

UNDERSTANDING PSYCHOSOCIAL FACTORS IN SEVERE AND ENDURING  
PSYCHOSIS

by

Kezia Jones

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Department of Clinical Psychology

School of Psychology

The University of Birmingham

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## **Thesis Overview**

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology (ClinPsyD) at the University of Birmingham. This thesis comprises two volumes: a research and clinical volume.

Volume I consists of three chapters. The first chapter is a systematic literature review examining psychosocial factors associated with negative symptoms. The second chapter is an empirical study of how mental health staff make sense of self-neglect in people with severe and enduring psychosis. The third chapter is an executive summary, a public domain document providing an overview of the literature review and empirical paper.

Volume II consists of five clinical practice reports (CPR's). The first CPR explores the case of a 23-year-old woman presenting with anxiety and anger. The case is formulated from a cognitive behavioural and psychodynamic approach. The second CPR is a service evaluation exploring the views of mental health staff working in the community in relation to staff support when working with service users with a personality disorder. The third CPR is a case study of a 70-year-old woman presenting with generalised anxiety disorder with descriptions and reflections of the assessment, formulation and intervention. The fourth CPR is a single case experimental design evaluating the effectiveness of progressive muscle relaxation for a 20-year-old male with a mild learning disability. The fifth CPR is the abstract of an oral presentation of a case study of a 63-year-old female presenting with weight management difficulties. The formulation and intervention of this case is based on compassion focused therapy. To ensure confidentiality all identifying information in these reports has been anonymised.

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**Literature Review:**

**WHAT PSYCHOSOCIAL FACTORS ARE ASSOCIATED WITH NEGATIVE  
SYMPTOMS? A SYSTEMATIC REVIEW OF THE LITERATURE**

## **Abstract**

**Background:** There have been efforts to determine the aetiology of negative symptoms to address the need for an evidence-based treatment. Previous research has found relationships between negative symptoms and biological factors. There is also evidence to support an association between negative symptoms and genetic factors. Currently, there is little research examining psychosocial factors in association with negative symptoms.

**Aim:** This systematic review aims to synthesise previous research that has examined the psychosocial factors associated with negative symptoms.

**Method:** Electronic databases were systematically searched for relevant studies. Twenty-five papers met the inclusion criteria and were included in the systematic review. The quality of the studies was assessed and evaluated using a quality assessment tool.

**Results:** The results of the review identified a number of psychosocial variables that were associated with negative symptoms. Within different clinical populations (clinical high risk, first episode psychosis, and severe and enduring psychosis) there were themes in the psychosocial factors related to negative symptoms. Across the studies there was a theme of social functioning being related to negative symptoms.

**Conclusion:** The findings of this review provides insight into what psychosocial factors are associated with negative symptoms. Recommendations for further research are suggested to establish causation and identify psychosocial factors that prevent the development and maintenance of negative symptoms.

## **1. Introduction**

### **1.1 Overview**

Negative symptoms are a group of symptoms presenting within various diagnoses but occur most commonly in cases of schizophrenia (American Psychiatric Association, 2013). Negative symptoms differ from positive symptoms in that they tend to be enduring and less responsive to medication (Tamminga, Buchanan, & Gold, 1998). Due to their unrelenting, disabling nature and negative functional and health outcomes there has been much research in efforts to better define and measure negative symptoms (Winograd-Gurvich, Fitzgerald, Georgiou-Karistianis, Bradshaw, & White, 2006). First conceptualised by Kraepelin in 1919, negative symptoms were characterised by a lack of emotional response and loss of interest (Kraepelin, 1919). Consensus on the definition of negative symptoms has since broadened to include a loss of emotional and socio-occupational function and/or decrease in quality of life seen in healthy people. This loss in function can be recognised by both clinicians and family members (Kirkpatrick, Fenton, Carpenter & Marder, 2006).

The National Institute of Mental Health Measurement and Treatment Research to Improve Cognition in Schizophrenia (NIMHS-MATRICS) consensus panel defined five distinct properties of negative symptoms (Kirkpatrick et al., 2006). These include blunted affect (reduced emotional reactivity verbally or non-verbally), lack of speech, asociality (withdrawal from social contact due to indifference or lack of desire to have social contact), anhedonia (an inability to enjoy pleasurable activities), and avolition (a lack of motivation or initiative to complete goal-oriented activities) (Kirkpatrick et al., 2006). These properties can be independent or intersect. The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) describes negative

symptoms as “diminished emotional expression and avolition”. *Diminished emotional expression* includes “reduction in expressions of emotions in the face, eye contact and intonation of speech, movements of the hand, head and face that normally give an emotional emphasis to speech” (American Psychiatric Association, p. 87, 2013). Research conducted by Blanchard and Cohen (2006) questioned whether negative symptoms are a unitary or multidimensional construct. Using factor analysis of the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1984), Blanchard and Cohen (2006) proposed that blunted affect and lack of speech comprise one factor of negative symptoms (diminished expression), and asociality, anhedonia and avolition another (anhedonia-asociality). These descriptions were thought to be most representative of negative symptom presentations. This narrowing of labels for negative symptoms may allow for a simplification of observation, assessment and evaluation of negative symptoms for clinicians and researchers. Conversely, further reducing the properties of negative symptoms may lead to neglect of understanding the nuances of negative symptom presentation.

