEP) and their experiences of negative symptoms. Gee and colleagues reported that participants experienced negative symptoms in five keyways, as identified and labelled by five key themes in their study:

> *"like a zombie, diminished internal experience, medication side-effects, a confidence thing and active avoidance."*
>
> *(Gee et al 2019, 773-779)*

These themes are similar to those seen in the thesis author's qualitative study, which revealed that negative symptoms are persistent. Furthermore, the findings from the thesis author's qualitative study echoes previous findings that individuals withdraw as a coping strategy to minimise rejection (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013). This also fits the model proposed by Rector and colleagues (Rector, Beck, & Stolar, 2005), which suggests that if an individual participates in an event but does not find it enjoyable, and finds it exhausting, they will remember that feeling and have a low expectancy of pleasure and enjoyment and thus withdraw and not engage in activities. In the thesis author's qualitative study, participants were able to coherently articulate their current feelings, symptoms and experiences in an interview, despite poverty of speech often being regarded and noted as a key negative symptom (Andreasen, 1982). This highlights that

individuals do not lack awareness of their current experiences and symptoms, which is contrary to anecdotal evidence within wider society that suggests that the majority of individuals with a diagnosis of schizophrenia do not have an awareness of their diagnosis or the world around them. Whilst causation between traumatic life events and negative symptoms cannot be inferred, it is vitally important that the patient's voice is listened to, therefore, these responses should not be considered lightly or dismissed.

The in-depth exploration of an individual's experience of negative symptoms enables researchers to understand, in more detail, how an individual regards the world in which they live. If the research field is to broaden and move forward, to the extent that positive psychotic symptoms investigation has, then more research that utilises qualitative methodologies should be conducted with those who experience negative symptoms. This research should focus on the longitudinal exploration of negative symptoms through a qualitative longitudinal study that asks individuals about negative symptoms from their onset until recovery. This research should therefore seek to understand the development of negative symptoms over time. Additionally, individuals should be asked how they cope with their negative symptoms through the use of qualitative methodologies.

Moreover, if negative symptoms are 'the problem that won't go away', then it is crucial that there is an understanding of what it is like to experience these disabling symptoms (Stahl & Buckley, 2007). Carers and clinicians can form a more compassionate approach when working with individuals who present with negative symptoms to allow them to understand these symptoms in greater depth. This qualitative study highlights that negative symptoms are not laziness but are persistent and affect all aspects of the life of an individual with a diagnosis of schizophrenia.

## 6.5. Research question 4 findings

**What is the association between trauma, attachment style and negative symptoms?**

The fourth research question that this PhD examined, was the association between traumatic life events, attachment style and negative symptoms. This study was conducted as the thesis author's systematic review identified that a number of studies had been conducted, which had explored certain factors that may mediate the association between trauma and negative symptoms (Van Dam et al., 2014), such as the use of cannabis (Baudin et al., 2016) and attachment style (Williams, Bucci, Berry, & Varese, 2018).

Attachment style was selected as an area of interest, as during the last twenty years there has been a steady surge of research that has assessed the role of attachment style in negative and positive symptoms (Berry, Wearden, Barrowclough, & Liversidge, 2006; Carr, Hardy, & Fornells-Ambrojo, 2018; Gumley, Taylor, Schwannauer, & MacBeth, 2014a). More recently, studies have been conducted into the impact of attachment style on negative symptoms and recovery from psychosis.

The current literature suggests that individuals with an insecure attachment style are more likely to experience positive psychotic symptoms. This finding has been verified through studies that use different measures of attachment, such as the Adult Attachment Interview (AAI) (George, Kaplan, & Main, 1996) or the Relationship Styles Questionnaire (RSQ) (Bartholomew & Horowitz, 1991). In this current thesis, the PAM was used to assess attachment style for the reasons stated in Chapter 5, but in summary, because this measure has been widely used across the literature and is brief. Additionally, the PAM applies to all relationships as opposed to only romantic relationships.

It is broadly acknowledged in the literature that negative symptoms do not only affect individuals but also the individual's family and carers, as well as wider society (Brohan, Elgie, Sartorius, Thornicroft, & Group, 2010). Prior to conducting this quantitative study, as part of the topic guide that was utilised in the qualitative study, one of the additional questions that was asked was, 'how have these experiences affected your relationships?' Individuals identified that the negative symptoms they experienced had impacted on their relationships in both positive and adverse ways, as identified in the themes from this study by the thesis author. Individuals expressed that having dependants to look after was beneficial, whilst others expressed the feelings of withdrawal from others.

The finding from Gumley et al.'s study, along with the evidence of an association between insecure attachment style and negative symptoms in the wider literature, highlighted that it is necessary to examine the role of attachment style in order to explain any association between trauma and negative symptoms. During the completion of this study, another extensive meta-analysis was published by Carr and colleagues (Carr et al., 2018), which proposed that the association between attachment style and negative symptoms remains unclear. It was reported in Carr et al.'s papers that the association between attachment and negative symptoms was not significant in the clinical samples but significant in the non-clinical samples.

This study conducted by the thesis author revealed that there was no statistically significant association between traumatic life events, attachment style and negative symptoms, and that a mediation model therefore could not be conducted. This null finding suggests there is more to the trauma-attachment style-negative symptoms construct, than initially thought that requires exploration. This study was a small study with small effect sizes and no association between traumatic life events and negative symptoms was evidenced. Furthermore, all participants in this study were receiving psychological and pharmacological treatment that included the use of antipsychotic medication, which may have dampened the negative symptoms as observed in previous research (Arango, Garibaldi, & Marder, 2013). Medication was not controlled for in the analysis of the quantitative study as not all clinicians and participants provided details of their current medication. Without a full dataset with every individual's medication the results would have been inaccurate. Thus, the results from this quantitative study may not be wholly representative of the target population. Attachment scores in this study were similar to those obtained in other cross-sectional studies that examined attachment and psychosis, thus indicating that the individuals were an accurate representation of the target population with regards to attachment style.

In summary, solely based on the findings from the studies within this PhD, it can be concluded that there is no association between traumatic life events across the life span, attachment style and negative symptoms.

## 6.6. Research question 5 findings

**Do trauma and attachment style have an impact on the occurrence of negative symptoms over a period of six-months?**

The thesis author, having conducted the systematic review and qualitative study, noted that negative symptoms may change over time. The current literature provides evidence that negative symptoms can change within a period of six to 12 months (Gumley et al., 2014b; Van Dam et al., 2014). Upon conducting the extensive systematic review, it was evident that there were very few studies that examined the association between traumatic life events and negative symptoms over time. There have been a few studies that have examined attachment and negative symptoms over this time period but none of these have included traumatic life events in their analysis. Gumley et al's (2014) large longitudinal follow up study of 68 individuals, with a diagnosis of first-episode psychosis, examined the association between insight (as measured on the PANSS), duration of untreated psychosis, attachment style and positive and negative symptoms over time. The findings from this study showed a change in negative symptoms over a 12-month- period and an association between attachment at baseline and symptomology. This study by the thesis author differed from Gumley and colleagues' study (Gumley et al., 2014b) in several ways: all individuals had to have a diagnosis of schizophrenia, two measures of negative symptoms were utilised; the CAINS and the PANSS at both time points, and the presence or absence of traumatic life events across the life span were administered.

Interestingly, the findings from this study in the PhD did not replicate Gumley et al.'s (2014), and no association was found between trauma, attachment and negative symptoms over a six-month period. This finding could be explained by the difference in the sample in Gumley et al.'s study and the thesis author's study, as the former study used individuals with a diagnosis of first-episode psychosis and the latter used a sample of 85 individuals, none of whom had a first-episode psychosis diagnosis, but all had a diagnosis of early/chronic schizophrenia. It is well documented in the literature that negative symptoms emerge over time, with negative symptoms being more prominent in the prodrome phase, and in the acute psychotic phase they are shadowed by the more prominent positive symptoms (Möller, 2007). When comparing the findings from Gumley and colleagues (Gumley et al., 2014b) study and the thesis author's cross-sectional and longitudinal study it should be noted that these two studies differed in measures of attachment style used, with Gumley's study using the AAI (George et al., 1996) whilst the thesis author's study

used the PAM; the AAI is an interview conducted by a clinician/researcher whilst the PAM is a self-report measure completed by the individual. The AAI is more likely to find an effect as it is observer rated and is more sensitive than the PAM, which is a self-report measure of attachment. Gumley's study utilised a 12-month follow up period, whilst this study in this PhD assessed these constructs over a six-month period; therefore, it could be that there is not a difference in these three constructs over six months but that there is over 12 months. To conclude, the cross-sectional study and longitudinal study in this PhD had different aspects to Gumley and colleagues' study (Gumley et al., 2014b), which may explain the dissimilar findings obtained from the two studies.

## 6.7. Summary of findings

This PhD has identified one major gap in the literature, which is that there appears to be a paucity of research that explores traumatic life events and negative symptoms. There are even fewer studies that have sought to explore traumatic life events, attachment style and negative symptoms. This gap is substantial in comparison to the research between traumatic life events and positive psychotic symptoms, which has also explored the role of attachment style. Furthermore, this PhD has considered the role of service engagement in the traumatic life events, attachment style and negative symptoms construct.

The quantitative study revealed that difficulty in service engagement was associated with greater severity of negative symptoms when using the CAINS at six- months- follow up period. Although this finding was not a primary research question, it is critical to note that there are other factors involved in the trauma, attachment style and negative symptoms construct. Figure 6.1. illustrates Rector, Beck and Stolar's model of cognitive expectancies that are involved in the production of negative symptoms. Figure 6.2. highlights the findings from this PhD.

*Figure 6.1. Rector, Beck and Stolar's (Rector et al., 2005) Cognitive expectancies in the production of negative symptoms*

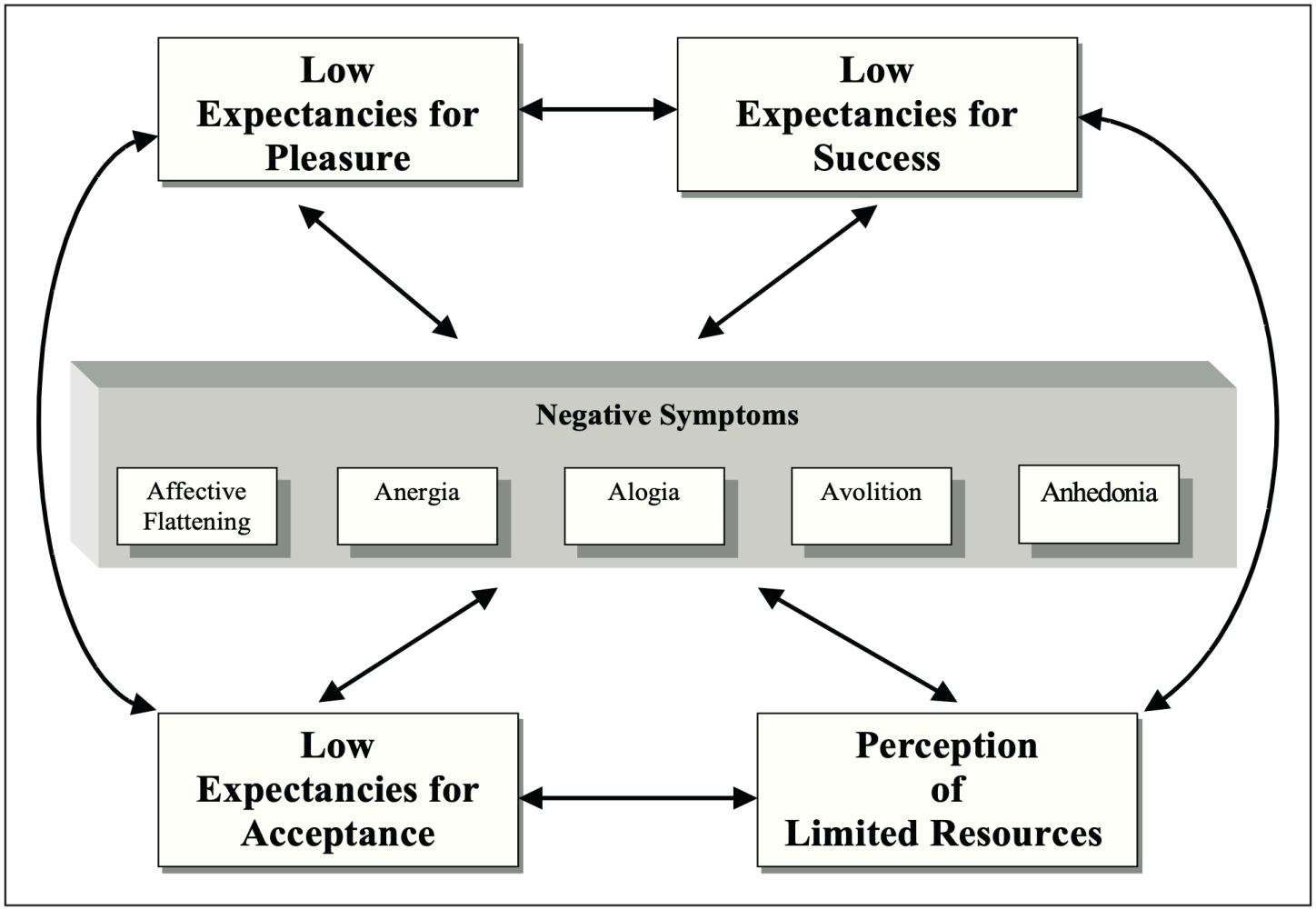
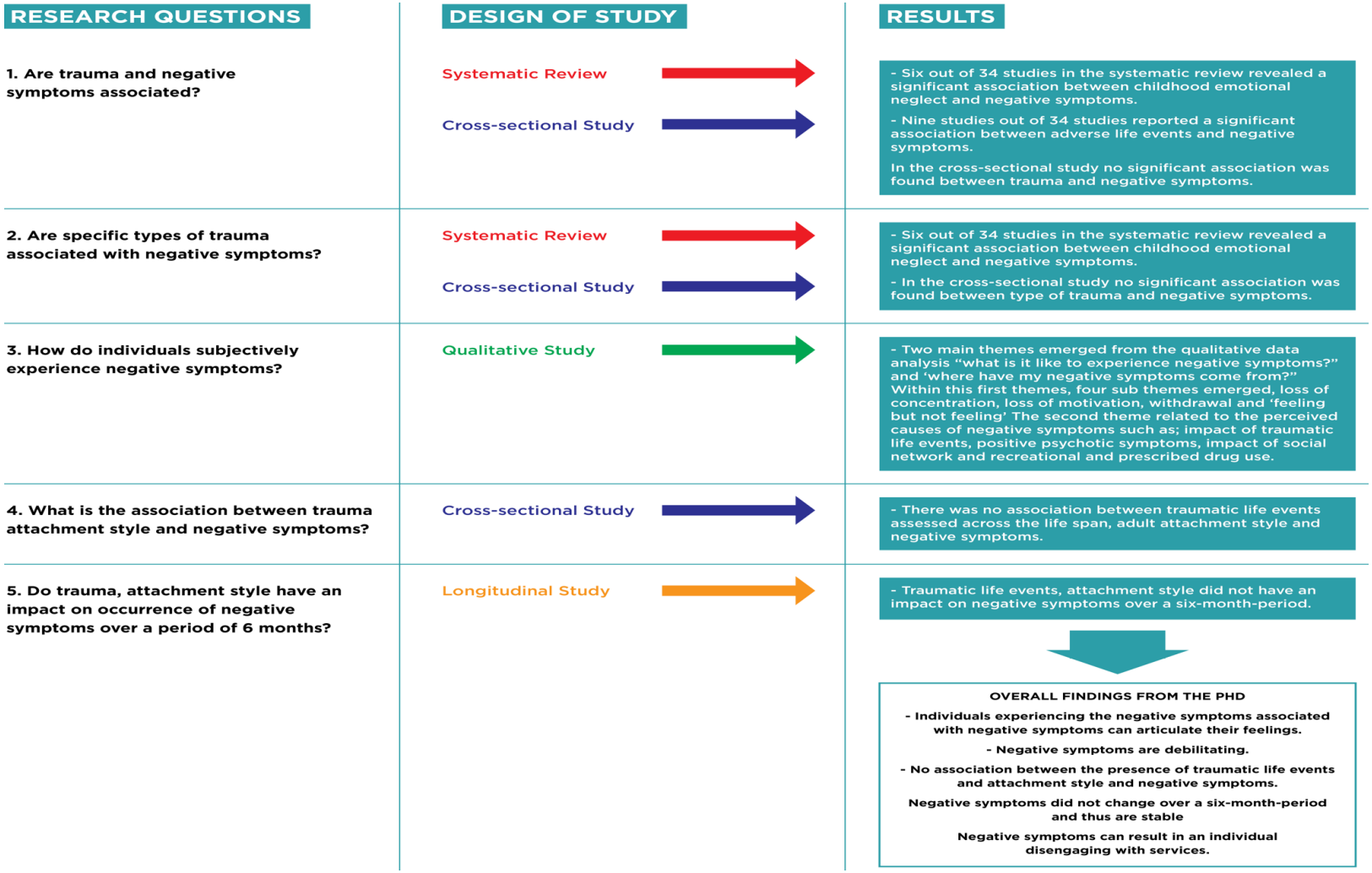


*Figure 6.2. Illustration of the findings from each study within this PhD*



The crucial finding and crux of this PhD is that individuals who are experiencing negative symptoms of schizophrenia are able to articulate their experiences and the debilitating nature of these often forgotten about symptoms. These findings may not be representative of the entire target population of individuals who are diagnosed with schizophrenia and are experiencing negative symptoms, yet it emphasises a glimpse of the disabling nature of negative symptoms to a greater extent than does a score on an observer rated measure of negative symptoms.

This PhD highlights that not all individuals who have a diagnosis of schizophrenia have experienced, to their knowledge, a traumatic life event. This was evidenced as not all individuals reported the existence of a traumatic life event. This is contrary to the plethora of research on trauma and positive symptoms of schizophrenia, which suggests that there is an unequivocal link between the experience of trauma and the diagnosis of schizophrenia.

## 6.8. Clinical Implications

It is acknowledged that the studies within the PhD only touch the surface of negative symptoms research and more investigation is urgently needed from both a psychological and pharmacological perspective. Despite this, there are several key clinical implications arising from this thesis that can be summarised as follows:

Facilitate greater empathy, understanding and compassion for those with negative symptoms. Unconditional positive regard (Rogers, 1957) is the ability to isolate behaviours from the person who displays them. That is the acceptance and support of a person regardless of what the individual says or does. This was a concept that was evident from the qualitative study evidenced in Chapter 4, where individuals articulated that negative symptoms are not laziness or a product of themselves not wanting to do a task, but the result of being physically and mentally unable to do an ‘everyday’ task. This concept has been used in therapeutic settings for sixty years but is often overlooked with carers and clinicians stating that individuals who display and experience negative symptoms can never change. Unconditional positive regard states that each individual is born with the skills to develop and clinicians play a key role in enhancing this through encouragement, as opposed to a focus on the behaviours an individual is displaying.

This PhD has reinforced previous studies (Gee et al., 2019; Hodgekins et al., 2015), which report that negative symptoms are disabling for an individual. Thus, by acknowledging that

the feelings and actions of individuals, who present with negative symptoms, are not indications of laziness but are more deeply rooted in their personal experiences, a different approach could be used by clinicians including unconditional positive regard. Therefore, improved tailor-made support packages should be considered.

This PhD highlights that individuals with negative symptoms present as people in different ways and cannot be described in a simple score on a validated scale. For example, poverty of speech and blunted affect are key negative symptoms that are measured by clinicians and researchers on validated scales. However, the qualitative study, within this PhD, has demonstrated that individuals with negative symptoms can articulate their feelings. Thus clinically, individuals should be treated as their own person rather than solely the score they receive on the PANSS-NS or similar. A one size fits all, based on a common scale, is not the most appropriate approach. This PhD, through the systematic review and the two studies, highlights that there needs to be a novel method of assessing negative symptoms because, despite the abundance of scales and questionnaires used to assess negative symptoms, few use a self-report method with the rating undertaken by an independent rater such as a clinician or a researcher. Thus, without such a measure there is no allowance for the individual to share or expand outside of the questions asked.

There has been a recent shift towards utilising transdiagnostic measurements to assess symptoms, such as apathy, by using the Apathy Evaluation Scale (Marin, Biedrzycki, & Firinciogullari, 1991). This is pertinent because it emphasises that an individual can experience only one negative symptom and they do not have to experience all five key negative symptoms. This shift is also important as negative symptoms that are associated with a diagnosis of schizophrenia, although controversial, are akin to symptoms of clinical depression and other prevalent mood disorders. In the studies conducted in this PhD there appeared to be no strong association between depression and negative symptoms. In a recent qualitative study by Watson and colleagues (Watson, Harvey, McCabe, & Reynolds, 2020), which explored how 34 adolescents with a diagnosis of depression experienced anhedonia; it was reported that individuals experienced anhedonia in a similar manner as individuals in this thesis' qualitative study reported on their experiences of negative symptoms. Watson and colleagues highlight that individuals experienced anhedonia as:

> *"a loss of joy and a flattening of emotion, struggling with motivation, losing a sense of connection and belonging and questioning sense of self, purpose and the bigger picture." (Watson et al., 2020) page 491*

These four themes map directly onto the thesis author's findings from the qualitative study. To conclude, due to the marked overlaps between negative symptoms and symptoms of other mood disorders, specific scales for specific symptoms should be adopted by clinicans and researchers.

The PANSS is well used in trials and adopted by researchers and clinicians globally and has been reported as highly sensitive in detecting change in symptoms (Esfahlani, Sayama, Visser, & Strauss, 2017). However, the PANSS does not explicitly allow for the rater to ask about specific instances of remembered pleasure and anticipated pleasure, which the CAINS does. Furthermore, the PANSS is an assessment that can be onerous for the participant as it is lengthy and requires the individual to speak and communicate with the researcher for at least forty minutes whilst the questions are being asked. More succinct and greater information on negative symptoms can be captured from newer, shorter scales such as the CAINS and the BNSS. Additionally, it is important to note that negative symptoms fall into two categories: expressive and experiential deficits (Savill et al., 2016). The two are not mutually exclusive and thus should be measured separately, such as on the CAINS. The PANSS does not allow for a sub score on expressive deficit items and experiential deficit items. This PhD, therefore, highlights that alternate measures of assessing negative symptoms need to be considered and adopted by clinicians. The adoption of other tools used to assess negative symptoms should be encouraged, where possible.

Through the findings from the qualitative study this PhD, and despite the null findings from the quantitative study emphasises the huge impact that an individual's life experiences can have on their mental health. Traumatic, unpleasant events that occurred in childhood can indeed be recalled years later. Clinicians should consider an individual's life, when attempting to assist in the recovery from negative symptoms. For example, questioning an individual about their entire life could be at the centre of an initial diagnosis and feed into the treatment of the symptoms. Psychological formulations are now more widely used with individuals who have a diagnosis of schizophrenia (Johnstone, 2018) but within these formulations, the experience of unpleasant events must be recorded in a systematic manner. There is no pharmacological medication that will enable an individual to suddenly no longer experience apathy or anhedonia. An understanding of an individual's life and working with them psychologically may help to dampen the negative symptoms and enhance and promote recovery.

Additionally, this PhD, particularly the qualitative study, highlighted the positive impact that having dependants and a social network can have on an individual experiencing negative symptoms. In order to help individuals, integrate into society, clinicians should consider having a multi-agency approach through utilisation and promotion of support networks. 'Social prescribing' for example, in the United Kingdom, is a part of the NHS's Long-Term Plan (England, 2019). Social prescribing is a method of linking individuals in communities with a wide range of people across a body of agencies (such as pharmacies, police services, social care services and voluntary care services) who can, together, help improve an individual's health and wellbeing. During the COVID-19 pandemic, social prescribing was well utilised in the United Kingdom; for example, in the borough of Trafford people were linked with a number of agencies within the community to assist with shopping and where wanted provided a phone call for those who wanted a conversation with someone. Post COVID-19 social prescribing will perhaps be needed by more people than prior to the pandemic. Through adoption of this approach, clinicians can work together with other agencies and charities such as MIND and could foster and enhance the individuals' wellbeing.

After presentation of some of the findings from this PhD at conferences to psychiatrists and psychologists, such as the World Psychiatric Association: World Congress of Psychiatry in Portugal in 2019 (Appendix 19), it became apparent that despite the differences of opinion often held between psychiatrists and psychologists, all agreed that negative symptoms are a key area of clinical concern, due to limited options for treatment. This agreement between psychologists and psychiatrists provides an opportunity for the sharing of knowledge between different domains in clinical and academic settings. This overlap in research domains should be optimised with further research into traumatic life events, attachment style and negative symptoms, which may be conducted with researchers from a wide range of disciplines. This has been evidenced in the formation of the European Network for Negative Symptom (EuroNES), which is led by psychiatrists and psychologists from across Europe with the goal of conducting and advancing research into negative symptoms. The thesis author had the opportunity to participate in a symposium organised by a member of this group at the 7$^{th}$ European Conference on Schizophrenia Research in Germany in 2019. This offered the thesis author further insight into the array of projects that are being conducted across Europe into negative symptoms, some from a neuroscientific perspective and others that explore psychological mechanisms. To expedite

research in the field of negative symptoms, these connections and working groups should be maximised.

This PhD highlights that not seeking information on an individual's history may impede the potential to deal with the root cause of the problem. Identification of this information, as highlighted in this study, can be elicited through several different measurement tools that explore the presence and absence of trauma in addition to the severity of trauma. Clinicans and health care professionals (Walters, Hogg, & Gillmore, 2016) do however report a lack of confidence when they are asked to examine an individual's experience of trauma but they should be encouraged to do so.

Finally, the recent guidelines published in August 2020 by the National Institute for Health and Care Excellence (National Institute for Health and Care Excellence, 2020) highlight that rehabilitation services for individuals with complex psychosis should encourage participation in activities to improve daily living skills for example through self-care, laundry, shopping and using public transport. The findings from the studies within this PhD highlight the difficulties that individuals face regarding completing these daily living tasks and so this PhD supports the recommendations given by NICE.

## 6.9. Strengths of this PhD

A strength of this PhD is that it utilises a mixed method approach and thus enables both qualitative and quantitative data to be collected and examined. The intertwining of quantitative and qualitative methods, within this thesis, have enabled the 'story' of the PhD to be told in greater depth, without appearing disjointed. Additionally, each study was led by the findings from the previous study and this facilitated the building of a complete picture of negative symptoms and their disabling impact, which can be perceived through a single lens. Often in research, and particularly in this field of psychosis research, negative symptoms are thought of as stand-alone symptom(s), rather than as a part of a bigger picture. This PhD 'joined the dots' through three different constructs, primarily to enable insight into the whole of an individual's life. This thesis, through utilising a mixed methods approach, provides numerical evidence about the nature of negative symptoms and their disabling impact. Despite the null findings in the quantitative study the use of a quantitative design provided objective insight into an individual's attachment style, experience of unpleasant life events and the presence of negative symptoms.

A further strength of this PhD is that it explores an under researched but much needed area of investigation, that of negative symptoms, which are fascinating and affect both individuals and the wider community. Further research into this area is warranted. Large trials do not always report the negative symptom scores; this is evidenced by the small number of papers that were evaluated in the review. Thus, it is crucial that more research is promoted, funded, and conducted into negative symptoms. Positive psychotic phenomena can respond well to pharmacological and psychological interventions. Conversely, negative symptoms do not seem to respond well to any pharmacological interventions and few psychological interventions have proved effective/helpful (Aleman et al., 2017).

A strength of this PhD is that the quantitative study used several well validated measurements in order to assess each construct being explored. For example, two measures of negative symptoms were utilised, the CAINS and the PANSS, thus providing a full picture of an individual's negative symptoms. This study also utilised a range of well validated measures to assess the presence/absence of traumatic life events; this is in contrast to previous quantitative studies that have primarily focused on the use of the CTQ to assess childhood traumatic events, which does not include the absence or presence of parental loss or parental separation. This study's use of the CTQ, THQ and Olweus' bullying questions enabled the thesis author to explore the presence or absence of traumatic life events across the life span, as opposed to solely concentrating on traumatic childhood life events.

A strength of this PhD is that despite the paucity of literature available on traumatic life events and negative symptoms, a thorough and systematic review was conducted. The systematic review was conducted through the adoption of a transparent and systematic approach by registration of the study on PROSPERO, and through the use of independent researchers in the screening process. The transparent nature of the review that was undertaken allowed for the process to be systematic and well documented. This first study of the PhD enabled a strong foundation for the subsequent studies in the rest of the PhD.

A further strength of the three studies within this PhD is that each study employed a different research design; and within each study a large and sufficient sample size was achieved to allow a full investigation of the study hypotheses. The qualitative study recruited individuals until data saturation and sufficiency was reached, which was achieved after 20 individuals had been recruited and the cross-sectional and longitudinal study recruited 85 individuals at baseline of which 71 were retained at the six- month- follow up

period. This sample size allowed for sufficient analyses of the hypotheses to be examined. Furthermore, the studies within the PhD recruited and purposively sought to recruit individuals from a wide range of backgrounds and geographic settings from across the United Kingdom.

## 6.10. Limitations of this PhD

A key limitation of this PhD is that this study primarily focuses on two factors when considering negative symptoms: attachment style and traumatic life events. The PhD also considers the potential role of other factors such as service engagement. This PhD focussed on these aspects and was conducted from a psychological perspective and approach. Studies have evidenced that there are neurological differences in individuals who have experienced specific traumas versus those who have not. The psychological aspect of this PhD did not allow for any neuroscientific evidence, such as brain volume, to be examined.

Furthermore, the quantitative study, within this PhD, relied on each participant recalling any unpleasant event(s) that had occurred in their lifetime and so some individuals may not have recalled and reported all unpleasant events, only those that were more salient. Furthermore, some individuals may have recalled unpleasant events but may not have wanted to report them. Moreover, when individuals were asked about their experiences of unpleasant events these were not checked against cases notes, or otherwise verified and therefore were open to bias. Despite being open to memory recall bias, retrospective self-report is one of the most reliable ways in which to examine past traumatic life events. The CTQ includes a three item response bias scale, known as the minimisation-denial scale to check for response (MacDonald et al., 2016). However, this minimisation and denial scale was not included in the data analysis of the quantitative study due to an initial exploration of the dataset and preliminary analyses did not show any significant scores on this scale. This suggests that the data obtained from the CTQ is reliable.

With regard to the qualitative study, the sample was restricted to two NHS Trusts in the United Kingdom. Therefore, the findings from these 20 individuals may not be representative of all individuals in the United Kingdom who experience negative symptoms.

A limitation of the quantitative study was that attachment was solely assessed using the PAM, which is a self-report measure and thus could be open to social desirability bias

given that it was also completed in the presence of the thesis author. Two measures of negative symptoms were used in the cross-sectional and longitudinal study, whereas only one measure of attachment was used. The gold standard AAI interview was not utilised in this study and thus the findings on PAM may not be truly reflective of an individual's attachment style(s).

A limitation of this PhD, but perhaps an inevitable limitation is that not all 85 individuals at baseline in the cross-sectional study were retained at six months follow up. Given the population under study this attrition is inevitable, however it is a limitation of the study as it could be that. the baseline characteristics of participants lost to follow up were different to those who were followed up at six months. Analyses of the cross-sectional and longitudinal dataset did not reveal any differences in severity of negative symptoms between those who completed both timepoints and those that did not complete the six months' time period.

## 6.11. Future work

Future work needs to focus on negative symptoms in larger longitudinal trials that can follow individuals over a period of years to fully understand how the triumvirate of 'trauma - attachment - negative symptoms' interact. A larger trial would enable further research to be conducted into therapeutic treatments for negative symptoms. The thesis author commented (in her field notes when recruiting for both studies) that psychiatrists and psychologists in each NHS Trust were keen to help facilitate recruitment. This struck the thesis author as encouraging, as often psychiatrists focus on the biological causes of schizophrenia. However, after discussion with psychiatrists in several of the recruitment Trusts who expressed the view that there is no 'drug for apathy or avolition,' it became clear that they too were interested in potential psycho-social or psychological interventions that underpin negative symptoms.

This shift in thinking was highlighted succinctly in a recent paper by Kingdon (Kingdon, 2020), which states that there needs to be a re-think into how research into mental health disorders is conducted, with neuroscientific research thus far producing little evidence and insight into mental health disorders.

> *'Isn't listening to patients' perceptions of causation more likely to provide insights rather than looking down a microscope? Nothing should be completely ruled out but judgements about where it is most likely that developments will occur need to be rethought.*
>
> *(Kingdon, 2020) page 108-page 109*

This thesis' findings, particularly the qualitative study, highlight that by asking individuals with negative symptoms about their symptoms a huge amount of information and insight into negative symptoms can be obtained. There has been a recent surge of research into exploration of negative symptoms using a transdiagnostic approach, which considers symptoms one at a time. This approach is being driven by the overlap between key negative symptoms and symptoms of clinical depression, such as apathy and anhedonia, which are present in a multitude of mental health issues. This PhD highlights that future work needs to consider different ways of assessing negative symptoms and not be reliant upon PANSS-NS. There needs to be further research that considers the expressive and experiential deficits associated with negative symptoms, as well as the ability to recall and anticipate pleasure. Scales such as the CAINS assess these but have not been widely adopted in large-scale clinical trials.

To gain a greater understanding, it is important to consider the factors that link negative symptoms and their relationship with each other. This PhD emphasises that further work is needed to connect different perspectives in various research domains. For example, when considering the psychological impact of trauma, clinicians should consider the impact of trauma experienced in early life and individuals' subsequent ability to cope with an adverse life event. Findings from this thesis can help to promote further research from both a psychiatric and psychological perspective by publication of the results. This in turn will lead to greater awareness and conversations amongst professionals surrounding negative symptoms which it is hoped will subsequently result in greater research and action.

Furthermore, as stated in Chapter 3, the Methods chapter, there is a need for greater qualitative research into negative symptoms. The use of methodologies, such as Interpretative Phenomenological Analysis would enhance existing qualitative and quantitative research into negative symptoms. This would also enable the body of qualitative research into negative symptoms to grow. Reflecting on the PhD in its entirety, the thesis author acknowledges that, if time was unlimited, the thesis author, who has been trained in IPA and previously conducted an IPA project, would have conducted a smaller

IPA-led study on a group of individuals who met the criteria of this qualitative study to answer the same research question as addressed in this study. Future research may consider IPA, as well as thematic analysis, to further explore the patients' voice on negative symptoms. This would enable greater insight into the experiences of negative symptoms to be obtained and would build upon the findings from the qualitative study produced in this thesis.

If the thesis author had time, the questions explored in an IPA study would be i) what forms of social support are helpful to individuals experiencing negative symptoms? and ii) how do negative symptoms impact on personal relationships?

To advance the field of negative symptoms, the following research questions need to be answered in greater depth:

are negative symptoms conclusively associated with specific types of trauma across the life span?

is there a sensitive period in an individual's lifespan whereby any trauma experienced then will lead to the development of negative symptoms?

is secure attachment style a 'buffer' to negative symptoms?

Furthermore, there needs to be greater reporting of negative symptoms data in all papers that assess positive and negative symptoms. Following on from Beck and Rector's model (2005) of cognitive expectancies in the production of negative symptoms, this PhD magnifies the gap in the current literature on traumatic life events and negative symptoms and a potential association. This PhD also highlights the perpetuation of a vicious cycle of negative symptoms created by low expectancies for pleasure and acceptance.

This PhD confirms that greater consideration needs to be given to the impact of engaging with services on an individual's mental health. This should include the development of scales that are self-reported in addition to the long-standing clinician rated measures. As society is changing and embracing technology, the definition of engaging with services may well look different. For example, groups and individual meetings may be held online or via mobile application on mobile phones as well as face to face meeting.

Lastly, and by no means least future work into negative symptoms must consider those individuals who do not speak the English language. The translation of the CAINS and measures of traumatic life events as well as measures of attachment style into other languages should be conducted. It is important to consider and ensure that when utilising translated measures that the words have the same meaning as they do in each language, as highlighted by the interpretation of the word 'pleasurable' differing from the United States of America compared to the United Kingdom and Germany.

## 6.12. Dissemination of findings

Throughout the PhD the research conducted was presented at various conferences, both at a local level and at an international level. These included a poster presentation at the Schizophrenia International Research Society conference in April 2019 as well as local research conferences organised by local NHS Trusts. As a result, the findings from this PhD have been disseminated to a wide range of audiences that includes, clinicians, carers and service users  Additionally at the beginning of December 2020 the findings from the qualitative study were discussed in an online podcast organised by students at the University of Toronto, Canada. The lead author will continue, over the next twelve months, to continue to raise awareness of the completed research and will make herself available for presentations through a variety of media.

## 6.13. Conclusion

This PhD thesis concludes by reiterating that negative symptoms are disabling and can have a huge and varying impact on an individual's quality of life. Negative symptoms, despite being overshadowed by research into positive symptoms, should continue to be researched with a focus on individuals' lives as to when and what may have led to the development of these negative symptoms. That said, if research into negative symptoms is to be advanced, this needs to develop and evaluate treatment options for individuals who are experiencing negative symptoms. These treatment options will be born out of further qualitative and large-scale quantitative studies. This thesis does not highlight any ground-breaking quantitative findings, but it highlights that future research is essential and should be shared across disciplines. In spite of the disabling nature of negative symptoms, the voice of the participants is rich and strong and merits further research.

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# Appendices

## Appendix 1: Data extraction form

| Study Authors and date | Population (m/f) | Country conducted | Diagnosis of sample | Where sample were recruited from | Recruited from | Measure of Trauma | Measure of Negative Symptoms | Answer to Question 1: Is there an association between adversity and the severity of negative symptoms? | Answer to Question 2: Are specific types of trauma related to negative symptoms? |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| | | | | | | | | | |
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# Appendix 2. AXIS supplementary materials

**Appraisal tool for Cross-Sectional Studies** (AXIS)

Critical appraisal (CA) is used to systematically assess research papers and to judge the reliability of the study being presented in the paper. CA also helps in assessing the worth and relevance of the study [1]. There are many key areas to CA including assessing suitability of the study to answer the hypothesised question and the possibility of introducing bias into the study. Identifying these key areas in CA requires good reporting of the study, if the study is poorly reported the appraisal of suitability and bias becomes difficult.

The following appraisal tool was developed for use in appraising observational cross-sectional studies. It is designed to address issues that are often apparent in cross-sectional studies and to aid the reader when assessing the quality of the study that they are appraising. The questions on the following pages are presented in the order that they should generally appear in a paper. The aim of the tool is to aid systematic interpretation of a cross-sectional study and to inform decisions about the quality of the study being appraised.

The appraisal tool comes with an explanatory help text which gives some background knowledge and explanation as to what the questions are asking. The explanations are designed to inform why the questions are important. Clicking on a question will automatically take you to the relevant section in the help text. The appraisal tool has areas to record a "yes", "no" or "don't know" answer for each question and there is room for short comments as well.

## Contents

**Appraisal of Cross-sectional Studies**

| | Question | Yes | No | Don't know/ Comment |
|---|---|---|---|---|
| ***Introduction*** | | | | |
| 1 | Were the aims/objectives of the study clear? | | | |
| ***Methods*** | | | | |
| 2 | Was the study design appropriate for the stated aim(s)? | | | |
| 3 | Was the sample size justified? | | | |
| 4 | Was the target/reference population clearly defined? (Is it clear who the research was about?) | | | |
| 5 | Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation? | | | |
| 6 | Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation? | | | |
| 7 | Were measures undertaken to address and categorise non-responders? | | | |
| 8 | Were the risk factor and outcome variables measured appropriate to the aims of the study? | | | |
| 9 | Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously? | | | |
| 10 | Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals) | | | |
| 11 | Were the methods (including statistical methods) sufficiently described to enable them to be repeated? | | | |
| ***Results*** | | | | |
| 12 | Were the basic data adequately described? | | | |
| 13 | Does the response rate raise concerns about non-response bias? | | | |
| 14 | If appropriate, was information about non-responders described? | | | |
| 15 | Were the results internally consistent? | | | |
| 16 | Were the results presented for all the analyses described in the methods? | | | |
| ***Discussion*** | | | | |
| 17 | Were the authors' discussions and conclusions justified by the results? | | | |
| 18 | Were the limitations of the study discussed? | | | |
| ***Other*** | | | | |
| 19 | Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results? | | | |
| 20 | Was ethical approval or consent of participants attained? | | | |

## Introduction

The introduction serves to establish the context of the work that is about to be presented in the text of the paper. Relevant primary literature should be discussed and referenced throughout the introduction. The history and current understanding of the problem being researched should be presented. This should be concluded giving a rational as to why the current study is being presented and what the aims and/or hypothesis under investigated are [2,3].

### Aims

The aim(s) of the study tells us if the study addresses an appropriate and clearly focused question. If the aim is not clearly stated or not stated at all, it will be difficult and in some cases impossible to assess the extent to which the study objectives were achieved. Ideally, an aim should be stated both at the beginning of the abstract and at the end of the introduction [3]. If the answer to question 1 is no, then it will make it difficult to assess some of the other questions in the critical appraisal process.

## Methods

The methods section is used to present the experimental study design of the paper. The methods should be described clearly in easy to understand language and clearly identify measures, exposures and outcomes being used in the study [4]. More specific issues are addressed below.

### Study Design

Question 2 is used to assess the appropriateness of using a cross-sectional study to achieve the aim(s) of the study. Cross-sectional studies are observational studies that provide a description of a population at a given time, and are useful in assessing prevalence and for testing for associations and differences between groups [5]. Examples of cross-sectional designs include point-in-time surveys, analysis of records and audits of practice [6]. The reader should try and decipher if a cross-sectional study design is appropriate for the questions being asked by the researcher.

### Sample Size Justification

Sample size justification is crucial as sample size profoundly affects the significance of the outcomes of the study. If the sample size is too small then the conclusions drawn from the study will be under powered and may be inaccurate. This can occur by failing to detect an effect which truly exists (type II error) sometimes referred to as a "false negative". The probability of a type I error is also taken into account when determining sample size. A type I error is drawing significant conclusions when no real difference exists and is a function of the p-value (see Statistics section below) sometimes referred to as a "false positive".

Question 3 asks if sample size justification was reported, but it should also be clear what methods were used to determine the sample size. In some cases clustering of observations within groups can occur (e.g. patients within hospitals or livestock within herds) and this should be taken into account if sample size has been determined. It should be clear whether the inferences drawn actually relate to the attributes for which the sample size was calculated [7]. If sample size justification isn't given or restrictions make it difficult to reach the desired sample size then this should be declared in the text.

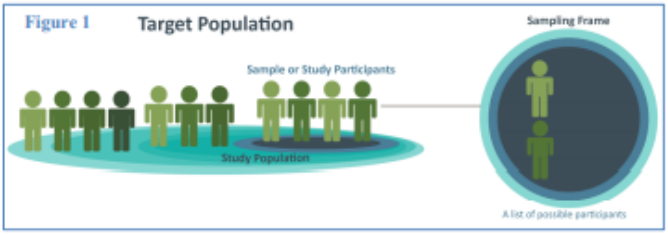
### Target (Reference) Population

The target or reference population is the overall population that the research is directed towards. When doing a cross-sectional study, a target population is the overall population you are undertaking the study to make conclusions about or the population at risk of acquiring the condition being investigated [8–10] e.g. the total female population in the UK, or all dogs in the USA with cardiovascular disease. (See Figure 1) Question 4 asks if this is clearly defined in the study. It is important that this is understood both by the researcher and the reader; if it is not clearly defined then inferences made by the researcher may be inappropriate.

### Sampling Frame

As a reader you need to determine if the sample frame being used is representative of the target population. The study population should be taken from the target population; units from this study population have information that is accessible and available which allows them to be placed in the study. The sampling frame is the list or source of the study population that the researcher has used when trying to recruit participants into the study (Figure 1). Ideally it should be exactly the same composition or structure as the target population. In practice it is generally much smaller, but should still be representative of the target population. Generally, for convenience, the sampling frame is a list of units that are within the target population e.g. list of

Figure 1 Target Population




telephone owning households, computerised patient records etc. A sample of units is selected from the study population to take part in the study and is generally only a small proportion of the study population (see Sample Selection below) - this proportion ratio is known as the sampling fraction. It is very important that the sampling frame is representative of the target population as results from the study are going to be used to make assumptions about the target population [8–10].

Convenience sampling can be carried out in some situations and are used because the participants are easy to recruit. Convenience samples generally lead to non-representative or biased samples and therefore cannot be used to make assumptions about the characteristics of the target population [11]. Convenience samples are often used for pilot or analytical studies where the need for a representative sample is not required [12], however the authors should make this clear in the text.

### *Census*

A census is where the target population and the study participants are the same at the time the census is taken. In theory questions 5, 6 and 7 don't apply to census studies. However even if a study is described as a census it should be very clearly stated where the study participants have been recruited from, and the reader should make the decision if the study truly is a census. A census may include all the population from the sample frame, but not all the target population; in this scenario questions 5 to 7 need to be addressed.

## Sample Selection

Question 6 is used to establish how the researchers got from the sample frame to the participants in the study. It examines the potential for selection bias and how the researcher developed methods to deal with this. The sample selection process is important in determining to what extent the results of the study are generalizable to the target population. For question 6 we are looking in depth at how the sample (study participants) was selected from the sampling frame. It is important to know if there were any inclusion or exclusion criteria used, as inappropriate criteria can dramatically shift how representative the sample is of the target population [8,10,13].

Selection bias can occur if every unit in the sample frame doesn't have an equal chance of been included in the final study [11,14]. Randomisation is used to ensure that each participant in the sampling frame has an equal chance of being included in the sample. If methods of randomisation are not used, not described or are not truly random, this may lead to a non-representative sample being selected and hence affect the results of the study [10,11].

There are many other situational issues to take into account when determining if the population in the sample is likely to represent the target population. Often these issues are outside the control of the researcher, but sometimes are overlooked. One such issue is the healthy worker effect which is a well-known phenomenon in human cross-sectional studies [13]. An example of this is, a researcher trying to do a cross sectional study to determine health factors in a factory population and decides to sample from workers at work on a particular day. Unfortunately there is a tendency to over select healthy workers as ill workers may tend to be at home on the day of selection. This will in turn lead to inferences been made about the health of the worker population but is only relevant to healthy workers and not ill workers. A veterinary example of this is a researcher trying to do a cross-sectional study to determine health factors in the general dog population and decides to sample from a local park. Unfortunately there is a tendency to over select healthy animals as sick animals will tend to be left at home and not taken for a walk. This will in turn lead to inference been made about the health of the dog population but is only relevant to healthy dogs and not sick dogs.

Self-selection is another example of selection bias that can be introduced and should be assessed [13]. For example, when using a postal questionnaire to examine eating habits and weight control, people who are overweight might read the survey and be less inclined to complete and return the survey than those with normal weight leading to over representation of people with normal weight. Similarly, if using a postal questionnaire to examine mastitis levels on cattle farms, farmers that have a high somatic cell counts (SCC) might be less inclined to complete the survey than those with normal or low SCC leading to over representation of farms with good SCC (see Non-responders below).

## Non-responders

Non-response in cross-sectional studies is a difficult area to address. A non-responder is someone who does not respond either because they refuse to, cannot be contacted, or because their details cannot be documented. As a rule, if participants don't respond it is often difficult and sometimes impossible to gain any information about them. However other baseline statistics may exist that can be used as a comparator to assess how representative the sample is [14] e.g. age, sex, socio-economic classification. Methods used, if any, should be well described so that the results from the analyses can be interpreted. This is important as non-responders may be from a specific group, which can lead to a shift in the baseline data away from that group. This shift can lead to results that don't represent the target population. In some situations the sampling frame doesn't have a finite list or a fully defined baseline population. This also makes it difficult, and in some cases impossible, to quantify non-response and it may be inappropriate to do so in these situations. If the researchers are using non-defined populations this should also be declared clearly in the materials and methods section [15,16].

## Measurement Validity & Reliability

Measurement validity is a gauge of how accurately the study measurements used assess the concepts that the researcher is attempting to explore. Measurement reliability is a gauge of the accuracy of the measurements taken or the procedures used during the study. Question 8 is used to address the concepts of measurement validity, and is specifically aimed to address the appropriateness of the measurements being used

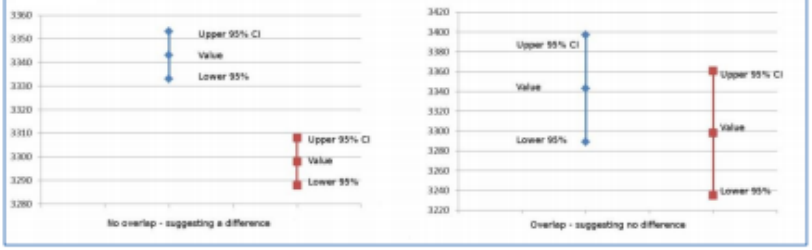
The importance of measurement validity is that it gives weight to applying the statistical inferences from the study to members of the target population. If inappropriate measures are used in the study it could lead to misclassification bias and it will be difficult to determine to what extent the study results are relevant to the target population [12,17].

Question 9 is an attempt to gauge the measurement reliability of the study measures. Measurements must be able to be reproduced and produce identical results if measured repeatedly, so that the measurements would be exactly the same if performed by another researcher. With this in mind, the measurements must be of international or globally accepted standards (e.g. IU standards) where possible and appropriate. If they are being used for the first time they must be trialled, or in the case of questionnaires, they should be piloted before being used.

## Statistics

While interpretation of statistics can be quite difficult, a basic understanding of statistics can help you to assess the quality of the paper. Often many different methods can be used correctly to test the same data, but as there is such a wide range available, knowing what tests are most appropriate in particular situations can be hard to decipher. There is an expectation that the researcher has this understanding or has at least sought statistical assistance to ensure that the correct methods are used. Therefore for question 10 the emphasis for the reader is that the statistical methods, software packages used and the statistical significance levels are clearly stated even if the paper is just presenting descriptive statistics. The statistical significance level is usually described as a p-value. In most cases the p-value, at which the null hypothesis is rejected, is set at 0.05. The higher the p-value is set the greater the possibility of introducing a type I error. Confidence intervals should also be declared with p-values or instead of p-values as an indication of the precision of the estimates. It is usual to present a confidence interval of 95% which means that the researchers were 95 per cent confident that the true population value of the outcome lies between these intervals. This can be used to compare groups where an overlap would suggest no difference and a gap between confidence intervals would suggest a difference (Figure 2).

Figure 2




## Overall Methods

Question 11 asks if the methods are sufficiently described to enable them to be repeated. If there are sections or even small pieces of information missing it could make a great difference for the reader when interpreting the results and the discussion as they may be unsure if the correct methods are being used.

## Results

The results section of a paper is solely for the purpose of declaring the results of the data analysis and no opinion should be stated in this section. This gives the reader the opportunity to examine the results unhindered by the opinion of the researcher. It is important for the reader to form their own ideas or opinions about the results before progressing to the discussion stages.

## Basic Data

Question 12 asks for a description of the basic data. Basic descriptive analysis aims to summarise the data, giving detailed information about the sample and the measurements taken in the study. The basic data gives an overview of the process of recruitment and if the sampling methods used to recruit individuals were successful in selecting a representative sample of the target population. If the sampling methods are unsuccessful in selecting a representative sample of the target population, those participants included in the study can often be different to the target population; this leads to inaccurate estimates of prevalence, incidence or risk factors for disease. Descriptive data of the measurements taken in the study give an overview of any differences between the groups, and may give insight into some of the reasons for statistical inferences that are made later in the paper.

## Response Rate

As stated previously it can often be difficult to deal with non-responders. Question 13 requires that there is some attempt made to quantify the level of non-response by the researchers and asks the reader to interpret if the response rate is likely to lead to non-response bias. Question 14 is examining if any information on non-responders was available and if so were they comparable to those that did respond as this could help in answering question 13. Non-response bias occurs if the non-responders are substantially different to the rest of the population in the sample [15]

## Internally Consistent Results

Question 15 is an exploration of the basic data and asks that the reader spends some time exploring the numbers given in the results; in the text, figures and tables. Information about the level of missing data should also be declared in the results. It is important to check that the numbers add up in the tables and the text. If the study has recruited 100 participants, the tables and the text should include data about 100 participants. If not, the missing data should be clearly declared and the reason for its non-appearance explained.

## Comprehensive Description of Results

It is important to check that all the methods described previously lead to data in the results section (question 16). Sometimes the results from all analyses are not described. If this is noted it will be unclear whether the researcher found non-significant results or just didn't describe what was found. If there are results missing that you would expect to find, there is a concern that these missing results may not have been what the researcher wanted to see and hence the authors have omitted them. It is also important that the significance level declared in the methods is adhered to. As the reader, it is important to watch out for phrases such as "tended towards significance" in the text, and if these are used to pay close attention to the results.

**Discussion**

The discussion of a paper should summarise key results of the study objectives. It should give an overall interpretation of the results of the study keeping in mind the limitations and the external validity of the document. The discussion section should also address both significant and non-significant findings of the study and make comparisons with other research, citing their sources [2,4].

## Justified Discussions and Conclusions

In question 17 there is an expectation that the researcher gives an overall summary of the main findings of the study and discusses these in detail. It is important that the reader considers the study as a whole when reading the researcher's conclusion. If the researcher's conclusion is different or is more definitive than the study suggests it should be, it can be an indication that the researcher has misunderstood their own study or has other motives or interests for coming to that conclusion.

It is up to the reader to explore the discussion fully in order to answer question 17. The following points should be taken into account:

***Aim***

In the discussion section the researcher should discuss all results that pertain to the overall aim of the study, even if they are not significant. If some results are overlooked in the discussion it could suggest that the researcher either doesn't believe the results, or doesn't want to draw attention to controversial discoveries from the study and may therefore be giving a biased overview of the research conducted.