If Blanchard and Cohen’s proposal is applied, negative symptoms could perhaps be viewed as an umbrella term encompassing more specific symptoms related to either diminished expression or anhedonia-asociality. Historically, research has focused on negative symptoms holistically and rarely separates the comprising symptoms (Blanchard & Cohen, 2006). From a treatment perspective, this approach to negative symptom research could be limiting; addressing negative symptoms as a single experience may reduce the efficiency and likelihood of selecting treatment options that are tailored to the person’s negative symptom presentation. Consequently, any treatment selected may respond to aspects of negative symptoms and not others, varying in

success if not matched to symptoms appropriately (Blanchard & Cohen, 2006; Erhart, Marder & Carpenter, 2006).

Although “negative symptoms” is a widely accepted term for a group of symptoms within schizophrenia there is limited understanding about the cause or affecting factors of the symptoms within this term. Separating negative symptoms into primary and secondary factors has aimed to tackle this (Carpenter, Heinrichs & Alphas, 1985). “Primary and enduring” negative symptoms refer to the symptoms that are the cause of an individual’s mental health presentation rather than a consequence of another underlying cause. Symptoms of this nature are consistently present and are unaffected by medication. Secondary symptoms refer to symptoms occurring in association with, or as a consequence of long-term institutionalisation, lack of environmental stimuli, positive symptoms, affective symptoms, medication side effects or illness related factors (Carpenter, Heinrichs & Wagman, 1988; Kelley, Kammen & Allen, 1999; Kirschner, Aleman & Kaiser, 2017). Primary negative symptoms are consistent and are considered to have a unique psychopathological cause, rather than being caused by other psychotic processes such as positive symptoms or treatment side effects. (Carpenter et al., 1985).

Current classification and diagnostic tools (American Psychiatric Association, 2013; ICD-10; World Health Organisation, 2016) associate negative symptoms with schizophrenia. However, there have been studies of negative symptoms across diagnoses, particularly comparing schizophrenia and major depression. Findings have indicated that negative symptoms are a feature of both disorders but are more common in schizophrenia (Bottlender et al., 2003; Herbener & Harrow, 2004; Sax et al., 1996). Further evidence suggests that negative symptoms are present in other diagnoses such

as personality disorders (Lyne et al., 2012; Mitra, Mahintamani, Rao Kavoor & Nizamie, 2016). This evidence therefore supports the idea of a specific “deficit syndrome” as suggested by Kirkpatrick, Buchanan, Ross and Carpenter (2001), which indicates that negative symptoms may occur transdiagnostically, but there may be a separate subtype of schizophrenia, with the deficit syndrome as a prominent manifestation of negative symptoms. These negative symptoms are not transient, but are severe, enduring and unresponsive to antipsychotic medication (Kirkpatrick et al. 2001). The deficit syndrome is defined by the presence of two negative symptoms for a period of 12 months, that are not secondary to anxiety, medication, positive symptoms, cognitive deficits or depression (Kirkpatrick, Buchanan, McKenny, Alphs & Carpenter, 1989).

It is important to note that (as a construct) schizophrenia has been questioned in terms of its validity (Bentall, 2004). Schizophrenia has been found to be reliable based on diagnostic agreement and similar reporting of incidence and prevalence rates (Bromet, Naz, Fochtmann, Carlson, & Tanenberg-Karant, 2005), however this does not support the argument for schizophrenia as a valid construct.

There is evidence to suggest that there are no categorical breaks in positive symptoms of psychosis, and instead experiences of delusions, paranoia and hallucinations (in particular) occur on a continuum (in terms of frequency and potency) in the general population (Johns et al., 2004). A continuum of psychotic experiences may support the view that schizophrenia cannot be defined as a discrete disease as symptoms reported cannot be separated from everyday experiences (Beavan, Read, & Cartwright, 2011). Furthermore, when cultural context is considered there is variation in the understanding of experiences labelled as psychotic. Cultures and subcultures vary in

terms of whether particular experiences are viewed as signs of schizophrenia or normal experiences (spiritual beliefs, for example) (Division of Clinical Psychology, 2016).