***Selection Bias***

There is an expectation that the researcher discusses selection biases and takes these into account when interpreting the results of the study. This also gives a clear view of whether the researcher has an overall understanding of the study design. (See notes on selection bias in the methods section).

***Non-response***

Was there an interpretation of the results that included non-response? This is particularly important if the response rate was low, as non-responders may be a specific group, and lead to a shift in the baseline data (See notes on non-response in the methods section).

***Confounding***

Confounding is a major threat to the validity of practical inferences made from statistical analyses about cause and effect. Confounding occurs when the outcome of interest is associated with two different independent variables and one of those variables is closely associated with the outcome only because it is closely associated with the other variable (confounder). This can sometimes be accounted for using statistical methods however sometimes these associations are missed because the confounder isn't measured or isn't considered to be a confounder in the analyses. What then happens is an erroneous conclusion is made; that the variable might have a causal relationship with the outcome. The researcher should consider confounding both in the analyses and in the interpretation of the results [18]. An example would be where in a study on cancer a researcher concludes that increased alcohol intake causes lung cancer; however there was confounding in the sample that the researcher didn't discover. People in the study that were inclined to drink more alcohol were also inclined to smoke more (the confounder) and smoking was the cause of lung cancer not increased alcohol intake. Similarly, a study was undertaken to examine surgical deaths in cats. The researcher concluded that cats that had gaseous anaesthesia were more likely to die during surgery than those that had just injectable anaesthesia. There was confounding in the sample: cats that underwent surgery using gaseous anaesthesia were more likely to be ill or undergoing major surgical procedures (the confounders) and this was the cause for cats being more likely to die during surgery and not the use of gaseous anaesthetics.

***Non-significant Results***

Discussing non-significant results is as important as discussing significant results and should also be included in the discussion, especially if they have a direct association with the aim being investigated. Non-significant results can be influenced by factors associated with study design and

sample size. If there are biases introduced during the study design this can lead to non-significant results that in reality may be significant (this can work the other way around as well). If there are only small differences between groups, non-significant results may be apparent because the sample size is too small (see sample size justification). Again it is important that the researcher has a clear understanding of this and conveys that in the discussion.

### Limitations

In question 18 we explore whether limitations are discussed. Unfortunately all forms of research have some limitations. The question here is whether the researcher has an understanding of the limitations involved in their study design. If this issue is not explored, this is cause for concern that the limitations don't stop at the design and that the researcher has a poor understanding of the study as a whole.

## Other

### Conflicts of Interest

It is very important that conflicts of interest or bodies involved in funding the study are declared in the text (question 19). This can give an impression as to background reasons for carrying out the study. Where studies are funded by a specific agency the researcher may unconsciously interpret in favour of the agencies' ideals; if the researcher has worked in a specific area their own ideas and beliefs may affect the interpretation of the results. It is up to the reader to identify these and come to the conclusion as to whether these conflicts of interest are relevant or not. This can be declared in different areas of the text and should be stated.

### Ethical Approval

Question 20 deals with ethical approval and participant consent. It is important that these are sought before carrying out research on any animal or person.

**References:**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## Appendix 3a. Letters documenting the external peer review for the qualitative and quantitative study

Universiteit Leiden

Faculty of Social and Behavioral Sciences
Institute of Psychology
Unit of Clinical Psychology

To whom it may concern

*Number*
*Your reference*
*Subject*

*Date* November 13, 2017
*Telephone*
*Contact*

Dear Sir, Madam,

I have externally reviewed the protocol for this study titled ' life experiences, engagement , attachment and negative symptoms'.

Please contact me if you need any further information.

Sincerely,

Jacqueline Guicherit-Dicke

Pieter de la Courtbuilding
Wassenaarseweg 52
P.O. Box 9555
2300 RB Leiden, The Netherlands
Telephone +31 71 527 3377 /3737
Fax +31 71 527 4678

To whom it may concern,

I have externally reviewed the protocol for Isabelle Butcher's study titled @ Life experiences, engagement, attachment and negative symptoms".

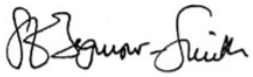
The documents read well and provide a thorough presentation.

November 15th 2017

Dr Sarah Seymour-Smith

Project: Subjective experiences of negative symptoms of schizophrenia.

This document confirms that I have externally reviewed in favour of the research protocol written by Isabelle Butcher for the above study that she intends to conduct. Due care was taken in outlining the ethical issues.



Dr Sarah Seymour-Smith

Nottingham Trent University

## Appendix 3b. Good clinical practice refresher course certificate

NHS
National Institute for Health Research

# Certificate of Completion

Isabelle Butcher

has completed

## Good Clinical Practice (GCP) Refresher

A practical guide to ethical
and scientific quality standards in clinical research

on

20th April 2017

Including EU Directives, Medicines for Human Use (Clinical Trials) Regulations & the Department of Health Research Governance Framework for Health & Social Care, as applied to the conduct of Clinical Trials & other studies conducted in the NHS

**Modules completed:**

Recent and Forthcoming Changes
Research standards and GCP
Study set-up at site
Delegation of Duties and PI Oversight
Participant Eligibility
Electronic Source Data and Site Files

*This course is worth 3 CPD credits*

CPD
The CPD Certification Service

***Delivering research to make patients, and the NHS, better***

## Appendix 3c. Letters documenting ethical approval for the qualitative and quantitative study

NHS
Health Research Authority

Miss Isabelle Laura Butcher
PhD researcher
University of Manchester/Medical Research Council
Zochonis Building
Brunswick Street
Manchester
M13 9PL

Email: hra.approval@nhs.net

04 April 2017

Dear Isabelle,

**Letter of HRA Approval**

| | |
|---|---|
| **Study title:** | **An exploration of individuals subjective experience of negative symptoms of schizophrenia.** |
| **IRAS project ID:** | **219492** |
| **REC reference:** | **17/NW/0191** |
| **Sponsor** | **University of Manchester** |

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 noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical 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 and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

**Appendices**

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

**After HRA Approval**

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.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

**Scope**

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

**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 research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **219492**. Please quote this on all correspondence.

Yours sincerely

Alex Thorpe
Senior Assessor

Email: hra.approval@nhs.net

*Copy to:* *Mrs Lynne Macrae, Sponsor's Representative*
*Ms Rachel Rosenhead, Greater Manchester Mental Health NHS Foundation Trust, Lead R&D Contact*
NIHR CRN Portfolio Applications Team

| IRAS project ID | 219492 |
|---|---|

**Appendix A - List of Documents**

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

| *Document* | *Version* | *Date* |
|---|---|---|
| Contract/Study Agreement [Contract Letter] | | 03 March 2017 |
| Copies of advertisement materials for research participants [Advert for study] | version 1.4 | 29 March 2017 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance] | version 1.0 | 03 March 2017 |
| Interview schedules or topic guides for participants [Topic guide for Semi Structured Interviews] | version 1.6 | 29 March 2017 |
| Interview schedules or topic guides for participants [Demographics form] | version 1.6 | 29 March 2017 |
| IRAS Application Form [IRAS_Form_06032017] | | 06 March 2017 |
| IRAS Application Form XML file [IRAS_Form_06032017] | | 06 March 2017 |
| IRAS Checklist XML [Checklist_04042017] | | 04 April 2017 |
| Letter from funder [Letter from Funder Medical research Council] | | 11 February 2016 |
| Letter from sponsor [Letter from sponsor] | | 03 March 2017 |
| MHRA Notice of No Objection Letter (Medical Devices) and relevant correspondence [Research Governance Regulations Letter] | version 1.0 | 03 March 2017 |
| Other [Summary CV for co -supervisor] | | |
| Other [External Peer Reviewer 1 report] | | 01 March 2017 |
| Other | 1.0 | 03 March 2017 |
| Other [Consent to contact] | 1 | |
| Other [PROTOCOL FOR MANAGING DISCLOSURE OF RISK] | 1.1 | 17 January 2017 |
| Other [Advert] | version 1.4 | 29 March 2017 |
| Other [Statement of Activities] | 1 | 04 April 2017 |
| Other [Schedule of Events] | 1 | 04 April 2017 |
| Participant consent form [consent form] | version 1.4 | 29 March 2017 |
| Participant information sheet (PIS) [Participant Information sheet] | version 1.4 | 29 March 2017 |
| Research protocol or project proposal [Research Study Protocol] | version 1.7 | 29 March 2017 |
| Summary CV for Chief Investigator (CI) [CV for Chief Investigator IB] | | 10 January 2017 |
| Summary CV for student [CV for student IB] | | 10 January 2017 |
| Summary CV for supervisor (student research) [Academic supervisor CV] | version 1.0 | |

| IRAS project ID | 219492 |
|---|---|

**Appendix B - Summary of HRA Assessment**

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed 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 and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.**

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Isabelle Butcher

isabelle.butcher-2@postgrad.manchester.ac.uk

07515395182

**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 | The applicant has provided the Statement of Activities and Schedule of Events and intends for these to be used as the agreement between the sponsor and participating sites. |
| 4.2 | Insurance/indemnity arrangements assessed | Yes | NHS Indemnity covers study conduct on NHS premises. Sponsor's insurance covers the design and management of the study, and letter states that the |

| Section | HRA Assessment Criteria | Compliant with Standards | Comments |
|---|---|---|---|
| | | | policy will begin when the study receives a Favourable Opinion.<br><br>Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study. |
| 4.3 | Financial arrangements assessed | Yes | No funding will be provided to sites for this study. |
| | | | |
| 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 |
| 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 |

| IRAS project ID | 219492 |
|---|---|

## 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 single site-type study. After speaking to the applicant about the PIC sites listed in the IRAS form, it has been confirmed that these PICs are part of the recruiting organisations.<br><br>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.<br><br>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. |

## Confirmation of Capacity and Capability

| *This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.* |
|---|
| Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.<br>• Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.<br>• The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability. |

## 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).* |
|---|
| The Chief Investigator will be acting as the Principal Investigator at all participating sites.<br><br>GCP training is not a generic training expectation, in line with the HRA statement on training expectations. |

| IRAS project ID | 219492 |
|---|---|

### 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* |
|---|
| The student researcher will need to clear appropriate Research Passport, Letter of Access and Occupational Health clearances at each site. |

### 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 intend to apply for inclusion on the NIHR CRN Portfolio. |

NHS
Health Research Authority

**North West - Preston Research Ethics Committee**
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 020 71048008

04 April 2017

Miss Isabelle Laura Butcher
University of Manchester/Medical Research Council
Zochonis Building
Brunswick Street
Manchester
M13 9PL

Dear Miss Butcher

**Study title:** **An exploration of individuals subjective experience of negative symptoms of schizophrenia.**
**REC reference:** **17/NW/0191**
**IRAS project ID:** **219492**

Thank you for your response. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 29 March 2017

**Documents received**

The documents received were as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Participant consent form [consent form] | version 1.4 | 29 March 2017 |
| Participant information sheet (PIS) [Participant Information sheet] | version 1.4 | 29 March 2017 |

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

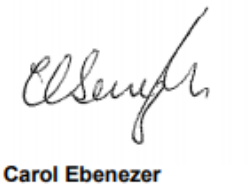
| *Document* | *Version* | *Date* |
|---|---|---|
| Copies of advertisement materials for research participants [Advert for study] | version 1.4 | 29 March 2017 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance] | version 1.0 | 03 March 2017 |
| Interview schedules or topic guides for participants [Topic guide for Semi Structured Interviews] | version 1.6 | 29 March 2017 |
| Interview schedules or topic guides for participants [Demographics form] | version 1.6 | 29 March 2017 |

| | | |
|---|---|---|
| IRAS Application Form [IRAS_Form_06032017] | | 06 March 2017 |
| IRAS Application Form XML file [IRAS_Form_06032017] | | 06 March 2017 |
| Letter from funder [Letter from Funder Medical research Council] | | 11 February 2016 |
| Letter from sponsor [Letter from sponsor] | | 03 March 2017 |
| MHRA Notice of No Objection Letter (Medical Devices) and relevant correspondence [Research Governance Regulations Letter] | version 1.0 | 03 March 2017 |
| Other [Summary CV for co -supervisor] | | |
| Other [External Peer Reviewer 1 report] | | 01 March 2017 |
| Other | 1.0 | 03 March 2017 |
| Other [Consent to contact] | 1 | |
| Other [PROTOCOL FOR MANAGING DISCLOSURE OF RISK] | 1.1 | 17 January 2017 |
| Participant consent form [consent form] | version 1.4 | 29 March 2017 |
| Participant information sheet (PIS) [Participant Information sheet] | version 1.4 | 29 March 2017 |
| Referee's report or other scientific critique report [ExternalPeerReviewer2 Comments] | version 1.0 | |
| Research protocol or project proposal [Research Study Protocol] | version 1.7 | 29 March 2017 |
| Summary CV for Chief Investigator (CI) [CV for Chief Investigator IB] | | 10 January 2017 |
| Summary CV for supervisor (student research) [Academic supervisor CV] | version 1.0 | |

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**17/NW/0191** **Please quote this number on all correspondence**

Yours sincerely



**Carol Ebenezer**
**REC Manager**

E-mail: nrescommittee.northwest-preston@nhs.net

*Copy to:* *Mrs Lynne Macrae*
*Ms Rachel Rosenhead, Greater Manchester Mental Health NHS Foundation Trust*

NHS
Health Research Authority

Miss Isabelle Butcher
Doctoral Researcher
Division of Psychology and Mental Health
Brunswick Street
Manchester
M13 9PL

Email: hra.approval@nhs.net

26 February 2018

Dear Miss Butcher

**Letter of HRA Approval**

| | |
|---|---|
| **Study title:** | **Life experiences, engagement with services, attachment and negative symptoms: a cross sectional and a 6 month follow up study.** |
| **IRAS project ID:** | **237146** |
| **REC reference:** | **18/IEC08/0003** |
| **Sponsor** | **University of Manchester** |

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 noted in this letter.

**Participation of NHS Organisations in England**

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical 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 and further information about working with the research management function for each organisation can be accessed from the HRA website.

**Appendices**

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

**After HRA Approval**

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.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

**Scope**

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through IRAS.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

**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.

**HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details on the HRA website.

Your IRAS project ID is **237146**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe
Assessor

Email: hra.approval@nhs.net

*Copy to:* *Ms Lynne Macrae, University of Manchester, Sponsor contact*
*Mrs Rachel Rosenhead, Greater Manchester Mental Health NHS Foundation Trust, Lead NHS R&D contact*

| IRAS project ID | 237146 |
|---|---|

**Appendix A - 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 [Advert] | 4 | 29 November 2017 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance letter] | 1 | 11 January 2018 |
| GP/consultant information sheets or letters [Referrer poster] | Version 2.0 | 29 November 2017 |
| GP/consultant information sheets or letters [Letter to clinician] | Version 4 | 29 November 2017 |
| HRA Schedule of Events [Validated SOE] | 1.0 | 26 January 2018 |
| HRA Statement of Activities [Validated SOA] | 1.0 | 26 January 2018 |
| IRAS Application Form [IRAS_Form_16012018] | | 16 January 2018 |
| Letter from funder [Letter from MRC] | 1 | 21 December 2017 |
| Letter from sponsor | 1.0 | 11 January 2018 |
| Non-validated questionnaire [Demographics] | 1.2 | 03 November 2017 |
| Non-validated questionnaire [Ethnic category codes] | 1 | 11 January 2018 |
| Other [Response to REC Committee ] | 1 | 15 February 2018 |
| Other [Policy for managing distress] | 1 | 11 January 2018 |
| Other [Consent to contact form] | 1.0 | 21 December 2017 |
| Other [Lone working policy] | | |
| Other [Public Liability] | 1 | 30 May 2017 |
| Other [Consent Form] | 7.0 | 15 February 2018 |
| Other [Information sheet] | 7.0 | 15 February 2018 |
| Other [Debrief sheet] | 7 | 15 February 2018 |
| Other [Policy for managing distress] | 1.0 | 11 January 2018 |
| Referee's report or other scientific critique report [Peer review] | 1 | 13 November 2017 |
| Referee's report or other scientific critique report [External review ] | 1 | 15 November 2017 |
| Research protocol or project proposal [Research Protocol] | 1.5 | 21 December 2017 |
| Summary CV for Chief Investigator (CI) [CV Isabelle Butcher] | 1 | 04 January 2016 |
| Summary CV for student [CV I BUTCHER] | 1 | 04 January 2016 |
| Summary CV for supervisor (student research) [KB CV] | 1 | 04 January 2018 |
| Summary CV for supervisor (student research) [GH CV] | 1 | 01 January 2018 |
| Validated questionnaire [THQ and CTQ neglect items] | 1.0 | 11 January 2018 |
| Validated questionnaire [Service Engagement Scale] | version 1 | 01 January 2002 |
| Validated questionnaire [Psychosis Attachment Measure] | 1 | 11 January 2018 |
| Validated questionnaire [PANSS and PSYRATS] | 1.0 | 10 November 2008 |
| Validated questionnaire [CDSS Scale] | 1.0 | 11 January 2018 |

| IRAS project ID | 237146 |
|---|---|

**Appendix B - Summary of HRA Assessment**

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed 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 and arranging capacity and capability.

**For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations*, *capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.**

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Lynne Macrae
Tel: 01612755436
Email: FBMHethics@manchester.ac.uk

### 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 | The statement of activities will act as agreement of an NHS organisation to participate.<br>No further agreements expected. |
| 4.2 | Insurance/indemnity arrangements assessed | Yes | Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this |

| Section | HRA Assessment Criteria | Compliant with Standards | Comments |
|---|---|---|---|
| | | | research study |
| 4.3 | Financial arrangements assessed | Yes | Funding has been secured from the Medical Research Council Doctoral Training Scheme.<br>The statement of activities confirms there are no funds available to site from the sponsor. |
| | | | |
| 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 | REC FO dated 26/02/2018 |
| 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.* |
|---|
| Participating NHS sites will be recruiting sites; the external researcher will take consent and conduct all study activities after identification at site.<br><br>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.<br><br>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. |

## Confirmation of Capacity and Capability

| *This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.* |
|---|
| Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.<br>• Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.<br>• The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability. |

## 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).* |
|---|
| A Local collaborator is expected at participating NHS sites in order to identify potential participants and arrange access for the external researcher.<br><br>GCP training is not a generic training expectation, in line with the HRA/MHRA statement on training expectations. |

| IRAS project ID | 237146 |
|---|---|

## 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* |
|---|
| Use of identifiable patient records held by an NHS organisation to identify potential participants should be undertaken by a member of the direct care team for the patient, so it would not normally be acceptable for this to be done by staff not employed by that organisation.<br>A Letter of Access (or equivalent) would be expected for any external NHS/research staff undertaking any of the other activities for the study at the participating sites. The pre-engagement checks should include a standard DBS check and 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 intend to apply for inclusion on the NIHR CRN Portfolio. |

## Appendix 4a. Patient and Public Involvement consultation sheet used in the qualitative and quantitative studies

### Patient and Public Involvement consultation form

Thank you for agreeing to consult on the development of the study materials for this study. The aim of this study is to understand how individuals experience negative symptoms that are associated with a diagnosis of schizophrenia and how these can impact our relationships.

We would like to hear what you think about the interview topic guide and the study material.

Please note, we don't need you to participate in the interview. We only need your views on the readability and content of the interview topic guide, and the study material.

Please think about:

1. Appearance

What do you think about the font, layout, and overall quality of appearance?

2. Instructions

Please think about how clear the instructions were to follow – would you know what to do if you were asked to fill this out?

3. Language

How appropriate is the language used? Could any of the words used be offensive or misinterpreted?

4. Difficulty

How easy or difficult do you think the questions would be to answer? Are there any items that don't make sense?

5. Completeness

Do you think any of the items within the interview topic guide are missing?

6. Length

Do you think the length is appropriate?

7. Do you have any other comments?

Many thanks.

## Appendix 4b. Advertisements for the qualitative and quantitative studies

Researcher: Isabelle Butcher
Version 4.0 29/11/17

MRC Medical Research Council

NHS REC Reference:
IRAS 237146

MANCHESTER 1824
The University of Manchester

# L·E·A·N·S

LIFE EXPERIENCES, ENGAGEMENT, ATTACHMENT
NEGATIVE SYMPTOMS

## ARE YOU STRUGGLING WITH A LACK OF MOTIVATION OR A LACK OF CONCENTRATION?

## IS IT HARD TO BE AROUND PEOPLE AND ATTEND SOCIAL EVENTS?

## HAVE YOU LOST INTEREST IN LIFE?

**Some people with a diagnosis of schizophrenia have reported that they experience some of the things mentioned above.**

We are interested in hearing from people who have been in touch with services and who have a diagnosis of schizophrenia, and are experiencing these symptoms. We are interested to know whether life experiences may lead to experiencing these symptoms.

NHS Greater Manchester Mental Health NHS Foundation Trust

Pennine Care NHS Foundation Trust

NHS North West Boroughs Healthcare NHS Foundation Trust

Leeds and York Partnership NHS Foundation Trust

Sussex Partnership NHS Foundation Trust

If you are receiving help from mental health services and would like to find out more information about participating please contact Isabelle Butcher at :

**E-mail :** isabelle.butcher-2@postgrad.manchester.ac.uk
**Telephone :** 0161 306 0429 or 07502 441533

## Appendix 4c. Participant information sheets for qualitative and quantitative studies

Subjective experiences of schizophrenia
IRAS ID 219492 | NHS REC Reference: 17/NW/0191

Researcher Name - Isabelle Butcher
Version 1.4 29/03/17

### INFORMATION SHEET FOR PARTICIPANTS

Some people who have a diagnosis of schizophrenia hear voices and have also said that they experience some of the following:

- Losing normal thoughts, feelings and motivations.
- Losing interest in life.
- Cannot concentrate.
- Not bothering to get up or go out of the house.
- Not washing or tidying, or keeping clothes clean.
- Feeling uncomfortable with people.

Researchers at the University of Manchester are interested in finding out more about how individuals experience these symptoms above in their lives.

We would like to invite you to participate in this study to help us understand more about these things.

#### WHY HAVE I BEEN INVITED TO TAKE PART?

You have been invited to participate in this study which is sponsored by the University of Manchester and funded by the Medical Research Council because you currently experience some of these symptoms described above.

#### DO I HAVE TO TAKE PART?

Participation in this study is not compulsory. If you decide to not participate in this study, it will not affect your current treatment plans. We are recruiting only 15 individuals at this time for this study so if you volunteer and express an interest an interest in participating you may not be chosen for the interview.

#### WHAT WILL HAPPEN TO ME IF I TAKE PART?

If you decide you would like to take part in this study then you will be asked to provide contact details for your care worker or clinician in order for Isabelle Butcher to obtain any key information. Participants will be asked to participate in an audio-recorded interview, which will last no longer than 60 minutes and will take place where best suits you. The interview will invite you to talk about your experiences. The interview will be conducted and transcribed by Isabelle Butcher. Additonally you will be asked to complete a short questionnaire on demographic information.

#### WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF TAKING PART?

Taking part in this study will help the researchers and staff understand more about how you feel and what you are experiencing. There are no known risks to participating in this study.

#### WILL MY DATA BE KEPT CONFIDENTIAL?

All information will be kept confidential. Interviews will be anonymised upon completion and all data will be stored securely (in locked secure storage and password protected electronic files). Medical care workers will not have access this information unless the researcher feels that the participant is at imminent risk in which case their care team will be contacted.

If you disclose a risk to yourself or others confidentiality will have to be broken and a member of your care team will be informed. The only time in which someone may need to look at the study information is during an audit or monitoring visit. This is when people from the University of Manchester NHS Trust or regulatory authorities review all of the data to make sure that the study is being carried out as planned. If you agree they will include your identifiable data when doing the check. Anyone who does look at the data will have a duty to keep it confidential.

Research data generated by the study will be stored in a filing cabinet up to 5 years after it has been generated. The research data will be stored in locked filing cabinets in alocked room at the University of Manchester.
Only members of the research team will have access to this.

# INFORMATION SHEET FOR PARTICIPANTS (CONT.)

## WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this study will be written up and help to inform staff how people experience these symptoms. If you would like a copy of the final findings please let Isabelle Butcher know.

## WHAT HAPPENS IF I DO NOT WANT TO CARRY ON WITH THE STUDY?

You are free to withdraw from the study at any time without giving a reason and your data If you feel unable to complete the interview the interview can be stopped and if you wish the interview can be returned to at a later time and/ date. You are free to withdraw from the study at any time without giving a reason and your data will be withdrawn as long as it is within 6 weeks of the interview after this it will not be possible to withdraw your data.

## WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this study will be written up as part of a PhD project and will help to inform staff how people experience these symptoms Direct quotations from the interviews may be used in the final report produced and in subsequent research papers. These quotations will not be identifiable. If you would like a copy of the final findings please let Isabelle Butcher know.

## WHO IS FUNDING THE RESEARCH?

The Medical Research Council is funding this research.

## WHO HAS REVIEWED THE STUDY?

The University of Manchester, and the National Health Service Research Ethics Committee (REC) have reviewed this study.

## WHO SHOULD I CONTACT FOR FURTHER INFORMATION?

If you have any questions or require more information about this study, please contact Isabelle using the following contact details:

Isabelle Butcher, Division of Psychology and Mental Health, University of Manchester, 2nd Floor Zochonis building, Brunswick Street, Manchester, M13 9PL.
E-mail: **isabelle.butcher-2@postgrad.manchester.ac.uk** | Telephone: **0161 306 0429**

## WHAT IF I HAVE FURTHER QUESTIONS OR, CONCERNS?

If you have any additional questions or concerns please contact a member of your care team or the crisis team. Additionally please free to contact other members of the research team:

Dr Katherine Berry: Division of Psychology and Mental Health, University of Manchester, 2nd Floor Zochonis building, Brunswick Street, Manchester, M13 9PL.
E-mail: **Katherine.berry@manchester.ac.uk** | Telephone: **0161 306 0400**

Professor Gillian Haddock Division of Psychology and Mental Health, University of Manchester, 2nd Floor Zochonis building, Brunswick Street, Manchester, M13 9PL.
E-mail: **Gillian.Haddock@manchester.ac.uk** | Telephone: **0161 275 8485**

If you wish to make a formal complaint or if you are not satisfied with the responses you gained from the researchers please contact the Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PI.

E-mail: **research.complaints@manchester.ac.uk** | Telephone: **0161 275 2674 or 275 2046**

**THANK YOU FOR READING THIS INFORMATION SHEET AND FOR CONSIDERING TAKING PART IN THIS RESEARCH.**

Researcher: Isabelle Butcher
Version 10 21/01/19

MRC Medical Research Council

L·E·A·N·S
Life Experiences, Engagement, Attachment Negative Symptoms

NHS REC Reference:
IRAS 237146

MANCHESTER 1824
The University of Manchester

## INFORMATION SHEET

Some people with a diagnosis of schizophrenia experience some of the following;

**Lack of interest in life**

**Difficulty in concentrating**

**Lack of 'get up and go'**

**Feeling uneasy around other people**

**Difficulty in taking part in activities**

**Difficulty in talking with others**

We would like like to know more about your experience of these symptoms. Some research suggests that life experiences may have an impact on these symptoms.

Please read the following information about the study carefully. Please ask any questions you like. Please take the time to decide whether or not you wish to take part.

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

You have been invited to join our project because you currently experience some of the symptoms above. Someone in your care team may have suggested you take part in this study. You are over the age of 18 years. We hope to recruit 85 people who experience similar symptoms to take part in the study.

### Do I have to take part?

No, you do not have to take part in the study if you do not want to.

Taking part in the research is voluntary; this means it is completely up to you to decide whether or not to join the study.

Your decision to participate in this study will not be connected to the care you are receiving now or in the future.

If you decide to take part and sign the consent form you are free to withdraw at any point during the study. No reason is needed to withdraw. Withdrawing from the study will not affect your current or future treatment.

### What will happen to me if I take part?

If you would like to take part we will ask you to sign a consent form. With your consent we will also ask you to provide details of your key worker. The study will involve completing a set of 8 questionnaires some of which are delivered through Isabelle Butcher asking you questions, the others are answered by you writing on the questionnaire(s). It is estimated to take no longer than 90 minutes at the first time point. The questionnaires ask you about your life experiences which will include questions about your potential unwanted sexual experiences, harmful incidents that may have occurred to yourself or to a family member and other traumatic life events. Also the questionnaires will ask you about any incidents of bullying that you may have experienced. There will also be a short questionnaire which asks you about demographic information including your age and gender. Six months later Isabelle will come back and

ask you to complete 4 of the questionnaires/interviews plus the demographic information. This is estimated to take no longer than one hour.

At the six month time point you will also be asked to participate in a short interview which aims to ask you about your experience(s) of taking part in this study, this interview will take no longer than hour. As with the other questionnaires in this study you are free to withdraw at any moment.

The questionnaires and the interviews can be stopped at any time. These can be stopped and continued on the same day or stopped and Isabelle can return on alternative day to complete the questionnaires and interviews.

## What are the possible benefits and risks to taking part?

We cannot promise the research will help you but the information from this study will be useful. It may help in treating other people who experience these symptoms in the future. Some people enjoy completing questionnaires or interviews in research.

As a thank you for participating you will be given £10 after each assessment.

## Will my care team be informed?

Yes your key worker will be informed about you participating in this study and will provide information on your current medication and service engagement.

## Will my data be kept confidential?

Data will be anonymised and the interviews were appropriate will be transcribed by the lead researcher, Isabelle Butcher. Everything you say/report is confidential unless you tell us something that indicates you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

Contact details will be destoyed at the end of the 6 months of you participating in the study and records will be destroyed at the end of the study. Data will be kept for a minimum of 5 years after the date of any publication using the results, to follow the recommended good practice guidelines for research.

Isabelle Butcher and the research team (Gillian Haddock and Katherine Berry) will have access to the data. Please note that individuals from the University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the studies being carried out as planned. This may involve looking at identifiable data but all individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

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

The results of the study will be analysed and written up as part of Isabelle Butcher's PhD. The results wil also be published in journals. No information will be identifable. If you would like to receive a copy of the results from this study please let Isabelle Butcher know.

## What happens if I do not want to carry on with the study?

You can withdraw from the study completely at any time without giving a reason.

Withdrawing will not have any impact on your current or future treatment. No further data will be collected from the moment at which you withdraw.

## Who has reviewed the study?

All research which involves NHS patients has been reviewed by the National Health Service Research Ethics Committee (REC).

## Additional Information

University of Manchester is the sponsor for this study based in United Kingdom. We will be using information from you and your key workers in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Manchester will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Isabelle Butcher on 0161 306 0429

Isabelle Butcher will keep your name, and contact details confidential and will not pass this information to University of Manchester . University of Manchester will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from University of Manchester and regulatory organisations may look at your medical and research records to check the accuracy of the research study. University of Manchester will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

University of Manchester will keep identifiable information about you from this study 5 years after the study has finished.

University of Manchester will collect information about you for this specific Life experiences, engagement with services, attachment style and negative symptoms from yourself and from your key worker. Isabelle Butcher will not provide any identifying information about you to the University of Manchester . We will use this information as part of this research project.

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future

opportunities to participate in research.
It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

### Who should I contact for further information?

If you have any questions or require more information about this study please contact Isabelle using the following contact details.

**Isabelle Butcher**
Division of Psychology and Mental Health, University of Manchester,
2nd Floor Zochonis Building, Brunswick Street, Manchester, M13 9PL.
**Telephone :** 0161 306 0429 **Email :** isabelle.butcher-2@postgrad.manchester.ac.uk

## WHAT IF I HAVE FURTHER QUESTIONS OR, CONCERNS?

**If you have any additional questions please contact:**

**Professor Gillian Haddock**

**Telephone : 0161 275 8485**
**Email : Gillian.Haddock@manchester.ac.uk**

**Additionally please feel free to contact below with any complaints:**

### MINOR COMPLAINTS

**If you have a minor complaint in the first instance please contact:**

**Isabelle Butcher**

**Telephone : 0161 306 0429**
**Email : isabelle.butcher-2@postgrad.manchester.ac.uk**

### FORMAL COMPLAINTS

**If you wish to make a formal complaint or if you are not satisfied with the response that you have gained from the researchers in the first instance then please contact:**

**The Research Governance and Integrity Manager,
Research Office, Christie Building, University of Manchester,
Oxford Road, Manchester M13 9PL**

**Telephone : 0161 275 2674 or 275 2046.**
**Email : research.complaints@manchester.ac.uk**

## Appendix 5a. Referral poster for quantitative study

Researcher: Isabelle Butcher
Version 2.0 29/11/17

MRC Medical Research Council

NHS REC Reference:
IRAS 237146

MANCHESTER 1824
The University of Manchester

# L·E·A·N·S

Life Experiences, Engagement, Attachment
Negative Symptoms

We are looking at the relationship between life experiences, attachment, engagement and negative symptoms.

Participants will be invited to complete some questionnaires and participate in an interview. The study will take no longer than 90 minutes. Some of the questionnaires and interview will be done again in 6 month's time if participants agree.

You will be asked if possible to provide information on the participant's' engagement with services and medication at baseline and at 6 months.

| Inclusion criteria | Exclusion criteria |
|---|---|
| • 18 years of age or over.<br>• Individuals who are under the care of a mental health team and/ who have a care coordinator or equivalent.<br>• Individuals who meet criterion for schizophrenia/related psychosis diagnoses.<br>• Individuals experiencing negative symptoms which may include; lack of motivation, social withdrawal and reduced range of emotions.<br>• An adequate understanding of the English language. | • Individuals with an organic brain disorder.<br>• Insufficient English to understand and complete assessments.<br>• Intellectual disability which impacts on the ability to complete assessment. |

If you have anyone in mind who may be interested please contact Isabelle Butcher:
**Isabelle.Butcher-2@postgrad.manchester.ac.uk** - Telephone: **07502 441533**

I will be more than happy to discuss the project in more detail.

This project is a PhD and is supervised by two clinical psychologists and academics at University of Manchester. Both are able to provide further information if required.

Professor Gillian Haddock - **gillian.haddock@manchester.ac.uk**
Dr Katherine Berry - **katherine.berry@manchester.ac.uk**

## Appendix 5b. Consent to contact forms for qualitative and quantitative studies

MANCHESTER 1824
The University of Manchester

Version 1.0
IRAS ID:
237146

**Study Title:** *Life experiences, engagement, attachment and negative symptoms*
**Chief Investigator:** *Isabelle Butcher*

Please note the following points in relation to the processing of your data:

- Data will be held securely by the research team on behalf of the University of Manchester according to the University's data protection and information security policies.
- Access to the data will be restricted to the research team for the sole purpose of contacting you about this study.
- Your data will not be shared with any third party without your written permission.
- The details collected will only be stored for as long as required to find out if you wish to take part in the study. Once no longer needed, that data will be destroyed securely.
- If you decide to change your mind about being contacted about the study or would like your details to be destroyed you can contact Isabelle Butcher at Isabelle.butcher-2@postgrad.manchester.ac.uk

Once you have completed your details, please ensure that you have added your signature and *keep the top half of this form and tear off the bottom half and return to Isabelle Butcher.*

✂----------

I am happy **to provide/for my health care professional to provide** (delete as appropriate) my personal details so that I can be contacted about this study.

| | |
|---|---|
| Name | |
| Signature | |
| Today's date | |

Please complete the details below or hand back to your health care provider to complete on your behalf

| | | |
|---|---|---|
| **Contact by letter** | Address | |
| | | |
| | | |
| | Post Code | |
| **Contact by phone** | Preferred contact number | |
| | When would you prefer to be contacted? (please circle) | Morning/ Afternoon/ Evening/ Don't Mind |
| **Contact by email** | Email address | |

Version 1. 0

MANCHESTER 1824
The University of Manchester

Version 1.0
IRAS ID:
219492

**Study Title:** *Subjective Experiences of symptoms of schizophrenia*
**Chief Investigator:** *Isabelle Butcher*

Please note the following points in relation to the processing of your data:

- Data will be held securely by the research team on behalf of the University of Manchester according to the University's data protection and information security policies.
- Access to the data will be restricted to the research team for the sole purpose of contacting you about this study.
- Your data will not be shared with any third party without your written permission.
- The details collected will only be stored for as long as required to find out if you wish to take part in the study. Once no longer needed, that data will be destroyed securely.
- If you decide to change your mind about being contacted about the study or would like your details to be destroyed you can contact Isabelle Butcher at Isabelle.butcher-2@postgrad.manchester.ac.uk

Once you have completed your details, please ensure that you have added your signature and *keep the top half of this form and tear off the bottom half and return to Isabelle Butcher.*

✂----------

I am happy **to provide/for my health care professional to provide** (delete as appropriate) my personal details so that I can be contacted about this study.

| | |
|---|---|
| Name | |
| Signature | |
| Today's date | |

Please complete the details below or hand back to your health care provider to complete on your behalf

| | | |
|---|---|---|
| **Contact by letter** | Address | |
| | | |
| | | |
| | Post Code | |
| **Contact by phone** | Preferred contact number | |
| | When would you prefer to be contacted? (please circle) | Morning/ Afternoon/ Evening/ Don't Mind |
| **Contact by email** | Email address | |

Version 1. 0

## Appendix 5c. Consent forms for qualitative and quantitative studies



### EXPERIENCES OF SYMPTOMS OF SCHIZOPHRENIA – CONSENT FORM –

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box I am consenting to this element of the study. Blank boxes will mean that I do not consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.

| | | |
|---|---|---|
| 1. | I confirm that I have read and understood the information sheet dated Version 1.4 29/03/17 for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily. | ☐ |
| 2. | I understand that I will be able to withdraw my data up to 6 weeks after my interview. | ☐ |
| 3. | I understand that my participation is voluntary. I understand that I can stop and leave the interview at any time and no reason is needed. | ☐ |
| 4. | I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998. | ☐ |
| 5. | I confirm that relevant sections of data collected during the study may be looked at by regulatory authorities or individuals from NHS trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data. | ☐ |
| 6. | I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications | ☐ |
| 7. | I agree to be contacted in the future by University of Manchester researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. Declining for future studies will not deem you ineligible for this study. | ☐ |
| 8. | I consent to my interview being audio recorded, I understand that my interview will be anonymised and it will not be possible to identify me in the interviews. | ☐ |
| 9. | I understand that anonymous direct quotations may be used in the write up of this project and will not be able to be traced to myself. | ☐ |

1 copy for participant, 1 original copy for researcher site file:

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Researcher | Date | Signature |

Researcher: Isabelle Butcher
Version 9.0 21/01/19

MRC Medical Research Council

L·E·A·N·S
Life Experiences, Engagement, Attachment
Negative Symptoms

NHS REC Reference:
IRAS 237146

MANCHESTER 1824
The University of Manchester

## CONSENT FORM

Thank you for considering taking part in this research. If you have any questions arising from the information sheet, please ask the researcher before you decide whether to take part.

**Study Title: Life experiences, engagement, attachment and negative symptoms**

| | | Please initial |
|---|---|---|
| 1) | I confirm that I have read and understand the attached information sheet (Version Number 10) dates (21.01.2019) on the above project and have the opportunity to consider the information. | |
| 2) | I confirm that I have had the opportunity to ask questions about the study and that these questions have been answered satisfactorily. | |
| 3) | I consent to the interviews being audio recorded, Isabelle will be transcribing the interviews at the University of Manchester. | |
| 4) | I understand that the data collected may be published as part of a research project. My identity will not be revealed in any publication. | |
| 5) | I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data. | |
| 6) | I give permission for my keyworker or other relevant medical professional to provide information on my engagement with services and on my current medication at both time assessment points. | |
| 7) | (Optional) I agree to be contacted in the future by University of Manchester researchers who would like to invite me to participate in follow up studies to this project, or in future studies or a similar nature. Declining for future studies will not deem you ineligible for this study. | |
| 8) | I agree to take part in the above study. | |
| 9) | (Optional). I would like the researcher to send me a copy of the final findings and report in the post once this information is available. | |

| Name of Participant | Date | Signature |
|---|---|---|
| Name of Researcher | Date | Signature |

When completed: 1 copy for Participant, 1 copy for Researcher site file, 1 (original) to be kept in medical notes.

Sussex Partnership NHS Foundation Trust · Greater Manchester Mental Health NHS Foundation Trust · Pennine Care NHS Foundation Trust · North West Boroughs Healthcare NHS Foundation Trust · Leeds and York Partnership NHS Foundation Trust

## Appendix 5d. Debrief sheet for quantitative study

Researcher: Isabelle Butcher
Version 7 15/02/18

NHS REC Reference:
IRAS 237146

L·E·A·N·S
Life Experiences, Engagement, Attachment
Negative Symptoms

### PARTICIPANT DEBRIEF SHEET

LEANS study :
Life experiences, engagement with services, attachment and negative symptoms.

Thank you for participating in this research. We hope that you have found it interesting and have not been upset by any of the topics in the questionnaires or interview. However, if you have found any part of this experience to be distressing there are a number of people and organisations that you can contact for support.

If you would like to speak to one of the researchers, please contact Isabelle:

**Isabelle Butcher**
**Isabelle.butcher-2@postgrad.manchester.ac.uk**
0161 304 60429

Alternatively, you can contact Dr Katherine Berry or Professor Gillian Haddock by writing to University of Manchester, Oxford Rd, Manchester M13 9PL or emailing:

**Katherine.Berry@manchester.ac.uk**
or
**Gillian.Haddock@manchester.ac.uk**

If you feel as though you are struggling to cope, or you are feeling low in mood, it is important that you access support. You can talk to your care co-ordinator or a member of your mental health team for further support. You can also go to your GP for support.

There are also a number of organisations listed below that you can contact for support.

### ORGANISATIONS

**The National Association for People Abused in Childhood (NAPAC)**

Call 0808 801 0331 free from all landlines and mobiles.

NAPAC provides a national freephone support line for adults who have suffered any type of abuse in childhood.

Telephone support line opening hours:
Monday – Thursday 10:00am-9.00pm and Friday 10.00am-6.00pm
**www.napac.org.uk**

**Samaritans**

Phone: 0845 7909090

Open 24 hours a day. They offer confidential emotional support by telephone, email, text, letter and face to face.

**Hearing Voices Network (HVN)**

c/o Sheffield Hearing Voices Network,
Limbrick Day Service, Limbrick Road, Sheffield, S6 2PE

Phone: 0114 271 8210 | Email: nhvn@hotmail.co.uk

An organisation run by those with experience of hearing voices that offers information, support and understanding to people who hear voices and those who support them.

**Mind**

Infoline: 0300 123 3393 | Email: info@mind.org.uk

An organisation that provides advice and support to empower anyone experiencing a mental health problem.

**NHS Direct**

111
Open 24 hours a day. They provide health advice and information.

**Assist Trauma Care**

Helpline: 01788 560800 | Website: assisttraumacare.org.uk

ASSIST Trauma Care employ experienced therapists trained to work with Post Traumatic Stress Disorder(PTSD) and the after-effects of trauma in line with current evidence-based practices.

## Appendix 5e. Demographic forms for qualitative and quantitative studies

Version 1.2 03.11.17




**Study: Life experiences, engagement, attachment and negative symptoms.**

**Demographics Form**

*Sponsored by the University of Manchester and the Medical Research Council.*

Isabelle Butcher

PhD Student

Division of Psychology and Mental Health

School of Health Sciences

University of Manchester

Room S42, Zochonis Building

Brunswick Street

Manchester, M13 9PL

E-mail: isabelle.butcher-2@postgrad.manchester.ac.uk

**Supervisors:**

Dr Katherine Berry: Division of Psychology and Mental Health, School of Health Sciences, University of Manchester. Email: Katherine.berry@manchester.ac.uk

Professor Gillian Haddock, Division of Psychology and Mental Health, School of Health Sciences, University of Manchester. Email: Gillian.haddock@manchester.ac.uk

2

Version 1.2 03.11.17

Demographics Form

| | |
|---|---|
| **Participant ID:** | |
| **Age:** | |
| **Ethnicity:**<br><br>**Please select one from the attached NHS ethnicity categories.** | |
| **Gender:**<br><br>**Female Male Unspecified** | |
| **Marital Status:** | |
| **Employment:**<br><br>**If a student please state this.** | |
| **Age of onset:**<br><br>**Age at which help was sought for psychosis.** | |

2

To be completed by key worker.

| | |
|---|---|
| **Time point:** | |
| **Participant ID:** | |
| **Diagnosis of individual:** | |
| **Current service currently under the care of:** | |
| **Medication currently taking:** | |

Version 1.6 29.03.17

Project Title:

**Subjective experiences of negative symptoms of schizophrenia.**

Demographics Form

*Sponsored by the University of Manchester and the Medical Research Council.*

Isabelle Butcher

PhD Student

Division of Psychology and Mental Health

School of Health Sciences

University of Manchester

Room S42, Zochonis Building

Brunswick Street

Manchester, M13 9PL

E-mail: isabelle.butcher-2@postgrad.manchester.ac.uk

**Supervisors:**

Dr Katherine Berry: Division of Psychology and Mental Health, School of Health Sciences, University of Manchester. Email: Katherine.berry@manchester.ac.uk

Professor Gillian Haddock, Division of Psychology and Mental Health, School of Health Sciences, University of Manchester. Email: Gillian.haddock@manchester.ac.uk

IRAS ID 219492

MRC Medical Research Council

MANCHESTER 1824 The University of Manchester

Demographics Form

| | |
|---|---|
| **Participant ID:** | |
| **Age:** | |
| **Ethnicity:** | |
| **Gender:** | |
| **Marital Status:** | |
| **Current accommodation type:** | |
| **Living status:** | |
| **Employment:** | |
| **First contact with mental health services :** | |
| **Have you ever been given a diagnosis?: If yes please state what this is:** | |
| **Current service currently under the care of:** | |

# Appendix 6. Disclosure and distress protocol

Managing Disclosure Of Risk and Distress for

2017

VERSION 1.0

## PROTOCOL FOR MANAGING DISCLOSURE OF RISK

### Rationale

During a session or other contact with Isabelle Butcher (IB) a participant may indicate an intention to harm themselves or others. Alternatively they may provide information to the effect that a child or other vulnerable person may be in danger. Any information of this nature **must** be acted upon.

At the beginning of each research interview the participant will be informed that what is discussed is private and confidential except if they indicate any current intention to harm themselves or others, or if they provide information to the effect that a child or other vulnerable person may be in danger. In such situations the staff member has a legal duty to break confidentiality. The particular setting within which risk is disclosed (i.e. hospital ward or community) will determine the specific actions to be taken.

In the case that the individual indicates current intention to harm themselves or others the action taken is to remind the participant of the staff member's Duty of Care to break confidentiality where risk is identified (as previously outlined at the commencement of the interview) and contact the appropriate clinician. IB will also immediately supervisors Gillian Haddock (GH) and Katherine Berry(KB) to inform them of this. The appropriate action will then be determined.

In situations where the researcher is uncertain of whether information disclosed by a participant constitutes a risk, contact should be made with Gillian Haddock or Katherine Berry by phone who will advise on the appropriate action. If it is not possible to make contact with GH or KB before the researcher needs to leave the ward the situation should be reported to the appropriate clinician who the individual is under the care of.

Identifying and managing disclosure of risk should always feature within monthly supervision sessions.

In the case that the participant discloses an incident in which they or someone else was at risk, which has not been previously recorded, in addition to notifying the clinician whom the individual is under the care of, IB should also immediately notify GH and KB. GH and KB will decide the next course of action to be taken.

If the individual indicates that a child / other vulnerable person may be in danger the action taken would be to call the respective Child or Adult Safeguarding Team (see contact details below).

1

In either eventuality the participant will be informed that confidentiality needs to be broken and, if at all possible, will be encouraged to work in collaboration with the staff member to this end..

If this scenario occurs during a face to face contact the individual may be given the option of phoning the care co-ordinator themselves in the presence of the staff member or staying in the room whilst a call is made. Alternatively the individual may choose to wait in a safe place such as an adjoining room. Based upon the telephone discussion the worker will act on any part of the action plan generated that involves action on their part.

In the eventuality that the care co-ordinator and psychiatrist are not contactable a call should be made within the hours of 9am – 5pm Monday to Friday to the Duty worker for the appropriate Community Mental Health Team or. Outside of these hours a call should be made to the Crisis Team or A&E. Details are listed in Appendix K. Once again the worker will act in accordance with any action plan agreed. This may involve faxing information over to A&E, accompanying the individual to A&E etc.

If the scenario occurs during a telephone contact the individual will be informed that confidentiality will need to be breached. The same plan as above will be implemented and the individual should be called back to feedback the planned actions.

In the eventuality that the individual discloses that a child / vulnerable adult may be in danger the Child / Adult Safeguarding Team should be contacted. If it is outside of 9am –5pm and there is considered to be imminent risk to a child / vulnerable adult the police should be informed. Inform these staff also. Details of out of hours Child / vulnerable Adult Safeguarding Team services are listed in Appendix J.

If the worker is uncertain as to the appropriate course of action to take they should initially contact the research team – GH and KB. If the project lead is unavailable contact your clinical supervisor. If they are unavailable the flow diagram of contacts found on page 17/18 should be followed.

In the unlikely event that all avenues are exhausted the worker should follow the previously outlined plan (commencing with contacting the Care Coordinator).

If the client is currently harming him or herself or has done so recently, and there is a need for medical attention, it would be important to negotiate with the client that they attend hospital or that they allow an ambulance to be called. The mental health team or duty psychiatrist would ensure that anyone refusing medical attention was assessed under the Mental Health Act. A decision regarding the need for a compulsory admission to hospital will then be made by an approved social worker in

accordance with the Mental Health Act 1983. Such situations should be reported to GH or KB immediately.

If the participant or someone else has committed a crime then it may be necessary to phone the police as soon as possible.

In the case that the participant discloses an incident in which they or someone else was at risk, which has not been previously recorded, in addition to notifying the relevant staff within their care team GH and KB will be notified

**All information and actions taken, including telephone calls and discussions with GH and KB regarding disclosure of risk will be stored in an encrypted password protected file at the University of Manchester on a university computer.**

Please see **Appendix 1** for further guidelines and examples of managing disclosure of risk during an interview with a patient in an inpatient ward setting.

## FACTORS TO CONSIDER IF A PARTICIPANT EXPRESSES HARM TO SELF OR OTHERS

If a participant you are working with expresses ideas of harm to self or others these are important factors to consider and pass on.

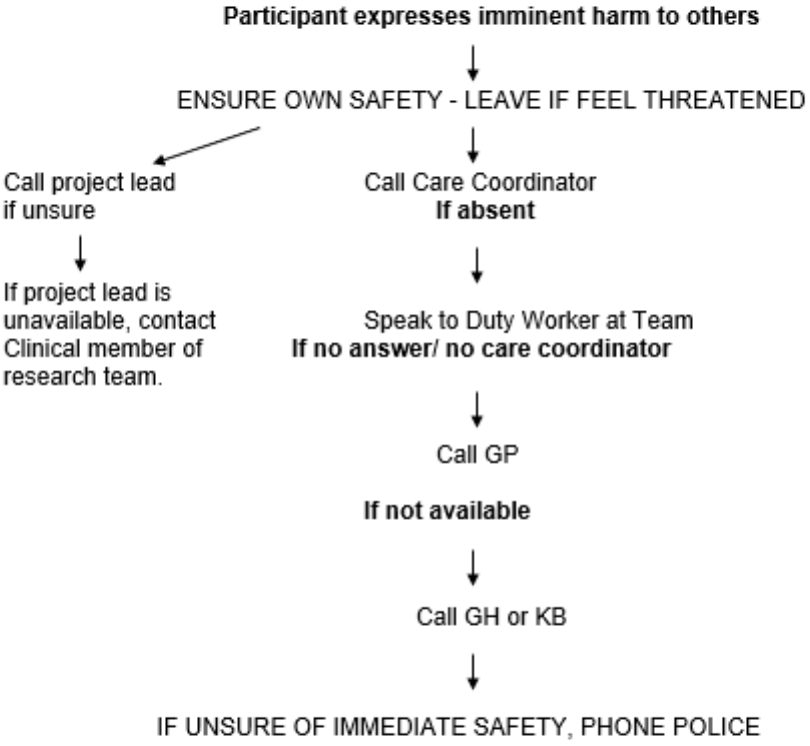
- Ideation (frequency, intensity, duration, triggers)
- Plans/intent
- Access to means to carry out plans
- Timeframe
- Protective factors
- Access to support/isolation
- Hopelessness
- Drug or alcohol use
- Command hallucinations and perceived power or control over voices

Any concerns you have should be discussed with the GH and KB as soon as is possible .