These findings highlight the fact that experiences collected under the label of schizophrenia may be too varied to have scientific value (Bentall, 2004). Nevertheless, it should be considered that the evidence to support psychotic experiences in non-clinical settings is based mostly on delusions and hallucinations (Allardyce, Gaebel, Zielasek, & van Os, 2007); there are other symptoms that encompass schizophrenia (as it is currently understood). It is also possible that delusions and hallucinations experienced in non-clinical populations are not a core component of schizophrenia and are instead unrelated, abnormal experiences (Goldman-Rakic, 1994).

van Os (2016) suggested that psychotic diagnoses, such as schizophrenia, do not explain the cause of a condition and rather clusters symptoms to group individuals, for example, symptoms of psychosis and mania classifies schizoaffective disorder, if psychosis is not reported then it is reclassified as mania (van Os, 2016). He argued that clustering is based on observable symptoms, rather than information regarding aetiology, and therefore experiences cannot be directly attributed to an illness. Developing knowledge of aetiology may help to clarify schizophrenia's validity as a construct, moving away from understanding based on symptom presentation.

A diagnosis of schizophrenia also fails to explain prognostic course for individuals diagnosed with schizophrenia (Bentall, 2004). There is little consensus on what is useful – individuals with the same diagnosis may find different treatments helpful. This suggests that schizophrenia as a diagnosis may not reflect real similarities and therefore can be challenged as a concept (Bentall, 2004; Campbell, O'Rourke, & Slater, 2011).

## **1.2 Prevalence of Negative Symptoms**

The use of different definitions and methods of evaluating negative symptoms means the data for the prevalence of negative symptoms is limited and inconsistent (Szkulicka-Debek et al., 2015). Bobes, Arango, Garcia-Garcia and Rejas (2010) used a cross sectional design to analyse the prevalence of negative symptoms in 1108 adult psychiatric outpatients with schizophrenia in Spain and found 60% had the presence of at least one negative symptom, with 12% presenting with primary negative symptoms. In the UK, Patel et al. (2015) found that out of 7678 patients receiving care during 2011 41% of patients with schizophrenia had two or more negative symptoms.

The prevalence of negative symptoms across psychotic diagnoses was measured using the SANS in 330 patients in Dublin presenting with first episode psychosis (FEP) by Lyne et al. (2012). Negative symptoms had a high prevalence in the group of patients diagnosed with a schizophrenia spectrum disorder (87%), compared to “all other psychotic presentations” (51%), which included substance induced psychosis, major depressive disorder, brief psychotic disorder, delusional disorder and bipolar disorder (Lyne et al., 2012). It appears that negative symptoms are most prominent in schizophrenia spectrum disorders but are not exclusive to this group of diagnoses. The use of a cross sectional approach for these studies capturing prevalence only gives a snapshot of presentation and does not substantiate long term conclusions about the prevalence of negative symptoms in schizophrenia. Overall, the evidence regarding prevalence should be viewed in light of the possibility that the number of people with negative symptoms is higher if gaps in diagnosis are considered (Szkulicka-Debek et al., 2015).

### **1.3 Aetiology of Negative Symptoms**

In 1974, Strauss, Carpenter and Bartko noted that determining the aetiology of negative symptoms in schizophrenia poses much difficulty, more so than for positive symptoms (Strauss, Carpenter & Bartko, 1974). Early evidence pointed towards brain structure differences in people diagnosed with negative symptoms of schizophrenia. Andreasen, Olsen, Dennert and Smith (1982) used clinical correlates to compare 16 patients with large ventricles with 16 patients with the smallest ventricles from a sample of 52 patients diagnosed with schizophrenia. Patients with enlarged ventricles had a higher number of negative symptoms, compared to those with small ventricles who had a higher number of positive symptoms. Their findings suggested that brain structure, particularly ventricular enlargement, was a clinical indicator of negative symptoms. Marks and Luchins (1990) consolidated Andreasen et al.'s (1982) findings, reviewing 28 studies exploring brain imaging in schizophrenia. Eighteen articles supported the hypothesis regarding increased negative symptoms significantly correlating with larger ventricles. However, 10 did not, illustrating that brain structure as a cause for negative symptoms is an argument based on partially supporting evidence. Furthermore, from Marks and Luchins' (1990) findings, there was no differentiation between primary and secondary negative symptoms. If negative symptoms were associated with enlarged ventricles it may be that enlarged ventricles in negative symptoms are a by-product of an alternative cause of negative symptoms and not a cause in and of itself (DeLisi, 2008; Zipursky, Reilly & Murray, 2012).

In more recent research, Cuesta et al. (2017) used neuroimaging to compare 50 FEP patients with 21 of their healthy siblings and 24 sex-matched healthy controls, with the aim of determining whether enlarged ventricles have a genetic connection to

negative symptoms. FEP patients had statistically significantly larger ventricles than healthy siblings and controls, those with a higher number of negative symptoms had statistically significantly larger lateral and third ventricles (Cuesta et al., 2017). These findings support the concept of negative symptoms being associated with differences in brain structure but still fail to address the questions around whether these changes occur as a result of negative symptoms or whether brain structure changes cause negative symptoms.