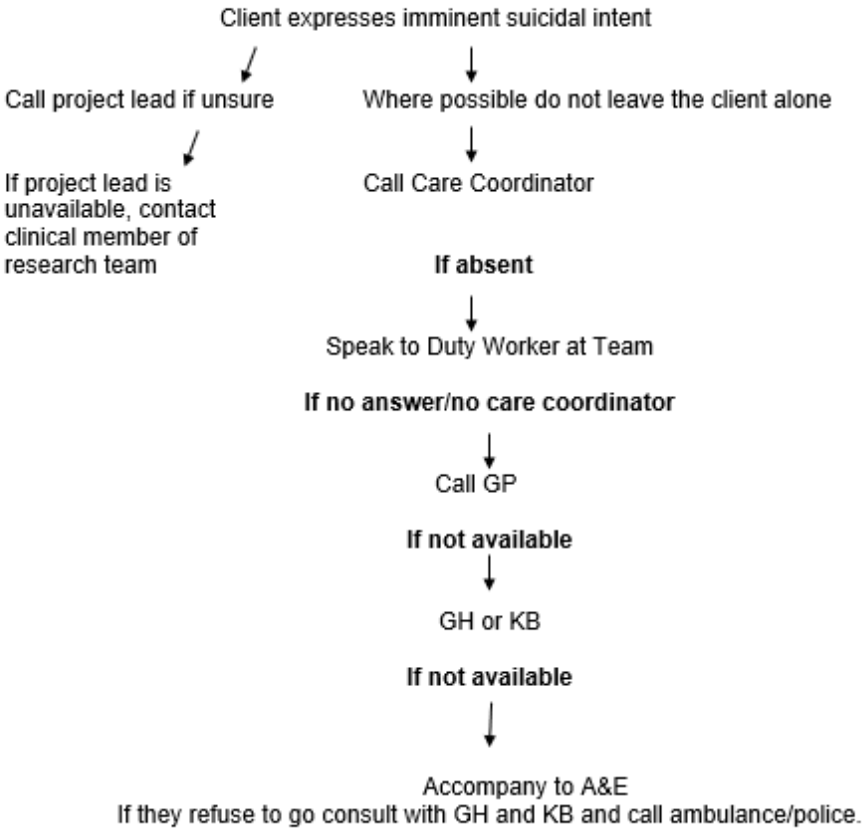
Please see **Appendix 2** for a guideline for administrative staff taking a call with a patient expressing ideas of suicide or self-harm.

## FLOWCHART OF CONTACTS FOR COMMUNITY PARTICIPANTS WITH IDENTIFIED INTENT TO HARM OTHERS

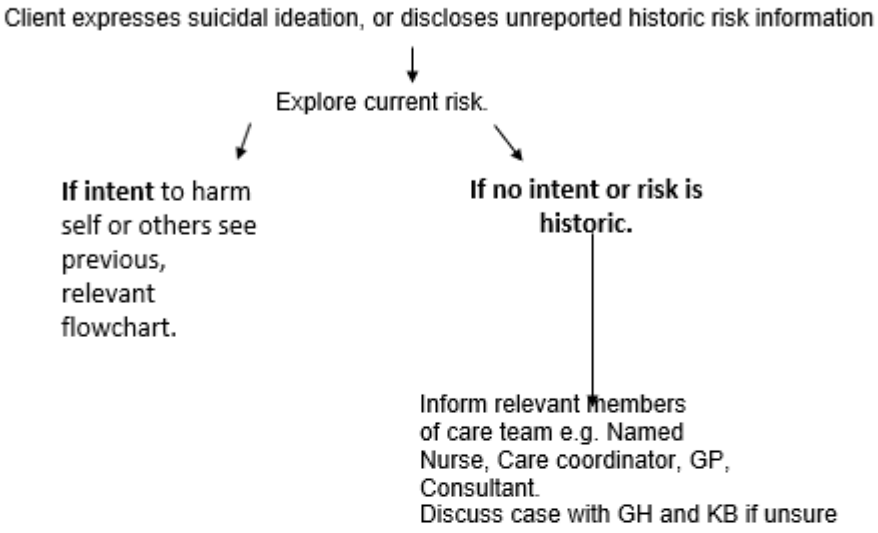
**In situations where a Child / vulnerable Adult is at risk the appropriate Safeguarding Team should be contacted.**



## FLOWCHART OF CONTACTS FOR COMMUNITY PARTICIPANTS WITH IDENTIFIED IMMINENT SUICIDAL INTENT



## FLOWCHART OF CONTACTS FOR PARTICIPANTS WHO EXPRESS SUICIDAL IDEATION OR UNREPORTED HISTORIC RISK INFORMATION



## APPENDIX 1: DISCLOSURE OF RISK DURING AN INTERVIEW

IB will follow these instructions when conducting an interview, if they identify that a patient might be at risk, or could pose a risk either to themselves or to others. The examples presented here are to be modified according to the situation.

- **Prior to commencing an interview** with a patient, the researcher will carefully explain that, although the interview is going to be confidential, if any risk is identified or disclosed during the interview, then the researcher will have to communicate these concerns to other professionals:

  *"Before we begin the interview, I just want to explain again that what we will talk about will be confidential, but if I feel that there might be a risk in what you are saying, for example to yourself or to others, I will need to pass this on to other staff members. But if I do this, I will tell you".*

- If during the interview a patient's account indicates that there might be distressed or they disclose some type of suicidality or risk factors, the researcher will reflect the distress they appear to be in and will ask if they want to continue the interview, and/or offer a brief break:

  *"You seem to be going through a hard time at the moment – do you want to continue with the interview? You know we can take a break at any time or we can stop if you want to".*

  *"It sounds like there have been a few things upsetting you recently – are you okay to continue with the interview or would you prefer to take a bit of a break for a few minutes?"*

- If during the interview the patient has disclosed a **clear riskof suicidality (**for instance, a description of plans for self-harming, or explaining that they are in possession of medication to take an overdose), at the end of the interview the research assistant will explain the need to communicate this to staff:

  *"You've spoken about wanting to take an overdose with some medication you have, and it sounds like you are quite upset about some of the things we've been talking about. What I'm going to do, like we'd talked about at the beginning, is to speak with the nurse on duty and tell them how you are feeling so that they know what's going on for you and so that they can help you"*

- If during the interview the patient's account indicates or suggests a **possibleriskof suicidality** (for example, talking about occasional fleeting feelings of wanting to die, or sometimes wishing they could just be gone to end their problems), the research assistant will try to ascertain some further information:

  > *"You've said that you sometimes wish you could just be gone and end your problems this way, have you recently had this kind of thoughts? Do you mean that you have a plan for this or are they just thoughts?"*
  >
  > *"You said that you sometimes have felt like you want to die – if you were to feel like this again, do you think you would communicate this to staff?"*

  At the end of the interview, the research assistant will talk about this with the participant:

  > *"You said that sometimes you have felt like you want to die, although not in the last week – do you mind if I just mention this to the nurse on shift, so that they are aware too?"*

  If the patient accepts, this information can be given to staff.

  If the patient declines, the researcher will contact Gillian Haddock to consult with her, on a case by case basis, the need to report this to staff.

- If any risk of suicidality has been disclosed by a patient during an interview and this **risk needs to be reported to staff**, the researcher will do so verbally to a staff nurse, Clinical Practice Lead or shift leader.

## APPENDIX 2: ADMINISTRATIVE STAFF – CRISIS RESPONSE PROCEDURE

To be used by IB when taking a telephone call or dealing face to face with a very distressed client who is expressing ideas of suicide or self-harm.

1. *"I have to take certain details before I can go any further"*
2. Name of client
3. Telephone number
4. *"Which therapist do you see?"*
5. *"When did you last see your therapist?"*

Where possible check the admin database to verify details and note address to pass on to CMHT if necessary.

6. *"Who is your care co-ordinator / psychiatrist?"*
7. *"Are you calling from your home telephone number now?"*

Note number if different from above:

8. *"Please wait a moment while I try and contact ....."* (therapist)

If therapist available, transfer call or (if presented in person) ask therapist to see client.

If therapist not available say:

9. *"Unfortunately, I am unable to get in touch with ..... at the moment. I will pass on the message that you called him/her as soon as possible. In the meantime, if you feel the need to talk to someone urgently the only thing I can suggest is that you contact your care co-ordinator or the A & E Crisis Service"*
10. Date and time of phone call/contact

Check the client has the number for their care co-ordinator. If not, check in relevant Service Directory and give them the number. Alternatively, give them the phone number of A&E Crisis Service, also available in the Service Directory.

---

Subsequent actions by IB

**Client has number for either care co-ordinator or A&E Crisis Service**
**YES/NO**

**Call made to care co-ordinator on client's behalf**
**YES/NO**

(if so) **Information given to care co-ordinator:**

**GH and KB informed** **YES/NO** **Date / Time:**

**Care co-ordinator informed** **YES /NO** **Date / Time:**

---

**Administrative staff to sign and date**

**Signed:**

**Print name:** **Date:**

## APPENDIX 3: LIST OF USEFUL CONTACTS

### Project Contact details

| | |
|---|---|
| **Isabelle Butcher** | 0161 306 0429/ 07515395182 |
| **Katherine Berry** | 0161-306-0400 |
| **Gillian Haddock** | 0161 275 8485 / 07889323071 |

### Community Support Resources For Participants:

| | |
|---|---|
| **Manchester and Salford Samaritans** | Address: 72-74 Oxford St, Manchester M1 5NH<br>Phone:0161 236 8000 |
| **Manchester Mind** | Address: Zion Community Centre, 339 Stretford Road, Hulme, Manchester, M15 4ZY<br>Phone: 0161 226 9907 |
| **Manchester Assertive Outreach** | Address: PO Box 201 Manchester M21 8WR<br>Phone: 0161 881 4799 |

### Child Protection Service Contact Details:

**If a child is at immediate risk, contact the police on 999**

**Manchester**

0161 234 5001 (24 hour service) or email mcsreply@manchester.gov.uk

**Salford** (8.30 – 4.30) 0161 603 4500
Duty (out of hours) 0161 794 8888

**Trafford**(8.30 – 4.30) 0161 912 5125
Duty (out of hours) 0161 912 2020

**Bolton**(9 - 5) 01204 337729
Duty (out of hours) 01204 337777

**Other**

- NSPCC Child Protection helpline on 0808 800 5000 (free 24 hour service)
- Childline 08001111 (a free 24 hour helpline for children)

## ACCIDENT AND EMERGENCY NUMBERS

| | |
|---|---|
| Manchester Royal Infirmary | Oxford Road, Oxford Road, Manchester, M13 9WL<br>0161 276 4147 |
| North Manchester General | Delaunays Road, Crumpsall, Manchester, M8 5RB<br>0161 624 0420 |
| Wythenshawe Hospital | A Block, Wythenshawe Hospital, Southmoor Road, Manchester M23 9LT<br>0161 291 6041 |
| Salford Royal Infirmary | Hope Building, Salford Royal, Stott Lane, Salford, M6 8HD<br>0161 789 7373 |
| Trafford General Hospital | 0161 748 4022 |
| Royal Bolton Hospital | 01204 390390 |

## CRISIS TEAM CONTACT NUMBERS:

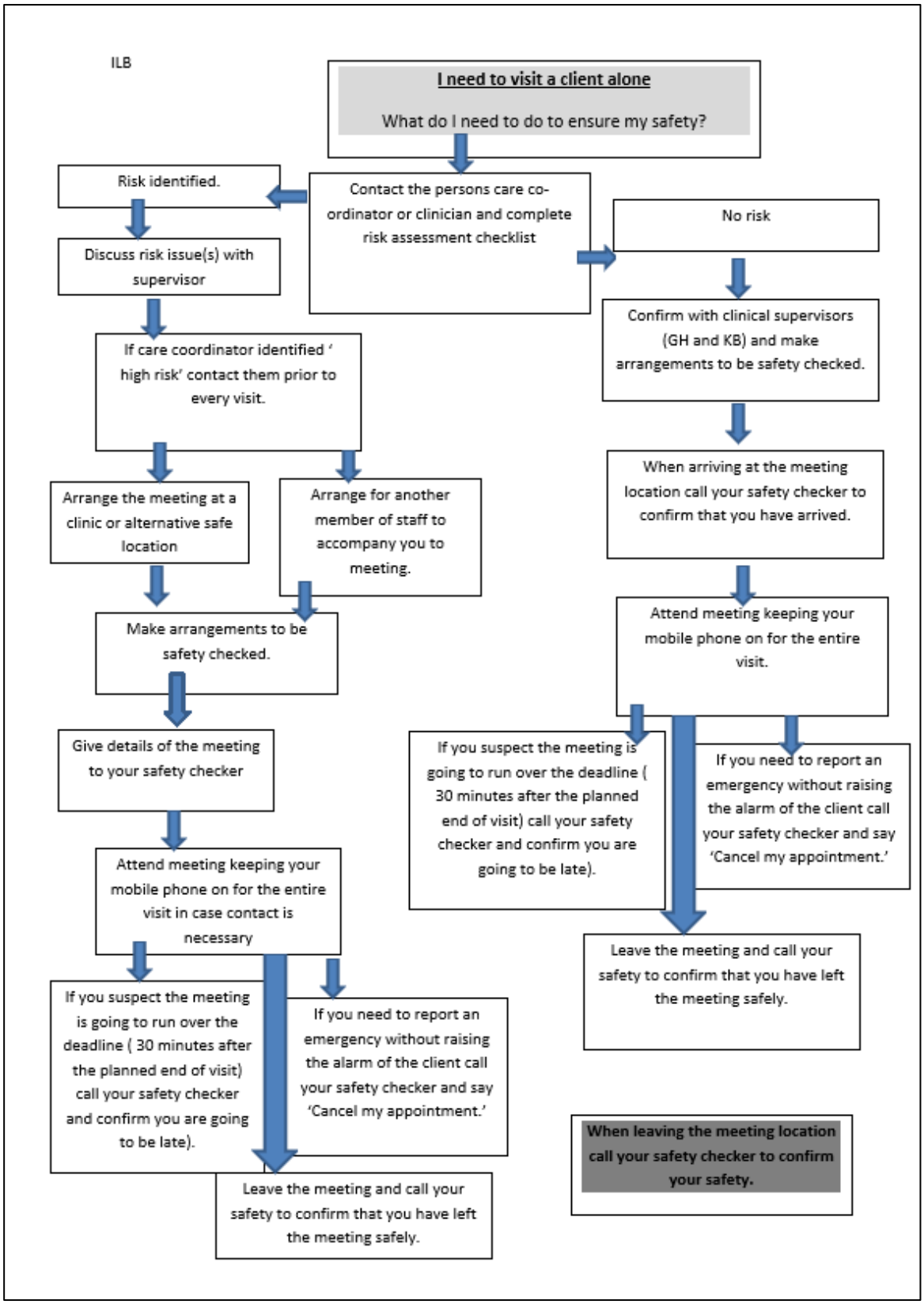
**MMHSCT**

**Crisis Line:** 0161 922 3801
This line is in operation from Mon-Thurs 5pm - 9am and from 5pm on a Friday until 9am Monday. The Crisis line is also open on Bank Holidays).

**GMW Area**

**Crisisline**: 0800 028 8000
GMW service users may contact Crisisline directly.
Crisisline operates:Monday to Friday: 5pm – 9am, Saturday, Sunday and bank holidays: open 24 hours

## Appendix 7. Risk assessment decision tree for qualitative and quantitative studies



ILB

**Risk information for**

**Risk checklist**

**To be completed as far as possible when the CC is interviewed by IB.**

Self-neglect:

- Note the time-scale; nature/severity, duration; last period of self-neglect; how remedied; mental state at the time.
- Exploitation by others (sexual, financial, residential)
- Accidental harm at home (falls, smoking, kitchen accidents)
- Self –neglect ( self-care, diet)
- Any untreated physical illness.
- Alcohol and /drug misuse ( what, how much, when, with whom)

Environmental risk

- Note: How applicable are any/all of the following to client also?
- Means of communicating with colleagues while on visits
- Safe place for researcher to safely access the building
- Risk from animals
- Risk from relative/ others
- Risks to client from re admission (boredom. Aggressive patients, medication side effects)

Self-harm

- Note: Nature; method/planning/concealment; severity, number of attempts outcome of attempts, date and most recent mental state at time, family history
- Overdose/ self-poisoning ( how when with what, outcomes)
- Self-injury ( self-cutting, swallowing items. Off buildings/in traffic)
- Plans/thoughts of self-harm
- Exacerbation of physical illness – removing dressings
- Alcohol and or drug misuse (what how much when why, with whom)
- Previous hospitalisation for self-ham (what, how much, when, why, with whom)

Harm to others

- Note Victim (), number of incidents and outcomes; dates and most recent, mental state at time (elated? Deluded? Intoxicated?)
- Arson
- Incidents involving police ( nuisance)
- Harm to children ( annoyance, physical or sexual abuse)

ILB

- Other harm (for example stalking)
- Sexual assault (including touching, exposure)
- Threats, thoughts, impulses, hallucinations, delusions which include potential harm
- Alcohol and or drug misuse ( what, how much, when, why, with whom)
- Violence to family (elated, deluded, intoxicated, organic disorder, state victim/victims)
- Weapons used, alone. Accompanied, planned/impulsive

General information

- Does this person have a warning indicator on their case notes?
- Imprisonment/Equivalent: Date and circumstances: prison, regional secure unit special hospital, secure/locked ward, formal admission
- On section 25: community supervision order: when listed and why
- On probation order? Probation officer
- Key information from other sources (friends, relatives, neighbours, GP)

Complete by _____ with _____)care coordinator/keyworker) on _____

# Appendix 8. Lone worker policy

MANCHESTER 1824
The University of Manchester

**Safety Services Guidance**

## Guidance on lone working

| | |
|---|---|
| Key word(s): | Lone working, remote working, working without supervision |
| Target audience: | Anyone working beyond earshot of another person, or otherwise unable to summon assistance; managers responsible for preparing risk assessments for lone workers. |

**Contents**



| Management cycle | Useful paragraphs |
|---|---|
| Plan | 1-7 |
| Do | 8-20 |
| Monitor | |
| Review | 21-22 |

**Introduction**

1. This Guidance should be read in conjunction with the University Arrangements Chapter 10 on Lone Working. This chapter defines lone working as; "A person working without close or direct supervision and without contact from others. It can take place both out of hours and during the normal working day." The key point is that the lone worker may not be able to summon assistance quickly in the event of an emergency.

2. This definition covers those workers who could be working in a university building or similar environment, in a community or research setting.

3. This guidance should be used to develop or revise local arrangements and systems to protect lone workers, reflecting the local needs of staff and the environments within which they work.

4. Line managers and staff who supervise students have a duty of care and responsibility to ensure that risk assessments and local procedures are developed, implemented, monitored and adhered to. Lone workers also have a responsibility to follow the procedures for their own safety.

5. In order that lone workers feel safe and secure, and perform their duties in a relatively safe environment they must be confident that there is organisational commitment and support, backed up by strong management procedures.

6. Incidents involving lone workers are very rare; however, it is important that lone workers are encouraged to report all incidents of physical and non-physical assault, using the University's incident report form. This will also ensure that any lessons learned can be fed back into risk management processes and further preventive measures can be developed. Some incidents may need to be reported to the enforcing authorities via the University Safety Office.

**Objectives**

7. This guidance is designed to provide lone workers and their line managers with practical advice to assist in preparing for a lone worker situation and meet legislative responsibilities under the Health and Safety at Work Act 1974 and the Management of Health and Safety at Work Regulations 1999. In particular, it can be used to:

    - raise staff awareness of safety issues relating to lone working

- ensure that lone working is risk-assessed in an appropriate way and that safe systems and methods of work are put in place to reduce the risk, so far as is reasonably practicable
- help staff recognise risks and provide practical advice on safety when working alone, including, where appropriate, how to use technological solutions
- identify the organisational structures, communication links, and those with responsibilities to support lone workers if they need assistance
- encourage full reporting and recording of any adverse incidents relating to lone working.

**Managing risk**

8. The University is required to implement measures to manage, control and mitigate risks to lone workers. Once an incident occurs, the level of follow-up action should be proportionate to the risk. As a minimum, the risk assessment should be reviewed. Other measures might include removing weaknesses or failures that have allowed an incident to take place (procedural, systematic or technological), and identifying further training needs of staff and students in relation to the prevention and management of verbal or physical assault, or other training such as correctly identifying and operating the relevant technology.

**Risk assessment**

9. Schools and Directorates should use their existing risk assessment arrangements to manage risks in relation to lone workers: to identify risks in relation to lone working to:

    - assess the risks to lone workers
    - implement measures to reduce the risks to lone workers, including appropriate information, instruction, training and supervision to minimise these risks
    - evaluate the control measures and ensure that risks to lone workers are appropriately managed.

10. A suitable and sufficient risk assessment for lone working should be based on the University's Lone Working Chapter 10, and consider the following factors, together with any specific risks associated with the work being undertaken:

    - Who is going to be working alone?
    - Where will they be working?
    - Are they competent to carry out the work?

- Does the workplace present a special risk to the lone worker in addition to risks associated with the work itself?
- Is there a safe means of access and egress from the work location?
- Can all plant, substances and materials involved in the work be safely handled by one person? (Consider whether the work involves lifting objects too large or awkward for one person or whether more than one person is needed to operate essential controls for the safe running of equipment).
- Are some individuals more at risk than others when working alone?
- Are young persons especially at risk if they work alone?
- Is the person medically fit and suitable to work alone?
- Are the fire precautions for the building fully operational and understood by the lone worker?
- Are all fire precautions available if the work takes place out-of-hours?
- Is the lone worker fully familiar with how to respond in an emergency? E.g. do they know how to activate the fire alarm, phone numbers to call, who to contact?
- Are there effective communication links in the area they will be working at the time they are working?
- Is the level of supervision at other times sufficient to ensure that any problems are identified and dealt with?
- Is there a risk of accidental release of material which could cause acute injury or require extensive decontamination? e.g. gas release, explosion, spillage (Work such as this should not take place unaccompanied)
- Are any other precautions necessary?

**Example risk assessments**

11. To assist with the production of risk assessments, the following lone worker example risk assessments and checklists have been produced:

    - Community based lone worker risk assessment
    - Community based lone worker checklist
    - On-campus lone worker in an office setting risk assessment
    - On-campus lone worker in an office setting checklist

    The above documents can be accessed at
    http://www.healthandsafety.manchester.ac.uk/toolkits/lone_working/example_ras/

**Dynamic risk assessment**

12. There may be a requirement for risk assessments to be carried out by the lone worker on a dynamic basis, e.g. in response to frequent changes in circumstances. A generic risk assessment will need to explain the circumstances under which dynamic risk assessments take place, and address the competency and training needs of the individuals carrying them out.

13. See Guidance on generic and dynamic risk assessment

**Lone worker movements**

14. The specific controls necessary must be proportionate to the risk and will be informed by the risk assessment process but could include:

    - details of location and anticipated time of return left with a manager or colleague
    - details of vehicles used by lone workers left with a manager or colleague, for example, registration number, make, model and colour
    - regular contact with a manager or relevant colleague, particularly if they are delayed or have to cancel an appointment
    - panic buttons in isolated offices or consultation rooms
    - mobile phone solutions with text, panic, GPS, 'man down' and smartphone solutions.

15. Where there is genuine concern, for example, as a result of a lone worker failing to attend a visit or an arranged meeting within an agreed time, or to make contact as agreed, the manager should use the information provided in a log or Outlook diary to locate them and ascertain whether they turned up for previous appointments that day. Depending on the circumstances and whether contact through normal means (mobile phone) can be made, the manager or colleague should involve University Security if necessary (see escalation process para 22).

16. If it is thought that the lone worker may be at risk, it is important that matters are dealt with quickly, after considering all the available facts. Security will advise if police involvement is needed, and will need full access to information held and personnel who may hold it, if that information might help trace the lone worker and provide a fuller assessment of any risks they may be facing.

17. It is important that contact arrangements, once in place, are adhered to. Many such procedures fail simply because staff forget to make the necessary call when

they finish their shift. The result is unnecessary escalation and expense, which undermines the integrity of the process.

**The buddy system**

18. It is essential that lone workers keep in contact with colleagues and ensure that they make another colleague aware of their movements. This can be done by implementing management procedures such as the 'buddy system'.

19. To operate the buddy system, managers must ensure that a lone worker nominates a buddy. This is a person who is their nominated contact for the period in which they will be working alone. The nominated buddy will:

    - be fully aware of the movements of the lone worker
    - have all necessary contact details for the lone worker
    - attempt to contact the lone worker if they do not contact the buddy as agreed
    - follow the agreed local escalation procedures for alerting their senior manager and Security if the lone worker cannot be contacted or if they fail to contact their buddy within agreed and reasonable timescales.

20. The buddy must understand their role and what the procedures and requirements are. Contingency arrangements should be in place for someone else to take over the role of the buddy in case the nominated person is unavailable, for example if the lone working situation extends past the end of the nominated person's normal working day or shift, if the shift varies, or if the nominated person is away on annual leave or off sick.

**Escalation process**

21. It is important for School and Directorates to have a risk-based escalation process, outlining who should be notified if a lone worker cannot be contacted or if they fail to contact the relevant individual within agreed or reasonable timescales. The escalation process should provide identification of contact points at appropriate stages which may include, line manager, senior manager, security and, ultimately, the police. Any individual nominated in an escalation process should be fully aware of their role and responsibilities.

**Researcher safety**

22. Researcher safety is well documented by the Social Research Association (SRA), in their code of practice.

23. The University of Manchester has issued Guidance on conducting interviews and research in fieldwork. Safety Services Lone Working toolkit contains useful checklists.

**Further sources of guidance**

Suzy Lamplugh Trust

For information on lone worker alarms and alerting devices:
http://www.suzylamplugh.org/Pages/Category/lone-worker-devices

For safety apps
http://www.suzylamplugh.org/Pages/Category/app-directory

For advice on safe travelling alone
http://www.suzylamplugh.org/Pages/FAQs/Category/personal-safety

HSE Publication on Lone Working

Royal College of Nursing Guide to Lone Working

| Document control box | |
|---|---|
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## Appendix 9a. Integrated training protocol for positive and negative syndrome scale, psychotic symptoms rating scales and the Calgary depression scale for schizophrenia

# Integrated Protocol for PANSS, PSYRATS, CDSS.

### Incorporating training procedure, guidelines for administration rating scales and anchor points

**Description of the Assessment Measures**

**Positive and Negative Syndrome Schedule (PANSS) (Kay et al., 1987).**

A seven-point rating instrument evaluating positive, negative and other symptom dimensions on the basis of a formal semi-structured clinical interview and other informational sources. -

**Psychotic Symptom Rating Scale (PSYRATS) (Haddock et al., 1999).**

The PSYRATS consists of two scales designed to rate auditory hallucinations and delusions. A five point ordinal scale is used to rate symptom scores. The PSYRATS will be used as an adjunct to the PANSS in order to gain further insight into auditory hallucinations and delusional symptoms. *(Appendix 1)*

**Calgary Depression Scale (CDS) (Addington et al., 1990).**

A four-point rating scale assessing depressive symptoms separate from positive, negative and other symptoms in people with schizophrenia. The PANSS has just one depression item therefore the CDS can be used as an additional measure of depression. *Guidelines for administering the CDS are provided in Appendix 2.*

See *Appendix 6* for scoring sheets and notes during interviews.

**TRAINING PROCEDURE**

- Read/become familiar with the protocol.
- Read the PANSS training manual, PANSS rating scales and PANSS questions very thoroughly. Ensure you understand all words and concepts contained within the PANSS e.g. different types of delusions and hallucinations.
- For further explanation and clarification of symptoms, and suggestions for further interview questions, read the modified KGV[1], PSE[2], mental state chapter[3], thought, language and content document[4] and Sims' book[5].
- Watch PANSS role play DVDs and try to rate them.
- Self-directed interview practice i.e. at least 3 role plays with fellow assistants. Audiotape interviews and obtain feedback from your supervisor, Dr Katherine Berry or Professor Gillian Haddock.
- Observe trained interviewers administer the PANSS. Attempt to rate the interview in discussion with expert interviewers. Aim to observe at least 2 or 3 interviews.
- Administer PANSS interview when trained interviewers are present. Audiotape interviews and obtain feedback from your supervisor, Dr Katherine Berry or Professor Gillian Haddock.
- Rate standardised PANSS video interviews to required gold standard

[1] http://www.hearingvoices.org.uk/pdf/KGVM_Symptom_Scale_7.pdf

[2] http://bjp.rcpsych.org/content/bjprcpsych/150/2/201.full.pdf

3 mental state chapter?

4 thought, language and content document?

[5]Sims, A. (2011). *Is Faith Delusion? Why Religion is Good For Your Health*. London: Continuum.

**GUIDELINES FOR ADMINISTERING THE PANSS AND PSYRATS**

**PANSS**

- Remember the PANSS ratings are based on the **past week.**
- When conducting a PANSS interview, make detailed notes. This acts as a record of evidence on which the ratings are based, allowing you or others to check the accuracy of ratings and maintain high levels of reliability in scoring the PANSS.
- Ask as many probing questions as is necessary to obtain a detailed elaboration of all items on the PANSS, e.g. establish presence of symptoms, severity, frequency, disruptive impact on person, person's beliefs /explanations of symptoms, etc.
- In rating PANSS items use a cumulative approach to scoring (i.e. to score all 6 elements of 3, 4 and 5 are needed.
- In rating PANSS items use a holistic perspective in deciding which rating best characterizes the patients' functioning (i.e. not every single element of the rating need be present).
- Remember the general definitions of ratings:
    - *A rating of **1** indicates the item (e.g. depression) is absent.*
    - *A rating of **2** indicates questionable, subtle or suspected pathology and / or the extreme end of the normal range.*
    - *A rating of **3** (mild) indicates that a symptom is present but is not pronounced and has little impact on functioning.*
    - *A rating of **4** (moderate) indicates a serious problem is present; however, it only occurs occasionally or impacts on functioning only to a modest extent.*
    - *A rating of **5** (moderate severe) indicates marked presence of symptoms which distinctly impact on functioning; but they are not all consuming or can be contained.*

- *A rating of **6** (severe) indicates major pathology that is present very frequently, is highly disruptive to functioning, and often requires direct supervision.*

- *A rating of **7** (extreme) refers to the most serious level of psychopathology, where symptoms drastically interfere in most or all of life's functions, usually requiring close supervision and assistance in many areas.*

- If you are unsure of how to rate an item for a specific case, bring it up in reliability meetings or supervision to discuss.

- In ambiguous cases where criteria are not fully met for any rating, rate conservatively.

- In cases where someone experienced a symptom as a one-off in the week, but has been fine otherwise, the rating should reflect this (as in the general descriptions above). We therefore do not make ratings solely on the 'peak' of the week (i.e. worst case scenario), nor on the 'mode' (i.e. what they are like most of the time). Rather, we rate on what they are generally like, taking into account any additional concerns that are reported. For instance, on P6, someone who was very guarded for a day or two, could rate as a 3, even if they are not guarded in interview. If at the time, there was evidence of persecutory delusions or their behaviour was significantly affected, they may rate as a 4. They cannot reach a 5 however, as this would not distinguish them from someone whose beliefs and/or impact of these beliefs, have prevailed for a longer period of time.

- Causality is not taken into account with the PANSS. i.e. hallucinations related to coming off of alcohol are still rated. Depression is still rated if it is in relation to an event that would understandably make someone sad.

- If the individual does not answer directly then use assurances and remind them that anything they do tell you is confidential, use reflective statements, change the topic and return to it later and don't make assumptions, rate conservatively.

**PANSS Items**

- Some items on the PANSS do not require any direct questions, ratings being based on your objective observation and overall impression of the person's thinking and behaviour during the interview. You should rate these items at the end of the interview. Items whose ratings are mainly based on the interviewer's observation / overall impression of the person throughout the interview are:

  ***P2*** *conceptual disorganization*
  ***P4*** *excitement*
  ***P7*** *hostility*
  ***N1*** *blunted affect*
  ***N3*** *poor rapport*
  ***N6*** *lack of spontaneity and flow of conversation*
  ***N7*** *stereotyped thinking*
  ***G4*** *tension*
  ***G5*** *mannerisms and posturing*
  ***G7*** *motor retardation*
  ***G8*** *uncooperativeness*
  ***G9*** *unusual thought content*
  ***G11*** *poor attention*
  ***G13*** *disturbance of volition*
  ***G14*** *poor impulse control*
  ***G15*** *preoccupation*

- The remaining items' ratings are mainly based on answers to interview questions, but the person's behaviour should also be taken into account (e.g. if a person is responding to hallucinations during the interview, e.g. if person says they are very depressed all the time but throughout the interview appear cheerful):

  ***P1*** *delusions*
  ***P3*** *hallucinations*
  ***P5*** *grandiosity*
  ***P6*** *suspiciousness I persecution*
  ***N2*** *emotional withdrawal*
  ***N4*** *passive / apathetic social withdrawal*

***N5*** *difficulty in abstract thinking*

***G1*** *somatic concern*

***G2*** *anxiety*

***G3*** *guilt feelings*

***G6*** *depression*

***G10*** *disorientation*

***G12*** *lack of judgement and insight*

***G16*** *active social avoidance*

- For items relating to social functioning, N2, N4 and G16, it may be necessary to ask those who work with the individual for their opinion, especially if it appears that the individual has no opportunity for social contact so can not report how they might otherwise feel.

- When rating the PANSS, any information that you have previously obtained from medical records / care coordinators / main carers can be taken into account where specified. Remember that any additional information used must be based on the same seven-day period asked about during interview with the client. However, the client's report is given the most weight when rating the items. (i.e., if the medical records state that a client experiences auditory hallucinations but the client flatly denies hearing voices, then the client must be rated according to what they have said).

- In a similar way, baseline PANSS information can be used at 12 and 24 months to provide questions to prompt clients

**Positive Item Subscale**

**P1, P3 and PSYRATS**

**PSYRATS**

- The PSYRATS is rated only when delusions and hallucinations have been scored as 3 or above on PANSS.
- The delusions PSYRATS is only based on the past week, except for when rating conviction of beliefs when you should ask about conviction at the time of interview.
- The hallucinations PSYRATS is also only based on the past week, except when:

  ***(a)*** *asking about beliefs regarding the cause of voices — rate the patient's response based on what they believe at the time of interview*

  ***(b)*** *loudness of voice should be rated according to the loudness of voices at the time of interview or the last time the patient experienced them.*

**PSYRATS Items**

**Delusions:**

*(1) Amount of Preoccupation*
*(2) Duration of Preoccupation*
*(3) Conviction*
*(4) Amount of Distress*
*(5) Intensity of Distress*
*(6) Disruption*

**Hallucinations:**

*(1) Frequency*
*(2) Duration*
*(3) Location*
*(4) Loudness*
*(5) Beliefs about origin of voices*

*(6) Amount of negative content of voices*

*(7) Degree of negative content*

*(8) Amount of distress*

*(9) Intensity of distress*

*(10) Disruption*

*(11) Control*

- When rating PSYRATS, rate all delusions as a composite, using the highest score. Likewise, rate all hallucinations as a composite, using the highest score.

- 'Disruption to life' — rate as an objective observer, not just on how much the person believes their beliefs / voices are affecting their life. Attempt to split how much disruption is caused by the person's beliefs vs. how much is caused by the person's voices — In doing this it may help to imagine that their voices were to disappear, then think how much their beliefs alone would disrupt their life.

- When rating 'loudness' use your own or their own voice as a comparison.

- When rating 'degree of negative content of voices' you must ask about what the voices are actually saying.

- When person has more than one delusion, rate all delusions on the PSYRATS and use the highest score. E.g. if they had an 80% conviction in one belief but only a 40% conviction in another belief, they should be rated a 3 on PSYRATS 'conviction'.

- When person has more than more voice, rate them all on PSYRATS and use the highest score, e.g. someone who hears a pleasant voice once a day and an unpleasant voice only once a week which tells them to harm others should be rated as 2 on frequency and 4 on degree of negative content.

- When asking about intensity of distress, you need to distinguish whether it is the actual voice or the belief about the voice that causes the distress. A good question to determine this is 'if you were in bed at night and you couldn't hear the voice but you were thinking about it, would this cause distress?'

It is suggested that the PSYRATS questions be incorporated into the PANSS interview, since the answers to PSYRATS questions for delusions and auditory hallucinations can be helpful in rating these items on PANSS (e.g. the PSYRATS indicates frequency, amount of distress, delusional interpretation, life disruption, therefore higher scores on these all support a higher rating on the PANSS).

**P1 Delusions**

- If person has not thought about delusion for the past week but they still have the delusion, this still counts as a delusion and they should therefore be rated on PANSS delusions and asked the PSYRATS questions.

- Generally, we will use >50% conviction in belief as criteria for a 'delusion'. This definition does not need to apply, however, to 'vague', 'poorly formed' or 'unstable' delusions. Here, the term 'delusion' can be read more as 'notion' or 'belief' and refers to ideas with <50% conviction. A rating of 4 on delusions requires at least one delusion with >50% conviction, maybe several others with <50% conviction. 3 or more delusions with >50% conviction will qualify for a rating of 5 on delusions.

- In cases where someone reports believing something earlier in the week but not believing it now (e.g. "On Saturday I thought people were out to get me but I know now it was just in my head"), they can still rate despite holding no current conviction, but the rating will be less than that of someone who still holds the belief. As the delusion is loosely formed (in that it didn't persist), they should get a 3 and at most a 4 (depending on the number of delusions).

- Ensure that people rated on the following items are correspondingly rated on delusions where applicable:

  *P3* *hallucinations — if scores 4 or above, may have delusional interpretation / elaboration.*

  *P5* *grandiosity — if scores 4 may have poorly formed grandiose delusions; if scores 5 or above, will have grandiose delusions.*

  *P6* *suspiciousness / persecution — if scores 4 may have loosely formed persecutory delusions; if scores 5 may have clear-cut persecutory delusions; if scores 6 or 7, will have persecutory delusions*

*G1* *somatic concern — if scores 5, may have somatic delusions; if scores 6 or 7, will have somatic delusions.*

*G3* *guilt — if scores 5, may have delusions of guilt; if scores 6 or 7, will have delusions of guilt.*

*G6* *depression — if scores 7, may have depressive or nihilistic delusions.*

*G9* *unusual though content — scoring 4 or above on this scale can indicate the 'bizarreness' (e.g. delusion of being an alien ('bizarre') vs. delusion of being followed by neighbours) of any delusions held by the person. If a client has scored a 3 or above on delusions then the client must also score at least a 3 on unusual thought content.*

*G12* *lack of judgement and insight—if scores 4, 5 or 6, may have delusions (e.g. delusion that has no symptoms, e.g. delusion that symptoms are caused by medication); if scores 7, will have delusions.*

- When rating delusions take all aspects into account, e.g. frequency, quantity, conviction, and disruption to life.

- Criteria for scoring a 3 on delusions include one or two delusions/beliefs/notions which are vague, uncrystallized, and not tenaciously held (i.e. conviction of less than 50%). Delusions that do not interfere with thinking social relations of behaviour.

- Criteria for scoring 4 on delusions include at least one delusion with a conviction >50%. Either a kaleidoscopic array of poorly formed, unstable delusions (i.e. beliefs/notions more than one or two which is criteria for 3 rating) or a few well-formed delusions (i.e. 1-2 delusions with >50% conviction not more than 3 which would score a 5) that occasionally interfere with thinking, social relations, or behaviour (i.e. delusions do not disrupt life significantly, but may e.g. interfere with concentration or make person nervous about meeting new people).

- Criteria for scoring 5 on delusions include 3 or more delusions with a conviction of >50% (e.g. someone who has persecutory delusions concerning his father, mother and sister would not count as having 3 delusions; someone with persecutory delusions, thought interference and thought broadcast would count as having 3 delusions). Numerous (i.e. 3 or more) well-formed delusions that are tenaciously held (conviction >50% for 3 or more delusions) and occasionally interfere with thinking, social relations or behaviour (i.e. to same degree as with 4 rating).

- Criteria for scoring a 6 on delusions include as many delusions as for a 5 rating (3 or more). A stable set of delusions which are crystallized, possibly systematized, tenaciously held (i.e. over 50% conviction), and clearly interfere with thinking, social relations and behaviour (i.e. this is a criteria to separate a 5 from a 6 rating, e.g. delusions may stop person going out or prevent them from talking to people).

- Criteria for scoring a 7 on delusions include a stable set of delusions (as for a 5 rating), which are either highly systemized or very numerous, and which dominate major facets of the patient's life. This frequently results in inappropriate and irresponsible action, which may even impact on the safety of the patient or others (i.e. very significant disruption to life).

**NB clarification of delusions of misinterpretation and delusions of reference –** delusions of misinterpretation is when the client sees special meanings/messages in things that could be meant for anyone, whereas delusions of reference are when the clients sees special meaning in things that are meant solely for him/her. Also when rating this item, take into account delusions of grandiosity and suspiciousness (i.e. a client who thinks that God is sending him messages would score on delusions of grandiosity as well as reference

**NB clarification of delusions of thought interference (inc. withdrawal, block, echo, broadcast etc).** These items (thought echo, thought withdrawal, though block etc) are not 'delusions' per se; they can only be classed as delusions and therefore contribute to a P1 rating if the participant holds a delusional belief about their cause or origin. When questioning, the researcher should focus on eliciting beliefs regarding to cause/origin of these phenomena, rather than simply establishing that the participant experiences them or not.

**P2 Conceptual disorganization**

Think about how relevant thoughts are to questions asked, if they are relevant they can't score higher than a 3 regardless of how long winded their answers might be.

Be aware that rating 4 and above on P4 excitement may affect P2 conceptual disorganization. Likewise some scores on the N scale may relate to P2.

**P3 Hallucinations**

- Voices and delusions are often intertwined – should rate them in their own right (i.e. separate voice and delusion when rating, e.g. voice may affect thinking or emotions but delusion about the voice may have no affect on person) but still take into account beliefs about voices when rating hallucinations on PANSS (i.e. degree that beliefs about voices affect person).

- Because people often have a delusional interpretation of voices, need to rate this on the delusion scale, e.g. when asking the PSYRATS question about where they think the voice is coming from (internal or external), someone who is convinced the voice they are hearing is from an alien but has no other delusions should still be rated on the delusion scale for this delusional interpretation of their voice (and rated on PSYRATS delusions for this).

- If a score of 4 is given for hallucinatory behaviour, then the client must score at least a 3 on delusions (except when the client is 100% certain that the hallucination/s is/are a symptom of illness.

- Should not score 4 on delusions if only have '100% convinced external cause for voices' on PSYRATS and no further elaboration e.g. must be evidence that 'external cause' is a specific person. Need to push for elaboration or at least exclude an internal cause to clarify whether it is a delusional belief about the voices.

- When rating hallucinations need to take into account all aspects, e.g. frequency, duration, distress caused, disruption to life (and persistence of this disruption), whether hallucinations in more than one sensory modality, whether they shout back at voice, whether they have a delusional interpretation of the voice, etc, etc. So someone who says they talk back to the voices should not score a 5 on hallucinations for this fact alone (also need to clarify the nature of verbal response, as just talking back to voices is not an indication of severity of hallucinations).

- True vs. pseudo hallucinations — convention of how to define a pseudo hallucination is that it is one that sounds like it is coming from inside the person's head. However, we do not need to differentiate true and pseudo hallucinations as both are rated as 'hallucinations' on the PANSS. Do not rate vague / abnormal perceptions as 'hallucinations' though e.g. flashes of light, seeing shadows out of the corner of eye,

hypnogogic / hypnopogic experiences — these should not be rated above a 3 on PANSS.

- Less than once a week will be used to define 'Infrequent' i.e. score 3 or less if less than once a week – but if occurred in past week then can rate as 4 because PANSS is based on the past week (even though may only occur every few weeks usually).

- Take into account both 'frequency' and 'duration' of hallucinations, and also the persistence with which the person is affected by it e.g. person may only have a voice for a few seconds once a week, but this may cause distress and life disruption which continues all week.

- Don't count hypnogogic / hypnopogic experiences as hallucinations (e.g. hearing a voice only when falling asleep) — only rate these as 3 or less on PANSS.

- Criteria for rating a 3 on hallucinations include one or two clearly formed but infrequent hallucinations (i.e. less than once a week), or else a number of vague, abnormal perception (e.g. sees movements out of corner of eye, hears bangs in the house, or only hears voice when falling asleep) which do not result in distortions of thinking or behaviour (i.e. no delusional interpretation, does not disrupt person's life).

- Criteria for rating 4 on PANSS includes frequency of at least once a week ('hallucinations occur frequently, but not continuously') and the patient's thinking and behaviour are affected only to a minor extent (e.g. interferes with watching TV, causes some distress)

- Criteria for rating a 5 on PANSS include hallucinations are frequent (i.e. at least once a week, the same as a 4 rating), may involve more than one sensory modality (e.g. visual), and tend to distort thinking and/or disrupt behaviour (i.e. more impact on person's life, e.g. stops person doing things, causes considerable distress and more persistent disruption than a 4 rating). The PSYRATS rating on life disruption can be taken into account — a score of 1 may indicate a 4 rating on PANSS, whereas a score of 2 is more likely to indicate a 5 rating on PANSS. Patient may have a delusional interpretation of these experiences (4 ratings can also have a delusional interpretation; a 5 rating is more likely to have delusional elaboration of hallucinations) and respond to them emotionally and, on occasion, verbally as well (e.g. shouting and swearing at voices —4 ratings will also include cases who verbally respond to voices).

- Criteria for rating 6 on PANSS include frequency of hallucinations to be almost continuously (i.e. a 3 or 4 on PSYRATS frequency question), causing major disruption of thinking and behaviour (i.e. more than a 5 rating). Patient treats these as real perceptions (i.e. must have delusional interpretation of hallucinations), and functioning is impeded by frequent emotional and verbal responses to them (e.g. person is so distressed by voices they cannot leave the house). I.e. if hallucinations have no or very little affect on person, do not rate as 6; rate as 5 (e.g. if more than one sensory modality) or 4.

- Criteria for rating a 7 on PANSS includes patient is almost totally preoccupied with hallucinations, which virtually dominate thinking and behaviour (i.e. even more severe and persistent disruption to life than a 5 rating). Hallucinations are provided a rigid delusional interpretation (i.e. high conviction in delusion) and provoke verbal and behavioural responses, including obedience to command hallucinations (this criteria should only be adhered to if commands are serious e.g. telling person to kill others rather than telling person to make a cup of tea. Don't rate as 7 for this reason alone: hallucinations should also be severe on other criteria such as frequency, life disruption and delusional interpretation).

- Differentiating thought insertion from hallucinations — sometimes need to probe re beliefs about origin. E.g. of thought insertion: person hears own voice / thoughts in head, but believes they are not his thoughts, someone/thing else has put them there. E.g. of hallucination: 'I can hear the voice of the devil' vs. thought insertion: 'The devil is putting thoughts in my head'.

**P4 Excitement**

Look out for hyperactivity as reflected by increased motor behaviour, heightened response to stimuli, hypervigilance or excessive mood fluctuations within the interview. Clients who score highly on this scale may be difficult to interview due to their excitable behaviour. For example, they might struggle to remain still for the duration of the interview or perhaps go off on tangents about topics which they appear to find more stimulating. Clients who score highly on this scale may therefore also score on G11 (poor attention), N3 (poor rapport) and P2 (conceptual disorganisation).

**P5 Grandiosity**

Scores:

3. Here the participant may have a boastful or expansive attitude, but without a delusional quality.

4. The participant feels unrealistically superior to others, with poorly formed delusions (less than 50%) about special status or abilities, which are not acted upon.

5. The participant has clear-cut delusions (more than 50%) about special abilities/status/power which influence attitude, but do not impact on behaviour

6. The participant has clear-cut (more than 50%) delusions involving more than one parameter (wealth, knowledge, fame) which significantly influence interactions

7. Thinking, behaviour and interactions are dominated by multiple delusions of grandeur, which may take on a bizarre quality.

Examples for P5 ratings:

The participant believed that he was in the top 1% of the population for intelligence. He brought this up spontaneously during the interview, and mentioned it on more than one occasion. It was decided that whilst this was more boastful than average, it was not necessarily delusional, as the participant appeared quite intelligent during the interview. Rated **3**.

The individual reported that he was more intelligent and had more to offer the world. He had a particularly sensitive mind and was able to see things before they happened. It was agreed that although boastful this wasn't necessarily grandiose (the group decided that by seeing things the individual was not referring to clairvoyance more a better understanding of how things might pan out). However, during delusions the client mentioned that he thinks people use his mind to think through battle strategies and to come to terms with their own self worth (Conviction less than 50%). Rated **4.**

The participant had a dream about a man he knew, and then roughly a week later saw this man on the bus. A few weeks after this he found out that the man had been murdered. The participant was 100% sure this dream was a premonition and that it was a small glimpse of

the future, and of what might happen. He believed that having this ability made him superior to others, rather than a general skill possessed by everyone. He reported the murder could have been something to do with his dream, but was unsure. Participant was rated as a 5 due to the delusional, and unrealistic quality of his grandiose belief, but minimal impact upon behaviour. Rated **5.**

**P6 Suspiciousness/Persecution**

*Scores:*

3. A guarded or distrustful attitude, in the absence of delusions of persecution and with minimal effect on thoughts, interactions and behaviour.

4. Distrustfulness impacts on behaviour, but without evidence of persecutory delusions. Alternatively, there may be indication of persecutory delusions (not clear-cut, less than 50%) which do not affect attitude and relations.

5. Marked distrustfulness leading to major interpersonal disruption. Alternatively there may be clear-cut (more than 50%) persecutory delusions with limited impact on interpersonal relations/behaviour.

6. Clear-cut delusions of persecution (conviction more than 50%) with significant interference to interpersonal relations.

7. Thinking, interpersonal relations, and behaviour are dominated by systems of persecutory delusions.

Examples for P6 ratings:

The participant reported that when people were having a conversation at work she thought that they may be talking about her. At the time she believed this 5-10% but afterwards thought that this wasn't the case. Other than this, the participant was not suspicious about anything else and trusts most people. It was agreed that this was within "normal limits". Rated **1.**

Individual felt anxious and aroused when he is in public places i.e. the pub. He described it happening when he sees someone he thinks is laughing at him/judging him and he gets 'evil

thoughts' to hurt them. He then feels anxious about what he might do to them, often resulting in him leaving. Other behaviours included waiting for a fairly empty double decker bus so he can sit upstairs and avoid looking at people. These beliefs were considered not necessarily delusional, and so was Rated **4**.

Individual was not suspicious about the general public and was open in the interview but was suspicious about his voices harming him. He also felt that he was being monitored by people who had been involved in his case when he was younger. He felt they were monitoring him for negative reasons. Conviction here was < 50%. Due to some indication of persecutory delusions, but low conviction, and lack of interference with attitude/relationships he was rated **4**.

The participant experiences visual and auditory hallucinations, where she sees rats and the image of people she knows who have died. She also hears voices telling her that she is evil and she is the devil. She believes she has "bad blood" and that she sees the rats and dead people and hears the voices as punishment. Her conviction in this belief is 100%. Other than this, she trusts most people that she knows and is not suspicious of anyone or anything else. It was decided she should score a **5** because she had clear-cut persecutory delusions but they do not significantly interfere with interpersonal relationships (which would rate 6).

**Negative Item Subscale**

**N1 Blunted Affect**

2. Emotional range slightly subdued or reserved but displays appropriate facial expressions

3. Emotional range overall is diminished, subdued or reserved, without many spontaneous and appropriate emotional responses.

4. Emotional range is noticeably diminished: individual does not show emotion, smile or react to distressing topics except infrequently. Displays of emotion or gestures are usually followed by a return to flattened affect

5. Emotional range very diminished; individual doesn't show emotion, smile or react to distressing topics except minimally, few gestures, facial expression doesn't change very often.

6. Very little emotional range or expression. Mechanical in speech and gestures most of the time. Unchanging facial expression.

7. Virtually no emotional range or expressiveness, stiff movements.

**N2 Emotional withdrawal**

Refers to engagement in social relationships on an emotional level. Overlaps with N4 as it is the 'emotional' component of the 'behavioural' withdrawal seen in N4.

2. Expresses little interest in other people or social activity. Is 'shy' and reserved. Can come across as rather aloof from others.

3. Little apparent interest in social interaction. May convey/express being 'bored' by company or lacking warmth. Prefers to be left alone but can 'warm up' if the topic interests him/her.

4. Emotionally withdrawn, disinterested in surroundings or events. Little warmth in response to the social efforts of other people.

5. Shows no interest in others and resists social advances by his air of aloofness and disinterest. Can be briefly involved but mainly for practical issues. Needs prompting to keep up personal care. Another patient who goes regularly to a local day centre of his own volition and while there joins with others in a range of activity, nevertheless shows the same 'flat' emotional response to both sad and happy events. For example, on receiving a gift from his sister, he showed no signs of having appreciated her generosity, taking the package from her without a flicker of emotion. She mildly rebuked him '…well is that all I get?' to which he replied 'I suppose so….' This is typical of his response and she was neither surprised nor offended. Rate 5

6. No interest expressed in surroundings or other people, apparently uncaring about appearance or aspects of his behaviour that might be considered rude or slovenly by others. Requires frequent prompting and encouragement to achieve even quite minimal emotional/interpersonal response.

7. Withdrawn, uncommunicative, neglectful of needs and lack of emotional commitment. Shows no emotion even to circumstances that would provoke strong emotion in others. E.g. Patient is generally self-absorbed and disinterested in others to the extent that when another patient choked on his dinner he showed no emotion or interest whatsoever, merely staring at the incident and its goings on. Rate 7

**N3 Poor rapport**

Rapport is defined as a relationship of mutual understanding or trust and agreement between people. A commonality of purpose. Rapport in the PANSS involves an individual working with the interviewer, answering the questions as best they can. Poor rapport would be demonstrated by an open lack of interest whether through verbal complaints, bored tone of voice or if the individual looks around the room, watches TV etc while the interview is taking place. Poor rapport should be distinguished from an individual not giving the information needed because they find it too distressing or are having problems understanding the questions.

2. May be given when conversation flows freely and is informative but there is no discussion of feelings or emotions.

3. May be given when an individual answers questions in a functional way but appears bored.

4. Might be appropriate if the individual answers all the questions, often with one-word answers and does not elaborate. They may comment on the interview in a negative way or tries to make it clear that they are bored.

5. Might be given when an individual does not answer questions or answers mostly with one word answers. They may spend some of the session looking away/ looking at other things.

6. Represents no involvement with the interviewer. Answers questions mechanically. The individual will spend most of the time looking away from the interviewer.