Other evidence surrounding difference in brain structure for people with negative symptoms has illustrated tissue reductions in the frontal lobes (Buchanan et al., 1993; Roth, Flashman, Saykin, McAllister & Vidaver, 2004). The severity of negative symptoms has also been found to significantly correlate with increased grey matter in the superior temporal gyrus (Kim et al., 2003). Establishing a biological cause of negative symptoms is difficult due to determining whether presenting issues are a primary symptom or whether changes in biology are secondary to other factors (e.g., medication, drug use, positive symptoms). Furthermore, biological changes could occur as a result of symptoms rather than vice versa (Harrop, Trower, & Mitchell, 1996). Biological changes can also be seen in individuals with schizophrenia who do not present with negative symptoms (Yue et al., 2016).

There is emerging evidence investigating a genetic basis for negative symptoms, addressing the limitations of attributing negative symptoms to changes in brain structure. A recent meta-analysis found specific genes to be significantly over represented in Irish patients with negative symptoms, when compared to healthy Irish controls (Edwards et al., 2016). This is promising evidence for a genetic basis of negative symptoms. However, this study did not control for the effects of medication

and the sample comprising of solely Irish patients means that conclusions cannot be generalised with confidence. Despite this emerging evidence it is still acknowledged that more information is necessary for how these genes affect the expression of negative symptoms (Xavier & Vorderstrasse, 2017).

#### **1.4 Treating Negative Symptoms**

Current options for treating primary negative symptoms are limited and currently no specific treatment is recommended. Pharmacological, organic stimulation and psychosocial interventions have all been investigated as tools for addressing negative symptoms (Remington et al., 2016).

Antipsychotics were initially used as a treatment for negative symptoms. This was with the view that addressing positive symptoms, such as hallucinations and delusions, would also improve clinical outcomes of negative symptoms. However, even with the resolution of positive symptoms, functional recovery associated with negative symptoms does not improve to the same extent (Austin et al., 2013). This implies that whilst drug treatments may be effective when considered in the context of positive symptoms, concurrent amelioration of negative symptoms may not be observed. However, there has been some recent evidence to support the use of antipsychotics to treat negative symptoms. Harvey, James and Shield (2016) performed a meta-analysis of the effects of 8 antipsychotics and a placebo for negative symptoms in schizophrenia. Three of the antipsychotics (Haloperidol, Olanzapine and Risperidone) had a statistically significant effect on negative symptoms compared to the placebo. However, it should be considered that Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein, & Opler, 1987) scores were the dependent variable for this study, and although negative symptoms were observed to have improved, changes in functional recovery or

quality of life associated with improvement in symptoms were not directly measured in this meta-analysis. In 2005, Bowie and Harvey found neuroleptic drugs had little effect on people diagnosed with schizophrenia who presented with negative symptoms (Bowie & Harvey, 2005). Overall, data suggests that there is insufficient evidence to support drug treatment for primary or persistent negative symptoms in schizophrenia, despite there being an increasing need to treat those living with negative symptoms (Szkulicka-Debek, 2015).

Brain stimulation (repetitive transcranial magnetic stimulation, rTMS) is another organic treatment for negative symptoms currently being investigated in the literature. Meta analyses indicate that the effects for treating negative symptoms with rTMS are variable, with effect sizes ranging from non-significant to 0.8 (Dlabac-de Lange, Kneegting & Aleman, 2010; Freitas, Fregni & Pascual-Leone, 2009; Prikryl & Kucerovala, 2013; Shi, Yu, Cheung, Shum & Chan, 2014). Moderators such as stimulus frequency, outcome measure and illness duration appeared to affect the effectiveness of rTMS for negative symptoms. Research into rTMS is at the beginning stages so any confident conclusions about its long-term effects cannot be made.

There is evidence supporting the notion that psychosocial treatments such as social skills training, exercise and cognitive behavioural therapy are effective in reducing negative symptoms in schizophrenia (Lutgens, Gariepy & Malla, 2018). What remains unclear however are the ingredients of these psychosocial treatments that render them effective compared to drug treatments (Elis, Caponigro & Kring, 2013). The lack of evidence-based treatments for negative symptoms may be indicative of the limited knowledge of the underlying aetiology of negative symptoms (Remington et al., 2016). Further knowledge of the psychosocial factors associated negative symptoms

could provide some insight into aetiology, with the potential of developing targeted treatment.

### **1.5 Psychosocial Factors**

For schizophrenia on a broad level, there is substantial evidence to suggest that psychosocial factors contribute to its development or maintenance (Dean & Murray, 2005). Growing up in urban environments, migration and childhood trauma have all been posed as examples of psychosocial factors affecting the likelihood of developing schizophrenia (Liddle, 2007).

Recently, psychosocial stress has also been found to increase the risk of psychosis, particularly when this stress is cumulative (van Winkel, Stefanis & Myin-Germeys, 2008). Two studies from the British National Psychiatric Morbidity Survey reported that in a sample of the general population of the United Kingdom (n=10,375) adverse life events during the preceding 6 months were associated with psychotic experiences both cross-sectionally and longitudinally (Johns et al., 2004; Wiles, Zammit, Bebbington, Singleton, Meltzer, & Lewis, 2006).

Tienari et al.'s (2004) adoption study separated genetic and environmental factors of schizophrenia-spectrum disorders. They tested the hypothesis that genetic factors mediate environmental risk factors of schizophrenia. Finnish adoptees whose biological mothers were diagnosed with a schizophrenia-spectrum disorder were compared with matched adoptees without a genetic connection to schizophrenia-spectrum disorders to investigate the impact of family environment. Genetic risk significantly raised the risk of an adopted child being diagnosed with a schizophrenia-spectrum disorder if the environment was dysfunctional (e.g., critical, constricted and problems with boundaries), compared to control adoptees. However, if the environment

was healthy, this buffered against genetic risk. The findings of this study imply that environmental factors can have a protective effect on whether a person develops a schizophrenia-spectrum disorder or not.

Kirkbride et al. (2017) identified all new FEP cases presenting to psychosis services in the East of England and found that in the most densely populated regions there were excessive rates of socioeconomic deprivation, supporting the notion that substantial socioeconomic adversity increases the incidence of schizophrenia. The psychological effects of urban areas on psychosis were investigated by Ellet, Freeman and Garety (2008). They assessed 36 patients randomly controlled to exposure of an urban environment or a mindfulness task. Post-exposure assessments of symptoms, reasoning and mood were taken. Individuals exposed to urban environments had increased levels of anxiety, increased paranoid thoughts and were more likely to jump to conclusions, compared to individuals exposed to the mindfulness task, demonstrating some association between urban environments and psychological and cognitive factors. In terms of negative symptoms, Varma et al. (1997) found that in rural environments people reported difficulties associated with negative symptoms, for example, a loss in interest in activities and self-care, indicating a link between social isolation and negative symptoms (Varma et al., 1997). Bentall (2004) suggested that this is perhaps due to the lack of social reinforcement necessary to maintain self-care skills. It is still unclear what aspects of either urban or rural environments have a negative impact on people with psychotic symptoms, however these studies do lend support to the argument that particular psychosocial factors are associated with specific symptoms within schizophrenia.

There is evidence linking specific childhood adversities to positive symptoms of psychosis. Bentall, Wickham, Shevlin and Varese (2012) examined the associations between physical and sexual abuse, bullying and spending periods in institutional care, and reports of auditory hallucinations and paranoid beliefs in the 2007 Adult Psychiatric Morbidity Survey. Childhood rape was statistically significant in its association with experiencing hallucinations later in life and being brought up in institutional care was significantly associated with paranoia. Furthermore, the number of childhood traumas correlated with the risk of experiencing a particular positive symptom, highlighting the influence of psychosocial factors on positive symptoms within schizophrenia. It is still not clear why particular childhood experiences give rise to specific symptoms or whether these experiences have a proxy effect on the development of schizophrenia via other psychological processes such as impressions of self and others and emotions (Morgan & Gayer-Anderson, 2016).

Although evidence presented demonstrates the role of psychosocial factors in schizophrenia, there is little data illustrating the specific effects of psychosocial factors on positive symptoms, and even less for negative symptoms within schizophrenia. This systematic review therefore aims to examine and report the evidence of the psychosocial factors associated with negative symptoms in schizophrenia and related disorders. For this review “psychosocial” will be defined as factors not biological or genetic in nature, that affect a person psychologically or socially. This includes, for example, mood states such as anxiety, depression, distress and positive affect; cognitive behavioural responses such as satisfaction, self-efficacy, self-esteem, and locus of control; social factors such as socioeconomic status, education, employment, religion, family, relationships with others, changes in personal roles and status (Limosin, 2014).

## **2. Method**

### **2.1 Initial Search for Previous Systematic Reviews**

The Cochrane Database of Systematic Reviews and Centre for Reviews and Dissemination were searched in September 2017 using the term “psychosocial negative symptoms”, which generated zero reviews. A further search of four databases (Web of Science, Ovid MEDLINE, Ovid PsycINFO, Ovid EMBASE) was executed with no date limits, which generated one review titled “Primary and persistent negative symptoms: Concepts, assessments and neurological bases” (Mucci, Armida, Merlotti, Ucok, Aleman, & Galderisi, 2017). This paper reviewed the development of concepts and modes of assessment relevant to primary and persistent negative symptoms.