7. Suggests the individual mostly not answering questions at all and no interaction with the interviewer. *It is likely that gaining informed consent to carry out the interview may be difficult*

**N4 Passive/apathetic social withdrawal**

Refers to social avoidance due to poor motivation, not fear. Basis for rating is meant to be reports on social behaviour from primary care workers/ family but questions are asked and client's answers are used in deciding the ratings. Reports from other workers/ relatives can be used to help the ratings but only if the client report is not clear enough to rate or carer report contradicts client's responses. A useful aspect of the N4 description is the behavioural element- "reduced interpersonal involvement" and "neglect of daily living". It is helpful to establish the client's level of functioning and social activities this week in order to ascertain whether this week has been the same as previous weeks or if the client has had reduced interactions specifically due to apathy. In terms of questioning for this rating it might be good to start with the more general questions and then move onto specific details about what the client offers.

2. Has a paucity of self-generated social activity given his/her social circumstances, avowed interests but will join in readily if invited.

3. No evidence of self-generated social activity. Will join others but requires prompting and encouragement. Once engaged can sustain a social conversation.

4. No self-generated activity. Difficult to persuade and when he/she goes along, is often found sitting quietly on his/her own, showing little sustained interaction with others. Can sustain a brief conversation that is more than immediately need based but this is not sustained. E.g. A 56 year old woman suffering from chronic schizophrenia and living in a supported group home. She can be found most days sitting in the lounge knitting and part-watching the television. Other residents and staff come and go with no apparent interaction. She also goes twice a week to a local day centre. On these days, she shows no apparent anticipation or interest but passively gets up and follows staff out of the building when it is time to go. At the

day centre she joins others in structured activities (e.g. bingo, quizzes) but makes no independent social interaction outside of the formal requirement to participate in whatever group activity is going on at the time. Rate her 4

5. No self-generated activity. Successfully resists most efforts to get him/her involved. Spends most time alone even when there are other people around but will engage briefly in conversation (mainly need-based).

6. As 5 but also some self neglect that would be off-putting to others –little effort to 'present' himself to the world – dishevelled, unconcerned about appearance of clothing etc. E.g. A middle aged man in supported accommodation: For most of the day he tries to stay alone in his room. He will come out when staff ask him, but he looks uncomfortable, with poor eye contact (looks away or at the floor), answers questions minimally unless prompted and seldom elaborates. If he has to sit in a room with other people he is seen sitting apart. He does go out with other residents on a Sunday to the pub but says he would prefer to stay in and 'rest' in his room. Clothing and personal hygiene are OK but not smart. Rate him 6

7. As 6 but personal neglect more marked. Very isolated from others, does not make spontaneous conversation, few requests/demands.

**N5 Difficulty with abstract thinking**

Rating this item is based on abstract thinking demonstrated throughout the interview, however the following tasks are administered to assist with this. The similarities task below is used on all occasions, and the proverbs are used mainly when the rater feels there is not enough evidence to rate this item.

**Similarities**

**Explain the task:** "I am going to give you a pair of words and ask you how those two things are similar. For example, if I said how a 'tiger' and a 'lion' are similar, you could say that are both animals, big cats, carnivores and live in the wild etc.

The pairs of words used for this are categorised into four levels of difficulty and are as follows:

1. (Easiest items)

- Apple and Banana?
- Ball and Orange?
- Pencil and Pen?
- Penny and Pound?

2.

- Table and Chair?
- Tiger and Elephant?
- Hat and Shirt?
- Bus and Train?

3.

- Arm and Leg?
- Rose and Tulip?
- Uncle and Cousin?
- The sun and the moon?

4. (Most difficult items)

- Painting and poem?
- Hilltop and valley?
- Air and Water?
- Peace and Prosperity?

Start by asking '**So can you tell me what is similar about an apple and a banana? Please give as many answers as you can think of'** If they only reply with one answer prompt for a second answer - such as 'anymore, one more, can you think of anything else'. However, don't worry too much if they can only give you one or two answers. The list is grouped into four sections of four items in order of difficulty, starting with the easiest and ending with the hardest. If the client has no problem with two of the simple items from the first section, continue to ask more difficult items from the next section. Continue to do this until the client stops giving correct answers. Do not continue with the harder items if the client does not answer the preceding easier ones correctly.

**If the client says 'I don't know'**

- Check that they understand the task
- Go over the example of the tiger and lion again
- Rephrase the question 'can you tell me how they are alike/what is the same about…?'
- You may use prompts.
- Discontinue if the client still doesn't understand and see rating guidelines below.

**Proverbs**

Explain the task : "I'm going to read some proverbs one at a time, and in your own words I'd like you to explain to me what they mean. What does this proverb mean…?"

**Proverbs**

1. (Easiest)
- Plain as the nose on your face?
- Carrying a chip on your shoulder?
- Two heads are better than one?
- Too many cooks spoil the broth?

2.
- Don't judge a book by its cover?
- One man's food is another man's poison?
- All that glitters is not gold?
- Don't cross the bridge until you come to it?

3.
- What's good for the goose is good for the gander?
- The grass is always greener on the other side?
- Don't keep all you eggs in one basket?
- One swallow does not make a summer?

4. (Most difficult)
- A stitch in time saves nine?
- A rolling stone gathers no moss?
- The acorn never falls far from the tree?
- People who live in glass houses shouldn't throw stones at others?

**These are just guidelines; remember when rating Abstract Thinking to take the whole interview into account, not just the similarities.**

1. Provides good answers for pairs from all levels of difficulty, and displays good abstract thinking throughout the interview.

   An example of a **good answer** for arm and leg could be, *"they are both limbs".*

2. Gives correct answers for each pair given. Responses here are not particularly personalised. Demonstrates abstract thinking throughout the interview.

An example of a **correct answer** for arm and leg could be, *"they are both body parts".*

3. Provides answers for all the easy pairs and some of the more difficult pairs. May have more difficulties and give more personalised answers. Also demonstrates some evidence of difficulties with abstract thinking during the interview (specify one example).

   An example of a **personalised answer** for table and chair could be*, "You use them to sit down and eat a meal".*

4. Gives at least one correct answer for the easy items, but not for the more difficult pairs. May answer some of the easier proverbs correctly but has difficulties with the others and demonstrated some more difficulties with abstract thinking during the interview, often using a concrete mode (at least two examples can be specified).

   An example of a **concrete answer** for table and chair could be, *"they are made out of wood".*

5. Very few correct answers given, abstract thinking problems demonstrated on a several occasions in the interview.

6. Almost none or no correct answers given. Little understanding of task, poor abstract thinking in the interview.

   An example of **not understanding** the task could be giving the answer, *"Writing desk and chair"* when asked how table and chair are similar.

**7.** No correct answers given to similarities or proverbs. Difficulties conducting the interview due to significant problems with abstract thinking.

**N6 Lack of spontaneity and flow of conversation**

Consider the anchor point "intended to avoid or curtail conversation" if rating higher than 5. Need to think about whether the reduction in flow of conversation is deliberate.

Things to pay attention to:

- Conversation may feel strained or uncomfortable
- The balance between the interviewer and the interviewee (who is doing more of the talking)
- How much additional information is provided by the client where appropriate
- Are leading questions needed?
- Does the conversation flow from one topic to another?
- Does the client answer all the questions asked of them?
- How long are the client's replies to questions?

1. A substantial & appropriate number of replies to questions include additional information provided by the client. Client elaborates spontaneously & initiates parts of the conversation & further lines of questioning.

2. Occasional replies don't include elaborated information where it would have been appropriate, but this does not really get in the way of the interview or make it less productive. The interviewer does not need to ask leading questions to get enough answers to make ratings.

3. Client answers questions asked of them but often does not elaborate on answers & leading questions are sometimes needed. When leading questions are asked, the interviewer is able to get enough information to make the rating. Though the client's answers are brief, the conversation flows reasonably.

4. The conversation does not flow very well and feels difficult, and the client does not elaborate on their answers. The interviewer is doing a bit more of the talking than the interviewee, and leading questions are frequently needed. If the interviewer did not ask leading questions, there would not be enough information to make ratings.

5. Client answers the questions but does not elaborate. Answers are monosyllabic or very brief sentences at best, such as "I don't know" or "Last week". It may be hard to obtain ratings for some scales, and impossible without leading questions. The interviewer is talking vastly more than the interviewee.

6. Conversation is highly unproductive and impaired, and you would probably be unable to complete the PANSS interview with this client. The client may not answer the questions asked of them, and their responses are rarely more than a few words. The client may use phrases intended to avoid or cut off communication.

7. Conversation is not possible. The client does not speak, except for maybe an occasional utterance. You would not be able to interview this client.

**N7 Stereotyped thinking**

Barren thought content is different from "I don't know responses" if the individual shows rich thought content elsewhere. Based on structure (the way they are talking) rather than content.

Reference has been made to the Thought Language and Communication document by Andreassen, where appropriate, to clarify terms and aid in anchor points.

- TLC – 2 - 'Poverty of content of speech' – replies seem to be at least of adequate length but convey little info relevant to the question asked. Language tends to be vague, often over abstract or over concrete, repetitive and stereotyped. May speak at length but not have given enough info to actually answer the question OR they provide enough info but are very long-winded about it. Differs from circumstantiality in that client doesn't actually provide lots of tangible details – on the contrary, they appear to have talked at length but not really made a point, or eventually make it but could have done it much quicker.

- TLC – 14 – 'Perseveration' – Persistent repetition of words, ideas or subjects so that, once a patient begins a particular subject or uses a particular word, he continually returns to it in the process of thinking. This is an example of decreased fluidity and flexibility of thinking in that the person can't move on from this one idea/phrase, so that their speech is repetitive and their thought content appears to be barren as a result.

E.g. when asked where they live, they say 'I live in South London. I used to live in Manchester but I moved down when my parents left so now I live in South London. So my current home is in South London.'

- There are several ways that someone could rate on this item e.g. rigid attitudes/beliefs vs. barren thought content. There therefore needs to be more than one example for some ratings on the scale. It is sometimes difficult getting the examples to fit in with the exact wording of the ratings e.g. perseveration of words for a moderate rating, does not seem to fit. It is unusual for just a single word or brief phrase to be used and a more usual moderate (e.g. 4) rating, will reflect someone stuck on a particular topic/theme instead.

- Giving exact examples for each scale would make this document several pages long! Instead, the TLC advises calculating the approximate proportion or amount of times, the examples occur in interview.

**Difficulties with rating this item**

- We are guiding the content of the interview so it may appear that the client is only talking about a selection of topics but often this is because we have instigated this. This is why it is important to use open-ended questions to start with e.g. 'How have things been?' etc, and then refine later. Also, we need to challenge some statements and ask for examples, elaborations etc, to establish whether thinking truly is stereotyped or if they are able to demonstrate more fluid/spontaneous thought when given the opportunity.

- 'Poverty of *speech'* (rather than 'thinking') may rate here but it is more likely to rate in N6 e.g. someone that repeatedly says 'I don't know' to questions. A low rating on N7 may be considered but we should also look for evidence throughout the interview, for more 'rich' thought content, before we push them up the scale.

1. Speech and content appear normal – nothing about the content/style of speech makes you stop and think.

2. May occasionally repeat the same word/ideas more than necessary when answering a question, or 'ramble' more than would be deemed socially normal before reaching a point.

3. Client may just seem stubborn in their responses e.g. respond with a belief and become fixed on that idea, seemingly unable to consider other possibilities (including delusions i.e. if person rates 3+ on delusions, they rate at least as a 3 on N7).

4. Client's thinking will probably seem fairly rigid or sparse e.g. don't have the capacity to think effectively about several options. May become fixed on a certain idea/theme (e.g. paranoia/source of OCD/physical concerns/religious beliefs), which is returned to and dominates the conversation at several points – significantly more than would be considered normal. This can include delusions e.g. the concern that next-door neighbours are out to get that person or that they have magical powers. Noticeable difficulty in shifting to new topics (e.g. client unnecessarily reverts back to a central theme on several occasions or starts to answer question relevantly then becomes unstuck and veers back to central theme) but progress is possible and other relevant info can be obtained.

5. Client will fit the rating for 4, but this occurs so much that they are only really able to discuss 2-3 topics. Discussion of other topics may revert back to the same 2-3 ideas or they may be unable to discuss other topics at all. Interviewer will therefore be unlikely to get a valid rating on many of the other items.

6. The same phrases come up time and time again, so that other things can't be discussed and interviewer struggles to continue with the conversation. Responses may often seem illogical in that the statements seem unrelated to the questions, or client is too distracted by this repetition to be able to consider other answers – mind is focused on the one statement/idea. Client will repeat the same word/phrase/idea over and over again, in response to a variety of questions. This will appear 'uncontrolled' in nature e.g. that they truly seem unable to diversify their thinking at all – no spontaneity or flexibility. More than half of the interview is made up of the client repeating the same words/ideas in response to questions, so that the interviewer cannot extract any valid information for the most part of the interview.

7. Can't get anything else out of the interview! Communication is made up solely of a repetition of a fixed idea/phrase etc so that no other relevant information is obtained and the interview is basically meaningless in its content. Almost all of the interview consists of the same responses given repetitively – either the exact phrases or a certain belief rephrased in numerous ways (e.g. 'I am the saviour' etc), showing rigid thinking and inappropriate responses, such that meaningful conversation is impossible.

**General Item Subscale**

**G1 Somatic concern**

To score on this item, there must be evidence that the client is **over** concerned about illness. Also, if client explains symptoms in a non-obvious way they can rate on this item.

Examples for rating G1:

Individual complained a lot about physical health but experienced a variety of illnesses so concerns were justified. However, he was clearly preoccupied about it and at times felt suicidal as a result. He explained the reasons for his illnesses as due to stress of living with an alcoholic 8 years ago rather than more obvious explanations (i.e. age). Rated **5**.

Individual appeared extremely unwell, he was sitting hunched up in front of his fire and complained of severe pain. His care coordinator reported that nothing has been found to be wrong with his physical health despite investigation. Rated **5**.

During the PANSS the individual discussed an operation he was due to have to improve the condition. However, when this was discussed with the care coordinator they made clear that there was no such operation – something which they had explained to the client previously. Although the preoccupation might be understandable, he had delusions regarding the themes of his illness. Rated a **5.**

**G2 Anxiety**

Examples for rating G2:

- Individual believed that pagans are out to get him because people think he is a paedophile. He continuously paced during the session, picked his fingers and reported that he cannot go out of the house as he panics and has to come home. Rated **7**.
- Client who frequently worries about the future, causing him to suffer panic attacks. As a result he struggles to have a social life and finds it difficult to use public transport. **Rated 5**
- Client who constantly worried about the cleanliness of his flat and what others would think about him as a consequence. He apologized for the "state of the flat" during the session even though it was not noticeably untidy or dirty. He did not report any somatic or behavioural consequences and was as a result **rated 3.**

**G3 Guilt**

To score on guilt, the individual must feel guilty or remorseful about a real or imagined past event. To score a 4, there needs to be concern about the guilt but not preoccupation, and the incident must be real. To score a 5, there must be a belief that they deserve punishment. To score a 6 there needs to be delusional quality to the guilt.

Examples for rating G3:

Individual felt guilty about an alleged assault that he carried out. However, the client knew that he did not do this; he felt that *other* people were making him feel guilty about doing it. This item is still rated as guilt as the PANSS includes 'real or imagined misdeeds'. Rated as **3** as a rating of 4 states that the guilt must be real.

One individual felt guilty over beliefs that he was Hitler in a past life and had killed millions of people. As punishment for this he believed that he would soon die and spend eternity in Hell, and to make it harder for him to escape he would be partially sighted. In addition to this he also kept a list of all his sins which he had committed in the past, and had been told by an alien that he must read this list out to everyone he meets to make up for them. This was rated a **7**.

## G4 Tension

Tension scores are influenced by ratings on G2 – anxiety.

## G5 Mannerisms and Posturing

When assessing abnormal movements or postures consider the following:

- Involuntary Movements: Tics, tremors, dyskinesia, akathisia. Do not include these movements
- Mannerisms: Odd, stylised movements or acts, usually idiosyncratic to the client, sometimes suggestive of a special meaning ie the client repeatedly salutes or uses elaborate hand gestures
- Stereotypies: Persistent repetition of movements or postures ie rocking to and fro in a chair, rubbing head round and round with the hand, nodding the head. These movements do not seem to have a special meaning to the client.
- Catatonic Movements: Negativism (doing the opposite of what is asked), ambitendence (fluctuating between two alternatives), echopraxia (imitation of body movements), echolalia (imitation of words or phrases), mitgehen and waxy flexibility (excessive cooperation in passive movements)
- Unusual Postures: Voluntarily adopting strange postures, possibly with a special meaning to the client, or holding uncomfortable postures for long periods
- Persistently Rigid Posture: The client may sit rigidly upright in the chair or even stand upright for most of the interview
- Persistently Withdrawn Posture: The client adopts a closed posture, with head down and eyes averted from the interviewer.
- Abnormal Staring: Prolonged periods of eye fixation with the interviewer to a degree that is culturally inappropriate, or prolonged staring into space
- Facial Mannerisms or Stereotypies: Distinct Idiosyncratic or repetitive movements of unclear meaning i.e. grimacing.

## G6 Depression

When assessing depression, raters should look for sadness, helplessness and low expectations of the future. When making a rating, consider the following factors:

- Remember that 'depression' can still be rated if it is in relation to an event that would understandably make someone sad.
- Clients who rate more highly on this scale are expected to be affected in a number of ways by depression, other than just reporting to be 'low', e.g. pessimistic attitude, poor social life, interference with sleep/appetite and persistently low mood which makes it difficult for them to be cheered up.
- If the client subjectively reports that they are 'depressed' but subsequently contradicts this with other information (e.g. they describe an active social life and ambitious plans for the future), raters should be cautious not to rate them too highly.

## G7 Motor Retardation

When assessing psychomotor retardation consider the following factors

- Slowness of limbs and body: Delays in performing movements, sitting abnormally still, walking abnormally slowly
- Reduced Frequency and Extent of Gesture: Gestures may be infrequent and when they do occur may be slow and slight
- Slow Speech: A reduced rate of speech, or long pauses between phrases, or long pauses before answering questions
- Stupor: In extreme cases there may be a total or near total absence of voluntary movement and/or muteness but with evidence of continuing conscious awareness
- Distinguish between psychomotor retardation and blunted affect: The client must show evidence of slowed thought processes to justify a positive rating for psychomotor retardation, i.e. a reduced rate of speech, or long pauses between phrases, or long pauses before answering phrases. Reduced frequency and extent of gesture in the absence of any slowing of mental processes and accompanied by lack of variation in facial or vocal expression should be rated under blunted affect.

**G8 Uncooperativeness**

When assessing cooperation, consider the following factors:

- Suspiciousness**:** The client may feel that all is not what it should be and thinks that there may be a deliberate attempt to harm or annoy. If persecutory delusions are present the client may believe the interviewer is involved in a wider conspiracy

- Hostility: The client may be overtly angry and hostile, criticizing the interviewer and refusing to answer questions, or cutting off the interviewer by saying no before the question is finished

- Misleading answers: The client may give replies that avoid answering the question, or may frequently contradict himself, or may deny that symptoms are present although there is evidence to the contrary

- Verbal Over Compliance: This is the tendency to agree passively with the interviewer's questions without seeming to have any regard to their content. He may be trying to please the interviewer, or may be unable to concentrate sufficiently to give a considered response

- Manifest Resentment or Apathy: The client seems unwilling to cooperate, talks very reluctantly, seems apathetic or listless, or repeatedly says 'no' without seeming to give proper thought to the questions

- In certain circumstances (eg following compulsory admission to hospital) the interviewer may feel that the client's lack of cooperation is understandable and to some degree justified. This should not be allowed to influence the rating, which should be based solely on the degree of observed cooperation during the interview.

**G9 Unusual Thought Content**

- We are taking G9 to be assessing how far removed the delusions are from reality and an understandable interpretation/explanation of events/experiences.
- Anyone who rates 3+ on delusions must rate at least a 3 on G9, so we are really considering delusions that warrant a rating of 4+ on G9 i.e. particularly unusual delusions.
- Delusions of reference/control are not considered particularly 'unusual' e.g. TV characters talking to you, pop stars sending messages etc. A 3 alone is probably enough unless they are particularly far-fetched or contain additional unusual content.
- Delusions with religious content/that relating to a known organisation (e.g. MI5, IRA etc) may be considered to be more 'normal' than that of say aliens. Attention should be paid to how far a 'normal' belief has been taken e.g. culturally accepted religious/moral beliefs that have been taken beyond the norm – how far and can the delusion and its development still be rationalised/understood?
- Grandiose delusions should especially be considered when rating G9. Questioning should be detailed to establish how systematised the delusion is e.g. if they think they caused 9/11, how did they do it e.g. thought something negative, which meant god is punishing people, or something more detailed and far-fetched regarding the cybertonic links between the person's sound waves of their voice and how these are transmitted via underground waves to the terrorist centre in the US, which produced a subpartical code, leading to the final wire of a bomb being completed and detonated.
- Ideas relating to having a 'third eye'/telepathic abilities etc are 'relatively normal' and these alone may only warrant a mid-range rating, but in combination with other beliefs may push someone up the scale.
- As the scale suggests, it is important to consider how many 'unusual' beliefs a person has, with accumulation pushing them up the scale. Therefore, one belief in isolation would probably not allow them to rate as a 5/6, no matter how 'bizarre' the belief; but a systematised belief with detailed explanation, may do.

Examples for G9 ratings

Each bullet point denotes a different person.

- Believes people talk behind his back because they think he is a paedophile or rapist. Believes he is being punished in life for being a paedophile or rapist in a past life and perhaps this is why so many bad things happen to him and also maybe why he is a drug user.
- Believes he may be one quarter Italian and belongs to a gangster mob in Italy.
- Sometime feels as if in a coma and that she's being monitored on a machine by people that know her.
- Believes a hypnotist is controlling his thoughts, behaviours, movements and sleep patterns. Believes that when people on 'Coronation Street' get drunk or fight they are making special reference to him.
- Believes he shares a sense of humour with God and God does things specifically to make him laugh.
- Has seen references to self on TV- the last time was Glen Hoddle announcing that he (the client) was his new signing.
- Believes he is a special person, he is protected by heaven as he is working for heaven and was sent to stop the second coming of Christ. He believes this has bought the devil into his life too who tries to get him to do 'bad things'
- Believes voices are caused by an implant behind his ear put there by aliens Client believes that Israeli intelligence took thoughts from his head and swapped them with thoughts to try and get him to spy on the minds of anti-Semitic people. Previously believed that he was being talked to by rock stars in his sleep and that 'Pink Floyd' and 'ZZ Top' were against him. Previously believed that recording technology was being used to produce population control through bass and treble sound waves.
- Believes he can astral project to other places and planets. Believes he was once an angel but now has fallen
- Used to think aliens were controlling his movements because he could walk across the road without looking many times and never had an accident. Felt he could control traffic lights and music out of speakers by the way he moved his arm.
- Believes the moon is evil and he has upset the moon. His behaviour is affected as a result of this as he has to be in bed before sunset and so drinks in the day in order to be able to sleep at night. Believes people are telepathic but isn't sure how or why. Used to think of a word and it would appear on the TV.
- Believes her ex-partner is a rogue scientist and has planted a chip in her neck and controls her thoughts and behaviour via an illegal computer, as well as being the source

of the voices she hears. Believes he tried to give her a heart attack so that he could get £1million from China.

- Believes he is the 'O' in God, God is the 'G' and the Devil is the 'D'. God has told him he is too powerful and wants his power so he is teaching God. He is here to teach God and fight corruption and has spoken to over 800,000 disciples whose voices he hears. Sees the spirits of 'Bangladeshians' when he is outside, that he has to shoot away. He couldn't divulge any more details due to the implications for the world, but explained that everything will become clear by 2030.
- Believes she is extremely evil as she has devil's babies in her kidneys that travel up through her spine and out through her optic nerve causing her to harm people. Feels she is responsible for the 7/7 bombings and her brother's illness.
- Believes he had a vision when he was 4 years-old, with predictions of his future, which he is destined to fulfil. Believes he is the reincarnation of Mohammed/King of Africa and his powers have allowed him to influence Bradford riots and possibly the attacks on the World Trade Centre in the early '90s. He has the ability to bless others, to cause things to happen. Had a dream that he had to help the yellow people fight a war. When he saw a yellow jacket he realised he had to wear it to help them with their war. He wore it for two years.
- Believed he lived in the same building as Jehovah. GB said something to his son and since then Jehovah has linked to his brain and taken his soul away. All his thoughts and actions are Jehovah's. Jehovah can appear in any form e.g. a BMW or a giant yam.
- Believes he hears the voice of the head of the IRA, who verbally abuses him and causes him physical pain. The voice tells him of fires that will happen in Australia and is a psychic child murderer going from womb to womb harming children. Most people are part of the IRA and can hear his thoughts.
- Believes he has x ray vision which allows him to see through buildings. Believes his 3rd eye allows him to see Tony Blair and the queen. Believes he is one of the 'queen's boys' in that she knows who he is due to his powers and protects him. Believes he can cause earthquakes through a scar on his back.

**G10 Disorientation**

Examples for G10 rating:

Individual knew the month but not the year and knew his cc but not the prime minister. Not knowing the year is an anchor point of a fairly high rating on G10 but it was decided that as he knew many other orientating information he rated a **3.**

**G11 Poor attention**

Clients who score on this scale will struggle to concentrate for the duration of the interview, may be distractible due to internal or external stimuli and/or may find it difficult to shift focus to new stimuli.

- Clients who score at the low end of the scale are likely to concentrate for the majority of the interview with only occasional loss of attention. Alternatively, they may maintain focus at the start of the interview with faltering attention towards the end.
- Clients who score highly on this scale are likely to be so inattentive that the progress of the interview is impeded and may even need to be terminated in extreme cases.
- Note that distraction may be caused by external events in the environment or by internal phenomena experienced by the client, e.g. hallucinations.

**G12 Lack of judgement and insight**

The ratings for this item assume someone is unwell and without insight, if an individual is currently well they should only score 1 or 2 depending on future planning. However, if they deny ever having been ill they will score more highly regardless of how well they are now.

Examples of G12 ratings

- Client who did not score on the positive scale at all but has a few mild symptoms on the negative and general scale, believes that he suffered drug induced psychosis in the past but is now well. He now hopes to stop taking medication. **Rated 2.**
- Individual who disagrees with her diagnosis of schizophrenia despite current positive symptoms. She believes that she may have been unwell in the past but that she has now

recovered, apart from suffering a "touch of depression." Hopes to stop taking medication soon. **Rated 5.**

- Client who believes he is playing a chess game against God in order to win power over 'everything', believes that he is only in contact with mental health services because they don't believe about the chess games. **Rated 6.**

**G13 Disturbance of volition**

For example, starting a sentence and not finishing it. Think about whether inability to come to an answer to questions is due to volition or thought disorder.

**G15 Preoccupation**

Concerned with autistic spectrum. Lower end of the scale refers to being overly involved with personal needs, showing little concern for what the interviewer wants to discuss. Above a 3 an individual needs to ignore questions and bring topic back to their own agenda. In more severe cases, they might be engaging in another activity while being interviewed.

Examples for G15 rating:

Individual spent much of the PANSS talking about himself and his misfortunes, with diminished concern for others. E.g. when he head butted his girlfriend he complained of her reaction when phoning the police, feeling that it was an overreaction. He also talked about how others were attempting to persuade him to see his son but how he wasn't interested. Although this item refers more to the autistic spectrum, a rating of **3** can be applied to someone who is excessively absorbed by their own problems.

**G16 Active Social Avoidance**

For active social avoidance, the individual should score if they feel uncomfortable in the company of others or outside of their home. The rating is higher if the client does not participate in social activities particularly because of anxieties about what might happen when out or suspiciousness around other people. Individuals also rate when they break off prematurely from social situations on account of these fears. The more the individual isolates him/herself, the higher the rating.

Examples of G16

Individual had not left the house for approximately 3 weeks because of fears that people were out to get him or that something bad might happen to him, and spent all of his time in his room listening to the radio. His mum did all of his shopping so that he had no need to leave the house. Although he was living with his mum and dad and saw his CPN when he visited, which gave him some social interaction, he had stopped talking to friends because he didn't know who he could trust, and had isolated himself by refusing to leave the house because of fears and worries. He was therefore rated **6.**

Individual was happy to see the researcher and visited his parents twice a week, although this used to be on a daily basis and had recently reduced due to the belief that his parents knew what he was thinking. He also visited Creative Support for his medication on a daily basis, but said that he only went because he had to, as he didn't trust the staff as far as he could throw them. However, he had played football and watched TV with others there during the week. He no longer went for nights out with friends (as he had done in the past) because of worries that he might drink to excess in an unfamiliar place and not be able to find his way home. At home he enjoyed playing the guitar and drawing his own artwork. This was rated **4**.

**PANSS questions and ratings scales**

**G1 Somatic concern**

- How have you been feeling over the past week?
- Are you having any concerns about your physical health?
- Have you had any worries about illnesses / concerns about the way your body is functioning?
- Do you have some medical illness or disease? If so, how serious is it?

**If yes:**

- What do you think might be causing this/these problem/s
- Have you seen the doctor about this/these problem/s?
- Do you have any medication for this/these problem/s?

- Have often have you thought about……..in the past week? Do you think about it most days? Do you find that these ideas are on your mind a lot? How much of the time?

**If delusional conviction about the cause:**

- Are you certain that……is causing this/these problem/s? How sure are you? Could you be mistaken? Is there any other possible explanation?

**Somatic concern**

Physical complaints or beliefs about bodily illnesses or malfunctions. This may range from a vague sense of ill being to clear-cut delusions of catastrophic physical disease.

Basis for rating: Thought content expressed in the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper stream of normal limits.
3. Mild – Distinctly concerned about health or somatic issues, as evidenced about occasional questions and desire for reassurance.
4. Moderate – Complains about poor health or bodily malfunction, but there is no delusional conviction, and overconcern can be allayed by reassurance.
5. Moderate-Severe – Patient expresses numerous or frequent complaints about physical illness or bodily malfunction, or else patient reveals one or two clear-cut delusions involving these themes but is not preoccupied by them.
6. Severe – Patient is preoccupied by one or a few clear-cut delusions about physical disease or organic malfunction, but affect is not fully immersed in these themes, and thoughts can be diverted by the interviewer with some effort.
7. Extreme – Numerous and frequently reported somatic delusions, or only a few somatic delusions or a catastrophic nature, which totally dominate the patient's affect and thinking.

**G2 <u>Anxiety</u>**

- **Have you been worrying at all about anything during the past week?**

**If yes:**

- What do you worry about? Anything else?
- What is it like when you worry, do unpleasant thoughts constantly go round and round in your head?
- How often have you been worried like this in the past week?
- When you feel worried, how long does it usually last? Does it last most of the day? Does it last for several hours or just a few minutes?
- When you start to feel worried/anxious can you reduce or stop the feeling by turning your attention to other things such as watching the TV or chatting to someone?
- Do you find that when you're worrying it stops you from doing things you would normally do? Has it stopped you from doing things in the last week?
- Do you sometimes find it difficult to get off to sleep because of worrying? How about in the last week?
- When you are out and about do you feel anxious? Do these feelings stop you from going out.
- Do you find you get physical symptoms such as heart racing, butterflies, sweaty palms, anything like that?
- **Have there been times in the last week when you have been particularly anxious or frightened? When you might have become quite panicky?**

**G2 <u>Anxiety</u>**

Subjective Experience of nervousness, worry, apprehension, or restlessness, ranging from excessive concern about the present or future to feelings of panic.

<u>Basis for rating</u>: Verbal report during the interview and corresponding physical manifestations.

1. <u>Absent – Definition does not apply</u>
2. <u>Minimal – Questionable pathology; may be at the upper stream of normal limits.</u>

3. Mild – Expresses some worry, overconcern, or subjective restlessness, but no somatic and behavioural consequences are evident.
4. Moderate – Patient reports distinct symptoms of nervousness, which are reflected in mild physical manifestations such as fine hand tremors or excessive perspiration.
5. Moderate-Severe – Patient reports serious problems of anxiety which have significant physical and behavioural consequences, such as marked tension, poor concentration, palpitations, or impaired sleep.
6. Severe – Subjective state of almost constant fear associated with phobias, marked restlessness, or numerous somatic manifestations.
7. Extreme – Patients life is seriously disrupted by anxiety, which is present almost constantly and at times reaches panic proportion or is manifested in actual panic attacks.

**G6 Depression**

**How would you describe your mood over the last week? Do you feel reasonably cheerful or have you had times when you felt a bit low?**

**If no depression reported:**

- Would you say that you are mostly a cheerful person?
- Do you never let things get you down?

**If low spirited:**

- How often have you felt that way in the last week? Every day?
- How long does the feeling usually last when you feel low? All day?
- When you feel low, is it quite an intense feeling? Or is it usually only a moderate or mild feeling?
- When you start to feel low do you find that you can sometimes cheer yourself up by watching TV, listening to music, going out or talking to friends/family
- What has your appetite been like lately? Have you lost any weight recently? Have you been dieting?
- Have you had trouble getting off to sleep recently? How long do you lie awake? How often does it happen?
- Have you found that you've lost interest in going out in the past week?

- How do you see the future?
- How do you cope with this?

**G6 Depression**

Feelings of sadness, discouragement, helplessness, and pessimism.

Basis for rating: Verbal report of depressed mood during the course of interview and its observed influence on attitude and behaviour.

1. Absent – Definition does not apply
2. Minimal – Questionable pathology; may be at the upper stream of normal limits.
3. Mild – Expresses some sadness or discouragement only on questioning, but there is no evidence of depression in general attitude or demeanour.
4. Moderate – Distinct feelings of sadness or hopelessness, which may be spontaneously divulged, but depressed mood has no major impact on behaviour or social functioning, and the patient usually can be cheered up.
5. Moderate-Severe – Distinctly depressed mood associated with obvious sadness, pessimism, loss of social interest, psychomotor retardation, and some interference in appetite and sleep. The patient cannot be easily cheered up.
6. Severe – Markedly depressed mood associated with sustained feelings of misery, occasional crying, hopelessness, and worthlessness. In addition, there is major interference in appetite and/or sleep as well as in normal motor and social functions, with possible signs of self-neglect.
7. Extreme – Depressive feelings seriously interfere in most major functions. The manifestations include frequent crying, pronounced somatic symptoms, impaired concentration, psychomotor retardations, social disinterest, self-neglect, possible depressive or nihilistic delusions, and/or possible suicidal thoughts or action.

**G3 Guilt feelings**

- In the past week have you experienced times when you blame yourself for things, feel guilty or down on yourself?
- Do you consider yourself a bad person in some ways?

**If yes:**

- What do you feel guilty about?
- Why do you feel this is your fault?
- When you think about ….. is it something that makes you feel quite low?
- Do you believe that you deserve some punishment for this? What kind of punishment do you deserve?
- How often have you thought about…….in the past week? Do you think about it most days? Do you find that these ideas are on your mind a lot? How much of the time?

**If guilt feelings have a delusional basis:**

- Are you certain that……is causing this/these problem/s? How sure are you? Could you be mistaken? Is there any other possible explanation?

**G3 <u>Guilt feelings</u>**

Sense of remorse or self-blame for real or imagined misdeeds in the past.

<u>Basis for rating</u>: Verbal report of guilt feelings during the course of interview and the influence on attitudes and thoughts.

1. <u>Absent</u> – Definition does not apply
2. <u>Minimal</u> – Questionable pathology; may be at the upper stream of normal limits.
3. <u>Mild</u> – Questioning elicits a vague sense of guilt or blame for a minor incident, but the patient is clearly not overly concerned.
4. <u>Moderate</u> – Patient expresses distinct concern over his/her responsibility for a real incident in their life but is not preoccupied with it, and attitude and behaviour are essentially unaffected.
5. <u>Moderate-Severe</u> – Patient expresses a strong sense of guilt associated with self-depreciation or the belief that he/she deserves punishment. The guilt feelings may have a delusional basis, may be volunteered spontaneously, may be a source of preoccupation and/or depressed mood, and cannot be allayed readily by the interviewer.

6. Severe – Strong ideas of guilt take on a delusional quality and lead to an attitude of hopelessness or worthlessness. The patient believes they should receive harsh sanctions for the misdeeds and may even regard their current life situation as their punishment.
7. Extreme – Patient's life is dominated by unshakable delusions of guilt, for which they feel deserving of drastic punishment, such as life imprisonment, torture, or death. There may be associated suicidal thoughts or attribution of others' problems to one's own past misdeeds.

**P5 Grandiosity**

- Do you think you are special in some way?
- What are your good points?
- Have you had any thoughts recently about having special powers, talents or abilities, or being more important than other people?

**If yes**

- What are your special powers/talents/abilities? (*Wealth, knowledge, fame, moral righteousness)*
- How often have you thought about this in the past week? Most days? How much of the time?
- Are you certain that you have this special power/talent/ability? 100% certain?
- How do these abilities affect your day to day life?
- Could you be mistaken? Is there any other possible explanation?

**P5 Grandiosity**

Exaggerated self-opinion and unrealistic convictions or superiority, including delusions of extraordinary abilities, wealth, knowledge, fame, power, and moral righteousness.

Basis for rating: Thought content expressed in the interview and its influence on behaviour.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.

3. Mild – Some expansiveness or boastfulness ids evident, but without clear-cut grandiose delusions.
4. Moderate – Feels distinctly and unrealistically superior to others. Some poorly formed delusions about special status or abilities may be present but are not acted upon.

5. Moderate-Severe – Clear-cut delusions concerning remarkable abilities, status, or power are expressed and influence attitude but not behaviour.
6. Severe – Clear-cut delusions or remarkable superiority involving more than one parameter (wealth, knowledge, fame, etc.) are expressed, notably influence interactions, and may be acted upon.
7. Extreme – Thinking, interactions, and behaviour are dominated by multiple delusions of amazing ability, wealth, knowledge, fame, and/or moral stature, which may take on a bizarre quality.

**P3 Hallucinatory behaviour**

- **Do you ever seem to hear noises or voices when there is no one about and nothing else to explain it?** *(auditory hallucinations)*
- **Do you sometimes hear noises like tapping or music? Do you hear muttering or whispering?** *(non verbal auditory hallucinations)* What are these like? How often have you heard them during the last week? Do they bother you? What do you think is the cause of the noise/s
- **Do you ever hear a voice talking?** *(verbal auditory hallucinations)*

**If yes:**

- **Have you heard voices in the last 7 days?**
- **How many voices have you heard in the last week?**

**RECORD THE FOLLOWING FOR EACH VOICE:**

- **Do the voices speak directly to you?** *(second person auditory hallucinations*) **Or do they refer to you as 'he' or 'she?**' *(Third person auditory hallucinations).*
- **Are the voices a man or a woman's voice?**

**PANSS hallucinations in other modalities**

- **Have you had any unusual visual experiences recently?** ***(visual hallucinations).***
- Was this in the last week? How often in the last week?
- What did you see? **RECORD NUMBER OF HALLUCNATIONS AND WHAT WAS SEEN**
- How real does this appear? As real as I do now? Was it in colour? Was it 3 dimensional or flat? Did you see it with your eyes or in your mind? Did other people see it? When you saw it were you falling asleep or waking up at the time?
- What do you think caused the vision/s? Factors relating to you or other people? On a scale of 0 to 100 how convinced are you that……..caused the vision/s? **RECORD FOR EACH VISION**
- **Do you sometimes notice strange smells that other people don't notice?** ***(olfactory hallucinations).***
- Was this in the last week? How often in the last week?
- What sort of thing do you smell? How do you explain it? **RECORD NUMBER AND WHAT WAS SMELT**
- What do you think caused the smell/s? Factors relating to you or other people? On a scale of 0 to 100 how convinced are you that……..caused the smell/s? **RECORD ORIGIN FOR EACH SMELL**
- **Do you ever feel that someone is touching you, but when you look there is nobody there?** ***(tactile hallucinations)***
- Was this in the last week? How often in the last week?
- What sort of thing do you feel? How do you explain it? **RECORD NUMBER AND WHAT WAS FELT**
- What do you think caused the feeling/s? Factors relating to you or other people? On a scale of 0 to 100 how convinced are you that……..caused the feeling/s? **RECORD ORIGIN FOR EACH FEELING**
- **Do you sometimes get strange feelings in your body?** ***(somatic hallucinations)***
- Was this in the last week? How often in the last week?
- What sort of thing do you feel? How do you explain it? **RECORD NUMBER AND WHAT WAS FELT**
- What do you think caused the feeling/s? Factors relating to you or other people? On a scale of 0 to 100 how convinced are you that……..caused the feeling/s? **RECORD ORIGIN FOR EACH FEELING**

- **Do you ever find that your food tastes unusual? *(gustatory hallucinations)*.**
- Was this in the last week? How often in the last week?
- What sort of thing do you taste? How do you explain it? **RECORD NUMBER AND WHAT WAS TASTED**
- What do you think caused the taste/s? Factors relating to you or other people? On a scale of 0 to 100 how convinced are you that……..caused the taste/s? **RECORD ORIGIN FOR EACH TASTE**

**P3 Hallucinatory Behaviour**

Verbal report or behaviour indicating perceptions which are not generated by external stimuli. These may occur in the auditory, visual, olfactory, or somatic realms.

Basis for rating: Verbal report and physical manifestations during the course of the interview as well as reports of behaviour by primary care workers of family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – One or two clearly formed but infrequent hallucinations, or else a number of vague abnormal perceptions which do not result in distortions of thinking or behaviour.
4. Moderate – Hallucinations occur frequently but not continuously, and the patient's thinking and behaviour are affected only to a minor extent.
5. Moderate-Severe – Hallucinations are frequent, may involve more than one sensory modality, and tend to distort thinking and/or disrupt behaviour. Patient may have a delusional interpretation of these experiences and respond to them emotionally and, on occasion, verbally as well.
6. Severe – Hallucinations are present almost continuously, causing major disruption or thinking and behaviour. Patient treats these as real perceptions, and functioning is impeded by frequent emotional and verbal responses to them.
7. Extreme – Patient is almost totally preoccupied with hallucinations, which virtually dominate thinking and behaviour. Hallucinations are provided a rigid delusional interpretation and provoke verbal and behavioural responses, including obedience to command hallucinations.

**P1 Delusions**

**RECORD NUMBER OF DELUSIONS WITH EXAMPLES**

- **Delusions of interference with thinking:** Can you think clearly or is there interference with your thoughts? What kind of interference?
- **Delusions of thought insertion:** Are you in full control of your thoughts? Are thoughts put into your head which you know are not your own? How do you know they are not your own? Where do they come from?
- **Delusions of thought broadcast:** Do you ever seem to hear your own thoughts spoken aloud in your head, so that someone standing near might be able to hear them? How do you explain this? Are your thoughts broadcast so that other people know what you are thinking?
- **Delusions of thought echo or commentary:** Do you ever seem to hear your own thoughts repeated or echoed? What is that like? How do you explain it? Where does it come from?
- **Delusions of thought block:** Do you ever experience your thoughts stopping quite suddenly so that there are none left in your mind, even though your thoughts were flowing freely before? What is that like? How does it occur? What is it due to?
- **Delusions of thought withdrawal:** Do your thoughts ever seem to be taken out of your head, as though some external person or force were removing them? Can you give an example? How do you explain it?
- **Delusions of thoughts being read:** Can anyone read your thoughts? How do you know? How do you explain it?
- **Delusions of control:** Do you ever feel under the control of some force of power other than yourself? As though you were a robot without a will of your own? As though you were possessed by someone or something else? What is that like?
- **Delusions of reference:** Do you find that complete strangers sometimes talk about you? What do they say? Do people seem to drop hints about you, or say things with a double meaning, or do things in a special way so as to convey a meaning? Can you give an example of what they say/do? Is there any reference to you in the newspapers or television? Do you see any special meaning for yourself in the colours of objects or the way things are arranged?

- **Delusional misinterpretation or misidentification:** Are there people around who are not what they seem to be? Do you ever feel that the place you are in is not what it seems to be? Is anyone keeping a special watch on you? Do you feel you are being tested out in some way?
- **Delusions of persecution:** Is anyone deliberately trying to harm you, e.g. trying to poison you or kill you? How? Is there any kind of organisation behind it? Is there any other kind of persecution?
- **Assistance:** Do you think people are organising things specially to help you? What are they doing*?*
- **Grandiose abilities**: Is there anything special about you? Do you have any special powers or abilities? Can you read people's thoughts? Is there a special purpose or mission to your life? Are you especially clever or inventive?
- **Grandiose identity**: Are you a very prominent person or related to someone prominent like royalty? Are you very rich or famous? How do you explain this*?*
- **Religious delusions**: Are you a very religious person? Specially close to God? Can God communicate with you? Are you yourself a saint?
- **Delusional explanations**: How do you explain the things that have been happening? Is anything like hypnotism or telepathy going on? Is anything like electricity or X-rays or radio waves affecting you?
- Do you think your appearance is normal?
- ***Depersonalisation:*** Is anything the matter with your brain?

**P1 Delusions**

Beliefs which are unfounded, unrealistic, and idiosyncratic.

Basis for rating: Thought content expressed in the interview on social relations and behaviour.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.

3. Mild – Presence of one or two delusions which are vague, uncrystallized, and not tenaciously held. Delusions do not interfere with thinking, social relations, or behaviour.
4. Moderate – Presence of either a kaleidoscopic array of poorly formed, unstable delusions or of a few well-formed delusions that occasionally interfere with thinking, social relations, or behaviour.
5. Moderate-Severe – Presence of well-formed delusions that are tenaciously held and occasionally interfere with think, social relations, and behaviour.
6. Severe – Presence of a stable set of delusions which are crystallized, possibly systematised, tenaciously held, and clearly interfere with thinking, social relations, and behaviour.
7. Extreme – Presence of a stable set of delusions which are either highly systematised or very numerous, and which dominate major facets of the patient's life. This frequently results in inappropriate and irresponsible action, which may even jeopardise the safety of the patient or others.

**P6 Suspiciousness/Persecution**

- Have you felt uneasy or suspicious about anything in the past week?
- Do you generally get on okay with other people?
- Do you trust most people that you know? Are there any people you distrust? Who? Why do you think that is?
- Do people sometimes talk about you behind your back/ spy on you/watch you? What do they say? Why?
- Are people out to harm you?

**If yes:**

- What is the evidence for all this? Who is behind all this? Why does this happen?
- Do your feelings about others affect the way you talk to people? Does it make you not want to talk to people?

**P6 Suspiciousness/persecution**

Unrealistic or exaggerated ideas of persecution, as reflected in guardedness, a distrustful attitude, suspicious hypervigilance, or frank delusions that others mean one harm.

Basis for rating: Thought content expressed in the interview and its influence on behaviour.

1. Absent – Definition does not apply.
2. Minim*al – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Presents a guarded or even openly distrustful attitude, but thoughts, interactions, and behaviour are minimally affected.
4. Moderate – Distrustfulness is clearly evident and intrudes on the interview and/or behaviour, but there is no evidence of persecutory delusions. Alternatively, there may be indication of persecutory delusions, but these do not seem to affect the patient's attitude or interpersonal relations.
5. Moderate-Severe – Patient shows marked distrustfulness, leading to major disruption of interpersonal relations, or else there are clear-cut persecutory delusions that have limited impact on interpersonal relations and behaviour.
6. Severe – Clear-cut pervasive delusions or persecution which may be systematised and significantly interfere in interpersonal relations.
7. Extreme – A network systematised persecutory delusions dominate the patient's thinking, social relations, and behaviour.

**G16 Active Social Avoidance**

- Have you found yourself turning down any opportunities to go out with your friends because of fears or worries? Has this happened in the last week? How often?
- Do you prefer to be with others or on your own? Do you feel uncomfortable with others/in groups?
- If you are out and start to feel anxious would you leave and go home?

**G16 Active social avoidance**

Diminished social involvement associated with unwarranted fear, hostility, or distrust.

Basis for rating: Reports of social functioning by primary care workers or family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Patient seems ill at ease in the presence of others and prefers to spend time alone, although he/she participates in social functions when required.
4. Moderate – Patient begrudgingly attends all or most social activities but may need to be persuaded or may terminate prematurely on account of anxiety, suspiciousness, or hostility.
5. Moderate-Severe – Patient fearfully or angrily keeps away from many social interactions despite others; efforts to engage them. Tends to spend unstructured time alone.
6. Severe – Patient participates in very few social activities because of fear, hostility, and distrust. When approached the patient shows a strong tendency to break off interactions, and generally they tend to isolate themselves from others.
7. Extreme – Patient cannot be engaged in social activities because of pronounced fears, hostility, or persecutory delusions. To the extent possible, he/she avoids all interactions and remains isolated from others.

**N2 Emotional Withdrawal**

- Do you have anyone to talk to about your problems? Do you talk to them?
- Do people ever come and discuss their problems with you?
- Is there anyone who you are particularly close to?

**N2 Emotional withdrawal**

Lack of interest in, involvement with, and affective commitment to life's events.

Basis for rating: Reports of functioning from primary care workers or family and observation of interpersonal behaviour during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Usually lack initiative and occasionally may show deficient interest in surrounding events.
4. Moderate – Patient is generally distanced emotionally from the milieu and its challenges but, with encouragement, can be engaged.
5. Moderate-Severe – Patient is clearly detached emotionally from persons and events in the milieu, resisting all efforts at engagement. Patient appears distant, docile and purposeless but can be involved in communication at least briefly and tends to personal needs, sometimes with assistance.
6. Severe – Marked deficiency of interest and emotional commitment results in limited conversation with others and frequent neglect of personal functions, for which the patient requires supervision.
7. Extreme – Patient is almost totally withdrawn, uncommunicative, and neglectful of personal needs as a result of profound lack of interest and emotional commitment.

**N4 Passive/Apathetic Social Withdrawal**

- Do you sometimes turn down opportunities to go out because you simply can't be bothered? Has this happened in the last week? How often?
- When you go out, say to a party or the pub, do you only go if someone asks you to? Do you tend to enjoy yourself? Do you join in the conversation?
- Do you ever arrange a day out or a night out with others?
- When you are out and people talk to you are you happy to talk back? Do you ever start conversations?

**N4 Passive/apathetic social withdrawal**

Diminished interest and initiative in social interactions due to passivity, apathy, anergy, or avolition. This leads to reduced interpersonal involvements and neglect of activities of daily living.

Basis for rating: Reports on social behaviour from primary care workers or family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Shows occasional interest in social activities but poor initiative. Usually engages with others but only when approached first by them.
4. Moderate – Passively goes along with most social activities but in a disinterested or mechanical way. Tends to recede into the background.
5. Moderate-Severe – Passively participates in only a minority of activities and shows virtually no interest or initiative. Generally spends little time with others.
6. Severe – Tends to be apathetic and isolated, participating very rarely in social activities and occasionally neglecting personal needs. Has very few spontaneous social activities.
7. Extreme – Profoundly apathetic, socially isolated, and personally neglectful.

**G12 Lack of judgement and insight**

- What is your relationship to …… (name of keyworker)?
- Why do you see them?
- Do you take any medication? Does it help? What does it do?
- What do you think the medication is supposed to help with?
- Do you feel that medication will be useful to take in the future? Will you carry on taking your medication?
- Have you been given a diagnosis for your illness?
- Do you agree with the diagnosis? (If no) Have you been ill in the past?
- Schizophrenia affects people in many different ways. How do you think it has affected you?
- What symptoms do you have associated with your illness? Do you think ***(insert delusional beliefs)*** is anything to with your illness/the schizophrenia?
- What do you think caused your illness?

**G12 Lack of judgement and insight**

Impaired awareness or understanding of one's own psychiatric condition and life situation. This is evidenced by failure to recognize past or present psychiatric illness or symptoms, denial or need for psychiatric hospitalisation or treatment, decisions characterised by poor anticipation or consequences, and unrealistic short-term and long-range planning.

Basis for rating: Thought content expressed during the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Recognizes having a mental disorder but clearly underestimates its seriousness, the implications for treatment, or the importance of taking measures to avoid relapse. Future planning may be poorly conceived.
4. Moderate – Patient shows only a vague or shallow recognition of illness. There may be fluctuations in acknowledgement of being ill or little awareness of major symptoms which are present, such as delusions, disorganised thinking, suspiciousness, and social withdrawal. The patient may rationalise the need for treatment in terms of its relieving lesser symptoms, such as anxiety. Tension, and sleep difficulty.
5. Moderate-Severe – Acknowledges past but not present psychiatric disorder. If challenged, the patient may concede the presence of some unrelated or insignificant symptoms, which tend to be explained away by gross misinterpretation or delusional thinking. The need for psychiatric treatment similarly goes unrecognised.
6. Severe – Patient denies ever having had a psychiatric disorder. He/she disavows the presence if any psychiatric symptoms in the past or present and, though compliant, denies the need for treatment and hospitalisation.
7. Extreme – Emphatic denial of past and present psychiatric illness. Current hospitalisation and treatment are given a delusional interpretation (e.g. as punishment for misdeeds, as persecution by tormentors, etc.), and the patient may thus refuse to cooperate with therapists, medication, or other aspects of treatment.

**G10 Disorientation**

I'm now going to ask some questions about memory if that's okay…

- Do you know what today's date is? (elicit day/month/year)
- What time of the day is it?
- What season are we in?
- Where are we now? (address/ward/hospital)
- Do you know name of your keyworker? What about your psychiatrist? Doctor?
- Who is the Prime Minister?

**G10 Disorientation**

Lack of awareness of one's relationship to the milieu, including persons, place, and time, which may be due to confusion or withdrawal.