“Psychosocial function” was explored in relation to negative symptoms, but this was included as part of a broad understanding of various factors that contribute to aspects of deficit syndrome and persistent negative symptoms. Due to the lack of specificity in reviewing psychosocial factors related to negative symptoms the systematic assessment and synthesis of the literature as proposed in the present review was deemed suitable.

### **2.2 Search Strategy for the Identification of Articles**

Search criteria were generated by selecting keywords from the title of the systematic review. For this literature review, the term “negative symptoms” was defined in line with NIMHS-MATRICS consensus: blunted affect, lack of speech, asociality, anhedonia and avolition (Kirkpatrick et al., 2006). In terms of the exclusion criteria, papers were excluded from review if participants were under age 13 to focus on early-onset or adult-onset schizophrenia, rather than very-early onset schizophrenia where schizophrenia is extremely rare (Margari et al., 2008). Including papers focused on intervention was thought to be too broad in developing the understanding of

psychosocial factors that might contribute to the development or maintenance of negative symptoms. The focus on primary negative symptoms, rather than negative symptoms as a side effect of other psychiatric conditions, justified the exclusion of papers researching negative symptoms in mood and personality disorders. Synonyms for the keywords were also generated for the search. Four electronic databases were searched for the keywords displayed in Table 1 below: Web of Science, Ovid MEDLINE, Ovid EMBASE and Ovid PsychINFO. References of the articles generated via electronic database search were hand searched for relevant articles.

Table 1

<i>Key Words or Terms Used in Search</i>	
Key word or term	
A.	“psychosocial”
B.	“factor*” or “cause*” or “associate*” or “relate*” or “influen*”
C.	“negative symptom*”
D.	A, B and C were combined
<i>Note.</i> “*” allows for articles containing words beginning with the search term to be located and included in resulting articles, for example “associate*” will identify articles including “associated.”	

### **2.2.1 Inclusion and exclusion criteria.**

Table 2 and Table 3 below contain the inclusion and exclusion criteria for the systematic review.

Table 2

*Inclusion Criteria*

Inclusion criteria
1. Peer reviewed empirical publication
2. Written in English language
3. Studies specified as investigating negative symptoms as a clinical variable
4. Studies investigating psychosocial factors and the relationship to negative symptoms
5. Studies reporting how negative symptoms are defined
6. Studies defining how psychosocial factors were measured (for example: a measure of quality of life)

Table 3

*Exclusion Criteria*

Exclusion criteria
1. Studies where the data for negative symptoms specifically could not be extracted from the study
2. Studies unrelated to negative symptoms in the context of psychosocial factors
3. Studies investigating negative symptoms in mood disorders or personality disorders
4. Studies primarily investigating psychosocial interventions for negative symptoms
5. Studies primarily investigating genetic or biological factors in relation to negative symptoms
6. Studies where the participants included children younger than 12 years of age
7. Studies where the participants have an acquired brain injury
8. Conference proceedings, dissertations, books

**2.3 Database Search Results**

Following the search, 654 articles were identified. Titles and abstracts of the articles were filtered based on the inclusion and exclusion criteria listed in Table 2 and Table 3. The full texts of the remaining 30 articles were then assessed based on the inclusion and exclusion criteria, after which 17 studies remained. The reference section of each remaining study was hand searched, and 8 studies were identified and included, meeting

the inclusion and exclusion criteria. A total of 25 studies were included in the systematic review. Results from the literature search are illustrated in the PRISMA diagram below (Moher, Liberati, Tetzlaff, Altman & Prisma Group, 2009; Figure 1).