Basis for rating: Responses to the interview questions on orientation.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – General orientation is adequate but there is some difficulty with specifics. For example, the patient knows there location but not the street address, knows hospital staff names but not their functions, knows the month but confuses the day of the week with an adjacent day, or errs in the date by more than two days. There may be narrowing interest evidenced by familiarity with the immediate but not extended milieu, such as ability to identify staff but not the Mayor, Governor, or President.
4. Moderate – Only partial success in recognising persons, places, and time. For example, patient knows they are in a hospital but not its name, knows the name of the city but not the borough or district, knows the name of their primary care therapist but not many other direct care workers, knows the year and season but not sure of the month.
5. Moderate-Severe – Considerable failure in recognising persons, places, and time. Patient has only a vague idea of where they are and seem unfamiliar with most people in their milieu. He/she may identify the year correctly or nearly so but now know the current month, day of the week, or even season.

6. Severe – Marked failure in recognising persons, place, and time. For example, patient has no knowledge of their whereabouts, confuses the date by more than one year, can name only one or two individuals in their current life.
7. Extreme – Patient appears completely disoriented with regards to persons, place, and time. There is gross confusion or total ignorance about one's location, the current year, and even the most familiar people, such as parents, spouse, friends, and primary therapist.

**N5 Difficulty in Abstract Thinking**

- Now I'd like you to tell me how these pairs of words are similar or alike (work your way down from easiest to most difficult. Keep working down the list until client can no longer provide an answer).

1. (easiest items)
    - Apple and Banana?
    - Ball and Orange?
    - Pencil and Pen?
    - Penny and Pound?
2.
    - Table and Chair?
    - Tiger and Elephant?
    - Hat and Shirt?
    - Bus and Train?
3.
    - Arm and Leg?
    - Rose and Tulip?
    - Uncle and Cousin?
    - The sun and the moon?
4. (most difficult items)
    - Painting and poem?
    - Hilltop and valley?
    - Air and Water?
    - Peace and Prosperity?

**N5 Difficulty in abstract thinking**

Impairment in the use of the abstract-symbolic mode of thinking, as evidenced by difficulty in classification, forming generalisations, and proceeding beyond concrete or egocentric thinking in problem-solving tasks.

Basis for rating: Responses to questions on similarities and proverb interpretation, and use of concrete vs. abstract mode during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Tends to give literal or personalised interpretations to the more difficult proverbs and may have some problems with concepts that are fairly abstract or remotely related.
4. Moderate – Often utilises a concrete mode. Has difficulty with most proverbs and categories. Tends to be distracted by functional aspects and salient features.
5. Moderate-Severe – Deals primarily in a concrete mode, exhibiting with most proverbs and categories.
6. Severe – Unable to grasp the abstract meaning of any proverbs or figurative expressions and can formulate classifications for only the most simple of similarities. Thinking is either vacuous or lacked into functional aspects, salient features, and idiosyncratic interpretations.
7. Extreme – Can use only concrete modes of thinking. Shows no comprehension of proverbs, common metaphors or similes, and simple categories. Even salient and functional attributes do not serve as a basis for classification. This rating may apply to those who cannot interact even minimally with the examiner due to marked cognitive impairment

**P2 Conceptual Disorganisation**

OBSERVATION

Does the patient reply to questions in an irrelevant manner?

Does the patient show a pattern of speech in which his/her ideas slip off the tract onto another one which is indirectly related or completely unrelated?

Does the patient show a pattern of speech in which conclusions are reached which do not seem to follow logically?

Do the patient's replied last for ages so that they have to be interrupted and urged to get to the point?

Can the patient focus his/her thoughts on the question?

**P2 Conceptual disorganisation**

Disorganised process of thinking characterised by disruption of goal directed sequencing, e.g. circumstantially, tangentially, loose associations, nonsequiturs, gross illogicality, or thought block.

Basis for rating: Cognitive-verbal processes observed during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Thinking is circumstantial, tangential, or paralogical. There is some difficulty in directing thoughts towards a goal, and some loosening of associations may be evidenced under pressure.
4. Moderate – Able to focus thoughts when communications are brief and structured, but becomes loose or irrelevant when dealing with more complex communications or when under minimal pressure.
5. Moderate-Severe – Generally has difficulties in organising thoughts, as evidenced by frequent irrelevancies, disconnectedness, or loosening of association even when not under pressure.

6. Severe – Thinking is seriously derailed and internally inconsistent, resulting in gross irrelevancies and disruption of thought processes, which occur almost constantly.
7. Extreme – Thoughts are disrupted to the point where the patient is incoherent. There is marked loosening of associations, which result in total failure of communication, e.g. "word salad" or mutism.

**P4 Excitement**

OBSERVATION

Can the patient sit still?

Does the patient get over excited or restless?

**P4 Excitement**

Hyperactivity as reflected in accelerated motor behaviour, heightened responsivity to stimuli, hypervigilance, or excessive mood lability.

Basis for rating: Behaviour manifestations as well as reports of behaviour by primary care workers or family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Tends to be slightly agitated, hypervigilant, or mildly over-aroused throughout the interview, but without distinct episodes of excitement or marked mood lability. Speech may be slightly pressured.
4. Moderate – Agitation or over-arousal is clearly evident throughout the interview, affecting speech and general mobility, or episodic outbursts occur sporadically.
5. Moderate-Severe – Significant hyperactivity or frequent outbursts of motor activity are observed, making it difficult for the patient to sit still for longer than several minutes at any given time.
6. Severe – Marked excitement dominates the interview, delimits attention, and to some extent affects personal functions such as eating and sleeping.

7. Extreme – Marked excitement seriously interferes in eating and sleeping and makes interpersonal interactions virtually impossible. Acceleration of speech and motor activity may result in incoherence and exhaustion.

**P7 Hostility**

OBSERVATION

Is the patient sarcastic / irritable / verbally abusive / violent?

**P7 Hostility**

Verbal and non-verbal expressions of anger and resentment, including sarcasm, passive-aggressive behaviour, verbal abuse, and assaultiveness.

Basis for rating: Interpersonal behaviour observed during the interview and reports by primary care workers and family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Indirect or restrained communication of anger, such as sarcasm, disrespect, hostile expressions, and occasional irritability.
4. Moderate – Presents an overtly hostile attitude, showing frequent irritability and direct expression of anger or resentment.
5. Moderate-Severe – Patient is highly irritable and occasionally verbally abusive and threatening.
6. Severe – Uncooperativeness and verbal abuse or threats notably influence the interview and seriously impact upon social relations. Patient may be violent and destructive but is not physically assaultive toward others.
7. Extreme – Marked anger results in extreme uncooperativeness, precluding other interactions, or in episode(s) of physical assault toward others.

**N1 Blunted Affect**

OBSERVATION

Does the patient have stilted / forced / artificial facial expressions?

**N1 Blunted affect**

Diminished emotional responsiveness as characterised by a reduction in facial expression, modulation of feelings, and communicative gestures.

Basis for rating: Observation of physical manifestations of affective tone and emotional responsiveness during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Changes in facial expression and communicative gestures seem to be stilted, forced, artificial, or lacking in modulation.
4. Moderate – Reduced range of facial expression and few expressive gestures result in a dull appearance.
5. Moderate-Severe – Affect is generally 'flat', with only occasional changes in facial expression and a paucity of communicative gestures.
6. Severe – Marked flatness and deficiency of emotions exhibited most of the time. There may be unmodulated extreme affective discharges, such as excitement, rage, or inappropriate uncontrolled laughter.
7. Extreme – Changes in facial expression and communicative gestures are virtually absent. Patient seems to constantly show a barren or 'wooden' expression.

**N3 Poor Rapport**

OBSERVATION

Does the patient show lack of openness in conversation, interest or involvement with the interviewer?

Does the patient avoid eye or face contact?

Does the patient seem bored?

**N3 Poor rapport**

Lack of empathy, openness in conversation, and a sense of closeness, interest, or involvement with the interviewer. This is evidenced by interpersonal distancing and reduced verbal and non-verbal communication.

Basis for rating: Interpersonal behaviour during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Conversation is characterised by stilted, strained or artificial tone. It may lack emotional depth or tend to remain on an impersonal, intellectual plane.
4. Moderate – Patient typically is aloof, with interpersonal distance quite evident. Patient may answer questions mechanically, act bored, or express disinterest.
5. Moderate-Severe – Disinvolvement is obvious and clearly impedes the productivity of the interview. Patient may tend to avoid eye of face contact.
6. Severe – Patient is highly indifferent, with marked interpersonal distance. Answers are perfunctory, and there is little non-verbal evidence of involvement. Eye and face contact are frequently avoided.
7. Extreme – Patient is totally uninvolved with the interviewer. Patient appears to be completely indifferent and consistently avoids verbal and non-verbal interactions during the interview.

**N6 Lack of Spontaneity and Flow of Conversation**

OBSERVATION

Does the patient have diminished fluidity and productivity of the verbal-interaction process?

Does the patient use his initiative?

Does the patient need direct questions?

**N6 Lack of spontaneity and flow of conversation**

Reduction in the normal flow of communication associated with apathy, avolition, defensiveness, or cognitive deficit. This is manifested by diminished fluidity and productivity of the verbal interactional process.

Basis for rating: Cognitive-verbal processes observed during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Conversation shows little initiative. Patient's answers tend to be brief and unembellished, requiring direct and leading questions by the interviewer.
4. Moderate – Conversation lacks free flow and appears uneven or halting. Leading questions are frequently needed to elicit adequate responses and proceed with conversation.
5. Moderate-Severe – Patient shows a marked lack of spontaneity and openness, replying to the interviewer's questions with only one or two brief sentences.
6. Severe – Patient's responses are limited to a few words or shot phrases intended to avoid or curtail communication. (E.g. "I don't know", "I'm not a liberty to say".) Conversation is seriously impaired as a result, and the interview is highly unproductive.
7. Extreme – Verbal output it restricted to, at most, an occasional utterance, making conversation not possible.

**N7 Stereotyped Thinking**

OBSERVATION

Is the patient rigid or repetitious or show evidence of barren thought content?

**N7 Stereotyped thinking**

Decreased fluidity, spontaneity, and flexibility of thinking, as evidence in rigid, repetitious, or barren thought content.

Basis for rating: Cognitive-verbal processes observed during the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Some rigidity shown in attitudes or beliefs. Patient may refuse to consider alternative positions or have difficulty in shifting from one idea to another.
4. Moderate – Conversation revolves around a recurrent theme, resulting in difficulty in shifting to a new topic.
5. Moderate-Severe – Thinking is rigid and repetitious to the point that, despite the interviewer's efforts, conversation is limited to only two or three dominating topics.
6. Severe – Uncontrolled repetition of demands, statements, ideas, or questions which severely impairs conversation.
7. Extreme – Thinking, behaviour, and conversation are dominated by constant repetition of fixed ideas or limited phrases, leading to gross rigidity, inappropriateness, and restrictiveness of patient's communication.

**G4 Tension**

OBSERVATION

Look for physical manifestations resulting from anxiety.

**G4 Tension**

Overt physical manifestations of fear, anxiety, and agitation, such as stiffness, tremor, profuse sweating, and restlessness.

Basis for rating: Verbal report attesting to anxiety and, thereupon, the severity of physical manifestations of tension observed during the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Posture and movements indicate slight apprehensiveness, such as minor rigidity, occasional restlessness, shifting of position, or fine rapid hand tremor.
4. Moderate – A clearly nervous appearance emerges from various manifestations, such as fidgety behaviour, obvious hand tremor, excessive perspiration, or nervous mannerisms.

5. Moderate-Severe – Pronounced tension is evidenced by numerous manifestations, such as nervous shaking, profuse sweating, and restlessness, but conduct in the interview is not significantly affected.
6. Severe – Pronounced tension to the point that interpersonal interactions are disrupted. The patient, for example, may be constantly fidgeting, unable to sit still for long, or show hyperventilation.
7. Extreme – Marked tension is manifested by signs of panic or gross motor acceleration, such as rapid restless pacing and inability to remain seated for longer than a minute, which makes sustained conversation not possible.

**G5 Mannerisms and Posturing**

OBSERVATION

Does the patient have unnatural movements or posture?

**G5 Mannerisms and posturing**

Unnatural movements or posture as characterised by an awkward, stilted, disorganised, or bizarre appearance.

Basis for rating: Observation of physical manifestations during the course of the interview as well as reports from primary care workers and family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Slight awkwardness in movements or minor rigidity of posture.
4. Moderate – Movements are notably awkward or disjointed, or an unnatural posture is maintained for brief periods.
5. Moderate-Severe – Occasional bizarre rituals or contorted posture are observed, or an abnormal position is sustained for extended periods.
6. Severe – Frequent repetition of bizarre rituals, mannerisms, or stereotyped movements, or a contorted posture is sustained for extended periods.
7. Extreme – Functioning is seriously impaired by virtually constant involvement in ritualistic, manneristic, or stereotyped movements or by an unnatural fixed posture which is sustained most of the time.

**G7 Motor Retardation**

OBSERVATION

Does the patient give slowing or lessening of speech or movements?

**G7 Motor retardation**

Reduction in motor activity as reflected in slowing or lessening or movements and speech, diminished responsiveness to stimuli, and reduced body tone.

Basis for rating: Manifestations during the course of the interview as well as reports by primary care workers or family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Slight but noticeable diminution in rate of movements and speech. Patient may be somewhat unproductive in conversation and gestures.
4. Moderate – Patient is clearly slow in movements, and speech may be characterised by poor productivity, including long response latency, extended pauses, or slow pace.
5. Moderate-Severe – A marked reduction in motor activity renders communication highly unproductive or delimits functioning in social and occupational situations. Patient can usually be found sitting or lying down.
6. Severe – Movements are extremely slow, resulting in a minimum of activity and speech. Essentially the day is spent sitting idly or lying down.
7. Extreme – Patient is almost completely immobile and virtually unresponsive to external stimuli.

**G8 Uncooperativeness**

OBSERVATION

Does the patient refuse to comply with significant others?

**G8 Uncooperativeness**

Active refusal to comply with the will of significant others, including the interviewer, hospital staff, or family, which may be associated with distrust, defensiveness, stubbornness, negativism, rejection of authority, hostility, or belligerence.

Basis for rating: Interpersonal behaviour observed during the course of the interview as well as reports by primary care workers or family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Complies with an attitude of resentment, impatience, or sarcasm. May inoffensively object to sensitive probing during the interview.
4. Moderate – Occasional outright refusal to comply with normal social demands, such as making own bed, attending scheduled programs, etc. The patient may project a hostile, defensive, or negative attitude but usually can be worked with.
5. Moderate-Severe –Patient frequently is incompliant with the demands of their milieu and may be characterised by others and an 'outcast' or having 'a serious attitude problem'. Uncooperativeness is reflected in obvious defensiveness or irritability with the interviewer and possible unwillingness to address many questions.
6. Severe – Patient is highly uncooperative, negativistic, and possibly also belligerent. Refuses to comply with most social demands and may be unwilling to initiate or conclude the full interview.
7. Extreme – Active resistance seriously impacts on virtually all major areas of functioning. Patient may refuse to join in any social activities, tend to personal hygiene, converse with family or staff, and participate briefly in an interview.

**G9 Unusual Thought Content**

OBSERVATION

Does the patient have strange / fantastic / bizarre ideas that range from being remote / atypical to being disordered / illogical / absurd?

**G9 Unusual thought content**

Thinking characterised by strange, fantastic, or bizarre ideas, ranging from those which are remote or atypical to those which are distorted, illogical, and patently absurd.

Basis for rating: Thought content expressed during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Thought content is somewhat peculiar, or idiosyncratic, or familiar ideas are framed in an odd context.
4. Moderate – Ideas are frequently distorted and occasionally seem quite bizarre.
5. Moderate-Severe – Patient expresses many strange and fantastic thoughts (e.g. being the adopted son of a king, being an escapee from death row) or some which are patently absurd (e.g. having hundreds of children, receiving radio messages from outer space through a tooth filling).
6. Severe – Patient expresses many illogical or absurd ideas or some which have a distinctly bizarre quality (e.g. having three heads, being a visitor from another planet).
7. Extreme – Thinking is replete with absurd, bizarre, and grotesque ideas.

**G11 Poor Attention**

OBSERVATION

What sorts of things do they do during the day?

How is their concentration

Are they distracted by things easily?

**G11 Poor attention**

Failure in focused alertness manifested by poor concentration, distractibility from internal and external stimuli, and difficulty in harnessing, sustaining, or shifting focus to new stimuli.

Basis for rating: Manifestations during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Limited concentration evidenced by occasional vulnerability to distraction or faltering attention toward the end of the interview.
4. Moderate – Conversation is affected by the tendency to be easily distracted, difficulty in long sustaining concentration on a given topic, or problems in shifting attention to new topics.
5. Moderate-Severe – Conversation is seriously hampered by poor concentration, distractibility, and difficulty in shifting focus appropriately.
6. Severe – Patient's attention can be harnessed for only brief moments or with great effort, due to marked distraction by internal or external stimuli.
7. Extreme – Attention is so disrupted that even brief conversation is not possible.

**G13 Disturbance of volition**

OBSERVATION

Does the client appear to have control over his or her thoughts and actions?

**G13 Disturbance of volition**

Disturbances in the wilful initiation, sustenance, and control of one's thoughts, behaviour, movements, and speech.

Basis for rating: Thought content and behaviour manifested in the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – There is evidence of some indecisiveness in conversation and thinking, which may impede verbal and cognitive processes to a minor extent.
4. Moderate – Patient is often ambivalent and shows clear difficulty in reaching decisions. Conversation may be marred by alternation in thinking, and in consequence verbal and cognitive functioning are clearly impaired.
5. Moderate-Severe – Disturbance of volition interferes in thinking as well as behaviour. Patient shows pronounced indecision that impedes the initiation and continuation of social and motor activities, and which also may be evidenced in halting speech.
6. Severe – Disturbance of volition interferes in the execution of simple, automatic motor functions, such as dressing and grooming, and markedly effects speech.
7. Extreme – Almost complete failure of volition is manifested by gross inhibition of movement and speech, resulting in immobility and/or mutism.

**G14 Poor Impulse Control**

OBSERVATION

Does the patient exhibit impulsive episodes of threatening, destructive or verbally abusive behaviour without concern about the consequences?

**G14 Poor impulse control**

Disordered regulation and control of action on inner urges, resulting in sudden, unmodulated, arbitrary, or misdirected discharge of tension and emotion without concern about the consequences.

Basis for rating: Behaviour during the course of interview and reported by primary care workers or family.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Patient tends to be easily angered or frustrated when facing stress or denied gratification but rarely acts on impulse.
4. Moderate – Patient gets angered and verbally abusive with minimal provocation. May be occasionally threatening, destructive, or have one or two episodes involving physical confrontation or a minor brawl.
5. Moderate-Severe – Patient exhibits repeated impulse episodes involving verbal abuse, destruction of property, or physical threats. There may be one or two episodes involving serious assault, for which the patient requires isolation, physical restraint, or p.r.n sedation
6. Severe – Patient frequently is impulsively aggressive, threatening, demanding and destructive, without any apparent consideration of the consequences. Shows assaultive behaviour and may also be sexually offensive and possibly respond behaviourally to hallucinatory commands.
7. Extreme – Patient exhibits homicidal attacks, sexual assaults, repeated brutality, or self-destructive behaviour. Requires constant direct supervision or external constraints because of inability to control dangerous impulses.

**G15 Preoccupation**

OBSERVATION

Does the patient seem self-absorbed, as if day dreaming or involved with internal experiences?

Does s/he talk / mutter / laugh to him / herself?

Are they an attentive interviewee?

**G15 Preoccupation**

Absorption with internally generated thoughts and feelings and with autistic experiences to the detriment of reality orientation and adaptive behaviour.

Basis of rating: Interpersonal behaviour observed during the course of the interview.

1. Absent – Definition does not apply.
2. Minimal – Questionable pathology; may be at the upper extreme of normal limits.
3. Mild – Excessive involvement with personal needs or problems, such that conversation veers back to egocentric themes and there is diminished concern exhibited towards others.
4. Moderate – Patient occasionally appears self-absorbed, as if day dreaming or involved with internal experiences, which interferes with communication to a minor extent.
5. Moderate-Severe – Patient often appears to be engaged in autistic experiences, as evidenced by behaviours that significantly intrude on social and communicational functions, such as the presence of a vacant stare, muttering or talking to oneself, or involvement with stereotyped motor patterns.
6. Severe – Marked preoccupation with autistic experiences, which seriously delimits concentration, ability to converse, and orientation the milieu. The patient frequently may be observed smiling, laughing, muttering, or shouting to themselves.
7. Extreme – Gross absorption with autistic experiences, which profoundly affects all major realms of behaviour. The patient constantly may be responding verbally and behaviourally to hallucinations and show little awareness of other people or the external milieu.

# APPENDIX 1

## PSYCHOTIC SYMPTOMS RATING SCALES (Haddock et al., 1999)

## DELUSIONS

## GENERAL INSTRUCTIONS

The following structured interview is designed to elicit specific details regarding different dimensions of delusional beliefs. When asking questions, the interview is designed to rate the patient's experiences over the last week for the majority of items. There is one exception to this. When rating conviction, ask the patient about their conviction at the time of interview.

Name: ……..…

Age: ……..…

Sex: M / F

Diagnosis: (if relevant) ……..…

Length of time delusional beliefs (years) ……..…

Please specify individual delusional beliefs:

**DELUSIONS: SCORING CRITERIA**

1. AMOUNT OF PREOCCUPATION WITH DELUSIONS

How much time do you spend thinking of your beliefs?
- all the time / daily / weekly etc.?

0. No delusions, or delusions which the subject thinks about less than once a week.

1. Subject thinks about beliefs at least once a week.

2. Subject thinks about beliefs at least once a day.

3. Subject thinks about beliefs at least once an hour.

4. Subject thinks about delusions continuously or almost continuously.
Subject can only think about other things for a few seconds or minutes.

2. DURATION OF PREOCCUPATION WITH DELUSIONS

When the beliefs come into your mind, how long do they persist?
-Few seconds/minutes/hours, etc.?

0. No delusions

1. Thoughts about beliefs last for a few seconds, fleeting thoughts

2. Thoughts about delusions last for several minutes

3. Thoughts about delusions last for at least one hour

4. Thoughts about delusions usually last for hours at a time

3. CONVICTION (at the time of interview)

RECORD FOR EACH DELUSION

At the present time how convinced are you that your beliefs are true? Can you estimate this on a scale from 0 – 100, where 100 means that you are totally convinced by your beliefs and 0 being that you are not convinced at all?

0. No conviction at all

1. Very little conviction in reality of beliefs, less than 10%

2. Some doubts relating to conviction in beliefs, between 10-49%

3. Conviction in belief is very strong, between 50 – 99%

4. Conviction is 100%

4. AMOUNT OF DISTRESS

Do your beliefs cause you distress?

How much of the time do they cause you distress?

0. Beliefs never cause distress

1. Beliefs cause distress on the minority of occasions.

2. Beliefs cause distress on less than 50 % of occasions

3. Beliefs cause distress on the majority of occasions when they occur between 51-99% of time

4. Beliefs always cause distress when they occur

5. INTENSITY OF DISTRESS

When your beliefs distress you*, how severe does this feel?

0. No distress

1. Beliefs cause slight distress

2. Beliefs cause moderate distress

3. Beliefs cause marked distress

4. Beliefs cause extreme distress, couldn't be worse

6. DISRUPTION TO LIFE CAUSED BY BELIEFS

How much disruption do your beliefs cause you?

-Do they prevent you working or carrying out a day-time activity?
-Do they interfere with your relationships with family or friends?

-Do they interfere with your ability to look after yourself, e.g. washing, changing clothes, etc?

0. No disruption to life, able to maintain independent living with no problems in daily living skills. Able to maintain social and family relationships (if present)

1. Beliefs cause minimal amount of disruption to life, e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.

2. Beliefs cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The patient is not in hospital although may live in supported accommodation or receive additional help with daily living skills.

3. Beliefs cause severe disruption to life so that hospitalisation is usually necessary. The patient is able to maintain some daily activities, self-care and relationships whilst in hospital. The patient may also be in supported accommodation but experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.

4. Beliefs cause complete disruption of daily life requiring hospitalisation. The patient is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

## *DELUSIONS: SCORE SHEET*

ID Number_____ Time point_____ Date_____

SCORE

1. AMOUNT OF PREOCCUPATION
2. DURATION OF PREOCCUPATION
3. CONVICTION
4. AMOUNT OF DISTRESS
5. INTENSITY OF DISTRESS
6. DISRUPTION

## *HALUCINATIONS*

## *GENERAL INSTRUCTIONS*

The following structured interview is designed to elicit specific details regarding different dimensions of auditory hallucinations. When asking questions, the interview is designed to rate the patient's experiences over the last week for the majority of items. There are two exceptions to this e.g. when asking about beliefs regarding cause of voices, rate the patient's response based on what they believe at the time of the interview. Also loudness of voices should be rated according to the loudness of voices at the time of interview or the last time the patient experienced them..

Name: ……..…

Age: ……..…

Sex: M / F

Diagnosis: (if relevant) ……..…

Length of time delusional beliefs (years) ……..…

Please specify individual delusional beliefs:

## *AUDITORY HALUCINATIONS: SCORING CRITERIA*

### 1. FREQUENCY

*-How often do you experience voices? e.g. every day, all day long etc.*

0. Voices not present or present less than once a week (specify frequency if present)
1. Voices occur for at least once a week
2. Voices occur at least once a day
3. Voices occur at least once an hour
4. Voices occur continuously or almost continuously i.e., stop for only a few seconds or minutes

### 2. DURATION

*-When you hear your voices, how long do they last, e.g. for a few seconds, minutes, hours, all day long?*

0. Voices not present
1. Voices last for a few seconds, fleeting voices
2. Voices last for several minutes
3. Voices last for at least one hour
4. Voices last for hours at a time

### 3. LOCATION

*-When you hear your voices, where do they sound like they're coming from?*
*-inside your head and/or outside your head?*
*-if voices sound like they are outside your head, whereabouts do they sound like they are coming from?*

0. No voices present
1. Voices sound like they are inside head only
2. Voices outside the head, but close to ears or head. Voices inside the head may also be present.
3. Voices sound like they are inside or close to ears and outside head away from ears
4. Voices sound like they are from outside the head only

## 4. LOUDNESS

*-How loud are your voices?*

*-Are they louder than your voice, about the same loudness, quieter or just a whisper?*

0. Voices not present

1. Quieter than own voice, whispers.

2. About same loudness as own voice

3. Louder than own voice

4. Extremely loud, shouting

## 5. BELIEFS RE-ORIGIN OF VOICES

RECORD FOR EACH VOICE

*-What do you think has caused your voices?*

*-Are the voices caused by factors related to yourself or solely due to other people or factors?*

*If patient expresses an external origin:*

*-How much do you believe that your voices are caused by …… (add patient's contribution) on an scale from 0-100 with 100 being that you are totally convinced, have no doubts and 0 being that it is completely untrue?*

0. Voices not present
1. Believes voices to be solely internally generated and related to self
2. Holds a less than 50% conviction that voices originate from external causes
3. Holds 50% or more conviction (but less than 100%) that voices originate from external causes
4. Believes voices are solely due to external causes (100% conviction)

## 6. AMOUNT OF NEGATIVE CONTENT OF VOICES

RECORD FOR EACH VOICE

*-Do your voices say unpleasant things or negative things?*

*-Can you give me some examples of what the voices say? (record these examples)*

*-How much of the time do the voices say these types of unpleasant or negative items?*

0. No unpleasant content
1. Occasional unpleasant content
2. Minority of voice content is unpleasant or negative (less than 50%)
3. Majority of voice content is unpleasant or negative (50% or more)
4. All of voice content is unpleasant or negative

## 7. DEGREE OF NEGATIVE CONTENT

RECORD FOR EACH VOICE

*(Rate using criteria on scale, asking patient for more detail, if necessary).*

0. Not unpleasant or negative
1. Some degree of negative content, but not personal comments relating to self or family e.g. swear words or comments not directed to self, e.g. "the milkman's ugly"
2. Personal verbal abuse, comments on behaviour e.g. "shouldn't do that or say that"
3. Personal verbal abuse relating to self-concept e.g. "you're lazy, ugly, mad, perverted"
4. Personal threats to self e.g. threats to harm self or family, extreme instructions or commands to harm self or others and personal verbal abuse as in (3)

## 8. AMOUNT OF DISTRESS

*-Are your voices distressing?*

*-How much of the time?*

0. Voices not distressing at all

1. Voices occasionally distressing, majority not distressing (<10%)

2. Minority of voices distressing (<50%)

3. Majority of voices distressing, minority not distressing (³ 50%)

4. Voices always distressing

## 9. INTENSITY OF DISTRESS

*-When voices are distressing, how distressing are they?*

*-Do they cause you minimal, moderate, severe distress?*

*-Are they the most distressing they have ever been?*

0. Voices not distressing at all

1. Voices slightly distressing

2. Voices are distressing to a moderate degree

3. Voices are very distressing, although subject could feel worse

4. Voices are extremely distressing, feel the worst he/she could possibly feel

## 10. DISRUPTION TO LIFE CAUSED BY VOICES

*-How much disruption do the voices cause to your life?*

*-Do the voices stop you from working or other daytime activity?*

*-Do they interfere with your relationships with friends and/or family?*

*-Do they prevent you from looking after yourself, e.g. bathing, changing clothes, etc?*

0. No disruption to life, able to maintain social and family relationships (if present)

1. Voices cause minimal amount of disruption to life e.g. interferes with concentration although able to maintain daytime activity and social and family relationships and be able to maintain independent living without support.

2. Voices cause moderate amount of disruption to life causing some disturbance to daytime activity and/or family or social activities. The patient is not in hospital although may live in supported accommodation or receive additional help with daily living skills.

3. Voices cause severe disruption to life so that hospitalisation is usually necessary. The patient is able to maintain some daily activities, self-care and relationships whilst in hospital. The patient may also be in supported accommodation but

experiencing severe disruption of life in terms of activities, daily living skills and/or relationships.

4. Voices cause complete disruption of daily life requiring hospitalisation. The patient is unable to maintain any daily activities and social relationships. Self-care is also severely disrupted.

## 11. CONTROLLABILITY OF VOICES

*-Do you think you have any control over when your voices happen?*

*-Can you dismiss or bring on your voices?*

0. Subject believes they can have control over the voices and can always bring on or dismiss them at will
1. Subject believes they can have some control over the voices on the majority of occasions
2. Subject believes they can have some control over their voices approximately half of the time
3. Subject believes they can have some control over their voices but only occasionally. The majority of the time the subject experiences voices which are uncontrollable
4. Subject has no control over when the voices occur and cannot dismiss or bring them on at all.

**AUDITORY HALLUCINATIONS: SCORE SHEET**

ID Number_____ Timepoint_____ Date_____

SCORE

1. FREQUENCY

2. DURATION

3. LOCATION

4. LOUDNESS

5. BELIEFS RE-ORIGIN OF VOICES

6. AMOUNT OF NEGATIVE CONTENT OF VOICES

7. DEGREE OF NEGATIVE CONTENT

8. AMOUNT OF DISTRESS

9. INTENSITY OF DISTRESS

10. DISRUPTION

11. CONTROL

## APPENDIX 2

## GUIDELINES FOR ADMINISTERING THE CALGARY DEPRESSION SCALE (Addington et al, 1990).

- The Calgary Depression Scale (CDS) is administered as a semi-structured interview and consists of 9 items.
- **It is suggested that the items from the Calgary Depression Scale are incorporated into the Depression (G6) item of the PANSS.**
- **However, the Calgary is based on the last <u>two weeks</u>, whereas the PANSS is based on the last week only.**
- The CDS items will help you to rate G6 – depression of the PANSS.
- Item 5 of the CDS (pathological guilt) will also help you in rating G3 (guilt feelings) of the PANSS.
- Ask the CDS questions as they are written although follow up probes can be used for further clarification.
- The last item (9) is based on **observations** from the entire interview

**Calgary Depression Items**

1. **Depression**
2. **Hopelessness**
3. **Self Depreciation**
4. **Guilty ideas of reference**
5. **Pathological Guilt**
6. **Morning Depression**
7. **Early Wakening**
8. **Suicide**
9. **Observed Depression**

## Scoring the Calgary Depression Scale

Items in the Calgary Depression Scale are scored as follows:

**0 – Absent**
**1 – Mild**
**2 – Moderate**
**3 – Severe**

The overall total is calculated. This produces a range of scores from 0 (not depressed) to 27 (severely depressed).

**Calgary Depression Scale**

**ID Number:_____ Observation Period _____ Date _____**

Interviewer: Ask the first question as written. Use follow up probes or qualifiers at your discretion.. N.B. The last item (9) is based on observations of the entire interview.

**1. DEPRESSION: How would you describe your mood over the last two weeks? Do you keep reasonably cheerful or have you been very depressed or low spirited recently? In the last two weeks how often have you (own words) every day? All day?**

***0. Absent***
***1. Mild:*** *Expresses some sadness or discouragement on questioning.*
***2. Moderate:*** *Distinct depressed mood persisting up to half the time over last 2 weeks: present daily.*
***3. Severe:*** *Markedly depressed mood persisting daily over half the time interfering with normal motor and social functioning.*

**2. HOPELESSNESS: How do you see the future for yourself? Can you see any future? - or has life seemed quite hopeless? Have you given up or does there still seem some reason for trying?**

***0. Absent***

***1. Mild****: Has at times felt hopeless over the last two weeks but still has some degree of hope for the future.*

***2. Moderate:*** *Persistent, moderate sense of hopelessness over last week. Can be persuaded to acknowledge possibility of things being better.*

***3. Severe:*** *Persisting and distressing sense of hopelessness.*

**3. SELF DEPRECIATION: What is your opinion of your self compared to other people? Do you feel better, not as good, or about the same as other? Do you feel inferior or even worthless?**

***0. Absent***

***1. Mild:*** *Some inferiority; not amounting to feeling of worthlessness.*

***2. Moderate:*** *Subject feels worthless, but less than 50% of the time.*

***3. Severe:*** *Subject feels worthless more than 50% of the time. May be challenged to acknowledge otherwise.*

**4. GUILTY IDEAS OF REFERENCE: Do you have the feeling that you are being blamed for something or even wrongly accused? What about? (Do not include justifiable blame or accusation. Exclude delusions of guilt.)**

***0. Absent***

***1. Mild****: Subject feels blamed but not accused less than 50% of the time.*

***2. Moderate:*** *Persisting sense of being blamed, and/or occasional sense of being accused.*

***3. Severe:*** *Persistent sense of being accused. When challenged, acknowledges that it is not so.*

**5. PATHOLOGICAL GUILT: Do you tend to blame yourself for little things you may have done in the past? Do you think that you deserve to be so concerned about this?**

***0. Absent***

***1. Mild:*** *Subject sometimes feels over guilty about some minor peccadillo, but less than 50% of time.*

***2. Moderate:*** *Subject usually (over 50% of time) feels guilty about past actions the significance of which he exaggerates.*

***3. Severe:*** *Subject usually feels s/he is to blame for everything that has gone wrong, even when not his/her fault.*

**6. MORNING DEPRESSION: When you have felt depressed over the last 2 weeks have you noticed the depression being worse at any particular time of day?**

***0. Absent:*** *No depression.*

***1. Mild Depression:*** *present but no diurnal variation.*

***2. Moderate Depression:*** *spontaneously mentioned to be worse in a.m.*

***3. Severe Depression:*** *markedly worse in a.m., with impaired functioning which improves in p.m.*

**7. EARLY WAKENING: Do you wake earlier in the morning than is normal for you? How many times a week does this happen?**

***0. Absent:*** *No early wakening.*

***1. Mild:*** *Occasionally wakes (up to twice weekly) 1 hour or more before normal time to wake or alarm time.*

***2. Moderate:*** *Often wakes early (up to 5 times weekly) 1 hour or more before normal time to wake or alarm.*

***3. Severe:*** *Daily wakes 1 hour or more before normal time.*

**8. SUICIDE: Have you felt that life wasn't worth living? Did you ever feel like ending it all? What did you think you might do? Did you actually try?**

***0. Absent***

***1. Mild:*** *Frequent thoughts of being better off dead, or occasional thoughts of suicide.*

***2. Moderate:*** *Deliberately considered suicide with a plan, but made no attempt.*

***3. Severe:*** *Suicidal attempt apparently designed to end in death (i.e.: accidental discovery of inefficient means).*

**9. OBSERVED DEPRESSION: Based on interviewer's observations during the entire interview. The question "Do you feel like crying?" used at appropriate points in the interview, may elicit information useful to this observation.**

***0. Absent***

***1. Mild:*** *Subject appears sad and mournful even during parts of the interview, involving affectively neutral discussion.*

***2. Moderate****: Subject appears sad and mournful throughout the interview, with gloomy monotonous voice and is tearful or close to tears at times.*

***3. Severe:*** *Subject chokes on distressing topics, frequently sighs deeply and cries openly, or is persistently in a state of frozen misery if examiner is sure that this is present.*

## PANSS SCORING SHEET

| | Absent (1) | Minimal (2) | Mild (3) | Moderate (4) | Moderate Severe (5) | Severe (6) | Extreme (7) |
|---|---|---|---|---|---|---|---|
| *Positive Symptom Factor* | | | | | | | |
| P1 Delusions | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| P2 Conceptual disorganisation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| P3 Hallucinatory behaviour | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| P4 Excitement | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| P5 Grandiosity | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| P6 Suspiciousness/persecution | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| P7 Hostility | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *Negative Symptom Factor* | | | | | | | |
| N1 Blunted affect | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| N2 Emotional withdrawal | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| N3 Poor rapport | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| N4 Passive/apathetic social withdrawal | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| N5 Difficulty in abstract thinking | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| N6 Lack of spontaneity & flow of conversation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| N7 Stereotyped thinking | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| *General Symptom Factor* | | | | | | | |
| G1 Somatic concern | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G2 Anxiety | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G3 Guilt feelings | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G4 Tension | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G5 Mannerisms & posturing | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G6 Depression | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G7 Motor retardation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G8 Uncooperativeness | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G9 Unusual thought content | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G10 Disorientation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G11 Poor attention | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G12 Lack of judgement & insight | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G13 Disturbance of volition | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G14 Poor impulse control | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G15 Preoccupation | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| G16 Active social avoidance | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

| | |
|---|---|
| Total Positive Symptom Factor ( $P_{tot}$) | |
| Total Negative Symptom Factor ( $N_{tot}$) | |
| Total General Symptom Factor | |
| $P_{tot}$ - $N_{tot}$ = | |
| Overall Total | |

NOTES DURING INTERVIEW

**G1 SOMATIC CONCERN**

**G2 ANXIETY**

**G6 DEPRESSION**

**G3 GUILT FEELINGS**

**P5 GRANDIOSITY**



**P3 HALLUCINATORY BEHAVIOUR**



**P1 DELUSIONS**



**P6 SUSPICIOUSNESS/PERSECUTION**

**G16 ACTIVE SOCIAL AVOIDANCE**



**N2 EMOTIONAL WITHDRAWAL**



**N4 PASSIVE/APATHETIC SOCIAL WITHDRAWAL**



**G12 LACK OF JUDGEMENT AND INSIGHT**

**G10 DISORIENTATION**



**N5 DIFFICULTY IN ABSTRACT THINKING**



**P2 CONCEPTUAL DISORGANISATION**



**P4 EXCITEMENT**

**P7 HOSTILITY**



**N1 BLUNTED AFFECT**



**N3 POOR RAPPORT**



**N6 LACK OF SPONTANEITY AND FLOW OF CONVERSATION**

**N7 STEREOTYPED THINKING**



**G4 TENSION**



**G5 MANNERISMS AND POSTURING**



**G7 MOTOR RETARDATION**

**G8 UNCOOPERATIVENESS**



**G9 UNUSUAL THOUGHT CONTENT**



**G11 POOR ATTENTION**



**G13 DISTURBANCE OF VOLITION**

**G14 POOR IMPULSE CONTROL**



**G15 PREOCCUPATION**

# Appendix 9b. Service engagement scale

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## A new scale (SES) to measure engagement with community mental health services

Lynda Tait, Max Birchwood & Peter Trower

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# A new scale (SES) to measure engagement with community mental health services

LYNDA TAIT, MAX BIRCHWOOD & PETER TROWER

*Early Intervention Service, Northern Birmingham Mental Health Trust and School of Psychology, University of Birmingham*

**Abstract**

The need for a measure of engagement with Community Mental Health Services has been identified. This article reports on the development and preliminary psychometric evaluation of a scale, Service Engagement Scale (SES), to measure engagement with community mental health services. Five Community Psychiatric Nurses completed the SES for 66 clients receiving Assertive Outreach services with an ICD-10 diagnosis of schizophrenia. Test–retest reliability of the subscale items and scale total is in the good to excellent range. Validity is supported by good internal consistency and by the criterion group method. Although preliminary psychometric results are promising, further psychometric study is necessary to evaluate the scale's factor structure. The SES appears to evaluate engagement with services, and may therefore be a useful tool to identify areas of concern with clients experiencing engagement difficulties.

## Introduction

A significant number of persons with serious mental illness, particularly schizophrenia, are often difficult to engage in mental health community-based services (Mueser *et al.*, 1998; Sainsbury Centre, 1998), particularly individuals with a dual diagnosis of substance abuse (Watkins *et al.*, 1999). This issue has become important because of the shift from hospital-based to community-based treatment, and it is Government policy that increased emphasis should be given to targeting difficult to engage clients in providing mental health care (Department of Health, 2000).

Psychosocial factors have been implicated in the engagement process, but their role in building a trusting relationship between mental health care professionals and difficult to engage clients remains poorly understood (Levy, 1998; Watkins *et al.*, 1999). The psychological processes (e.g. empathy, negotiating goals, and coping strategies) that may be implicated have yet to be empirically examined (Levy, 1998). Identification and analyses of these processes may be important in guiding the development of interventions in building a trusting relationship (engagement). Furthermore, the importance of psychosocial processes in the development and maintenance of the working relationship be-

Address for Correspondence: Lynda Tait, School of Psychology, The University of Birmingham, Edgbaston, Birmingham B15 2TT, UK. Tel: 0121 414 4932; Fax: 0121 414 4897; E-mail: LAT726@bham.ac.uk

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tween mental health care professionals and difficult to engage clients may vary between men and women. Watkins *et al.* (1999) found that men and women differed in their perception of the engagement process and had different needs concerning engagement. This suggests that difficult to engage men and women may particularly benefit from the use of gender-based psychological interventions, but further definition of the engagement processes involved in the observed differences would be of value.

It may be argued that there is an element of coercion in requiring clients to 'engage' with mental health services and that this requirement, in addition to an exclusive focus on measuring client engagement from the perspective of professionals, reflects a one sided approach to the issue. Our research focus on client engagement with services suggests that non-engagement should not always be viewed as a problem of clients. There are often valid reasons for client withdrawal from services, or non-acceptance of services. For example, where services offered, or provided, are perceived as culturally insensitive or clients are dissatisfied with the services offered (Sainsbury Centre, 1998). Indeed, we agree with Onyett (1999) that one of the barriers to an effective relationship between clients and providers of mental health care is where the care provided by services is experienced by clients as being 'socially devaluing and oppressive'. Where services are inappropriate to client need, or insensitively delivered, then non-engagement with services as a reaction to these experiences can be seen as a rational and active choice. It is our belief that where services are designed to target the perceived needs and preferences of clients, achieving a collaborative and trusting relationship is key to delivering those services. Undoubtedly, the attitudes and characteristics of mental health professionals as well as clients contribute to the creation and maintenance of a trusting relationship between clients and professionals (Perkins & Repper, 1996). Therefore, the formation of an effective relationship between Community Mental Health Team staff members and clients is a crucial task for both parties, and strategies aimed at improving this relationship should be considered.

The problem of non-engagement with services has been addressed by a recent effort to identify the issues seen as important by persons with serious mental illness (Sainsbury Centre, 1998). This research included taking account of the perceptions of psychiatric services of, and issues of particular importance to, Black and minority ethnic clients who are over-represented in the group of persons holding negative expectations of services (Sainsbury Centre, 1998). Briefly, non-engagement may reflect either the extent to which service users' perceived social and clinical needs are met or unmet, or results from negative evaluations of the quality of care received, or results from social experience and personality characteristics that influence attitudes towards mental health services (Sainsbury Centre, 1998).

Engagement is of concern to providers of community-based care models of service delivery (e.g. case management and assertive community treatment), as difficult-to-engage clients are especially targeted in these approaches to community care (Mueser *et al.*, 1998). Engagement is one of several essential components identified in the practice of assertive community treatment and other case management models (Fiander & Burns, 2000; Ford *et al.*, 1995; Hemming & Yellowlees, 1997; Kanter, 1989; McHugo *et al.*, 1999). Client non-engagement with providers of treatment is a major obstacle to effective

treatment and support in the community and may be a risk factor for relapse and increased hospitalisation (Song *et al.*, 1998). Specific strategies aimed at enhancing the quality of engagement may be effective in improving treatment outcomes, as effective community care depends on the co-operation of clients (Watkins *et al.*, 1999).

Since one of the objectives of case management approaches is to ensure the engagement of persons with serious mental illness with mental health services, the assessment of engagement appears to be relevant. A measure of engagement with services is important for clinical and research reasons. First, it could be used as one outcome measure in assessing psychosocial interventions, enabling health care professionals to identify individuals with poor levels of engagement and to target intervention to specific areas of concern using strategies to enhance engagement. Secondly, it could be used as an additional measure when assessing the impact and importance of individual components of community-based care models. Some of the debate about the relative effectiveness of different models of community-based care centres on questions of whether the fidelity of model implementation is a factor in the success of services (Shepherd, 1998). Gournay (1999) has pointed out that researchers need to take into account differences in clinical skills of case managers as different levels of clinical skill may be a confounding factor in comparing different types of community-based teams. However, no specific measure exists with which to assess engagement with services. Therefore, the aim of this study is to develop an instrument with established measurement properties that can be used to assess the level of engagement with community-based services.

## Method

### Item selection

Items were developed by the first author to represent the most salient domains relevant to engagement identified by a review of the research literature and from discussions with MB and PT, who conceptually selected the variables based on their observations in clinical practice. A total of 16-items were judged by MB and PT to best reflect important aspects of engagement with services. The items were split into four subscales: (a) availability (4 items), which refers to the client being available for arranged appointments; (b) collaboration (4 items), which refers to the client actively participating in the management of illness; (c) help seeking (4 items), which refers to the client seeking help when needed; and (d) treatment adherence (4 items), which refers to the client's attitude toward taking medication. The items and subscales are presented in the Appendix.

### Response format

Clients were rated on a four-point Likert-type scale, with 0=not at all or rarely, 1=sometimes, 2=often, and 3=most of the time. Positively worded questions were reverse scored. The subscales were scored so that higher scores reflected clients' greater levels of difficulty engaging with services.

## Results

### Reliability of the SES

The SES was completed by five Community Psychiatric Nurses (CPNs) for each of their clients with an ICD-10 diagnosis of schizophrenia in the Northern Birmingham Mental Health Trust's Assertive Outreach Team. This facility serves a lower socio-economic, inner-city population with first-

episode psychosis. The study sample comprised 66 clients (43 males, 23 females). The age range was 18–40 years (M=25.3, SD=4.7).

### Item analysis

Item-total correlations for all 16 items were calculated to determine which items contributed least to overall reliability. Items with the item-total correlation coefficients less than $r$=0.30 were removed: two items were discarded, reducing the measure to 14 items. Item-total correlations were then recalculated for the remaining 14 items.

### Sensitivity

Descriptive statistics, including means, standard deviations, and range of scores for each SES subscale, and for the full scale, are presented in Table 1. Examination of the subscale scores show they span the full range of scores, and the full scale score distribution spans almost the total range of the scale (0–42), showing good variability. The mean score of the full scale, however, is below the midpoint of the scale and the skewness statistic (0.137, $p$<0.004) indicates that the data are positively skewed.

### Internal consistency

Corrected item-total correlations were examined for the 14 items of the SES, with all item correlations being greater than 0.32 (see Table 2). Cronbach's (1951) alpha coefficients for all the subscales were high (availability, $r$=0.82; collaboration, $r$=0.76; help seeking, $r$=0.90; and treatment adherence, $r$=0.82), as was the alpha coefficient for the overall scale (alpha=0.91).

## Test-retest reliability

Test-retest reliability of the SES was assessed on a subgroup of 15 clients (one female and 14 males) with a mean age of 26 years (range 21–32), with assessments separated by 2 months. The mean total scale scores of the two assessments were very similar at 11.2 (SD 10.40) and 11.8 (SD 9.74), with a range of 0–29 and 0–26 ($t$=-0.55; df=14, $p$>0.5). Agreement on the four subscales and total scale scores was substantial to almost perfect, with coefficients ranging between 0.80, $p$<0.000 and 0.97, $p$<0.000 (Table 3).

## Validity of the SES

In the absence of a gold standard for assessing engagement with services, validity was assessed by the criterion group method by examining the extent to which the scale scores differentiated between clients known to differ in engagement with services. An Assertive Outreach Team Leader responsible for the 66 clients in this study was asked to identify the 10 poorest and the 10 best service engagers on four criteria: availability, collaboration, help seeking and treatment adherence. These ratings were completed blind to SES scores. The subgroup comprised nine

**Table 1**: Means, standard deviations and ranges of the SES subscales and total scale ($n$ = 66)

| | Mean | Standard deviation | Range |
|---|---|---|---|
| Availability | 1.68 | 2.23 | 0–9 |
| Collaboration | 3.24 | 2.32 | 0–9 |
| Help seeking | 4.66 | 3.53 | 0–12 |
| Treatment adherence | 2.76 | 3.11 | 0–12 |
| Total scale | 12.31 | 9.11 | 0–42 |

**Table 2**: Means (M), standard deviations (SD), corrected item-total correlations ($r^{it}$), and Cronbach's a statistics for the SES ($n$=66).

| Scale and items | M | SD | $r^{it}$ | Cronbach's alpha |
|---|---|---|---|---|
| *Availability* | | | | 0.82 |
| Difficult to arrange appointments | 0.28 | 0.69 | 0.61 | |
| When visit arranged client is available | 0.71 | 0.88 | 0.56 | |
| Client avoids making appointments | 0.18 | 0.55 | 0.55 | |
| *Collaboration* | | | | 0.76 |
| Client resists advice | 0.62 | 0.76 | 0.47 | |
| Actively participates in planning treatment | 1.20 | 1.02 | 0.66 | |
| Client participates in managing illness | 1.18 | 0.98 | 0.67 | |
| *Help seeking* | | | | 0.90 |
| Client seeks help when needed | 1.32 | 1.07 | 0.72 | |
| Difficulty in asking for help | 0.90 | 0.94 | 0.76 | |
| Client seeks help to prevent crisis | 1.54 | 1.10 | 0.70 | |
| Client does not seek help | 0.73 | 0.98 | 0.72 | |
| Treatment adherence | | | | 0.82 |
| Client adheres to treatment | 0.67 | 0.93 | 0.32 | |
| Client understands need for medication | 0.79 | 1.04 | 0.70 | |
| Client refuses treatment | 0.39 | 0.71 | 0.61 | |
| Client has difficulties with medication | 0.47 | 0.72 | 0.59 | |

**Table 3**: Inter-rater reliability of the SES ($n$ = 15)

| Scales | *r* |
|---|---|
| Availability | 0.97* |
| Collaboration | 0.80* |
| Help seeking | 0.92* |
| Treatment adherence | 0.88* |
| Full scale | 0.90* |

*$p$<0.000

females and 11 males, with a mean age of 23.5 (range 19–32). It was predicted that difficult to engage clients would have higher scores on the SES than clients who had no difficulty engaging with services. The mean score for clients judged to engage well with services was 4.7 (SD 5.40, range 0–13), and the mean for the group judged to have most difficulty engaging with services was 19.7 (SD 9.10, range 6–29). Results indicated an overall significant difference between the two groups ($t$=4.48, df=18, $p$<0.0001). Total scores for the 'high' service engagement group showed a distribution clustered toward the lower end of the scale, with 60% of the group with scores between 0 and 2; in contrast, 80% of the 'low' service engagement group's total scores were in excess of 11 points. There was little overlap between the distributions of the criterion groups.

## Discussion

Engagement with services is an important component of assertive community treatment and case management approaches to effective treatment and support in the community. The aim of the present study was to develop a new scale that can assess the construct of engagement with services.

The number of items in the scale was reduced from 16 items to 14 items after psychometric testing. The items in the scale have good face validity and content validity, supported by the case manager ratings of engagement. In addition, feedback from the CPNs indicated that the scale was user-friendly and the brief 14-item engagement scale ensures that it is not time-consuming to complete.

The frequency distribution of the SES scores was found to be positively skewed to the lower end of the scale, indicating good to moderate levels of engagement in clients involved in Assertive Outreach treatment, which formed the basis of the validation. The discrepancy between the distribution of our data and an ideal normal distribution is therefore likely to be artefactual, since the clients in this study receive intensive engagement efforts in line with assertive community treatment approaches.

The four subscales and the overall scale demonstrated satisfactory Cronbach alpha coefficients and therefore the internal consistency of the engagement scale has been supported. Test–retest reliability of the SES scores was high, providing further evidence of the instrument's reliability. Construct validity of the measure was established by the criterion group method. The results indicated that the SES is capable of distinguishing between groups of clients based on their level of engagement with services.

The high internal consistency for the total scale indicates that the total score could be useful for research and clinical purposes. Individuals most at risk of non-engagement with services can be identified with the use of a short, reliable scale. The subscale scores could also be clinically useful in identifying particular aspects of non-engagement in need of further intervention strategies. Furthermore, it is anticipated that it will prove to be a valid and reliable measure to investigate theoretical and applied questions in the area of engagement with services.

We cannot ignore the possibility that the SES might not adequately reflect the construct of engagement. This is a complex area, and it is likely that multiple dimensions of engagement with services that are conceptually related may underlie the broader construct of engagement. Another issue is the extent to which other factors, such as stigma, beliefs about mental illness, and attitudes towards the effectiveness of treatment and support, contribute to the domains of engagement (e.g. adherence to treatment and help seeking) identified in this study. However, to date, no studies have defined the construct of engagement with services in a population diagnosed with schizophrenia. It is hoped that the development of the scale will begin the debate about what engagement means, and contribute to the understanding of the process of engagement. Future psychometric studies should explore the factor structure of the scale with larger samples in the same population. The aim of the present study was to develop a multidimensional scale to assess the level and quality of client engagement with services. However, developing an engagement scale from the perspective of service users, and involving service users in the construction of the scale, would also make a

valuable contribution to the understanding of the process of engagement, and is something we are currently working on. We would reiterate our view that the poles on the SES should not be interpreted pejoratively, i.e. high engagement = good, low engagement = bad; low engagement will reflect something about the service as well as something about the client.

In summary, this analysis demonstrates that the SES has good psychometric properties, and will benefit from further field-testing. It is a useful tool for research and clinical purposes for mental health care providers. Individuals who are experiencing difficulties in engaging with services can be identified; and may indicate work that needs to be done with the client or the service. Furthermore, specific components of concern can be targeted and monitored to assess progress.

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## Appendix

| | |
|---|---|
| Availability | |
| 1 | The client seems to make it difficult to arrange appointments |
| 2 | When a visit is arranged, the client is available [a] |
| 3 | The client seems to avoid making appointments |
| Collaboration | |
| 4 | If you offer advice, does the client usually resist it? |
| 5 | The client takes an active part in the setting of goals or treatment plans [a] |
| 6 | The client actively participates in managing his/her illness [a] |
| Help seeking | |
| 7 | The client seeks help when assistance is needed [a] |
| 8 | The client finds it difficult to ask for help |
| 9 | The client seeks help to prevent a crisis [a] |
| 10 | The client does not actively seek help |
| Treatment adherence | |
| 11 | The client agrees to take prescribed medication [a] |
| 12 | The client is clear about what medications he/she is taking and why [a] |
| 13 | The client refuses to co-operate with treatment |
| 14 | The client has difficulty in adhering to the prescribed medication |

Note: Items are rated 0 (not at all or rarely), 1 (sometimes), 2 (often), 3 (most of the time).
[a] Reverse scored.

## Appendix 9c. Correspondence from Professor Donald Addington regarding the use of the CDSS in this thesis

**Saturday, September 5, 2020 at 5:54:04 PM British Summer Time**

**Subject:** RE: CDSS in a PhD thesis.
**Date:** Saturday, 5 September 2020 at 17:52:58 British Summer Time
**From:** Donald E.N. Addington
**To:** Isabelle Butcher

Hello Isabelle,

Thank you for your interest in using the Calgary Depression Scale for Schizophrenia. I know that there has been a strong interest and important research on the topic of depression in first episode psychosis and in schizophrenia at the University of Manchester. I hope that your thesis has gone well.

You have my permission to include the scale in an electronic version of the thesis. If you also go on to publishing your findings in a peer reviewed article, I would be interested to read it.

Regards

Donald Addington
Professor, Department of Psychiatry, University of Calgary
Mathison Centre for Research & Education
Department of Psychiatry, Foothills Hospital
1403 29th Street NW
Calgary, AB, T2N 2T9, Canada
T. 403-944-2637
F. 403-270-3451
C. 403-650-7565

**From:** Isabelle Butcher <isabelle.butcher-2@postgrad.manchester.ac.uk>
**Sent:** September 5, 2020 6:08 AM
**To:** Donald E.N. Addington <addingto@ucalgary.ca>
**Subject:** CDSS in a PhD thesis.

[△EXTERNAL]

Dear Professor Addington,

I am contacting you to seek permission to include the CDSS scale in English in the electronic version of my PhD thesis.

The thesis will be made available within the University of Manchester's online research repository. This repository is non-commercial and openly available to all.

Please can you let me know whether you agree to this or would rather I did not include it in the electronic version of my thesis.

Kind regards,

Isabelle

**Page 1 of 1**

## Appendix 9d. Correspondence from Professor Dan Olweus regarding reproducing the Olweus Bullying Questionnaire in this PhD thesis

**Friday, September 4, 2020 at 9:31:56 PM British Summer Time**

**Subject:** FW: Q-materials free 2012XX (only for research purposes)
**Date:** Friday, 4 September 2020 at 21:31:45 British Summer Time
**From:** Isabelle Butcher
**Attachments:** QE06GenVersion1206XX.pdf, qe02instructx.doc, 1MonaArt1x03xxny2mb.pdf, QE06GenVersion1206CodeForm0607XX.pdf, USHandbookCh2PDFFinal0909.pdf, AnnReviewFinalMarch2013.pdf, BreivikOlweusIRT2015.pdf, CyberBullOverratedEJDP052012Final.pdf

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**From:** Dan Olweus <Olweus@uni.no>
**Date:** Wednesday, 9 May 2018 at 11:36
**To:** Isabelle Butcher <isabelle.butcher-2@postgrad.manchester.ac.uk>
**Subject:** FW: Q-materials free 2012XX (only for research purposes)

Hello-
Please find attached the Olweus Bullying Questionnaire (OBQ) materials

(Please note that, due to copyright regulations, you are not allowed to include a copy of the Questionnaire in a thesis/ dissertation or any other unpublished or (to be) published materials. However, selected text portions from the Questionnaire that have already been published, for example, in the attached Solberg & Olweus 2003 paper can be included/published without restrictions.

Kind regards

Dan Olweus

Research Professor

**Page 1 of 1**

## Appendix 9e. Correspondence from Dr Lynda Tait regarding reproducing the service engagement scale in this PhD thesis

Sunday, September 6, 2020 at 7:15:12 PM British Summer Time

**Subject:** Re: SES in a PhD thesis
**Date:** Sunday, 6 September 2020 at 11:43:40 British Summer Time
**From:** Lynda Tait
**To:** Isabelle Butcher

Hi Isabelle

You have my permission to include the SES in your electronic PhD thesis.

Best wishes for success.

Dr Lynda Tait

On 5 Sep 2020, at 13:10, Isabelle Butcher <isabelle.butcher-2@postgrad.manchester.ac.uk> wrote:

> Dear Dr Tait,
>
> I am contacting you to seek permission to include the SES scale in the electronic version of my PhD thesis.
>
> The thesis will be made available within the University of Manchester's online research repository. This repository is non-commercial and openly available to all.
>
> Please can you let me know whether you agree to this or would rather I did not include it in the electronic version of my thesis.
>
> Kind regards,
>
> Isabelle

Page 1 of 1

## Appendix 9f. Correspondence from Professor Katherine Berry regarding reproducing the psychosis attachment measure in this PhD thesis

Monday, September 7, 2020 at 1:07:16 PM British Summer Time

**Subject:** PAM
**Date:** Monday, 7 September 2020 at 07:13:33 British Summer Time
**From:** Katherine Berry
**To:** Isabelle Butcher
**CC:** Gillian Haddock

Dear Isabelle
Please take this email as confirmation that you can use the Psychosis Attachment Measure in your PhD thesis.
Best wishes Katherine

Katherine Berry
Professor of Clinical Psychology
Research Director
Division of Psychology and Mental Health

I am currently working from home but regularly checking emails.

Page 1 of 1

## Appendix 10. Consolidated criteria for reporting qualitative studies used in qualitative study

**Consolidated criteria for reporting qualitative studies (COREQ; Tong et al., 2007): 32 item checklists used in study 1.**



| NO<br>Domain & Subject | ITEM | GUIDE<br>Questions/Description | COMMENTS |
|---|---|---|---|
| Research team and reflexivity | | | |
| Personal characteristics | | | |
| 1. | Interviewer/facilitator | Which author/s conducted the interview or focus group? | I.B the study and thesis author conducted all the interviews. |
| 2. | Credentials | What were the researcher's credentials? | I.B is a white British, female, full-time PhD student at University of Manchester, with a BSc in Psychology and an MSc in Clinical Psychology. |
| 3. | Occupation | What was their occupation at the time of the study? | I.B was a full-time student at the time of the study. |
| 4. | Gender | Was the researcher male or female? | I.B is female. |
| 5. | Experience and training | What experience or training did the researcher have? | I.B has previously conducted several qualitative research studies in mental health and other related disciplines since completing her undergraduate degree in 2014. |
| Relationship with participants | | | |
| 6. | Relationship established | Was a relationship established prior to study commencement? | I.B established rapport with potential participants through the initial consent and information process prior to individuals taking part in the interview. |
| 7. | Participant knowledge of the interviewer | What did the participants know about the researcher? For example, personal goals, reasons for doing the research | The researchers were all aware that I.B was a PhD student funded by the MRC at University of Manchester, and the full title of the PhD. All participants were made aware of the importance of this research and why I.B is choosing to focus on negative symptoms. |
| 8. | Interviewer characteristics | What characteristics were reported about the interviewer/facililator? For example, bias, assumptions, reasons and interests in the research topic. | It was acknowledged that I.B had and has an interest in negative symptoms and no other bias was acknowledged. I.B wanted the interviews to be directed by participants. |
| Theoretical framework | | | |
| 9. | Methodological orientation and theory | What methodological orientation was stated to underpin the study? | Thematic analysis inductive was utilised to understand how individuals experience negative symptoms and to gauge whether similar experiences were had by other individuals presenting with negative symptoms. |

**Consolidated criteria for reporting qualitative studies (COREQ; Tong et al., 2007): 32 item checklists used in study 1.**



| NO<br>Domain & Subject | ITEM | GUIDE<br>Questions/Description | COMMENTS |
|---|---|---|---|
| **Participant selection** | | | |
| 10. | Sampling | How were participants selected? For example, purposive, convenience, consecutive or snowball | Individuals were selected purposively by age, gender to reflect the target population. |
| 11. | Method of approach | How were participants approached? For example, face-to-face, telephone, mail, email | Participants initially were approached face-to-face by I.B and subsequent follow-up information was offered over the phone prior to the interview taking place. The interview took place in all cases face-to-face. |
| 12. | Sample size | How many participants were in the study? | Twenty individuals kindly participated in this study. |
| 13. | Non-participation | How many people refused to participate or dropped out? Reasons? | Three individuals declined to participate for reasons not specified. |
| **Setting** | | | |
| 14. | Setting of data collection | Where was the data collected? For example, home, clinic, workplace | Data was collected either at the individual's own home, hospital or clinic setting. |
| 15. | Presence of non-participants | Was anyone else present besides the participants and researchers? | In all but three interviews it was the researcher, I.B and the participant, in these three cases, the participant's partner and/parent were also present. No staff were ever present in the interview. |
| 16. | Description of sample | What are the important characteristics of the sample? For example, demographic data, | All participants had to be experiencing a level of negative symptoms. Seventeen were male and three were female. Twelve were white British and eight were Black African. |
| **Data Collection** | | | |
| 17. | Interview guide | Were questions, prompts, guides provided by the authors? Was it pilot tested? | The topic guide was constructed by the thesis author, I.B and the research supervisory team. It was constructed by examining the literature to date surrounding negative symptoms. As discussed in the methods chapter of the thesis a service user reference group inputted into the development and construction of all materials used in this study. |
| 18. | Repeat interviews | Were repeat interviews carried out? If yes, how many? | No, they were not. |
| 19. | Audio/visual recording | Did the research use audio or visual recording to collect the data? | All interviews were audio recorded and transcribed by I.B. Visual equipment was not sued to capture non -verbal cues. |

**Consolidated criteria for reporting qualitative studies**
**(COREQ; Tong et al., 2007): 32 item checklists used in study 1.**



| NO<br>Domain & Subject | ITEM | GUIDE<br>Questions/Description | COMMENTS |
|---|---|---|---|
| Data Collection | | | |
| 20. | Field notes | Were field notes made during and/or after the interview or focus group? | Field notes were captured and made by I.B after each interview had taken place. |
| 21. | Duration | What was the duration of the interviews or focus group? | Each interview lasted between thirty-nine minutes and one hour. |
| 22. | Data saturation | Was data saturation discussed? | Yes, data saturation was discussed throughout the process by I.B and the other members of the research team. |
| 23. | Transcripts returned | Were transcripts returned to participants for comment and/ correction? | No transcripts were not returned to participants for comment and correction. I.B felt that the interview recordings provided enough data to elicit information. Furthermore, due to time constraints of a PhD it was not possible to end these back to participants for checking. |
| Analysis and findings | | | |
| 24. | Number of data coders? | How many data coders coded the data? | I.B coded all the data and the other members of the research team; KB and G.H contributed to this iterative process. |
| 25. | Description of the coding tree | Did the authors provide a description of the coding tree? | The authors did not provide a conceptual pictorial description of the coding tree. |
| 26. | Derivation of themes | Were themes identified in advance or derived from the data? | Themes as is the framework for conducting thematic analysis, were derived from the data solely. |
| 27. | Software | What software, if applicable was used to manage the data? | NVivo was used to manage the data. However, when analysing qualitative data as it is an iterative process, this was done in a 'hands on' manner. Each code was cut up and these were discussed and sorted by the research team by hands rather on NVivo or the computer. This enabled this process to be interactive and iterative. |
| 28. | Participant checking | Did participants provide feedback on the findings? | No. |
| Reporting | | | |
| 29. | Quotations presented | Were participant quotations presented to illustrate the themes/findings? | Yes, participant quotations were sued to illustrate the themes that were found in the data. This is a crucial part of thematic analysis. |

**Consolidated criteria for reporting qualitative studies (COREQ; Tong et al., 2007): 32 item checklists used in study 1.**



| NO<br>Domain & Subject | ITEM | GUIDE<br>Questions/Description | COMMENTS |
|---|---|---|---|
| Reporting | | | |
| 30. | Data and findings consistent | Was there consistency between the data presented and the findings? | This was achieved by ensuring that each theme was illustrated by a relvant quotation. Throughout the study in the results section quotations from a number of participants are presented. |
| 31. | Clarity of major themes | Were major themes clearly presented in the findings? | These are pictorially displayed as well as clearly depicted in writing. The pictorial figure is crucial as it succinctly emphasises the findings of this study. |
| 32. | Clarity of minor themes | Is there a description of diverse cases or discussion of minor themes? | The results section and the discussion allude to minor themes that were mentioned but were not a major theme. |
| | | | |

**Key:**

**GH** **Gillian Haddock**

**IB** **Isabelle Butcher**

**KB** **Katherine Berry**

## Appendix 11. Exemplar extract from an interview detailing the initial coding- analysis process

I: Yeah, I can imagine. And how does it feel now, to have some of these symptoms still here; what's that like?

P: Er, it's changed my life I had.Yeah. And it's like five to ten times difficult to do normal things like I used to be able to do.

I: When you say normal things, what do you mean, (...)?

P: Just like have a shower or … clean the flat. I'll go out to the shop or … it's like a struggle each time just to go to the shop.

I: Yeah. And does anything make it easier or better?

P:Er, when someone's with me, I got a support worker. Or one of m' mates, when I go out to the supermarket with them, I feel more at ease. Erm, (long pause) like the medication that I'm on.It's, er, leaves me pretty sedated. Before I was on medication, I was angry a lot. Now since I took the medication, I just completely … er, what's the word … like submissive to everyone. The support worker says you can't do this or (long pause) the CERT team says you gotta do this or you gotta do that … years ago, I would have said 'no, I'm not doing that' Evidently, with this stuff now I just go along with everything.

I: And you think that is because of the medication?

P: I think so. Aripiprazole

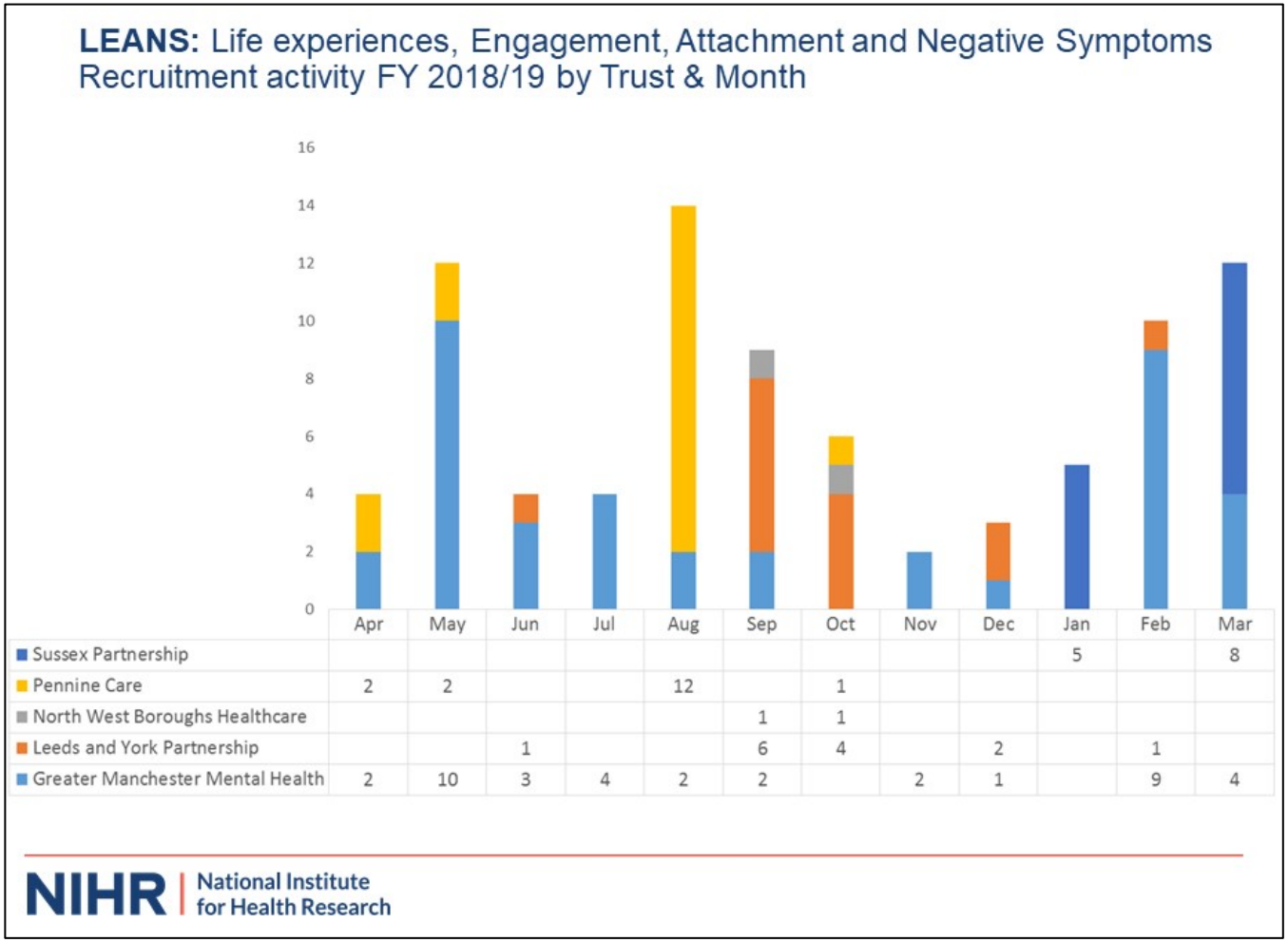
I: Ok. So, you think that helps, does it help with the symptoms, would you say?

P:Not really…Think they need to change the medication that I am on.

**Key**

**Yellow:** Experiences and feelings of negative symptoms
**Green:** Tasks that individual is unable to do
**Turquoise:** Coping strategies
**Pink :** Cause of these symptoms

## Appendix 12. National Institute of Health Research recruitment numbers for the quantitative study



## Appendix 13. Correspondence from Professor Bonnie Green regarding the use of the trauma history questionnaire and the publication with the trauma history questionnaire

**Friday, September 4, 2020 at 9:16:13 PM British Summer Time**

**Subject:** Re: Trauma History Questionnaire
**Date:** Saturday, 29 August 2020 at 17:02:52 British Summer Time
**From:** Bonnie Green
**To:** Isabelle Butcher

I think that's fine, as long as it is the article that appeared in the Journal of Trauma and Loss.

Bonnie L. Green, PhD
Professor Emeritus of Psychiatry
Georgetown University Medical School
bonnie.green@georgetown.edu

On Aug 29, 2020, at 11:09 AM, Isabelle Butcher <isabelle.butcher-2@postgrad.manchester.ac.uk> wrote:

Dear Bonnie,

Hope this finds you well.

I used the THQ in my PhD thesis and wondering is it acceptable to include a copy of the original paper with the THQ in, within the appendices of my thesis?

Kind wishes,

Isabelle

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# Development, Use, and Psychometric Properties of the Trauma History Questionnaire

Lisa M. Hooper , Patricia Stockton , Janice L. Krupnick & Bonnie L. Green

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# Development, Use, and Psychometric Properties of the Trauma History Questionnaire

LISA M. HOOPER

*Department of Educational Studies in Psychology, Research Methodology, and Counseling, University of Alabama, Tuscaloosa, Alabama, USA*

PATRICIA STOCKTON, JANICE L. KRUPNICK, and BONNIE L. GREEN

*Department of Psychiatry, Georgetown University School of Medicine, Washington, DC, USA*

*The authors describe the development and psychometric properties of the widely used Trauma History Questionnaire (THQ). Additionally, they describe how the THQ has been used both nationally and internationally in a range of studies conducted in the past 14 years (1996–2010). The reviewed studies provide accumulated, although preliminary, evidence that the THQ is reliable and valid in clinical and nonclinical samples. Finally, the authors describe the strengths and limitations of the THQ and make specific recommendations for researchers and practitioners going forward.*

Following the inclusion of posttraumatic stress disorder (PTSD) as a formal diagnosis in the DSM-III (American Psychiatric Association [APA], 1980) and the subsequent revision and refinement of the criteria in the DSM-III-R (APA, 1987) and DSM-IV (APA, 1994), numerous measures were developed as diagnostic or symptom-based instruments to assess PTSD for use in clinical and non-treatment-seeking populations (Foa, Riggs, Dancu, & Rothbaum, 1993; Hammarberg, 1992; Norris & Perilla, 1996; Vreven, Gudanowski, King, & King, 1995). Because early research often focused on specific populations with their own specific trauma measures (e.g., Vietnam War veterans

Received 2 August 2010; accepted 5 November 2010.
Address correspondence to Lisa M. Hooper, Department of Educational Studies in Psychology, Research Methodology, and Counseling, University of Alabama, 315 B Graves Hall, Box 870231, Tuscaloosa, AL 35487, USA. E-mail: lhooper@bamaed.ua.edu

or survivors of rape or natural disasters), less attention was given to general measurement of DSM Criterion A1, exposure to the traumatic experience initiating the disorder. However, in the 1990s, it became clear that over the course of a lifetime, most individuals are exposed to *multiple* events that are potential Criterion A1 stressors for PTSD (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Norris, 1992; Resnick, Kilpatrick, Dansky, Saunders, & Best, 1993). This research involved the development of multiple instruments to assess this more general exposure, covering a range of events that may meet Criterion A1. Categories include interpersonal violence, accidents, life-threatening illness, traumatic loss, natural and human-made disasters, and other events. The types of trauma history instruments that have been generated include self-report inventories designed to identify events that will be explored in follow-up interviews, self-report questionnaires in which the respondent is asked to make a subjective assessment of the level of trauma experienced from exposure to specific events, and interview-based instruments.

The specific events of focus in these various measures have been a function of the researcher's line of research, his or her target population in the study for which the measure was developed, and his or her judgment as a trauma researcher. While many of these instruments do not completely lend themselves to the establishment of psychometric properties through traditional procedures (see below), most researchers have tried to show that their questionnaires are reproducible and related to similar data collected in other ways (i.e., reliable and valid). The Trauma History Questionnaire (THQ)—the focus of the current article—is one of the above-mentioned omnibus measures of trauma exposure. None of these instruments (reviewed in the next section) are necessarily better than others, although the THQ (Green, 1996) appears to be one of the most widely used of the available trauma history collection instruments.

Filling a gap in the clinical, assessment, and research literature base, the purpose of this article is to provide a review of the development of the THQ, to describe its use with various populations, to present findings from a recently conducted validity study, and to describe the THQ's psychometric properties based on research conducted by the developers and other investigators. This article will serve as a resource for the THQ and should be useful to clinicians and investigators who seek to use the instrument and for those who may want to extend its application. Prior to the discussion on the development of the THQ, we review other trauma history measures and their reported psychometric properties.

## BACKGROUND: DIVERSE TRAUMA HISTORY MEASURES

Norris (1990) developed the Traumatic Stress Schedule (TSS), a measure consisting of 10 potentially traumatic events for use in a community sample,

which included an elaborative technique to elicit details in a follow-up interview. Vrana and Lauterbach (1994) developed the Traumatic Events Questionnaire (TEQ) for use with college students. This measure is based on 11 specific types of trauma reported in the DSM-III-R as potentially eliciting PTSD symptoms, along with an "other" category for unspecified events. Respondents to the TEQ are also asked to rank the level of trauma experienced in each event to generate a trauma intensity score (Crawford, Lang, & Laffaye, 2008). Similarly, the Traumatic Life Events Questionnaire (TLEQ) (Kubany, Haynes, et al., 2000), which assesses a broader range of potentially traumatic events such as stalking and witnessing family violence, asks the respondent to determine whether each event endorsed elicited "intense fear, helplessness, or horror," Criterion A2 for PTSD. The Stressful Life Events Screening Questionnaire (SLESQ) (Goodman, Corcoran, Turner, Yuan, & Green, 1998) was designed as a self-report screening instrument to detect Criterion A1 stressors, to be followed by face-to-face diagnostic interviews. Because the objective of the measure was to detect Criterion A rather than subthreshold events, each of the 12 items in the SLESQ includes objective and subjective probes regarding age, perpetrators, whether life was in danger, and so forth.

In contrast, the Life Events Checklist (LEC) (Gray, Litz, Hsu, & Lombardo, 2004), designed to be used in conjunction with the Clinician Administered PTSD Scale (CAPS) (Weathers, Keane, & Davidson, 2001), is a simple listing of 17 events for which the respondent is required to check whether each item "happened to me," was "witnessed," or was "learned about." A more recent instrument, the Lifetime Trauma and Victimization History (LTVH) (Widom, Dutton, Czaja, & DuMont, 2005), has been developed as a structured in-person interview consisting of 30 items covering seven categories of trauma and victimization experiences. The LTVH was designed for use in populations with low levels of education and known histories of trauma and victimization.

All of the above-mentioned questionnaires, and the items within them, have been subject to test-retest reliability assessments, with the same questionnaire being administered to the same participants on separate occasions. In some studies, convergent validity was assessed by comparing the results of the self-report questionnaire with the results of an interview using the same questionnaire. Although considerable variation was found in the reporting of specific items, temporal stability was found to be acceptable, and reasons for variation in reporting trauma history, either by self-report or in interview format, are discussed in detail by Goodman et al. (1998) for the SLESQ and by Kubany, Haynes, et al. (2000) for the TLEQ. For the LTVH (Widom et al., 2005), convergent validity was assessed by comparing items such as childhood physical abuse on different instruments (e.g., the LTVH and the Conflict Tactics Scale [Straus, 1979]).

For the TLEQ, discriminant validity was assessed by comparing the number of events that evoked intense fear, helplessness, or horror in participants with and without PTSD. For the TEQ, both the number of traumatic events and the trauma intensity of individual items have been assessed against measures of PTSD, depression, and anxiety (Crawford et al., 2008; Vrana & Lauterbach, 1994).

Both the TLEQ (with 57 citations) and the TEQ (with 51 citations) have been widely used in empirical research published in peer-reviewed journals, as has the THQ (with 94 citations). The THQ (Green, 1996), a self-report instrument, was developed to measure history of exposure to potentially traumatic events that may meet the A1 stressor criterion for PTSD. Researchers have employed the THQ in more than 60 non-overlapping published studies (see the reference list for a complete listing), with study populations including, but not limited to, residents of battered women's shelters (Humphreys, Lee, Neylan, & Marmar, 1999), people attending substance abuse clinics (Farley, Golding, Young, Mulligan, & Minkoff, 2004; Najavits, Gastfriend et al., 1998; Najavits, Weiss, & Shaw, 1999), police officers (Brunet et al., 2001; Neylan et al., 2002; Pole, Kulkarni, Bernstein, & Kaufmann, 2006), journalists in Iraq (Feinstein & Nicolson, 2005), Holocaust survivors (Yehuda, Halligan, & Grossman, 2001), adult survivors of childhood trauma and abuse (Hammersley et al., 2003; Heilemann, Kury, & Lee, 2005; Mueser et al., 2001; Sacks et al., 2008; Spertus, Yehuda, Wong, Halligan, & Seremetis, 2003), and people with life-threatening illnesses (Farley, Golding, & Minkoff, 2002; Green et al., 1998; Green, Krupnick et al., 2000; Spertus, Burns, Glenn, Loftland, & McCracken, 1999).

As with similar instruments (e.g., the TSS), the THQ was originally intended to be used in conjunction with an interview to elaborate upon the survey response. However, it has most often been used alone as a screening instrument. Because little has been published on the development and psychometric properties of the THQ, and research from various users has not thus far been aggregated, this article will serve as a central resource for clinicians and research investigators using the THQ.

## DEVELOPMENT OF THE TRAUMA HISTORY QUESTIONNAIRE

The THQ was developed for use in a number of psychosocial research projects in Washington, D.C., in the Department of Psychiatry at Georgetown University. The instrument was designed to gather information via self-report from general, community, and clinical populations about lifetime exposure to a range of potentially traumatic events. The THQ is not undergirded by any specific theoretical orientation; however, it follows a model of dimensions of trauma developed by Bonnie L. Green (1993). It covers a broad range of events that could be considered potentially traumatic and that could,

therefore, meet Criterion A1 (the occurrence of a stressor) for a DSM-III-R and DSM-IV diagnosis of PTSD.

The THQ questions were developed based on a structured "high-magnitude" stressor events interview later modified for the DSM-IV field trials (the Potential Stressful Events Interview, or PSEI; Falsetti, Resnick, Kilpatrick, & Freedy, 1994; Kilpatrick et al., 1998). The THQ items follow the general recommendations of the Kilpatrick/Resnick group, which contended that studies should elicit information about the presence or absence of each specific event rather than simply asking an open-ended question about any traumatic exposure (Resnick, Falsetti, Kilpatrick, & Freedy, 1996). The THQ follows their recommendations to use neutral behavioral language. Additionally, the PSEI (Falsetti et al., 1994) served as a primary item generation source for the THQ. The PSEI was developed at the Medical University of South Carolina (Falsetti et al., 1994; Kilpatrick et al., 1998) to enhance studies of sexual victimization; however, it was deemed by the THQ authors to be sufficiently detailed and representative of a range of events likely to be defined as traumatic. Because the THQ was developed to be applicable to a variety of populations, the information obtained on sexual assault and military experience from the PSEI was reduced, but questions relating to crime victimization, accidents, disaster, exposure to chemicals, life threat, death of a spouse or child, life-threatening illness, and news of death or injury to another were retained. Questions about physical attack/abuse, intended to address child abuse and spouse battery, were expanded, and all items were converted to a self-report format. Lending support for content validity, the items on the THQ overlapped substantially with omnibus instruments being developed by other investigators to address a full range of potentially traumatic events without being overly detailed or intrusive for use with general/community/clinical populations.

The complete THQ is provided in the appendix. It consists of 24 yes/no questions addressing a range of trauma events in three unique areas: (a) crime-related events (e.g., robbery, mugging), (b) general disaster and trauma (e.g., injury, disaster, witnessing death), and (c) unwanted physical and sexual experiences. For each item, the subject indicates whether he or she experienced it and, if so, the number of times and approximate age(s) of occurrence. Specifics are requested for most of the questions (e.g., if someone was injured, who was it?). For the six sexual and physical trauma questions, the subject is asked whether the experience was repeated and, if so, approximately how often and at what age. Thus, items focus primarily on situations involving life threat, assaults to physical integrity, tragic/accidental loss of loved ones, and witnessing death or violence—that is, items with significant consensus regarding their trauma status (Green, 1993). Among the 24 items, there is one "other" question ("Have you experienced any other extraordinary stressful situation or event that is not covered? If yes, please specify."). This allows subjects to report on personal

experiences that may have been unusually frightening or stressful but were not captured in the other 23 items. No assessment of the person's response (Criterion A2: intense fear, helplessness, or horror) is included.

## ADMINISTRATION AND SCORING OF THE THQ

The THQ can be administered as a self-report instrument or in an interview format. The self-report paper-and-pencil format takes approximately 10 to 15 minutes to complete, while administering it as an interview takes approximately 15 to 20 minutes, depending upon the number and types of trauma-exposed events the person endorses. The THQ is a trauma history data collection instrument, not a test, so there is no standard scoring method; it has therefore been adapted and modified to meet the needs of the projects in which it has been employed. The 24-item THQ can generate a total score representing the numbers and types of events endorsed as well as subscale scores, calculated by summing items associated with crime-related events (4 items), general disaster and traumatic experiences (13 items), and physical and sexual experiences (6 items). As previously mentioned, one item allows for reports of traumatic experiences not covered in the other statements. While this item is usually not scored unless the response provided has information and relevance that may be appropriately scored under one of the other 23 items, information from this question can be used at the discretion of the investigator.

The most common scoring convention is to count the *number of types of events endorsed* and/or subscale scores breaking down the counts by event type. This convention appeals to investigators who are interested in the number of types of interpersonal or sexual traumas to which subjects have been exposed (e.g., Bonne et al., 2001; Brunet et al., 2001; Green, Goodman et al., 2000; Hammersley et al., 2003; Keogh, Ayers, & Francis, 2002; Mueser et al., 2001; Najavits, Weiss, Shaw, & Muenz, 1998; Neylan et al., 2002; Rosenberg, Rosenberg, Williamson, & Wolford, 2000; Rosenberg et al., 2001; Sacks et al., 2008; Shalev et al., 1998; Spertus et al., 2003; Yehuda, Blair, Labinsky, & Bierer, 2007; Yehuda, Schmeidler, Wainberg, Binder-Brynes, & Duvdevani, 1998; Zlotnick, Najavits, Rohsenow, & Johnson, 2003). In addition, others have used the THQ to capture the participant's "earliest, most recent, and most severe life events" (Yehuda, Halligan, Golier, Grossman, & Bierer, 2004, p. 389) or to delineate the participant's "most troublesome, disturbing, or distressing" experience (Brunet et al., 2001, p. 1481). In the latter study, Brunet and colleagues asked participants to select from the items endorsed on the THQ the event they found the most distressing, which served as the index event in their study. Others have used a small subset of events of interest in a particular study (sexual trauma and physical trauma; Green, Krupnick et al., 2000). Still other researchers have

dichotomized the total trauma score in order to classify participants into categories of "low trauma" and "high trauma" (see Spertus et al., 1999) or dichotomized the reported events into "low-magnitude" or "high-magnitude" events (see Yehuda et al., 1998) for the purposes of their particular study.

## LOCATION OF STUDIES

To inform this overview of the use and psychometric properties of the THQ, we searched the following databases: PubMed, PsycINFO, Social Service Abstracts, National Institutes of Health Public Access, and the PILOTS database. The search procedure was to identify published articles whose titles or abstracts included a mention of the THQ. We performed hand searches of the *Journal of Traumatic Stress* and the *Journal of Loss and Trauma*. We also contacted select authors who are known to use the THQ regularly to uncover any in-press manuscripts that might be included in the current review. Finally, we wrote the corresponding authors of the articles identified by these methods to obtain additional work in the area of the psychometric properties or translation of the THQ that was unpublished or that may have been missed by our search. These procedures identified 60 unique studies (with many more published articles deriving from these studies) with usable information; they are noted in the reference section by an asterisk.

## PSYCHOMETRIC PROPERTIES OF THE THQ

We recognize that the development and ongoing validation of an instrument is a complex process. Moreover, we concur with Hoyt, Warbasse, and Chu (2006) that the "nature of validity evidence will vary depending on the population and setting to which the researcher plans to apply the construct" (p. 771). In this section, we discuss the preliminary evidence related to the reliability and validity of the THQ that has accumulated over time.

### Reliability

The concept of reliability is operationalized to mean that the data or results derived from scores of an instrument are reproducible (i.e., that measurements of individuals on different occasions, by different observers, and by similar parallel tests produce the same or similar results) (Cronbach & Meehl, 1955; Streiner & Norman, 2003). The initial THQ psychometric data were collected as part of a mail survey study composed of a convenience sample of 423 college students that served as a pilot for a later study (e.g., Green, Goodman et al., 2000; Green et al., 2005). From this larger pilot survey study, the THQ test-retest reliability study consisted of a subsample of 25 college-age women who had suffered a variety of traumas. Approximately

2–3 months after completion of the original mail survey, 25 women who were selected for interview based on their traumas filled out the THQ again prior to being interviewed for the primary study.

The results of the test-retest study revealed that the reporting of specific traumatic events (i.e., *yes this occurred at some point* vs. *no it never occurred*) was fair to excellent across administrations. Stability coefficients for specific events ranged from .51 (a close person killed) to .90 (attacked with a weapon) and .91 (robbed). Based on Cohen and Cohen's (1983) conventions of adequate reliability, coefficients of .70 or greater are considered acceptable. Not all of the items met this threshold and thus warrant a closer examination. Specifically, the items with the lowest reliability were "catch-all" or general categories (e.g., item 9 [other serious injury] and item 20 [other unwanted sex], both with correlations of .47). A few of the means shifted significantly on the second administration of the instrument. It was hypothesized that the shifts occurred primarily because (a) subjects who completed the instrument previously learned that the experiences they reported under one item would be subsumed under a more specific item or (b) additional experiences were recalled between administrations. The correlation for number of items endorsed across administrations was .70 (Green, 1996).

Other studies have included interrater reliability testing where the THQ has been used for the collection of trauma history by interview. At least one study was designed to assess trauma history on two separate occasions using trauma categories derived from the THQ (Mueser et al., 2001). Mueser and colleagues (2001) found moderate to high test-retest reliability for a range of traumatic events experienced over a lifetime in a psychometric evaluation of trauma and PTSD in persons with severe mental illness (i.e., an Axis 1 psychiatric diagnosis exclusive of PTSD symptoms or diagnosis). In their study, Mueser et al. used the following THQ events/categories: sexual abuse/assault, physical attack without a weapon, physical attack with a weapon, witnessing death or injury of another, car or work accident, natural or human-made disaster, life-threatening illness, close friend or relative killed by a drunken driver or murdered, and military combat. Participants included 30 primarily White psychiatric outpatients with severe mental illness. Two face-to-face interviews were conducted with each outpatient, one at baseline and one a mean of 17.1 ($SD = 6.6$) days later. During both interviews, participants were asked to indicate whether they had been exposed to each of the THQ categories during their lifetime. Kappas for lifetime traumatic events that were present in at least 20% of participants ranged from .57 (physical attack without a weapon) to .89 (natural or human-made disaster). The kappas for childhood and adulthood sexual abuse/assault were .64 and .82, respectively. According to Fleiss's (1971) guidelines, kappas in the range of .40 to .60 are considered fair, those of .60 to .75 are good, and those above .75 are excellent. Thus, the kappa coefficients evidenced in this study are considered fair to excellent.

Interrater reliability was also assessed among the three study interviewers who conducted the assessments. All interviews were recorded, and 17 (57%) baseline audiotaped interviews were randomly selected for rating by one of the other interviewers. Interrater reliability for trauma categories present in at least 20% of study participants showed kappas in the excellent category, ranging from .76 for sexual assault to 1.00 for accidents and witnessing killing or serious injury.

One issue that arises with regard to trauma history measures is shifts in the use of categories and items. This may occur because people who remember and want to report events may report them in response to a different question than the one the investigator may have chosen, or may report them under one category at one time and another category at another time. The latter would reduce reliability based on specific questions but would support reliability more broadly. Given these issues, it is encouraging that the total number of event types reported has good test-retest reliability for the THQ, with figures in line with other instruments (Norris, 1990; Kubany, Haynes, et al., 2000; Vrana & Lauterbach, 1994); however, reliability is lower for individual items. Taken together, we believe these findings point to reliability/stability for the THQ in general and for most items. However, some items may need to be revised, modified, or even deleted from the THQ; the THQ authors have initiated a new project to revise the instrument, possibly creating a shorter version.

## Validity

Several constructs contribute to the assessment of validity (Cronbach & Meehl, 1955). *Face validity* is subjectively determined by whether the instrument appears to be assessing the desired qualities based on a review of the instrument by one or more experts. *Content validity* is closely related to face validity and consists of a judgment of whether the instrument consists of items that include all relevant content or domains (Streiner & Norman, 2003). Face validity and content validity were addressed in the development of the THQ discussed earlier and are exemplified by the categories covering agreed-upon dimensions of traumatic events (Green, 1993), agreement among trauma instrument developers about which items/events are appropriately included in omnibus trauma inventories, having the THQ based on previously used measures, and its correspondence with DSM examples of Criterion A stressors. Other important types of validity include *construct validity* and *cultural validity*, which are described in the following sections.

### Construct validity: relationship to other measures

Traditional statistical methods (e.g., exploratory factor analysis, confirmatory factor analysis) are not appropriate to establish internal consistency and

construct validity of the THQ, because it is not a scale in the traditional sense. For example, there are not strong reasons to hypothesize that people who experience one particular type of event would necessarily experience other specific events. This would be true for all such inventories. Thus, we approached construct validity from the perspective of agreement with other trauma history measures and prediction of expected outcomes. A small study at our center examined the extent to which the THQ produced similar findings as another trauma history collection tool that we developed, the SLESQ (Goodman et al., 1998). This study was conducted in the context of a large randomized depression treatment study (Miranda et al., 2003). In that study, low-income African American, Latino, and White women were screened and recruited for a depression treatment trial in social service and family planning settings. Women meeting full criteria for major depression were randomized to cognitive behavior therapy, antidepressant medication, or community mental health referral. All randomly assigned participants were evaluated by baseline telephone and clinical interviews and followed by telephone for 1 year. As part of that study, the investigators included the SLESQ (Goodman et al., 1998) to assess for exposure to traumatic events.

For a small subsample ($n = 18$) of the larger study sample, and prior to the baseline clinical interview, women participants completed the THQ. Participants were then interviewed with the SLESQ. Using Cohen's (1968) coefficient kappa statistics, responses were compared between the two sets of items. While not all of the items matched closely enough to be compared directly, we identified a priori nine items that we believed to be comparable (see Table 1 for a complete listing of items). For example, on the THQ, Item 15 reads "Have you ever had a serious or life-threatening illness?" compared to the SLESQ, where the similar Item 1 reads "Have you ever had a life-threatening illness?" The kappa coefficient for the two items was excellent ($\kappa = 1.00$). A second example is the comparison between the THQ Item 11 (i.e., "Have you ever seen someone seriously injured or killed?") as compared to the SLESQ Item 11 (i.e., "Have you ever been present when another person was killed, seriously injured, or sexually or physically assaulted?"). The kappa coefficient for these two items was also found to be acceptable ($\kappa = .72$). As illustrated in Table 1, comparison of six of the nine items generated Cohen's kappa coefficients in the good to excellent range ($\kappa = .61$ to $\kappa = 1.00$). These findings—albeit with a small sample—further contribute to previous findings related to the validity of the THQ, but at the same time (given the low to fair kappas for three items) suggest possible revision of some items on the THQ. Low kappas in this and some other studies with small sample sizes, in addition to other issues, may also be a function of baseline rates of some of the events being measured.

In another study, Humphreys et al. (1999) measured the extent to which trauma history (measured by the THQ) in a sample ($n = 50$) of sheltered battered women was robustly related to conflict exposure, as measured by the

**TABLE 1** Kappa Scores for Comparisons Between Nine THQ and SLESQ Items.

| Item no. | Item description | Kappa |
|---|---|---|
| THQ Item 1 | Has anyone ever tried to take something directly from you by using force or the threat of force, such as a stick-up or mugging? | .45 |
| SLESQ Item 3 | Was physical force or a weapon ever used against you in a robbery or mugging? | |
| THQ Item 5 | Have you ever had a serious accident at work, in a car, or somewhere else? | .13 |
| SLESQ Item 2 | Were you ever in a life-threatening accident? | |
| THQ Item 11 | Have you ever seen someone seriously injured or killed? | .72* |
| SLESQ Item 11 | Have you ever been present when another person was killed, seriously injured, or sexually or physically assaulted? | |
| THQ Item 13 | Have you ever had a close friend or family member murdered, or killed by a drunk driver? | .67* |
| SLESQ Item 4 | Has an immediate family member, romantic partner, or very close friend died as a result of accident, homicide, or suicide? | |
| THQ Item 15 | Have you ever had a serious or life-threatening illness? | 1.00* |
| SLESQ Item 1 | Have you ever had a life-threatening illness? | |
| THQ Item 18 | Has anyone ever made you have intercourse, oral or anal sex against your will? | .87* |
| SLESQ Item 5 | When you were a child or more recently, did anyone (parent, other family member, romantic partner, stranger, or someone else) ever succeed in physically forcing you to have intercourse, or oral or anal sex against your wishes or when you were in some way helpless? | |
| THQ Item 19 | Has anyone ever touched private parts of your body, or made you touch theirs, under force or threat? | .60* |
| SLESQ Item 7 | Other than experiences described in Items 5–6, has anyone ever actually touched private parts of your body or made you touch theirs against your wishes, or when you were in some way helpless? | |
| THQ Item 20 | Other than incidents mentioned in Questions 18 and 19, have there been any other situations in which another person tried to force you to have unwanted sexual contact? | .82* |
| SLESQ Item 6 | Other than experiences described in Item 5, has anyone ever used physical force or threat to TRY to make you have intercourse, oral or anal sex, against your wishes or when you were in some way helpless? | |
| THQ Item 23 | Has anyone in your family ever beaten, "spanked," or pushed you hard enough to cause injury? | .33 |
| SLESQ Item 9 | Other than the experiences mentioned in Item 8, have you ever been kicked, beaten, slapped around, or otherwise physically harmed by a romantic partner, date, sibling, family member, stranger, or someone else? | |

*Note.* THQ = Trauma History Questionnaire (Green, 1996); SLESQ = Stressful Life Events Questionnaire (Goodman, Corcoran, Turner, Yuan, & Green, 1998).

*$p < .05$.

Conflict Tactics Scale. As expected, study results showed a positive significant relation between THQ scores and conflict scores ($r = .46$, $p < .001$). This correlation is similar to those found between other trauma history instruments and conflict scores (e.g., the LTVH and the Conflict Tactics Scale).

### Construct Validity: Relationship with Outcomes

Evidence of construct validity is also established when scores of a scale or instrument are a good correlate or predictor of an outcome or criterion they are expected to relate to (e.g., psychological distress) or predict (e.g., PTSD). Predictive validity has been evaluated by correlating THQ items and PTSD symptoms, as measured by paper-and-pencil instruments or interviews (e.g., CAPS, CIDI, or PCL). Several studies buttress the theory-derived prediction that the THQ predicts PTSD. For example, Mueser et al. (1998) examined the extent to which lifetime trauma history, as measured by THQ scores, related to rates of PTSD, as measured by PTSD Checklist scores, in a sample of inpatients and outpatients ($n = 275$) with severe mental illness. In this study, the total number of traumas (Wald statistic [W] = 10.95, $p = .0009$) and type of trauma (sexual assault as a child) (W = 8.15, $p = .0043$) were significant predictors of PTSD in the overall sample. Additionally, there were gender differences evidenced in Mueser et al.'s study: Total number of traumas significantly predicted PTSD in the male sample (chi-square = 7.04, $p = .008$) only.

Lilly, Pole, Best, Metzler, and Marmar's (2009) study examining gender and PTSD in a sample of female police officers ($n = 281$) found that trauma history (as measured by the THQ) made a unique and statistically significant contribution to the variance in PTSD ($\beta = .16$). Other evidence for construct validity of the THQ is found in Pole and colleagues' study (2006) examining resilience in a small sample of retired police officers ($n = 21$). Pole et al. found that scores on the THQ were inversely related to resilience ($r = -.48$, $p < .05$) and mental health functioning ($r = -.56$, $p < .01$); as scores on the THQ increased, resilience and mental health functioning in the participants decreased.

In addition to the studies described above, numerous other studies have established the predictive power of the THQ. For example, other studies have reported on the relation between trauma history (as measured by the THQ) and PTSD symptomatology (Golier et al., 2003; Green, Krupnick et al., 2000; Najavits, Gastfriend et al., 1998; Spertus et al., 2003), depression (Spertus et al., 1999, 2003), and personality disorders (Golier et al., 2003). A few studies have found no relation between THQ scores and PTSD and other measurements of psychological distress (see Keogh et al., 2002). For example, Keogh found no significant relation between the THQ and PTSD symptoms in their sample of 40 women expecting their first child. There are many reasons that may account for negative findings between trauma

history and PTSD symptoms (e.g., small sample sizes, how PTSD symptoms are captured, memory or motivational factors, and the specificity and sensitivity of measurements of PTSD). Some of these factors may have impacted the results of Keogh and others' studies.

## Cultural validity

Instruments are developed and tested on population samples that may be quite different from those in which the instrument is used in subsequent studies. For example, a questionnaire may be validated on a sample of college students and then used in studies of poor and less educated populations. The concept of cultural validity has therefore become an appropriate focus for consideration.

An example demonstrates the potential difficulty of achieving equivalence and invariance in the cross-cultural use of assessment instruments in different socioeconomic and racial and ethnic groups. In the SLESQ study with low-income African American women, the authors used qualitative assessment methods (i.e., focus groups, cognitive interviews, and reviews of videotaped SLESQ interviews) to establish preliminary cultural validity. The authors found with these qualitative methods that most items on the SLESQ were well understood and had similar meanings in diverse samples. However, there were a few differences in nominating and endorsing items as traumatic, possibly reflecting experiential differences among the women. There was also a difference in how women interpreted a question designed to identify "attempted rape." Consequently, the SLESQ was slightly modified for future use (Green, Chung, Daroowalla, Kaltman, & DeBenedictis, 2006).

The difficulty of achieving cultural validity may be amplified when translating instruments into other languages. In the Health-Related Quality of Life study (Herdman et al., 1998), researchers from Spain used a qualitative approach to achieving various types of cultural equivalence when adapting instruments for different cultures. Some other researchers applied this process to cross-cultural adaptation of the THQ. For example, a Brazilian group of researchers (Fiszman, Cabizuca, Lanfredi, & Figueira, 2005) describe a six-stage process of translation and back-translation, performed independently by bilingual academics, both native Portuguese speakers and native English speakers, using an item-by-item analysis to achieve semantic equivalence; the process also involved synthesizing the two versions, pretesting in the target population, and then pilot testing the final instrument. In the Portuguese adaptation of the THQ, "risk of life" was used rather than "danger of death," and the examples of natural disasters in Brazil included "landslides" rather than "tornadoes."

In addition to Fiszman et al.'s (2005) study, the THQ has been translated into Spanish (Heilemann, Lee, & Kury, 2002), Hebrew (Shalev et al., 1997;

Freedman et al., 2002), French, Japanese, Kurdish, and Vietnamese, though studies for the last four languages have not yet been published.

In sum, the THQ has been used in multiple clinical and nonclinical studies in the United States (Jobson & O'Kearney, 2008; Keogh et al., 2002; Maguire et al., 2008) as well as in non-English speaking countries. This indicates that the THQ is perceived to have cultural validity, even where it has not been subject to qualitative assessment. Finally, while claims related to the cultural validity of the THQ are preliminary, the trauma experiences in the THQ appear to be universal for the most part, and investigators see them as appropriate to the cultures of the diverse populations in which the THQ has been used.

## DISCUSSION

The purpose of this article was to provide a comprehensive review and overview of the development of the THQ, to describe its use with various populations, and to describe its psychometric properties (i.e., reliability and validity) based on research conducted by the developers and other investigators. As described herein, the THQ has been used in numerous studies to describe the traumatic life history of clinical research samples and to examine the relationship between traumatic events and medical conditions, psychological distress, wellness, severe mental illness, substance use disorders, and personality disorders in a range of clinical and nonclinical populations. The substantial accumulated evidence suggests—at least preliminarily—that the THQ is relevant and adaptable to a wide range of populations, and it is beginning to accumulate evidence of sound psychometric properties.

Several characteristics and strengths of the THQ are noteworthy and may account for its wide use. It is relatively simple and short and relatively easy to comprehend, administer, and analyze, giving researchers and clinicians the potential to develop appropriate follow-up measures for their specific investigations. The empirical findings reviewed in this article describe the performance and psychometric soundness of the THQ and thus make the THQ a solid choice to capture trauma history. However, the THQ still has some noteworthy limitations.

Although studies have shown preliminary evidence of the THQ's reliability and validity, evaluating construct validity is an important ongoing obligation of researchers, even for widely used instruments. Additionally, because reliability and validity are context dependent (Schmidt & Hunter, 2003), it is important to continue to accumulate evidence related to cultural validity and generalizability in studies of diverse populations. Researchers (e.g., Bravo, 2003) suggest that the validity and reliability of an instrument's scores in one culture do not portend validity and reliability in another

culture. We recommend that researchers continue to examine the cross-cultural, linguistic, and translational equivalence of the THQ in other languages and cultures.