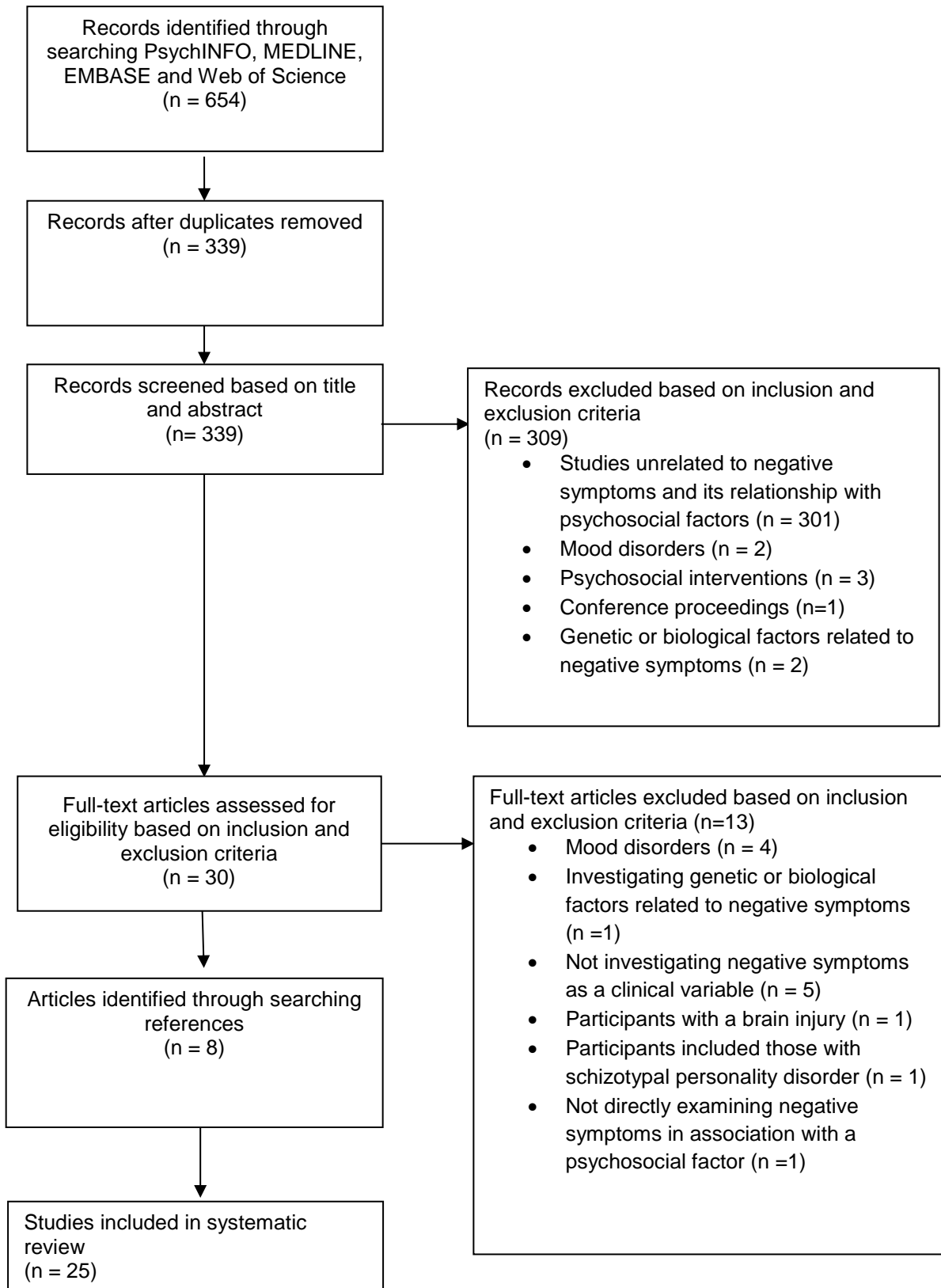


Figure 1. PRISMA diagram of literature search

## **2.4 Data Extraction**

A form tailored to the research question was devised to ensure relevant information was obtained from the included study. This form included identification information of the articles, study characteristics (e.g., location of the study and publication year), participant characteristics (e.g., mean age, sex and diagnosis), and findings related to negative symptoms and psychosocial factors. Information from this form is form is detailed in Table 6.

### 3. Quality Review

#### 3.1 Quality Assessment

The quality of the final studies was assessed by the quality assessment criteria proposed by Kmet, Lee and Cook (2004). The ability to apply the criteria for a wide range of study designs rendered it appropriate for the papers selected for review. Based on Kmet et al.'s (2004) criteria, studies are scored with an overall percentage, higher percentages represented a higher quality study. Table 4 details the method used for assessing and scoring each study. Lee, Packet, Tang and Girdler (2008) identified cut off points that were used for this review: >80% = strong, 70-80% = good, 50-70% = adequate and <50% = limited. Scores for the papers selected for this review are illustrated in Table 5.

Table 4

*Key for Table 5*

Key
Yes – 2
Partial – 1
No – 0
Not applicable – n/a
Score (%) = total sum divided by total possible sum x 100

Table 5

*Results of the Quality Assessment (including percentage scores)*

	Addington et al. (2002)	Addington et al. (2003)	Butjosa et al. (2016)	Corcoran et al. (2011)	Fervaha et al. (2014)	Fulford et al. (2013)	Gallagher and Jones (2016)	Kim et al. (2013)	Lee et al. (2017)	Liefker et al. (2009)	Lincoln et al. (2011)	Lysaker et al. (2005)	Makinen et al. (2010)	Masillo et al. (2016)	Milev et al. (2005)
Question / objective sufficiently described?	2	2	2	2	1	2	2	2	1	1	2	2	2	2	2
Study design evident and appropriate?	2	2	2	1	2	2	2	2	2	2	1	2	2	2	2
Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	2	2	2	1	2	2	1	1	1	1	1	2	2	1
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	1	2	2	2	2	0	2	2	1	2	2	2	2	2