A number of factors confound reliability (as classically defined) for most trauma history instruments, including the THQ. First, there is no standard scoring system, or standard "scale," from which norms may be developed. Second, memory or motivational factors may affect accurate reporting. For example, the stability of reporting of traumatic events (as described by Briere & Conte, 1993), particularly when based on lifetime experiences, may be confounded by memory loss, underreporting, overreporting (Najavits, Gastfriend et al., 1998), or minimizing. Alternately, individuals may be unwilling to report events such as childhood or ongoing abuse (Baker, 2009; Brewin, Andrews, & Gotlib, 1993), but willingness may change over time because of increasing familiarity with the assessment or the interviewer (Spertus et al., 1999), among other reasons. Furthermore, the categories that investigators choose to capture may or may not fit those of the person answering the questions. Finally, some studies reviewed in this article have been composed of small samples, which could have moderated and thus shaped the findings that have accumulated over time.

Our experience with the SLESQ (Goodman et al., 1998; Green et al., 2006) demonstrates the above limitations of trauma history instruments. In a 2-week test-retest study of the SLESQ, approximately one-third of the participants reported an event the first time that they did not report the second time, and vice versa, with the overall number of reported events unchanged (Goodman et al., 1999). We hypothesized that a respondent's state of mind might change from one time to the next, leading to changes in the ability or motivation to retrieve remote memories at any given time or in the appraisal of the event (e.g., whether an event was life threatening, a qualifier in several questions).

Hepp and colleagues (2006) also reported inconsistency in reporting of traumatic events. In their community-based cohort of middle-aged adults in Switzerland, the authors obtained long-term stability data of their trauma history measure over a 6-year period using a structured interview. Their figure for "first-time" but not "second-time" reporting of specific events was about 40%, while their figure for "second-time" but not "first-time" reporting was 33%, very similar to the figures for the SLESQ for a shorter period. In both the THQ and the SLESQ, events not reported tended to be more vague ones, such as "any life-threatening event"; however, the unreliable events were not limited to vague or more minor events. Therefore, it is important to note that these instruments are best used to provide global/general data regarding a sample rather than information about specific individuals. If the intent is to use the THQ to provide information that is more individual and more detailed, it is important to follow up with an interview or additional questions about the nature of the events endorsed. Alternately, some individuals may

feel more comfortable providing information about highly charged events on a questionnaire, or anonymously; in these cases, interviews will not necessarily result in more trauma being reported.

As Weathers and Keane (2007) and Van Hooff, McFarlane, Baur, Abraham, and Barnes (2009) point out regarding Criterion A, trauma is difficult to define, especially at the item level, and the DSM definition has changed over time. Furthermore, a list of events such as those we and others have developed does not take into account the severity of the events or the person's reaction to them (i.e., Criterion A2). For example, physical assaults can vary from mild to very severe, with expected variation in effects on symptom outcomes. Thus, researchers may consider modifying the THQ in the future to assess for both Criterion A1 and Criterion A2 to potentially expand the instrument's predictive validity, although findings from some studies (see Breslau & Kessler, 2001) suggest that capturing Criterion A2 information in addition to Criterion A1 information (compared with capturing Criterion A1 information alone) does not increase prediction of PTSD. Given all of these issues, it is important to be cautious about the limits of the THQ and other trauma history measures.

## CONCLUSION

Trauma is a complex construct, and reliably and validly measuring trauma is a complex endeavor (Corcoran, Green, Goodman, & Krinsley, 2000; Weathers & Keane, 2007). Many measures have been developed to capture trauma history, but there is no consensus on which self-report instrument best captures traumatic experiences. The THQ is one instrument that offers researchers and scientist-practitioners initial information regarding trauma history specifically related to Criterion A1 stressors for PTSD (APA, 1994). The THQ is an efficient, easy-to-use tool for reliably capturing lifetime exposure to diverse traumatic experiences among a range of populations (community, clinical, and nonclinical). Multiple studies have now contributed evidence about the THQ's psychometric characteristics and have documented its utility in numerous ways, indicating that the instrument is useful and sound. More work is warranted on its reliability and validity, and a shorter version of the instrument is under development.

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**Lisa M. Hooper** is Associate Professor in the Department of Educational Studies in Psychology, Research Methodology, and Counseling at the University of Alabama. She is a mental health therapist and researcher who has both clinical and research experience with underrepresented and underserved racially and ethnically diverse populations. She has studied the long-term after effects of family trauma and adversity in a range of populations.

**Patricia Stockton** is a Behavioral Scientist who received her undergraduate and post-graduate education in the United Kingdom. She has extensive research experience in the fields of aging, management of mental disorders in the community, and traumatic stress and associated disorders.

**Janice L. Krupnick** is a Professor of Psychiatry at the Georgetown University School of Medicine. Her research focuses on treatment development and assessment of psychotherapies for posttraumatic stress disorder and depression in low-income populations.

**Bonnie L. Green** is a Professor and Vice Chair for Research in the Department of Psychiatry at the Georgetown University Medical School. She has studied the psychological and physical health consequences of community traumas such as disasters and war and individual traumas, including breast cancer, traumatic bereavement, and interpersonal violence. She is Director of the Georgetown Center for Trauma and the Community, whose purpose is to develop innovative and sustainable interventions for the trauma-related mental health needs of low-income populations seen in primary care safety net settings in the Washington, DC region.

## APPENDIX: TRAUMA HISTORY QUESTIONNAIRE

The following is a series of questions about serious or traumatic life events. These types of events actually occur with some regularity, although we would like to believe they are rare, and they affect how people feel about, react to, and/or think about things subsequently. Knowing about

the occurrence of such events, and reactions to them, will help us to develop programs for prevention, education, and other services. The questionnaire is divided into questions covering crime experiences, general disaster and trauma questions, and questions about physical and sexual experiences.

For each event, please indicate (circle) whether it happened and, if it did, the number of times and your approximate age when it happened (give your best guess if you are not sure). Also note the nature of your relationship to the person involved and the specific nature of the event, if appropriate.

| | | | | *If you circled yes, please indicate* | |
|---|---|---|---|---|---|
| ***Crime-Related Events*** | | Circle one | | Number of times | Approximate age(s) |
| 1 | Has anyone ever tried to take something directly from you by using force or the threat of force, such as a stick-up or mugging? | No | Yes | | |
| 2 | Has anyone ever attempted to rob you or actually robbed you (i.e., stolen your personal belongings)? | No | Yes | | |
| 3 | Has anyone ever attempted to or succeeded in breaking into your home when you were *not* there? | No | Yes | | |
| 4 | Has anyone ever attempted to or succeed in breaking into your home while you *were* there? | No | Yes | | |
| ***General Disaster and Trauma*** | | | | | |
| 5 | Have you ever had a serious accident at work, in a car, or somewhere else? (**If yes**, please specify below) _____ | No | Yes | | |
| 6 | Have you ever experienced a natural disaster such as a tornado, hurricane, flood or major earthquake, etc., where you felt you or your loved ones were in danger of death or injury? (**If yes**, please specify below) _____ | No | Yes | | |
| 7 | Have you ever experienced a "man-made" disaster such as a train crash, building collapse, bank robbery, fire, etc., where you felt you or your loved ones were in danger of death or injury? (**If yes**, please specify below) _____ | No | Yes | | |
| 8 | Have you ever been exposed to dangerous chemicals or radioactivity that might threaten your health? | No | Yes | | |
| 9 | Have you ever been in any other situation in which you were seriously injured? (**If yes**, please specify below) _____ | No | Yes | | |

(*Continued*)

| | ***Crime-Related Events*** | Circle one | | *If you circled yes, please indicate* Number of times | Approximate age(s) |
|---|---|---|---|---|---|
| 10 | Have you ever been in any other situation in which you feared you *might* be killed or seriously injured? (**If yes**, please specify below) | No | Yes | | |
| 11 | Have you ever seen someone seriously injured or killed? (**If yes**, please specify who below) | No | Yes | | |
| 12 | Have you ever seen dead bodies (other than at a funeral) or had to handle dead bodies for any reason? (**If yes**, please specify below) | No | Yes | | |
| 13 | Have you ever had a close friend or family member murdered, or killed by a drunk driver? (**If yes**, please specify relationship [e.g., mother, grandson, etc.] below) | No | Yes | | |
| 14 | Have you ever had a spouse, romantic partner, or child die? (**If yes**, please specify relationship below) | No | Yes | | |
| 15 | Have you ever had a serious or life-threatening illness? (**If yes**, please specify below) | No | Yes | | |
| 16 | Have you ever received news of a serious injury, life-threatening illness, or unexpected death of someone close to you? (**If yes**, please indicate below) | No | Yes | | |
| 17 | Have you ever had to engage in combat while in military service in an official or unofficial war zone? (**If yes**, please indicate where below) | No | Yes | | |

| | ***Physical and Sexual Experiences*** | Circle one | | *If you circled yes, please indicate* Repeated? | Approximate age(s) and frequency |
|---|---|---|---|---|---|
| 18 | Has anyone ever made you have intercourse or oral or anal sex against your will? (**If yes**, please indicate nature of relationship with person [e.g., stranger, friend, relative, parent, sibling] below) _____ | No | Yes | | |
| 19 | Has anyone ever touched private parts of your body, or made you touch theirs, under force or threat? (**If yes**, please indicate nature of relationship with person [e.g., stranger, friend, relative, parent, sibling] below) _____ | No | Yes | | |
| 20 | Other than incidents mentioned in Questions 18 and 19, have there been any other situations in which another person tried to force you to have an unwanted sexual contact? | No | Yes | | |
| 21 | Has anyone, including family members or friends, ever attacked you with a gun, knife, or some other weapon? | No | Yes | | |
| 22 | Has anyone, including family members or friends, ever attacked you *without* a weapon and seriously injured you? | No | Yes | | |
| 23 | Has anyone in your family ever beaten, spanked, or pushed you hard enough to cause injury? | No | Yes | | |
| 24 | Have you experienced any other extraordinarily stressful situation or event that is not covered above? (**If yes**, please specify below) _____ | No | Yes | | |

## Appendix 14. Psychosis Attachment Measure (PAM)

### SELF-REPORT MEASURE

We all differ in how we relate to other people. This questionnaire lists different thoughts, feelings and ways of behaving in relationships with others.

### PART A

Thinking generally about how you relate to other key people in your life, please use a tick to show how much each statement is like you. Key people could include family members, friends, partner or mental health workers.

There are no right or wrong answers

| | Not at all | A little | Quite a bit | Very much |
|---|---|---|---|---|
| 1. I prefer not to let other people know my 'true' thoughts and feelings. | (..) | (..) | (..) | (..) |
| 2. I find it easy to depend on other people for support with problems or difficult situations. | (..) | (..) | (..) | (..) |
| 3. I tend to get upset, anxious or angry if other people are not there when I need them. | (..) | (..) | (..) | (..) |
| 4. I usually discuss my problems and concerns with other people. | (..) | (..) | (..) | (..) |
| 5. I worry that key people in my life won't be around in the future. | (..) | (..) | (..) | (..) |
| 6. I ask other people to reassure me that they care about me. | (..) | (..) | (..) | (..) |
| 7. If other people disapprove of something I do, I get very upset. | (..) | (..) | (..) | (..) |
| 8. I find it difficult to accept help from other people when I have problems or difficulties. | (..) | (..) | (..) | (..) |
| 9. It helps to turn to other people when I'm stressed. | (..) | (..) | (..) | (..) |

| | Not at all | A little | Quite a bit | Very much |
|---|---|---|---|---|
| 10. I worry that if other people get to know me better, they won't like me. | (..) | (..) | (..) | (..) |
| 11. When I'm feeling stressed, I prefer being on my own to being in the company of other people. | (..) | (..) | (..) | (..) |
| 12. I worry a lot about my relationships with other people. | (..) | (..) | (..) | (..) |
| 13. I try to cope with stressful situations on my own. | (..) | (..) | (..) | (..) |
| 14. I worry that if I displease other people, they won't want to know me anymore. | (..) | (..) | (..) | (..) |
| 15. I worry about having to cope with problems and difficult situations on my own. | (..) | (..) | (..) | (..) |
| 16. I feel uncomfortable when other people want to get to know me better. | (..) | (..) | (..) | (..) |

**PART B**

In answering the previous questions, what relationships were you thinking about?

_____

(E.g. relationship with mother, father, sister, brother, husband, wife, friend, romantic partner, mental health workers etc)

## Appendix 15. Correspondence from Professor William Horan regarding the use of the Clinical Assessment Interview for Negative Symptoms (CAINS) and the CAINS manual

**Friday, September 4, 2020 at 9:17:01 PM British Summer Time**

**Subject:** Re: CAINS query
**Date:** Monday, 31 August 2020 at 18:43:00 British Summer Time
**From:** William Horan
**To:** Isabelle Butcher

Hi Isbelle
It would be totally fine to include the CAINS manual as an appendix in your thesis.

Coincidentally, I just came across your qualitative paper on negative symptoms - very nice! We are currently conducting a qualitative study of functional capacity in schizophrenia - so quite closely related to yours. We hope to complete data collection around October.
If you are doing any other qualitative work I'd be interested to learn more.

Best regards,
Bill

William P. Horan, Ph.D.
Professor, UCLA Department of Psychiatry & Biobehavioral Sciences
Chief, Psychosis Section, VA Greater Los Angeles Healthcare System
Tel: 310.478.3711 x44041
horan@ucla.edu
http://greenlab.dgsom.ucla.edu

On Sat, Aug 29, 2020 at 10:29 AM Isabelle Butcher <isabelle.butcher-2@postgrad.manchester.ac.uk> wrote:

> Dear Bill,
>
> I hope this finds you well.
>
> I have used the CAINS as part of my PhD thesis, as you are aware from our previous correspondence. I am wondering whether I am allowed to include the CAINS manual in my thesis as an appendix? I would like to include the scale at least as think it is important as it is quite different to the PANSS.
>
> Look forward to hearing from you,
>
> Kind regards
>
> Isabelle

**Page 1 of 1**

# CAINS (v1.0)

**ID:** _____ **DATE:** _____ **RATER:** _____

**Overall Introduction:** ***In this interview, I'll be asking you some questions about things you have been doing over the past week. In the first section, I'm going to ask you some questions about your family, romantic partners, and friends, including how motivated you have been to spend time with them and how you felt when you were around them.***

## I. SOCIAL (MOTIVATION & PLEASURE)

**ITEM 1: MOTIVATION FOR CLOSE FAMILY/SPOUSE/PARTNER RELATIONSHIPS**

[Note: Romantic relationships can be rated in either Item 1 or Item 2 but NOT both. A spouse/ partner relationship in which the couple is living together should be assessed in Item 1. A dating/romantic relationship in which the couple is not living together should be assessed in Item 2.]

***The following questions are about your family. This can include relatives like parents, brothers or sisters and other relatives, as well as your spouse [if married] or live-in partner. Have you been in contact with or visited with any family members in the past week (in person, phone, email)? Any contact with a spouse or partner?***

**IF CONTACT:**

- *Who have you been in contact with? Anybody else?*
- *What things have you done with your family?*
- *IF RELEVANT: What things have you done with your spouse/partner?*
- *How much time did you spend together?*

Behavior

- *What have you done to see or contact your [family/spouse/partner] in the past week?*
- *When you were with your [family/spouse/partner] who decided what you would do?*
- *Who started the conversation? Did you start it? Did your [family/spouse/partner]? Were you involved in the conversation?*
- *Did you ever find that you quickly wanted to end your interactions with your [family/spouse/partner]? Did you want them to last longer?*

Motivation & Interest in Closeness

- *Have you been motivated to be around or in touch with your [family/spouse/partner] in the past week? (Why is that?)*
- *What did you talk about? Can you talk about good and bad times with your [family/spouse/partner]?*
- *How close do you feel to your [family/spouse/partner]? What does being close mean for you?*
- *Were there times in the past week when you just didn't want to be around or in touch with your [family/spouse/partner]?*
- *How important is being part of a family to you?*
- *What about that is important to you? Have you felt this way throughout the past week?*

**IF NO FAMILY CONTACT:**

[NOTE: This section applies when not part of a close family or if available relatives could be contacted but person has chosen not to interact. If the person is not currently in a relationship with a live-in spouse/partner, interest in romantic relationships is assessed in Item 2.]

- *Has your family tried to contact you or visit you in the last week?*
- *Has anything kept you or held you back from being in contact with your family?*
- *Do you wish you were closer to your family? OR Do you wish you were part of a close family?*
- *Did you miss interacting with your family in the past week?*
- *Is having a relationship with your family important to you? What about having a relationship is important to you?*
- *Have you preferred to spend your time alone rather than with your family?*

**Item 1 – Motivation for Close Family/Spouse/Partner Relationships**

**0 = No impairment:** VERY INTERESTED in and highly values close family bonds as one of the most important parts of life. Strongly desires and is highly motivated to be in contact with family. Regularly initiates and persists in interactions with family and actively engages in these interactions; good and bad times are openly discussed. Well within normal limits.

**1 = Mild deficit:** GENERALLY INTERESTED in and values close family bonds though response suggests some minor or questionable reduction. Generally desires and is motivated to maintain contact with family. Has a close relationship with family member(s) in which good and bad times can be discussed. Mild deficit in initiating and persisting in regular interactions with family – generally actively engaged when interactions occur.

**2 = Moderate deficit:** SOMEWHAT INTERESTED in family relationships and considers them somewhat important. May occasionally miss close connections with family but is only somewhat motivated to seek out interaction with family. Notable deficit in initiating and persistently engaging in interactions; discussion of good and bad times is limited. Interactions with family members may occur but are largely superficial and participation is best characterized as "going through the motions"; interactions are more likely initiated by family with mostly passive involvement of the person.

**3 = Moderately severe deficit:** LITTLE INTEREST in family relationships (could "take it or leave it") and does not describe family bonds as important. Describes hardly any motivation and minimal effort to have close family relationships. Rarely has discussion of good and bad times with family members. Contact and engagement with family is superficial and passive with almost all initiation and efforts to engage coming from others.

**4 = Severe deficit:** NO INTEREST in family relationships and does not consider them at all important. Prefers to be alone and is not at all motivated to be with family. If person does see family, it is done so grudgingly, passively and with no interest.

**ITEM 2: MOTIVATION FOR CLOSE FRIENDSHIPS & ROMANTIC RELATIONSHIPS**

***Let's talk about friends (and dating or romantic relationships) now. By friends, I mean people who you know and spend time with, anyone you consider a friend, or people you can rely on and count on. Have you had any contact with friends in the last week (in person, phone, email)? IF RELEVANT: have you been in contact with a romantic partner or dating in the last week?***

**IF CONTACT:**

- *In the past week, what have you done with your [friends/partner/dates]?*
- *Tell me about what you did [or what you talked about] during that [visit, activity, conversation]?*
- *How much time did you spend together with [friends/partners/dates]?*

Behavior

- What steps did you take to see or contact your [friends/partner/dates] in the past week?
- When you were with your [friends/partner/dates], who decided what you would do?
- When you spoke with your [friends/partner/dates], who started the conversation? Did you?
- Did you ever find that you quickly wanted to end your interaction with your [friends/partner/dates]? Did you want them to last longer?

Motivation & Interest in Closeness

- *Have you been motivated to be around your friends* (partner/dates) *in the past week? Why is that?*
- *Can you talk about both good times and bad times?*
- *Were there times in the past week when you just didn't feel like being around your friends* (partner/dates)*?*
- *How important is having friendships* (partner/dates) *to you? What about that is important to you?*
- *How close do you feel to your friends* (partner/dates)*? What does being close mean for you?*

**IF NO FRIENDS/ROMANTIC CONTACT:**

- *Are you interested in having friends or dating?*
- *Is having friendships [or being in a romantic relationship] important to you? If Yes, what about [specify friendships/romantic partner] is important?*
- *Did you miss these types of relationships in the past week?*
- *Would you like to have friends [or a romantic partner] with whom you could talk about good and bad times?*
- *(If any indication of interest) Have you taken any steps to meet someone who might be a friend (or romantic partner)?*
- *Has anything kept you or held you back from being in contact with your friends?*
- *Would you prefer to have friendships [or a romantic relationship] or would you prefer to be alone?*

**Item 2 – Motivation for Close Friendships & Romantic Relationships**

**0 = No impairment:** VERY INTERESTED in and highly values friend/romantic relationships as one of the most important parts of life. Strongly desires and is very motivated to engage in friendships. Regularly initiates and persists in interactions with friends/partner and actively engages in these interactions; good and bad times are openly discussed. Well within normal limits.

**1 = Mild deficit:** GENERALLY INTERESTED in and values friend/romantic relationships though response suggests some minor or questionable reduction. Generally desires and is motivated to engage in friendships. Has friendships/relationship in which good and bad times can be discussed though this may be less consistent. Mild deficit in initiating or persistently engaging during interactions with friends/partner. If no friends/relationship, misses friend/romantic relationships, is motivated to have friends/relationship, and makes efforts to seek out friends/relationship.

**2 = Moderate deficit:** SOMEWHAT INTERESTED in friend/romantic relationships and considers them somewhat important. May occasionally miss close connections with friends/partner and is somewhat motivated to have friends/partner. Notable deficit in initiating and persistently engaging in interactions; discussion of good and bad times is limited. Interactions with friends/romantic partner may occur but are largely superficial and participation is best characterized as "going through the motions"; interactions are initiated by others with mostly passive involvement of the person. If no friend/romantic relationships, is only somewhat motivated to have friends/partner and rarely if ever seeks out friends/partner.

**3 = Moderately severe deficit:** LITTLE INTEREST in friend/romantic relationships (could "take it or leave it") and does not describe friends/partner as important. Describes hardly any motivation to have friendships, and would just as soon be alone. Contact and engagement with others is superficial and passive with almost all initiation and efforts to engage coming from others.

**4 = Severe deficit:** NO INTEREST in friend/romantic relationships and does not consider them at all important. Prefers to be alone and is not at all motivated to have friends/partner.

**ITEM 3: FREQUENCY OF PLEASURABLE SOCIAL ACTIVITIES – *PAST* WEEK**

[NOTE: Ratings are based on **NUMBER OF DAYS IN THE WEEK** that pleasurable activity with other people is experienced. When there are reports of several different activities occurring, clarify if these happened on same or different days.]

***Now, I want to talk to you about how you felt during the times you spent with or were in contact with others during the past week. You can include times with any of the people we have talked about so far or anyone else. Did you have any enjoyable interactions with other people, such as:***

- *Family* (PAUSE)
- *Romantic or dating partners* (PAUSE)
- *Friends* (PAUSE)
- *Any other enjoyable social interactions or time spent with people*? (PAUSE)
- *IF NEEDED: Ask about people brought up in other sections* ***that were described as enjoyable interactions***

| Sun | Mon | Tue | Wed | Thu | Fri | Sat |
|---|---|---|---|---|---|---|
| | | | | | | |

**IF YES:**

- *What about that was enjoyable?*
- *How many days did you enjoy/get pleasure from these interactions [time spent with xx person(s)] (for each)?*
- [If many (i.e., 5 or 6) days mentioned or if not clear which days of week interactions were enjoyed] *Were there any days that you did not have enjoyable interactions with other people?*

**Item 3 – Frequency of Pleasurable Social Activities – Past Week**

**0 = No impairment**: Pleasure experienced daily.
**1 = Mild deficit**: Pleasure experienced 5-6 days.
**2 = Moderate deficit**: Pleasure experienced 3-4 days.
**3 = Moderately severe deficit**: Pleasure experienced 1-2 days.
**4 = Severe deficit**: No pleasure reported

**ITEM 4: FREQUENCY OF EXPECTED PLEASURABLE SOCIAL ACTIVITIES – *NEXT* WEEK**

[NOTE: Ratings are based on total **NUMBER OF EXPECTED PLEASURABLE ACTIVITIES,** regardless of days on which they are expected to occur].

***Now I would like you to think ahead to NEXT week (next 7 days), thinking about whom you will spend time with. You can include people you have already talked about or anyone else. What do you think you will enjoy doing in the NEXT week with other people?***

**FOR EACH ANSWER PROVIDED:**

- *What about it do you expect to enjoy?*
- *How often do you think you will enjoy this in the next week?*

**FOLLOW UP**

- *Are there other experiences with people you think you will enjoy in the next week?*

**ITEM 4 – Frequency of Expected Pleasurable Social Activities – Next week**

**0 = No impairment:** Expecting MANY (7 or more) pleasurable experiences.
**1 = Mild deficit:** Expecting enjoyment from SEVERAL (5-6) pleasurable experiences.
**2 = Moderate deficit:** Expecting enjoyment from a FEW (3-4) pleasurable experiences.
**3 = Moderately severe deficit:** Expecting a COUPLE (1-2) pleasurable experiences.
**4 = Severe deficit:** Expecting NO pleasurable experiences.

## II. WORK & SCHOOL (MOTIVATION & PLEASURE)

**ITEM 5: MOTIVATION FOR WORK & SCHOOL ACTIVITIES**

***Now I am going to ask you some questions about work and school, including how motivated you have been for work or school activities and how you felt while doing these things over the past week. Have you been working or going to school over the past week? Any volunteer work? Are you in a work-related treatment program?***

**IF IN A RELEVANT ROLE:**

- *Tell me about what you do in your [insert role here]*
- *How much time has this involved over the past week?*

Behavior

- *Have you been able to complete tasks at [insert role here]?*
- *In the past week has anyone raised any concerns with your [insert role here] performance?*
- *Have you missed any days in the past week? Why?*
- *Does someone need to remind you about [insert role here]? Why is that?*
- *Were there things you meant to do or were supposed to do but just never got around to doing them? Why?*

Motivation

- *How do you feel about [insert role here]?*
- *Have you been motivated to do your [insert role here]?*
- *What motivates you to do your [insert role here]?*
- *Were there times during the past week when you just didn't feel like [insert role here]?*
- *How important is your [insert role here] to you? What about it is important?*

**IF NO CURRENT ROLE:**

- *Is there a reason why you are not currently (work/school/volunteer)?*
- *Has anything held you back from looking for (work/school/volunteer)?*
- *How do you feel about working or going to school or volunteering?*
- *Have you felt much interest in work/school/volunteer? {Tell me more}*
- *Is working important to you? What about working/going to school/volunteering is important?*
- *Do you miss work/school/volunteer?*
- *Have you tried to take any steps to start working/going to school/volunteering? What steps have you taken? How often have you looked into work/school/volunteer?*

**ITEM 5 – Motivation for Work & School Activities**

**0 = No impairment:** Person is VERY MOTIVATED to seek out work or school, or new opportunities in work or school; initiates and persists in work, school, or job-seeking on a regular basis. Well within normal limits.

**1 = Mild deficit:** Person is GENERALLY MOTIVATED to seek out work or school or new opportunities in work or school; a mild deficit in initiating and persisting; may report instances of initiating, but with moderate persistence.

**2= Moderate deficit:** Person is SOMEWHAT MOTIVATED to seek out work or school or new opportunities in work or school; notable deficit in initiating; may have initiated activities, but needed reminders on multiple occasions, and/or not initiated any new activities, and/or not persisted for very long.

**3 = Moderately severe deficit:** Person is only SLIGHTLY MOTIVATED to seek out work or school or new opportunities in work or school; significant deficit in initiating; may have needed constant reminders, and/or initiated a few activities; did not persist for very long.

**4 = Severe deficit:** Person is NOT AT ALL MOTIVATED to seek out work / school; nearly total lack of initiation and persistence in work, school, or job seeking.

**ITEM 6: FREQUENCY OF EXPECTED PLEASURABLE WORK & SCHOOL ACTIVITIES - *NEXT* WEEK**
[NOTE: Ratings are based on total **NUMBER OF EXPECTED PLEASURABLE ACTIVITIES,** regardless of days on which they are expected to occur].

***Now I would like you to think ahead to NEXT week (next 7 days); thinking about work/volunteer/school.***

**IF HAS A RELEVANT ROLE:**
• *What do you think you will enjoy doing in the NEXT week at work/volunteer/school, etc.*

**IF NO RELEVANT ROLE:**
• *Do you think you will enjoy anything related to seeking paid or volunteer work, or school?*

**FOR EACH ANSWER PROVIDED:**
• *What about it do you expect to enjoy?*
• *How often do you think you will enjoy this in the next week?*

**FOLLOW UP:**
• *Are there other work/school experiences you think you will enjoy in the next week?*

**ITEM 6 – Frequency of Expected Pleasurable Work & School Activities – *Next* Week**

**0 = No impairment:** Expecting MANY (7 or more) pleasurable experiences.
**1 = Mild deficit:** Expecting enjoyment from SEVERAL (5-6) pleasurable experiences.
**2 = Moderate deficit**: Expecting enjoyment from a FEW (3-4) pleasurable experiences.
**3 = Moderately severe deficit:** Expecting a COUPLE (1-2) pleasurable experiences.
**4 = Severe deficit**: Expecting NO pleasurable experiences.

## III. RECREATION (MOTIVATION & PLEASURE)

**ITEM 7: MOTIVATION FOR RECREATIONAL ACTIVITIES**

***In the next section, I am going to ask you some questions about what you do in your free time – any hobbies or recreational activities. I will ask about your motivation and feelings about the things that you have done in your free time over the past week.***

• *What have you done in your free time in the past week?*
• *Have you participated in any hobbies or leisure activities such as sports or games, going to church, TV, music, reading, internet, walking or other such activities during the past week?*

**IF YES:**
Behavior
• *Tell me about (activity). How much time has this involved over the past week? Did you want to do (activity) more than that? Did it last longer than you had hoped? Why did it only last for (xx)?*
• *Did anything get in the way of doing these activities over the past week? What was that?*
• *Who initiated these activities? Did someone need to remind you to participate in these activities?*

Motivation

- *How has your motivation or drive to get involved in these activities been over the past week?*
- *Did you ever feel like you just weren't very interested in these activities?*
- *Are these types of activities important to you? Why? Have you been interested in these activities?*
- *Did you ever feel that you would just as soon do nothing instead of getting involved in these types of activities?*

**IF NO:**

- *Is there a reason why you haven't gotten involved in any hobbies or recreational activities in the past week?*
- *Have you wanted to or were you motivated to do something with your free time in the past week?*
- *Did anything ever get in the way of doing these types of activities over the past week? What was that?*

**ITEM 7 – Motivation for Recreational Activities**

**0 = No impairment:** Person is VERY MOTIVATED to seek out hobbies and recreational activities; initiates and persists in hobbies and recreational activities on a regular basis, well within normal limits.
**1 = Mild deficit:** Person is GENERALLY MOTIVATED to seek out hobbies and recreational activities; a mild deficit in initiating and persisting; may report initiating hobbies, but with moderate persistence.
**2 = Moderate deficit:** Person is SOMEWHAT MOTIVATED to seek out hobbies and recreational activities; notable deficit in initiating; may have initiated some activities and/or not persisted for very long. Others were somewhat more likely to initiate hobbies or activities.
**3 = Moderately severe deficit:** Person is only SLIGHTLY MOTIVATED to seek out hobbies and recreational activities; significant deficit in initiating and persisting; may have initiated a few activities and not persisted for very long. Others were much more likely to initiate hobbies or prompt initiation.
**4 = Severe deficit:** Person is NOT AT ALL MOTIVATED to seek out hobbies and recreational activities; nearly total lack of initiation and persistence in hobbies or recreational activities.

**ITEM 8: FREQUENCY OF PLEASURABLE RECREATIONAL ACTIVITIES – *PAST* WEEK**

[NOTE: Rating is based on both **VARIETY** of pleasurable activities and **DAILY FREQUENCY** that these are experienced. When there are reports of several different activities occurring, need to clarify if these happened on same or different days.]

***Did you have any enjoyable (pleasurable) experience from things you did in your free time last week? You can include any of the activities we've talked about so far or any other leisure activities in the past week, including TV, sports or games, going to church, music, reading, internet, walking or other such activities?***

- *What about [insert activity here] was enjoyable?*
- *How many days did you enjoy/get pleasure from these experiences?*
- *IF NEEDED: Ask about activities brought up in other sections* ***that were described as enjoyable***

**FOLLOW UP:**

*Any other enjoyable experiences from things you do in your free time or your hobbies?*

| Activity | Sun | Mon | Tue | Wed | Thu | Fri | Sat |
|---|---|---|---|---|---|---|---|
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |
| | | | | | | | |

**ITEM 8 – Frequency of Pleasurable Recreational Activities - Past Week**

**0 = No impairment:** At least A FEW (3) different types of pleasurable experiences, experienced daily.
**1 = Mild deficit:** At least A FEW (3) different types of pleasurable experiences, experienced more days than not.
**2 = Moderate deficit:** 1 or 2 different types of pleasurable experiences, experienced more days than not.
**3 = Moderately severe deficit:** 1 type of pleasurable experience, experienced on just a few days.
**4 = Severe deficit:** No pleasurable experiences.

**ITEM 9: FREQUENCY OF EXPECTED PLEASURABLE RECREATIONAL ACTIVITIES – *NEXT* WEEK**
[NOTE: Ratings are based on total **NUMBER OF EXPECTED PLEASURABLE ACTIVITIES,** regardless of days on which they are expected to occur]

***Now I would like you to think ahead to NEXT week (next 7 days), thinking about your free time/hobbies/ recreation. You can include any of the activities you have already talked about or anything else. What do you think you will enjoy doing in the NEXT WEEK in your recreational/free time?***

**FOR EACH ANSWER PROVIDED:**
• *What about it do you expect to enjoy?*
• *How often do you think you will enjoy [activity] in the next week?*

**FOLLOW UP:**
• *Are there other things you do in your free time like hobbies or recreational activities that you think you will enjoy in the next week?*

**ITEM 9 – Frequency of Expected Pleasurable Recreational Activities – Next Week**

**0 = No impairment:** Expecting MANY (7 or more) pleasurable experiences.
**1 = Mild deficit:** Expecting enjoyment from SEVERAL (5-6) pleasurable experiences.
**2 = Moderate deficit:** Expecting enjoyment from a FEW (3-4) pleasurable experiences.
**3 = Moderately severe deficit:** Expecting a COUPLE (1-2) pleasurable experiences.
**4 = Severe deficit:** Expecting NO pleasurable experiences.

## IV. EXPRESSION

**ITEM 10: FACIAL EXPRESSION**
When making the facial expression rating, consider facial movements across all parts of the face, including in the eyes (e.g., raised brows when surprised), mouth (smiling or grimacing), and mid-face (e.g., wrinkled nose when disgusted).

**ITEM 10 - Facial Expression**

**0 = No impairment:** WITHIN NORMAL LIMITS; frequent expressions throughout the interview.
**1 = Mild deficit:** MILD DECREASE in the frequency of facial expressions, with limited facial expressions during a few parts of the interview.
**2 = Moderate deficit:** NOTABLE DECREASE in the frequency of facial expressions, with diminished facial expressions during several parts of the interview.
**3 = Moderately severe deficit:** SIGNIFICANT LACK of facial expressions, with only a few changes in facial expression throughout most of the interview.
**4 = Severe deficit:** NEARLY TOTAL LACK of facial expressions throughout the interview.

**ITEM 11: VOCAL EXPRESSION**

This item refers to prosodic features of the voice. This item reflects changes in tone during the course of speech. Speech rate, amount, or content of speech is not assessed.

**Item 11 - Vocal Expression**

**0 = No impairment:** WITHIN NORMAL LIMITS. Normal variation in vocal intonation across interview. Speech is expressive and animated.
**1 = Mild deficit:** MILD DECREASE in vocal intonation. Variation in intonation occurs with a limited intonation during a few parts of the interview.
**2 = Moderate deficit:** NOTABLE DECREASE in vocal intonation. Diminished intonation during several parts of the interview. Much of speech is lacking variability in intonation but prosodic changes occur in several parts of the interview.
**3 = Moderately severe deficit:** SIGNIFICANT LACK of vocal intonation with only a few changes in intonation throughout most of the interview. Most of speech is flat and lacking variability, only isolated instance of prosodic change.
**4 = Severe deficit:** NEARLY TOTAL LACK OF change in vocal intonation with characteristic flat or monotone speech throughout the interview.

**ITEM 12: EXPRESSIVE GESTURES**

Expressive gestures are used to emphasize what is communicated verbally through gestures made with the hands, head (nodding), shoulders (shrugging), and trunk (leaning forward, leaning back).

**ITEM - 12 Expressive Gestures**

**0 = No impairment:** WITHIN NORMAL LIMITS; uses frequent gestures throughout the interview.
**1 = Mild deficit:** MILD DECREASE in the frequency of expressive gestures, with limited gestures in a few parts of the interview.
**2= Moderate deficit:** NOTABLE DECREASE in the frequency of expressive gestures, with lack of gestures during several parts of the interview.
**3 = Moderately severe deficit:** SIGNIFICANT LACK of expressive gestures, with only a few gestures throughout most of the interview.
**4 = Severe deficit:** NEARLY TOTAL LACK of expressive gestures.

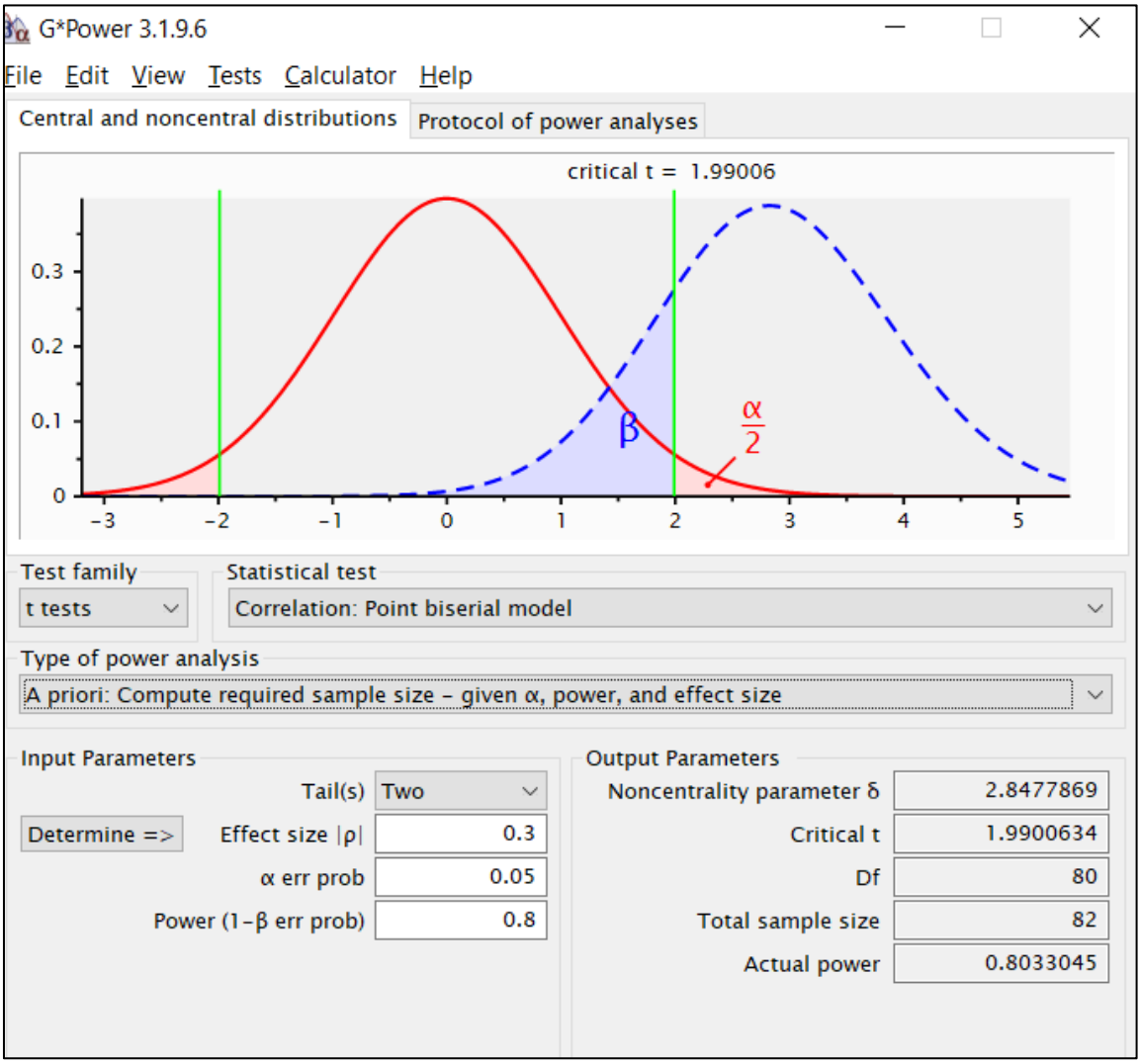
**ITEM 13: QUANTITY OF SPEECH**

This item refers to the quantity of words spoken. Other speech abnormalities, such as disorganization, neologisms, or psychotic content are not rated here. For instance, a disorganized person may produce a large quantity of speech and have a low (normal) score on this item.

**ITEM - 13 Quantity of speech**

**0 = No impairment:** NORMAL AMOUNT of speech throughout the interview. Replies provide sufficient information with frequent spontaneous elaboration.
**1 = Mild deficit:** MILD DECREASE in the quantity of speech, with brief responses during a few parts of the interview.
**2= Moderate deficit:** NOTABLE DECREASE in speech output, with brief responses during several parts of the interview.
**3 = Moderately severe deficit:** SIGNIFICANT LACK of speech, with very brief answers (only several words) in responses throughout most of the interview.
**4 = Severe deficit:** All or nearly all replies are one or two words throughout the entire interview.

**Appendix 16. The following information from the quantitative studies; GPOWER, Histograms showing distribution of variable and the Statistical product and Service Solutions (SPSS) outputs**



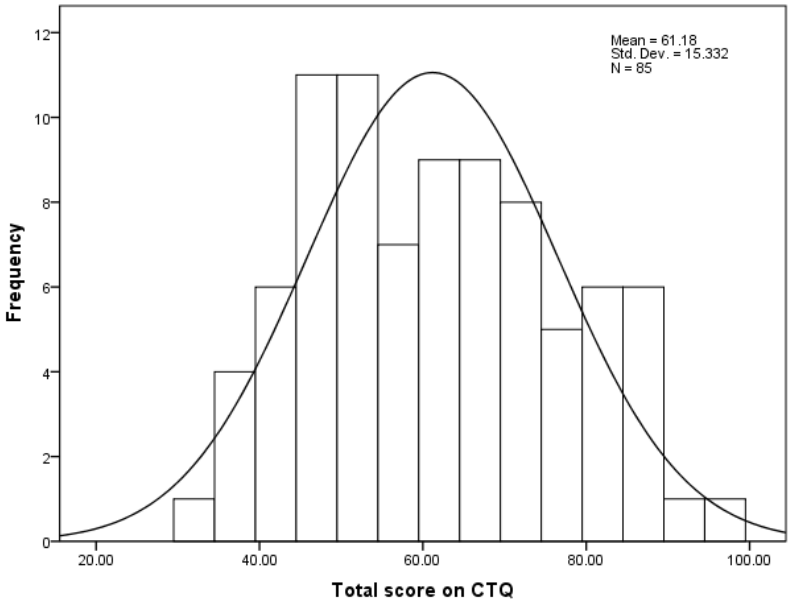



Figure 1.

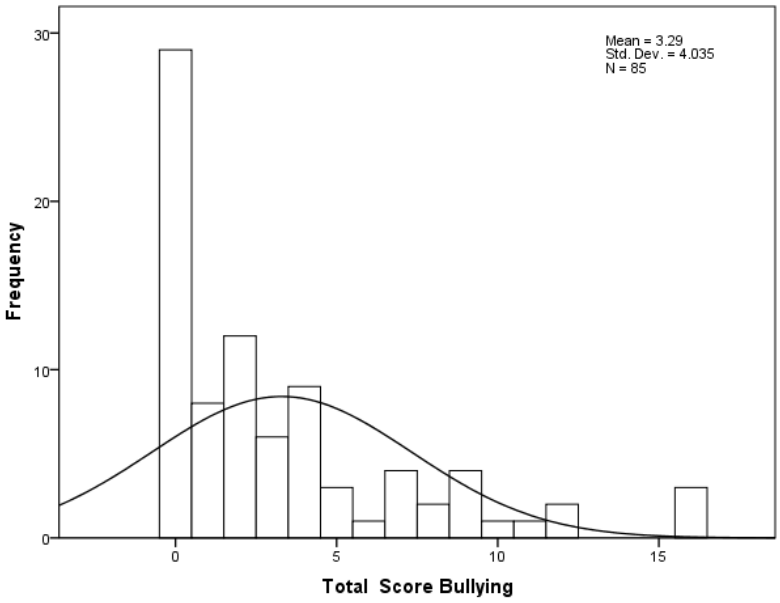



Figure 2.

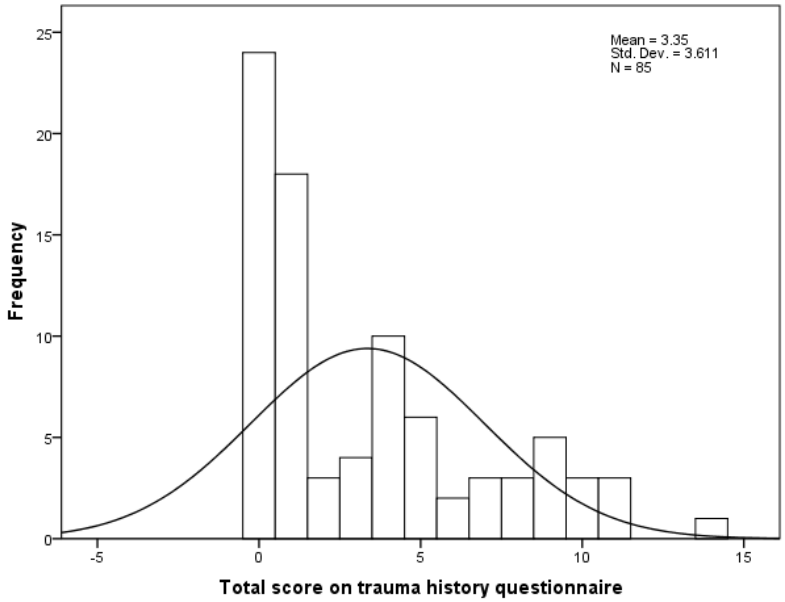



Figure 3.

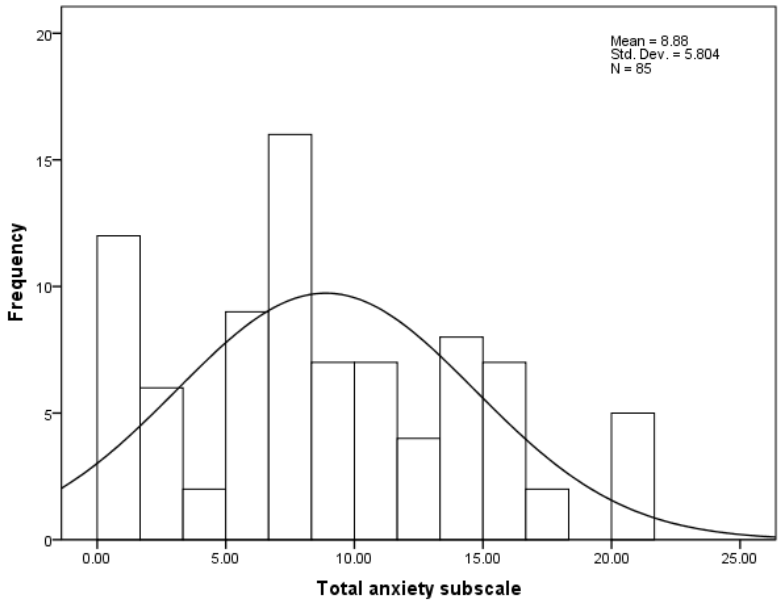



Figure 4.

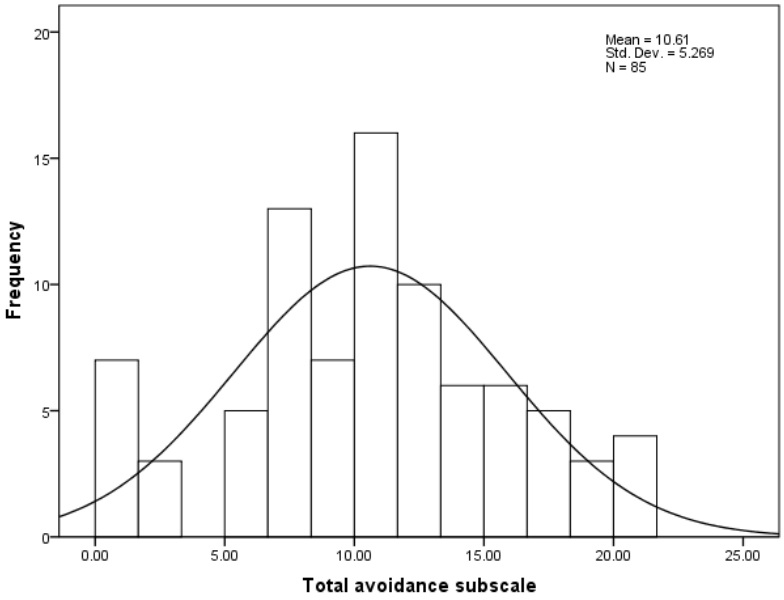



Figure 5.

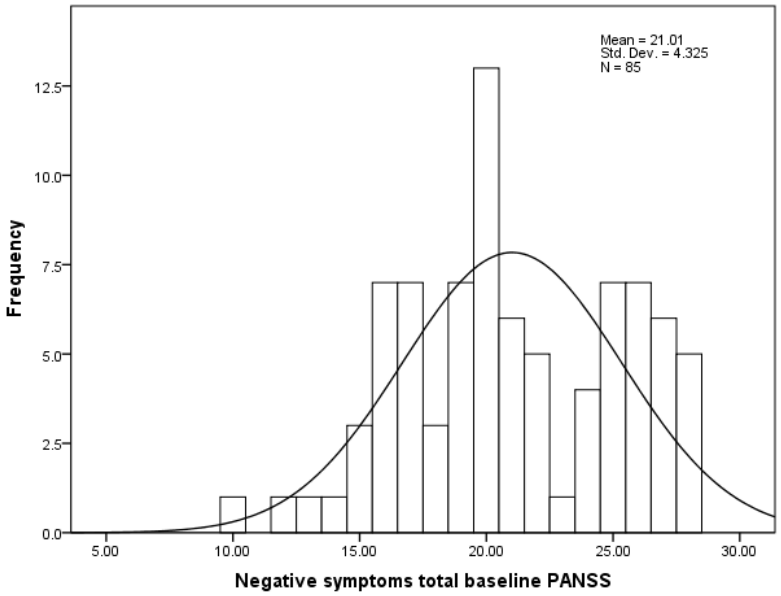



Figure 6.

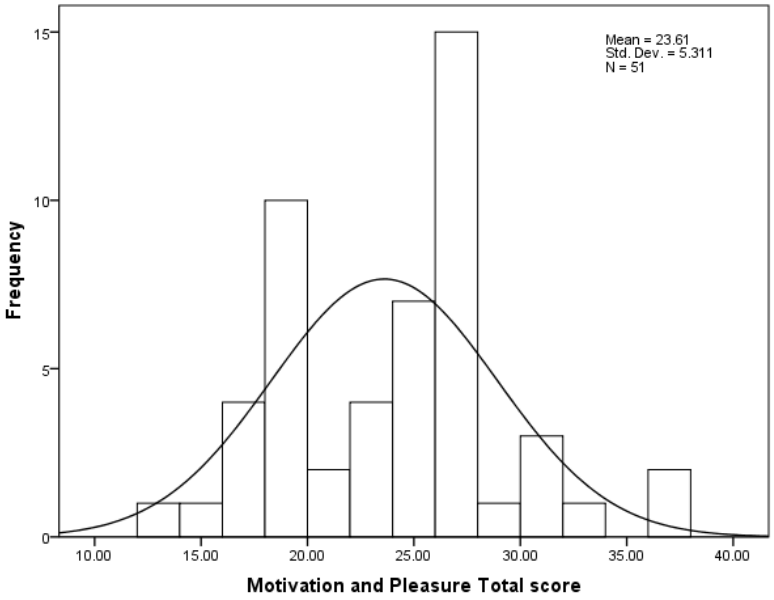



Figure 7.

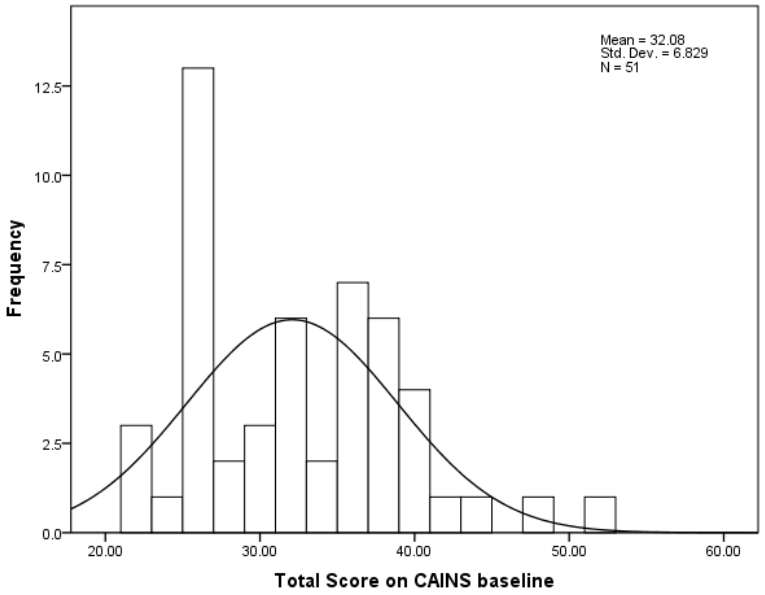



Figure 8.

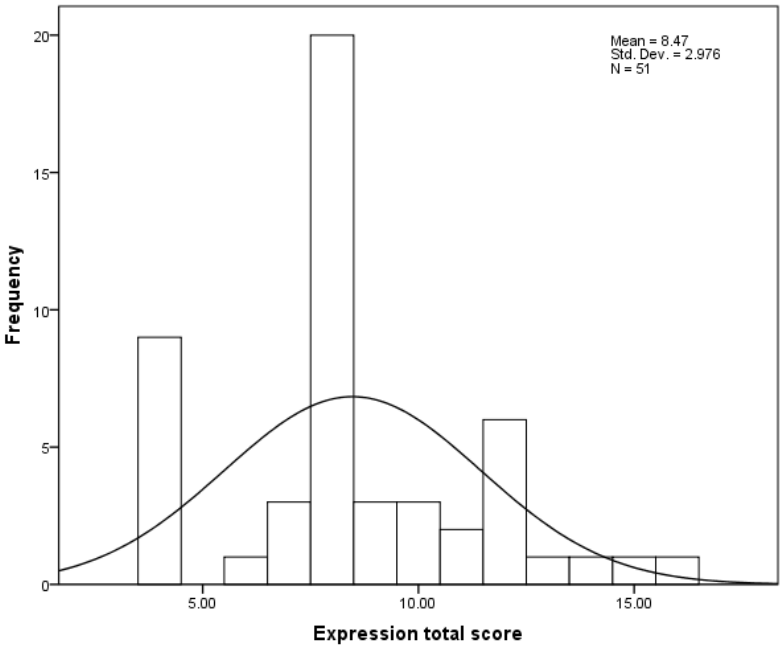



Figure 9.

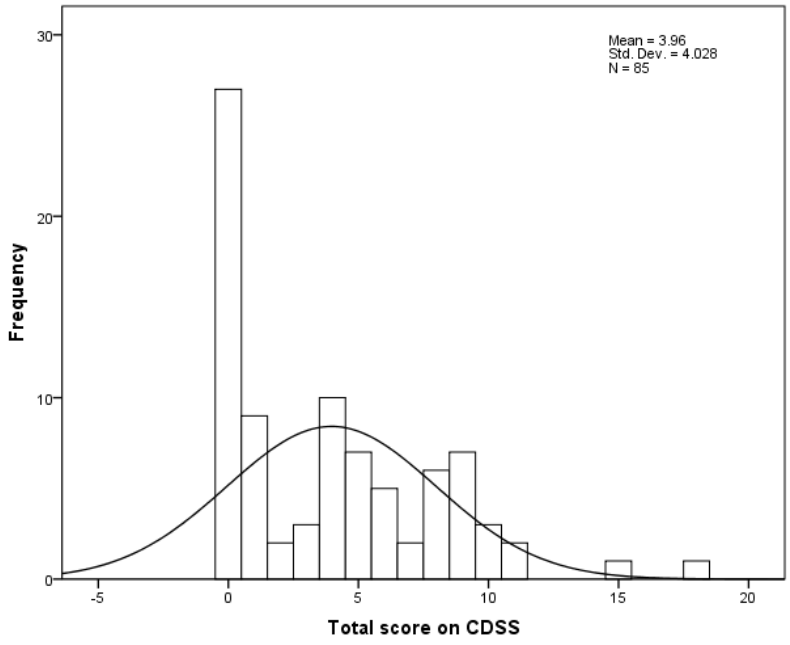



Figure 10.


Figure 11.

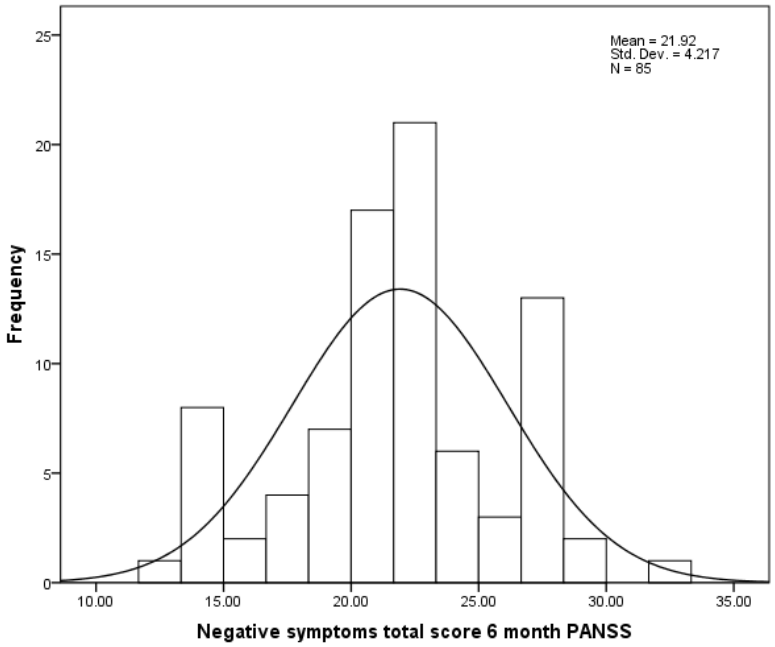



Figure 12.

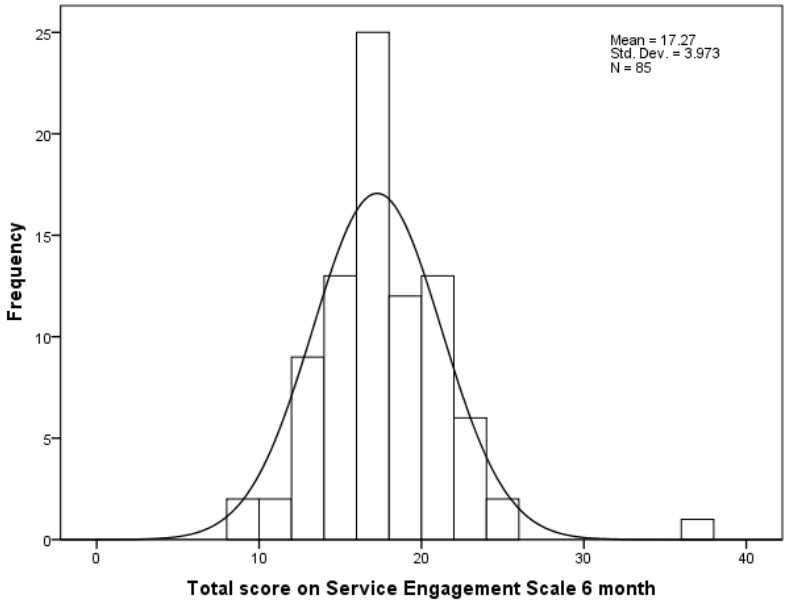



Figure 13.

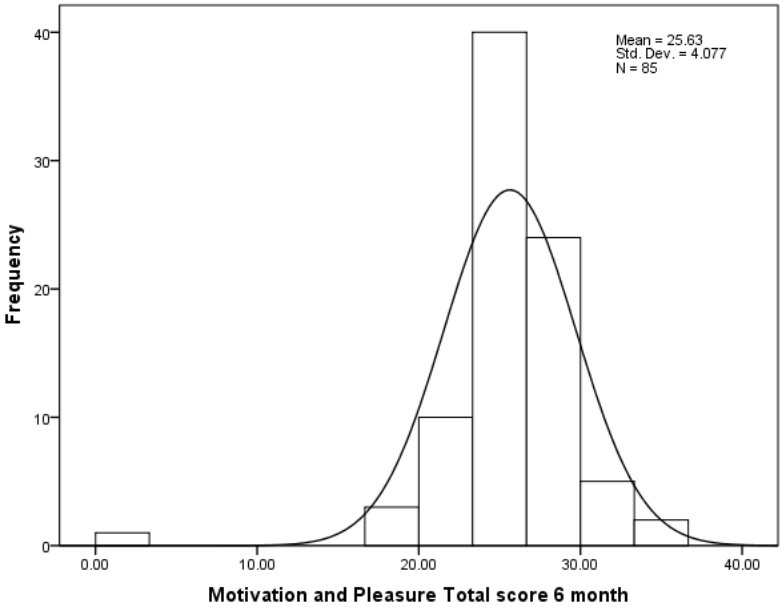



Figure 14.

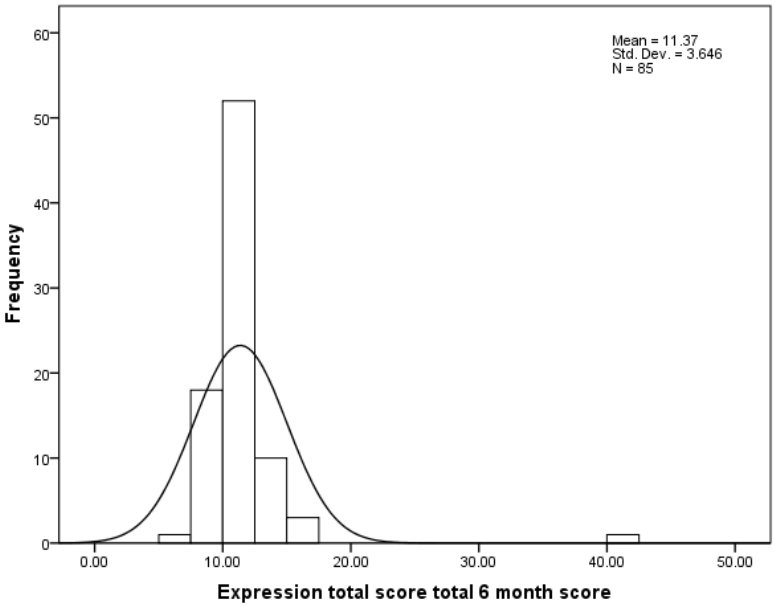
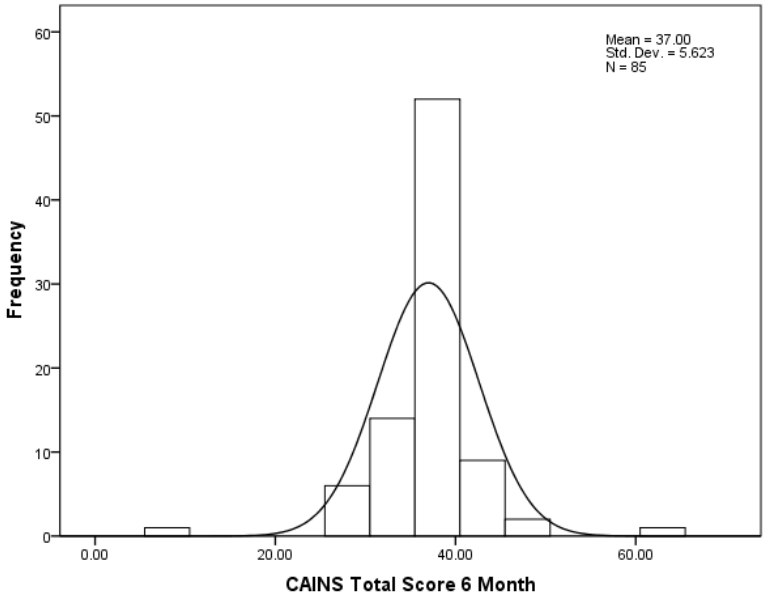

Mean = 11.37
Std. Dev. = 3.646
N = 85
Frequency
60
50
40
30
20
10
0
0.00
10.00
20.00
30.00
40.00
50.00
Expression total score total 6 month score

Figure 15.


Mean = 37.00
Std. Dev. = 5.623
N = 85
Frequency
60
50
40
30
20
10
0
0.00
20.00
40.00
60.00
CAINS Total Score 6 Month

Model 1.

**Model Summary**

| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate |
|---|---|---|---|---|
| 1 | .445[a] | .198 | .125 | 3.94357 |

a. Predictors: (Constant), Total score on CDSS, Total avoidance subscale , Total score on trauma history questionnaire , Negative symptoms total baseline PANSS, Total score on CTQ, TotalscoreBullying, Total anxiety subscale

**ANOVA[b]**

| Model | | Sum of Squares | df | Mean Square | F | Sig. |
|---|---|---|---|---|---|---|
| 1 | Regression | 296.009 | 7 | 42.287 | 2.719 | .014[a] |
| | Residual | 1197.484 | 77 | 15.552 | | |
| | Total | 1493.493 | 84 | | | |

a. Predictors: (Constant), Total score on CDSS, Total avoidance subscale , Total score on trauma history questionnaire , Negative symptoms total baseline PANSS, Total score on CTQ, TotalscoreBullying, Total anxiety subscale

b. Dependent Variable: Negative symptoms total score 6 month PANSS

**Coefficients[a]**

| Model | | Unstandardized Coefficients | | Standardized Coefficients | | |
|---|---|---|---|---|---|---|
| | | B | Std. Error | Beta | t | Sig. |
| 1 | (Constant) | 26.312 | 3.105 | | 8.474 | .000 |
| | Negative symptoms total baseline PANSS | -.215 | .101 | -.221 | -2.126 | .037 |
| | Total score on trauma history questionnaire | .125 | .121 | .107 | 1.034 | .304 |
| | Total score on CTQ | -.031 | .029 | -.114 | -1.068 | .289 |
| | TotalscoreBullying | .320 | .112 | .306 | 2.847 | .006 |
| | Total anxiety subscale | -.232 | .101 | -.320 | -2.306 | .024 |
| | Total avoidance subscale | .285 | .110 | .356 | 2.595 | .011 |
| | Total score on CDSS | -.098 | .112 | -.093 | -.871 | .387 |

a. Dependent Variable: Negative symptoms total score 6 month PANSS

Model 2.

**Model Summary**

| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate |
|---|---|---|---|---|
| 1 | .320[a] | .102 | -.044 | 4.91190 |

a. Predictors: (Constant), Total score on CDSS, Total score on trauma history questionnaire , TOTALSCOREON CAINSbaseline, Total avoidance subscale , TotalscoreBullying, Total score on CTQ, Total anxiety subscale

**ANOVA[b]**

| Model | | Sum of Squares | df | Mean Square | F | Sig. |
|---|---|---|---|---|---|---|
| 1 | Regression | 118.471 | 7 | 16.924 | .701 | .671[a] |
| | Residual | 1037.451 | 43 | 24.127 | | |
| | Total | 1155.922 | 50 | | | |

a. Predictors: (Constant), Total score on CDSS, Total score on trauma history questionnaire , TOTALSCOREON CAINSbaseline, Total avoidance subscale , TotalscoreBullying, Total score on CTQ, Total anxiety subscale

b. Dependent Variable: CAINSTOTALSCORE6MONTH

**Coefficients[a]**

| Model | | Unstandardized Coefficients | | Standardized Coefficients | | |
|---|---|---|---|---|---|---|
| | | B | Std. Error | Beta | t | Sig. |
| 1 | (Constant) | 37.318 | 4.837 | | 7.715 | .000 |
| | TOTALSCOREON CAINSbaseline | .012 | .104 | .017 | .114 | .910 |
| | Total score on trauma history questionnaire | .110 | .193 | .084 | .570 | .572 |
| | Total score on CTQ | -.026 | .051 | -.083 | -.507 | .615 |
| | TotalscoreBullying | -.096 | .185 | -.084 | -.521 | .605 |
| | Total anxiety subscale | .214 | .162 | .246 | 1.321 | .193 |
| | Total avoidance subscale | .016 | .181 | .017 | .087 | .931 |
| | Total score on CDSS | -.082 | .217 | -.061 | -.378 | .708 |

a. Dependent Variable: CAINSTOTALSCORE6MONTH

Model 3.

**Model Summary**

| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate |
|---|---|---|---|---|
| 1 | .160[a] | .026 | .001 | 4.30226 |

a. Predictors: (Constant), Total score on CDSS, Total score on Service Engagement Scale

**ANOVA[b]**

| Model | | Sum of Squares | df | Mean Square | F | Sig. |
|---|---|---|---|---|---|---|
| 1 | Regression | 38.643 | 2 | 19.321 | 1.044 | .357[a] |
| | Residual | 1462.248 | 79 | 18.509 | | |
| | Total | 1500.890 | 81 | | | |

a. Predictors: (Constant), Total score on CDSS, Total score on Service Engagement Scale

b. Dependent Variable: Negative symptoms total baseline PANSS

**Coefficients[a]**

| Model | | Unstandardized Coefficients | | Standardized Coefficients | | |
|---|---|---|---|---|---|---|
| | | B | Std. Error | Beta | t | Sig. |
| 1 | (Constant) | 19.703 | 1.540 | | 12.794 | .000 |
| | Total score on Service Engagement Scale | .090 | .075 | .133 | 1.191 | .237 |
| | Total score on CDSS | -.110 | .119 | -.103 | -.923 | .359 |

a. Dependent Variable: Negative symptoms total baseline PANSS

Model 4.

**Model Summary**

| Model | R | R Square | Adjusted R Square | Std. Error of the Estimate |
|---|---|---|---|---|
| 1 | .360[a] | .130 | .108 | 5.40921 |

a. Predictors: (Constant), Total score on CDSS, Total score on Service Engagement Scale

**ANOVA[b]**

| Model | | Sum of Squares | df | Mean Square | F | Sig. |
|---|---|---|---|---|---|---|
| 1 | Regression | 344.495 | 2 | 172.247 | 5.887 | .004[a] |
| | Residual | 2311.505 | 79 | 29.260 | | |
| | Total | 2656.000 | 81 | | | |

a. Predictors: (Constant), Total score on CDSS, Total score on Service Engagement Scale

b. Dependent Variable: CAINSTOTALSCORE6MONTH

**Coefficients[a]**

| Model | | Unstandardized Coefficients | | Standardized Coefficients | | |
|---|---|---|---|---|---|---|
| | | B | Std. Error | Beta | t | Sig. |
| 1 | (Constant) | 30.714 | 1.936 | | 15.863 | .000 |
| | Total score on Service Engagement Scale | .317 | .095 | .352 | 3.343 | .001 |
| | Total score on CDSS | .069 | .149 | .049 | .464 | .644 |

a. Dependent Variable: CAINSTOTALSCORE6MONTH

## Appendix 17. Topic guide for qualitative study



Project Title:

**Subjective experiences of negative symptoms of schizophrenia.**

**Topic Guide**

*Sponsored by the University of Manchester and the Medical Research Council.*

Isabelle Butcher

PhD Student

Division of Psychology and Mental Health

School of Health Sciences

University of Manchester

Room S42, Zochonis Building

Brunswick Street

Manchester, M13 9PL

E-mail: isabelle.butcher-2@postgrad.manchester.ac.uk

**Supervisors:**

Dr Katherine Berry: Division of Psychology and Mental Health, School of Health Sciences, University of Manchester. Email: Katherine.berry@manchester.ac.uk

Professor Gillian Haddock, Division of Psychology and Mental Health, School of Health Sciences, University of Manchester. Email: Gillian.haddock@manchester.ac.uk

The interview should take no longer than 60 minutes. The interviews will be audio recorded, if you agree to this. The interview will also be anonymised

If you wish to stop at any point please let me know.

Some people have told us that they often experience voices and hallucinations. Others have also said that they have lost normal thoughts, feelings and motivations. You may have little energy. You may lack 'get-up-and-go' it can make you not bothered to go out of the house. It can be hard to feel excited or enthusiastic about anything; for example when a friend gets married we can get excited but sometimes these events do not make us feel anything. Some people have said they cannot concentrate, for example following a television programme or reading a book is difficult. You may also find it hard to make eye contact with others when you are talking to them. Some people have also told us they can feel numb and that when they experience different emotions their faces do not change. For example when they are excited their faces do not change. You may also stop washing or tidying, or keeping your clothes clean. You may feel uncomfortable with people and not want to socialise with others.

People can find it hard to understand that these things are really symptoms – not just laziness. This can make it difficult for both you and your family. These things can be hard to live with.

- How does this fit with your experience(s) ?
- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

Prompts to be used to encourage respondent.

1) Sometimes it is hard to experience pleasure from activities that were once enjoyable – an example is playing football or listening to music.

2) There are times when we have very intense feelings for example when we are in love with somebody or when we dislike somebody. Sometimes when we have a close relationship with

someone we share intimate details.

Sometimes we have lots of thoughts in our head but other times we have none.

3) Our facial expressions change; for example when something we are happy about happens we may smile and move our mouths. There are times when we feel numbness and unmoved and so our faces do not change with how we are feeling.

What do you think, if anything, caused these experiences to occur?

Is there anything further that you would like to add?

Thank you for your time.

## Appendix 18. PDF of published paper in British Journal of Clinical Psychology

3 Check for updates

the british psychological society
promoting excellence in psychology

British Journal of Clinical Psychology (2020), 59, 319–334

www.wileyonlinelibrary.com

# Understanding individuals' subjective experiences of negative symptoms of schizophrenia: A qualitative study

Isabelle Butcher[1,2]*, Katherine Berry[1,2,3] and Gillian Haddock[1,2,3]

[1]Division of Psychology and Mental Health, School of Health Sciences, University of Manchester, UK
[2]Manchester Academic Health Sciences Centre, Manchester, UK
[3]Greater Manchester Mental Health NHS Foundation Trust, Manchester, UK

**Objectives.** Individuals with a diagnosis of schizophrenia often experience both positive and negative symptoms. Negative symptoms can be disabling and have a serious impact on everyday functioning. Despite the range of clinician-rated measurement tools used to assess negative symptoms, very little is known about how individuals subjectively experience these symptoms. This study sought to examine, using qualitative methods, how people living with a diagnosis of schizophrenia subjectively experience negative symptoms.

**Design.** Qualitative study.

**Method.** Semi-structured interviews were carried out with individuals with a diagnosis of schizophrenia who were experiencing negative symptoms. The sample was recruited from community and inpatient National Health Service mental health settings in the United Kingdom. Interviews were analysed using thematic analysis.

**Results.** Twenty individuals took part. Individuals highlighted the persistent and enduring nature of their negative symptoms. Two central themes were identified: What it is like to experience negative symptoms and where have my negative symptoms come from? Within the first theme, four sub-themes emerged: loss of concentration, loss of motivation, withdrawal, and 'feeling but not feeling'. Within the second theme, four sub-themes emerged related to the causes of negative symptoms: impact of traumatic life events, positive psychotic symptoms, impact of social network, and recreational and prescribed drug use.

**Conclusion.** Individuals, who experience negative symptoms, were able to articulate the persistent and disabling nature of negative symptoms and clearly described factors which they believed contributed to the onset, exacerbation, and amelioration of the experiences.



*Correspondence should be addressed to Isabelle Butcher, Division of Psychology and Mental Health, University of Manchester, Manchester M13 9PL, UK (email: Isabelle.butcher-2@postgrad.manchester.ac.uk).

DOI:10.1111/bjc.12248

## Practitioner points

- Negative symptoms for people diagnosed with schizophrenia are persistent and enduring and impact an individual's life.
- There has been little research conducted qualitatively on individuals' subjective experiences of negative symptoms.
- Individuals who experience negative symptoms attribute these to a number of factors, including adverse life events, recreational and prescribed drug use, an absence of social support, and positive psychotic symptoms.
- Understanding negative symptoms is important for services, clinicians, and family members, where misattributions made about negative symptoms can lead to such experiences being dismissed.

Negative symptoms have been recognized as a central feature of the diagnosis of schizophrenia dating back to early descriptions by Kraepelin, Barclay, and Robertson (1919) and Bleuler (1911). Negative symptoms have been defined as an absence of behaviours and include, for example, lack of motivation, flattened affect, anhedonia, and alogia (Andreasen, 1982). These symptoms have been noted to be some of the most disabling symptoms for people with a diagnosis of schizophrenia, resulting in significant adverse effects on longitudinal, social, and occupational functional outcomes (Ferhava, Foussias, Agid, & Remington, 2014). Such symptoms have an impact not only on the individual but also on their family and wider society, emotionally and economically. In the last decade, there has been considerable interest in how best to understand negative symptoms (Cella, Preti, Edwards, Dow, & Wykes, 2016).

Research has suggested that positive symptoms of schizophrenia, such as hallucinations and delusions, may be linked to stressful early life events, including childhood abuse and neglect (Gallagher & Jones, 2013; Gallagher, Jones, & Pardes, 2016; Read, van Os, Morrison, & Ross, 2005; Varese, Barkus, & Bentall, 2012). Little research, however, has been conducted on whether there is a link between traumatic life events and negative symptoms. Nevertheless, it has been noted that negative symptoms can be similar to the symptoms that individuals display in response to experiencing adverse life events, for example, numbness and emotional shutdown (Beichtman *et al.*, 1992), suggesting that exploration of the potential links between negative symptoms and early life adversity is warranted.

In terms of treatment, there has been a particular surge in research in the last 20 years (Remington *et al.*, 2016; Stahl & Buckley, 2007). Studies include evaluations of pharmacological interventions, such as the use of antipsychotics and antidepressants (Harvey, James, & Shields, 2016; Kraus *et al.*, 2018), as well as psychosocial-based therapies such as cognitive behavioural therapy (Staring, ter Huurne, & van der Gaag, 2013) and art therapy (Johnson *et al.*, 2009; Rohricht & Priebe, 2006). Despite this increased attention, there is currently no treatment that unequivocally reduces negative symptoms.

Traditionally, different aspects of negative symptoms have been identified through the use of observer or clinician-rated instruments, such as the Positive and Negative Syndrome Scale (PANSS) (Kay, Fiszbein, & Opfer, 1987), the Scale for the Assessment of Negative Symptoms (SANS) (Andreasen, 1982), and the Clinical Assessment Interview for Negative Symptoms (CAINS) (Kring, Gur, Blanchard, Joran, & Reise, 2013). An example of a self-report measure is the Subjective Experience of Negative Symptoms (SENS) scale (Selten, Silben, van den Bosch, Omloo-Visser, & Warmerdam, 1993), which is designed to assess and measure subjective aspects of negative symptoms, including the experiencer's awareness of them and their related disruption and distress. SENS has been shown to have

good psychometric properties, including test–retest reliability (Selten et al., 1993), but it does not allow for a full understanding of the individual's perspectives on the symptoms.

Most of the research on negative symptoms has not been carried out involving people experiencing the symptoms. However, there is evidence that highlights the importance of involving in research those who have lived experience of a mental health condition in order to fully understand the experience and to develop treatments and services which will meet their needs (Faulkner *et al.*, 2019). Research has been conducted into how individuals experience symptoms of psychosis (Tanskanen *et al.*, 2011), yet little research has been carried out into the subjective experience of negative symptoms (Selten *et al.*, 1998) using a qualitative methodology. One exception is a study carried out by Gee *et al.* (2018) which explored the lived experiences of 24 individuals experiencing first-episode psychosis, all of whom presented with negative symptoms. Reduced facial expression, motivation, and sociability featured commonly in the participants' accounts. Participants tended to attribute their negative symptom experiences to lack of confidence and medication side effects. The study was carried out with individuals who had experienced recent-onset psychosis, and there is a paucity of research examining experiences of negative symptoms in people with more long-standing diagnoses of schizophrenia. The paper also constituted a secondary analysis of a nested qualitative study within a trial of psychological therapy for psychosis, with the potential risk that pertinent themes to the question of subjective experiences were not followed up by interviewers.

Given this gap in the literature, the present study aimed to identify and understand how individuals, who vary in the time since the onset of psychosis, subjectively experience negative symptoms. Qualitative methods were considered to be the most appropriate for gaining a detailed understanding of individuals' experiences of negative symptoms. Ultimately, obtaining a more in-depth understanding of the subjective experiences of negative symptoms through qualitative research may help us pinpoint potential underlying mechanisms and develop effective and appropriate treatments.

## Method

### *Sample*

Purposive sampling was adopted to ensure that the sample obtained was diverse in relation to age, gender, and ethnicity. Eligible participants were English speakers aged 18 and over who were either mental health inpatients or outpatients under the care of a Community Mental Health Team in National Health Service Trusts in the United Kingdom. Individuals had to have a score of at least three on two or more of the negative symptom items on PANSS, as assessed by the first author. Individuals were also required to have a DSM IV or DSM V diagnosis of schizophrenia, schizophreniform disorder, schizoaffective disorder, or delusional disorder. Finally, individuals were required to consent to having the study interview audio-recorded.

### *Procedure*

This study was reviewed by a North West Ethics Committee and was carried out from April 2017 to July 2018. Four NHS trusts were used as sites for this project.

Participants were recruited from inpatient mental health settings and community mental health teams. Care co-ordinators and other clinicians were approached by the lead author to identify people who potentially met the inclusion criteria for the study. Potential

participants were given information about the study and completed a 'consent to contact' form with their contact details. The lead author, IB, then approached each individual's clinical care team to obtain risk information. Participants were then contacted and given an information sheet. If they were willing to take part, they signed a consent form. Participants were seen in either their home or a hospital setting. The lead author conducted the PANSS interview with each individual to ensure they met this inclusion criterion, and, if they met the criterion, the lead author conducted the qualitative interview.

Semi-structured interviews were conducted by the first author face-to-face and covered a range of pre-specified topics (Appendix) regarding participants' experiences of their negative symptoms, such as their effect on functioning and relationships with others, and their thoughts on what may have contributed to the development of their symptoms. The topic guide (Appendix) was derived from the literature on negative symptoms and refined through discussion amongst the authors (a post-graduate psychology researcher and experienced clinical psychologists who have worked with people with psychosis for many years). Individuals with experience of psychosis were consulted in the design of the study and helped inform the researchers with regard to the design of the topic guide.

Individuals were debriefed after the interview and given information about relevant organizations that could be contacted for further information and support if necessary. If any risk issues were raised during the interview, these were dealt with by the lead author who fed back to the clinical team and members of the research team. Recruitment ceased once data saturation had been reached. All interviews were recorded on an encrypted device, and any identifiable information was minimized.

Each interview was transcribed verbatim by the lead author with all data anonymized as much as possible, and all data were kept confidential and stored securely.

### *Demographic information*

Self-report information on the following demographic variables was obtained: age, gender, ethnicity, marital status, current accommodation type, living status, employment status, date of first contact with mental health services, and current service use. The diagnosis was obtained from case notes by the individual's key worker.

### *Thematic data analysis*

Thematic data analysis was chosen as it is a flexible process which enables the exploration of rich data in an efficient method. Furthermore, this study did not seek to build upon theory; rather, it sought to understand individuals' subjective experiences of negative symptoms. Thematic analysis is not tied to a specific epistemological approach (Norris, Nowell, White, & Moules, 2017) but is a systematic inductive approach, where patterns and common themes are identified to describe a dataset and to understand a given phenomenon (Braun & Clarke, 2006). An inductive approach was taken to analyse the data in that the codes and themes were led by the content that emerged from the interviews. A six-step approach to analysing the data was used, as outlined below. All the authors took part in steps 2–6 of the analysis process.

1. Data were transcribed verbatim by the lead author.
2. The transcripts were read and re-read by members of the research team to enable familiarization with the data. Interviews were electronically placed into NVivo11

qualitative analysis software to enable the data to be organized and stored systematically.
3. Systematic line-by-line coding was conducted separately by all three authors in order to identify common emergent themes in the data.
4. The themes were discussed to identify key common emergent themes across the interviews enabling a thematic map to be established. Any differences in themes were discussed amongst the authors.
5. The themes were defined and names generated.
6. The final themes were checked with all members of the research team.

### *Quality and rigour*

This study was conducted in a rigorous and high-quality manner. Reading and discussion of each transcript by the research team ensured that the process was iterative and transparent. It is acknowledged that each author's experiences inevitably shape data analysis (Willig, 2008). The lead author, IB, is a White British woman psychology post-graduate researcher with experience in interviewing individuals with psychosis. GH and KB are both White British women who are senior clinical academics and honorary clinical psychologists in the NHS, experienced in working with people with psychosis. Rigour was also achieved by recruiting and interviewing individuals until data saturation had been reached. Field notes were taken during each interview by the lead author, which also helped ensure the context of each interview was considered.

## Results

Of the 23 individuals approached about the study, three declined to participate. Twenty individuals participated: 17 males and three females. Individuals were from a range of settings: inpatient acute wards ($n$ = 7), community mental health teams ($n$ = 9), and rehabilitation and recovery wards ($n$ = 4). Of the participants included in this study, eight identified themselves as Black African, and the remaining individuals ($n$ = 12) were White British. Age ranged from 35 to 62, with the mean age range being 52 years. Out of the twenty participants, 18 were unemployed and two were in full-time employment.

Each interview lasted between 35 min and 1 hr; the mean duration of the interviews was 39 min. A total of 65 initial codes were generated, and these were organized into 30 codes, which comprised two main themes. Within each main theme, there were four sub-themes.

Two main themes were identified: *What is it like to experience negative symptoms?* and *Where have my negative symptoms come from?* The emerging themes highlighted the enduring nature of negative symptoms. The subjective experience of the negative symptoms appeared relentless as opposed to sporadic and impacted many aspects of individuals' lives. The sub-themes are illustrated in Figure 1.

### *Main theme 1: What is it like to experience negative symptoms?*

Individuals described their experiences in rich detail, highlighting the pervasive and disabling nature of the experience. Four sub-themes were evident within this overarching theme that related to how individuals experienced their symptoms: loss of concentration, loss of motivation, withdrawal, and 'feeling but not feeling'.


**Figure 1.** Main themes and sub-themes. [Colour figure can be viewed at wileyonlinelibrary.com]

*Loss of concentration*

Participants reported that even seemingly small daily tasks required a large amount of concentration, and this had a huge consequent effect on their lives. Individuals said that because their concentration was often affected, they were unable to participate in recreational activities or even something as seemingly undemanding as watching television or reading.

> Um . . . it's, it's not about picking up a book, it's about concentrating and understanding the book . . . (Participant 1005)
>
> Like, er like, see somebody was looking at teletext earlier on the tv and I had problems reading 'cause generally I read the first couple of lines and I forget what it is that I've read and have to go back to the beginning 'cause my mind keeps on collapsing. (Participant 1015)
>
> Concentration . . . dreadful . . . absolutely dreadful. Couldn't watch TV programme; couldn't listen to the radio couldn't even listen to music. (Participant 1007)

*Loss of motivation*

Participants frequently said that they lacked the 'get-up-and-go' to complete a task, or simply to function on an everyday basis. Small tasks were perceived as larger tasks that required an amount of energy the individual did not possess, and thus, the task was seen as unattainable. This lack of motivation was described as persistent over time and did not appear to come and go. Participants clearly stated that this was a physical experience which was independent and subjectively different from their feelings or mood.

> . . . brushing teeth felt like climbing the biggest mountain and I just couldn't be bothered to . . . no motivation ever . . . (Participant 1018)
>
> It's like a nightmare. . . living in a nightmare. . .you can't, you try and push yourself but you can't . . . you cannot do It . . . Summat holding you back all time . . . and it feels like I'm being pulled back . . . you're not going forward or anywhere like that. (Participant 1020)

*Withdrawal*

Individuals said they often preferred spending time on their own, and that being around other people was difficult. Individuals expressed problems in initiating conversations, reporting that they lacked the desire to do so. Withdrawal was both emotional and social, with individuals often choosing to be on their own with their thoughts rather than participating in social activities or interacting with others. It was evident that some participants experienced substantial social disconnection as a result of isolating themselves.

> I'd rather just chill out all on my own . . . until I am feeling more energetic. (Participant 1003)
>
> Erm, like . . . I like my own company. I love me own company . . . (Participant 1004)

*Feeling but not feeling*

Some individuals said that they were acutely aware of their feelings. In particular, participants highlighted that they specifically experienced 'feelings' of numbness and emptiness. Others reported that this was evident to others through their lack of ability to illustrate their feelings with, for example, their facial expressions.

> I used to feel numb sometimes. I just feel like no-one is listening to me sometimes. It just makes me feel empty. . . 'specially if I am trying to get my point across. . . all empty inside. (Participant 1003)
>
> About something; it just feels like I am not getting through . . . that's what makes me numb and, er, obviously I, er, er, er, I control my temper and . . . but just trying to get my point across makes me feel numb. (Participant 1004)
>
> I do feel numb . . . I just feel that no-one's listening to me sometimes. (Participant 1017)
>
> Facial expressions? I haven't got many expressions. . . (Participant 1003)

***Main Theme 2: Where have my negative symptoms come from?***

The second theme that emerged was participants' attributions about what had contributed to the development of their symptoms or where they believed their symptoms had come from. Individuals had strong beliefs about where their experiences of negative symptoms had arisen from and made clear links between life experiences and their current problems.

*Impact of traumatic life events*

Participants said that adverse life events, such as the experience of abuse or loss, had contributed to their negative symptoms. The adverse life events expressed tended to be those described as 'intentional interpersonal events', that is, events carried out by other people with the deliberate intention of inflicting harm. The most frequently mentioned adverse life events included sexual abuse, emotional abuse, and bullying (by peers). These

events could have been experienced some years previously but were still considered to have had an impact. All adverse life events occurred prior to adulthood. Each interviewee was asked what they thought had contributed, or led, to their negative symptoms.

> It's because you've been abused in the past, that's all. . . I've been abused in the past. . . have those emotions within in me; um, perhaps they are there. . . and so you end up withdrawing from people, and you know, life. (Participant 1011)

> Like I say, erm, being bullied at school . . . by three girls. My mum and dad take 'em to court, so that went to court; I were only eleven. Then twelve, I were nearly raped. Only stopped it because he knew me brother. He worked with me brother. . . and I told him, 'what d'ya think (K) gonna do to you?' and 'what about your job?' Er, I don't think that helped I don't want to be with people. I just can't, you know, go out and meet people, and I feel nothingness, you know. (Participant 1020)

> Well, I seen a lot of people die; a lot of friends die from doing drugs, in my lifetime. Er, recently I've been clean a couple of years, but a friend lost his arm. Cannot be bothered with life . . . and doing anything, and yeah, don't want to do anything. . . (Participant 1005)

*Positive symptoms as a root cause of negative symptoms*

Participants particularly mentioned the presence of auditory hallucinations as key factors which contributed to their experience of negative symptoms. They described the impact as exhausting, leaving them feeling enervated and unable to function. The voices appeared, in some cases, to be relentless, only stopping when individuals slept, and resulted in their feeling mentally and physically lethargic. In addition to auditory hallucinations, individuals also stated that feelings of paranoia led to negative symptoms. A belief that they were being followed or persecuted created difficulties in functioning and interacting with others, subsequently leading to withdrawal socially and emotionally from those around them.

> The voices just make me tired all the time, they never stop, only when I go to sleep. (Participant 1015)

> I could hear voices; they always seemed to be like external by the sound they had, and it made me exhausted you know. (Participant 1007)

> I don't know, because, you know, I think I am being chased when I go outta the house, and yeah I just stay in here with TV and, you know. . . (Participant 1016)

> Yeah, I don't wanna talk to people because, you know, it's just you never know what they are saying 'bout me . . . they talk, you know. . . about me being a loser (Participant 1019)

*Impact of social network*

Participants described difficult life circumstances, such as lack of money, that they believed had contributed to their negative symptoms. However, it was support from their loved ones that had pulled them through.

> If I didn't have the support of my family, I would be nailed against the wall. . . I was on the street in debt pretty much. If you don't have any money you can't do anything. I had long sleeps. I definitely overslept. (Participant 1002)

A small minority also referred to pet ownership and dependants as having a positive influence on their motivation to get up and be active. Having children and pets to look after gave them a sense of meaning and direction, enabling them to function.

> Having a pet helps because I have to feed her and let it out yeah, that's a good thing. (Participant 1020)
>
> Having to look after the children and my partner helped because I had to get up, I couldn't lie down all day and do nothing. (Participant 1015)

*The influence of prescribed and recreational drug use*

Individuals particularly said that the use of cannabis might have contributed to their negative symptoms. Individuals referred to past use of cannabis drugs in terms of the effect on their mental health symptoms. Smoking cannabis was particularly reported by individuals as contributing to feeling unmotivated.

> Like I said, I was smoking lots of skunk weed; I think it must have triggered the symptoms, you know. (Participant 1003)
>
> I smoked a lot of cannabis, you know, and it's easy to get, so I felt unmotivated to do anything after a smoke, you know. (Participant 1015)
>
> It started with the smoking cannabis, which was quite all-consuming and made me feel like s*** . . . Yeah cannabis, the reflective journal was good, it helped motivate me . . . the cannabis didn't and had the opposite effect. (Participant 1011)

Additionally, individuals voiced concern about their prescribed medication, which they perceived as contributing to their negative symptoms.

> Well it's the olanzapine . . . you know, makes me feel drugged up and s***. (Participant 1020)
>
> Meds, all they give me, PRN, '''''ing sh*** . . . I don't want to get out the bed. (Participant 1017)
>
> I dunno though, I mean it could be. . . but I think its aripiprazole, well but I just don't wanna talk, or do anything I feel . . . tired, ya know. (Participant 1006)

## Discussion

### *Summary of findings*

The study investigated subjective experiences of negative symptoms in people with a diagnosis of schizophrenia, in a diverse sample from across the United Kingdom. Individuals described the huge impact that experiencing negative symptoms presented to them, with poor concentration and motivation, which subsequently made it difficult to engage in 'normal' activities and often resulted in withdrawal. Individuals also described 'feeling but not feeling', whereby a feeling of numbness was the pervasive emotional experience. Furthermore, individuals highlighted the factors that they perceived and believed had influenced the occurrence of their negative symptoms. These factors included adverse life events, positive psychotic symptoms, and social networks, as well as recreational and prescribed drugs, with particular reference to cannabis and antipsychotic medication. Across all the interviews, negative symptoms were perceived as persistent, prolonged, and enduring; this was an overarching theme that underpinned all the themes, as illustrated in Figure 1.

These findings have similarities with those found by Gee *et al.* (2018), who sought to identify individuals' experiences of negative symptoms in a sample of individuals with a first-episode psychosis diagnosis. Both studies found that feelings of numbness and withdrawal, as well as poor concentration, attention, and motivation, were predominant in participants' accounts of their experiences. The findings suggest that these symptoms are hallmark negative symptoms that exist throughout the course of life for someone who receives a diagnosis of schizophrenia.

Individuals identified key contributing factors to their negative symptoms. Despite this study being unable to infer causality, it is of interest to reflect on those factors that individuals attributed as being important in the occurrence of their negative symptoms. Trauma was identified as a key factor. Arguably, the experience of trauma, and interpersonal trauma in particular, may be so overwhelming that it causes individuals to withdraw mentally and physically from the world around them. In support of this view, studies by Gallagher and Jones (Gallagher & Jones, 2013; Gallagher, Jones, & Pardes, 2016) showed an association between traumatic life events as assessed by a case note review, and negative symptoms as measured by PANSS and SANS. The authors also found that associations between specific life events and specific negative psychotic symptoms were associated with neglect experienced in childhood. Individuals who reported neglect presented with greater negative symptoms than those who experienced physical abuse.

Individuals also reported that they believed that their positive symptoms contributed to their negative symptoms, with voice-hearing and paranoia being highlighted as particularly pertinent. Previous theoretical accounts of negative symptoms have similarly conceptualized negative symptoms, such as withdrawal, as coping strategies in relation to stressful and overstimulating positive symptoms (Stampfer, 1990).

The finding that social environments contributed both positively and negatively to negative symptoms is also consistent with early psychosocial theories of schizophrenia, such as the stress vulnerability model, which posits that social stressors and social buffers influence relapse (Zubin & Spring, 1977). Findings here suggest that these social factors may be just as important for the course of negative symptoms as positive symptoms. Previous studies have identified that pets can benefit an individual's mental health in a positive manner (Brooks, Rushton, Walker, Lovell, & Rogers, 2016); therefore, it is interesting to note that in this study, having dependants in the form of children or pets was identified as being helpful with their experiences of negative symptoms.

Participants described prescribed and recreational drugs as having a negative consequence. Literature dating back to the late 19th century has consistently shown that there is a link between cannabis and motivation and specifically that heavy cannabis use is linked to apathy (Kalant, 1972; Pacheco-Colón, Ramirez, & Gonzalez, 2019). In more recent years, the link has been evidenced, with findings in a laboratory setting, showing that reduced motivation for reward-related behaviour is more evident in cannabis users than in healthy controls (Lane, Cherek, Pietras, & Steinberg, 2005). Similarly, research has also identified links between antipsychotic medication and a lack of energy; antipsychotic medications are evidenced to have sedating effects. The degree of lack of energy is often related to the dosage of medication that an individual is given (Miller, 2004).

Overall, the findings of the present study suggest that the impact of adversity and environmental factors need to be considered in understanding negative symptoms and these need to be taken into account when developing treatments and services for people with such symptoms.

### *Clinical implications*

Understanding the experience of negative symptoms and what individuals consider contributes to their occurrence is important for clinicians, researchers, and service planners to enable the design and delivery of effective treatment. This understanding may help to facilitate the development of idiosyncratic formulations and treatment approaches, enabling a cause-specific approach to 'tackling' negative symptoms to be utilized. If individuals identify that the impact of a traumatic life event contributes to their experience of negative symptoms, then this could be addressed clinically through interventions such as trauma-focused CBT. This has been shown to be effective in the treatment of PTSD and psychosis more generally and has recently been adapted to focus on complex childhood trauma (Cohen, Deblinger, & Mannarino, 2004). If individuals state that it is the positive psychotic symptoms that led to their negative symptoms, delivering CBT by targeting voices or paranoia may be of greater benefit to the individual. If an individual identified that it is lack of social support which resulted in negative symptoms, then family therapy or peer support approaches may help to maximize the social support available to them. However, if an individual identifies that they perceived that recreational drug use led to negative symptoms, then this could be targeted by delivering a motivational interviewing approach to therapy, which has been shown to be effective in reducing substance misuse in the context of psychosis (Barrowclough *et al.*, 2010). Where the medication is thought to be the cause, considering a treatment plan that involves changing dosage may increase an individual's motivation and energy levels. It is acknowledged that these treatment opportunities will take time to implement within clinical settings but in doing so, can serve to enable recovery from negative symptoms.

### *Strengths and limitations*

A key strength is that this study differs from much of the literature on negative symptoms, which has focused on assessing individuals' experiences of negative symptoms through a questionnaire or clinician-rated instrument. Individuals are also not often asked what they think might contribute to the occurrence of their symptoms.

The sample was diverse, in that individuals from a range of settings and geographic locations participated. There was a range of ethnicities, reflecting the diagnosis of schizophrenia in the wider population. There were a limited number of females; however, this reflects the gender imbalance of schizophrenia in the population (Braun & Clarke, 2006). The participants also all had long-standing diagnoses of schizophrenia, whereas previous research has focused on those with first episodes of psychosis (Gee *et al.*, 2018). An additional limitation of this study is that its aim and focus were on individuals' subjective experiences of negative symptoms. Therefore, from this study, we cannot identify any causal mechanisms from the results; the data illustrated and generated from this study merely highlight individuals' subjective experience of negative symptoms and perceived contributing factors.

### *Future research*

This study signposts researchers and clinicians towards conducting further work on the psychological mechanisms underpinning negative symptoms in order to aid an individual's recovery and improve functional outcomes across a range of domains whilst acknowledging the impact that positive psychotic symptoms can have on negative symptoms. The study emphasizes that there needs to be greater work conducted

qualitatively on the causes of individuals' negative symptoms; this should involve a broader and larger sample, with people recruited from those presenting in early intervention services at the prodromal stage to those with more long-standing diagnoses of schizophrenia. Further qualitative research could explore longitudinally how an individual's experiences of negative symptoms change and develop. Additionally, this study highlights the need for quantitative research that explores the themes evidenced in relation to the causes of the negative symptoms.

### *Conclusion*

Negative symptoms are a key aspect of the experience in people who have a diagnosis of schizophrenia (Andreasen, 1982). However, these symptoms are often overlooked by clinicians and researchers due to the difficulty in distinguishing negative symptoms from low mood and the side effects of medication (Bailey *et al.*, 2018). This study shows that individuals with a diagnosis of schizophrenia are able to describe their experiences of negative symptoms. This study also demonstrates the importance of asking individuals about their negative symptoms and their potential causes, and of understanding the individual's social environments. Individuals do have insight into what may be contributing to their negative symptoms. Recognizing that these experiences are extremely debilitating and persistent is important not only for services and clinicians, but also for families and carers, where misattributions can be made about negative symptoms, leading to conflict or to such experiences being dismissed (Horan, Brown, & Blanchard, 2007).

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## Conflicts of interest

All authors declare no conflict of interest.

## Author contributions

Isabelle Butcher (Conceptualization; Formal analysis; Investigation; Methodology; Project administration; Writing – original draft; Writing – review & editing) Katherine Berry (Conceptualization; Formal analysis; Investigation; Methodology; Supervision; Writing – review & editing) Gillian Haddock (Conceptualization; Formal analysis; Investigation; Methodology; Supervision; Writing – review & editing).

## Data availability statement

Research data are not shared. Due to the sensitive nature of the questions asked in this study, all individuals who participated in this study were assured that the data would be anonymized and the original full-length transcripts of the interviews therefore are not available to be shared outside of the research team.

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## Appendix:

### *Topic Guide*

The interview should take no longer than 60 min. The interviews will be audio-recorded, if you agree to this. The interview will also be anonymized. Please note if you say anything that indicates a risk of harm to yourself or someone, I will have to inform your key worker. If you wish to stop at any point, please let me know.

Some people have told us that they often experience voices and hallucinations. Others have also said that they have lost normal thoughts, feelings, and motivations. People can find it hard to understand that these things are really symptoms – not just laziness. This can make it difficult for both you and your family. These things can be hard to live with.

How does this fit with your experience(s)?

- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

You may have little energy. You may lack 'get-up-and-go' it can make you not bothered to go out of the house.

How does this fit with your experience(s)?

- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

It can be hard to feel excited or enthusiastic about anything; for example when a friend gets married, we can get excited but sometimes these events do not make us feel anything.

How does this fit with your experience(s)?

- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

Some people have said they cannot concentrate, for example, following a television programme or reading a book is difficult.

How does this fit with your experience(s)?

- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

You may also find it hard to make eye contact with others when you are talking to them. Some people have also told us they can feel numb and that when they experience different emotions their faces do not change. For example when they are excited, their faces do not change.

How does this fit with your experience(s)?

- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

You may also stop washing or tidying, or keeping your clothes clean. You may feel uncomfortable with people and not want to socialize with others.

How does this fit with your experience(s)?

- Can you give me some examples?
- How does this feel?
- How has this affected your relationships?

Prompts to be used to encourage respondent.

1. Sometimes, it is hard to experience pleasure from activities that were once enjoyable – an example is playing football or listening to music.
2. There are times when we have very intense feelings, for example, when we are in love with somebody or when we dislike somebody. Sometimes when we have a close relationship with someone, we share intimate details. Sometimes, we have lots of thoughts in our head but other times we have none.
3. Our facial expressions change; for example when something we are happy about happens, we may smile and move our mouths. There are times when we feel numbness and unmoved and so our faces do not change with how we are feeling.

What do you think, if anything, caused these experiences to occur?
Is there anything further that you would like to add?
Thank you for your time.

## Appendix 19. Poster from 9th World Psychiatric Association World Congress of Psychiatry, 2019

Appendix19: Poster from 9th World Psychiatric Association World Congress of Psychiatry, 2019

The University of Manchester

# Individuals' subjective experiences of negative symptoms of schizophrenia

Isabelle Butcher, Katherine Berry and Gillian Haddock.
The University of Manchester, UK

## Background

- Negative symptoms are usually considered to be a central feature of schizophrenia.
- Negative symptoms reflect an absence of behaviours and include, for example; lack of motivation, flattened affect, anhedonia and alogia.
- Negative symptoms are usually assessed through clinician and observer rated assessments, for example the Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein & Opler 1987).

## Aim

To examine, using qualitative methods, how people living with a diagnosis of schizophrenia subjectively experience negative symptoms.

## Methods

- Semi structured interviews with 20 people, recruited from National Health Service mental health trusts from across the United Kingdom.
- Inclusion criteria:a score of three on two or more of the negative symptom items on the PANSS, a case note diagnosis of schizophrenia, schizophreniform disorder, schizoaffective or delusional disorder and aged 18 years or older
- Topic guide contained questions around the experience of negative symptoms and the impact this had on functioning and relationships with others.
- Interviews were audio record, transcribed verbatim and analysed using thematic analysis. (Braun & Clarke,2006)

## Findings

### *What is it like to experience negative symptoms?*

**1. Loss of concentration**

*"Concentration..dreadful..absolutely dreadful. Couldn't watch TV programme; couldn't listen to the radio couldn't even listen to music.'*

**2. Loss of motivation**

*"It's like a nightmare…living in a nightmare..you can't you try and push yourself but you can't..you cannot do it..Summat holding you back all time..and it feels like I'm being pulled back…you're not going forward or anywhere like that"*

**3. Withdrawal**

*"I'd rather just chill out all on my own … until I am feeling more energetic."*

**4. "Feeling but not feeling"**

*"I used to feel numb sometimes..I just feel like no one is listening to me sometimes, it makes me feel empty.."*

### *Where have my negative symptoms come from?*

**1. Impact of traumatic life events**

*"It's because you've been abused in the past, that's all… I've been abused in the past… have those emotions within in me; um, perhaps they are there… and [Interviewer: 'yes'] so you end up withdrawing from people and you know life."*

**2. Positive symptoms as a root cause of negative symptoms**

*"I could hear voices; they always seemed to be like external by the sound they had, and it made me exhausted you know."*

**3. Impact of social network: support and meaning in life**

*"Having to look after the children and my partner helped because I had to get up, I couldn't lie down all day and do nothing".*

**4. Impact of prescribed and recreational drugs**

*"I smoked a lot of cannabis you know and it's easy to get so I felt unmotivated to do anything after a smoke you know".*
*"Well it's the olanzapine.....you know makes me feel drugged up and s***."*

## Conceptualising the findings


## Conclusions

- Negative symptoms are persistent, prolonged and enduring.
- Individuals with schizophrenia do have insight into what may be causing their negative symptoms.
- Future work is needed into understanding the negative symptoms of schizophrenia.

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MRC Medical Research Council

isabelle.butcher-2@postgrad.manchester.ac.uk