If interventional and random allocation was possible, was it described?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
If interventional and blinding of investigators was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
If interventional and blinding of subjects was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Sample size appropriate?	2	2	1	1	2	2	1	2	2	1	2	0	2	2	2
Analytic methods described/justified and appropriate?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Some estimate of variance is reported for the main results?	0	2	1	1	2	2	0	2	2	2	2	0	n/a	2	2

Controlled for confounding?	0	2	0	2	2	2	0	0	1	0	2	2	n/a	2	2
Results reported in sufficient detail?	2	2	2	1	2	2	2	2	2	1	2	2	2	2	2
Conclusions supported by the results?	2	1	2	2	2	2	2	2	2	2	2	2	2	2	2
Score	81.9	90.9	81.9	81.9	90.9	100	68.2	86.3	86.3	68.2	90.9	77.3	100	100	95.5

	O'Connor et al. (2013)	Oshima et al. (2005)	Patkar et al. (2002)	Rabinowitz et al. (2012)	Rocca et al. (2009)	Rocca et al. (2014)	Siegrist et al. (2016)	Suttajit et al. (2015)	Stouten et al. (2014)	Stouten et al. (2017)
Question / objective sufficiently described?	2	1	2	2	2	2	2	2	2	2
Study design evident and appropriate?	2	2	2	2	2	2	2	2	2	2
Method of subject/comparison group selection or source of information/input	2	1	1	2	2	2	2	2	1	2

t variables described and appropriate?										
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	2	2	2	2	2	2	2
If interventional and random allocation was possible, was it described?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
If interventional and blinding of investigators was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
If interventional and blinding of subjects was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?	2	2	2	2	2	2	2	2	2	2

Sample size appropriate?	2	2	2	2	2	1	2	2	2	2
Analytic methods described/justified and appropriate?	2	2	2	2	2	2	2	2	2	2
Some estimate of variance is reported for the main results?	2	1	2	1	2	2	2	2	2	2
Controlled for confounding?	1	1	0	0	1	2	2	0	1	0
Results reported in sufficient detail?	2	2	2	1	2	2	2	2	2	2
Conclusions supported by the results?	2	2	2	2	2	2	2	2	2	2
Score	95.5	81.9	86.3	77.3	95.5	95.5	100	90.9	90.9	90.9

### 3.2 Quality Scores

There was little variation found in the quality scores of the papers, with all articles scoring over 68%, and four articles scoring 100% (Fulford et al., 2013; Makinen, Miettunen, Jaaskelainen, Veijola, Isohanni. & Koponen, 2010; Masillo et al., 2016; Siegrist, Millier, Amri, Abballea, & Toumi, 2016). Gallagher and Jones (2016) and Leifker, Bowie and Harvey's (2009) studies had the lowest score (both scoring 68.8%). The most prominent methodological strengths and weaknesses identified when assessing the studies are described below.

All the studies provided a clear description of the tools used to measure negative symptoms and the psychosocial variables being assessed. Most studies also included the response options of these measures. Results were well reported, with all studies reporting both major and secondary outcomes, and 24 of the studies made conclusions supported by their data.

Regarding weaknesses, across the studies there was limited control of confounding factors. Confounding variables were not controlled in 10 studies and partially controlled in five studies, where some factors were controlled but others that may have affected the outcome were not. Factors that could potentially affect the outcome of results but were not considered included medication usage, duration of untreated psychosis, neurocognition and premorbid functioning. There is also a risk of selection bias from this collection of studies - most participants were recruited from hospitals in a single location. Makinen et al.'s (2010) was the only study to recruit participants taken from the general population and was perhaps more representative of the range of people living with negative symptoms.

## **4. Results**

### **4.1 Summary of Studies**

A summary of the data extracted from each study, including participant sample, design and measurement instruments for negative symptoms and psychosocial factors, and key findings are detailed in Table 6 below.

Table 6

*Authors, Participant Characteristics, Design, Psychosocial factor being Assessed, Measurement Instruments and Key Findings for each Study*

Authors	Participant characteristics	Design	Psychosocial factor	Measure of negative symptoms	Measure of psychosocial factors	Observed associations (if any)
Kim et al. 2013	107 participants 60 clinical high risk 47 healthy controls 55% males Mean age: 20 South Korean participants	Cross sectional	<b>Interpersonal relationships</b> – friends, social activity and initiative <b>Role functioning</b> – work and study <b>Intrapsychic foundations</b> – sense of purpose, motivation and anhedonia <b>Common objects and activities</b> - Use of objects and participation in activities	SANS	QLS	Statistically significant negative association between negative symptoms and interpersonal relationships and intrapsychic functioning: increase in negative symptom level, decrease in psychosocial factor score
Masillo et al. 2016	147 participants 39 clinical high risk 108 healthy controls 47% male Mean age: 17.9 Italian participants	Cross sectional	Interpersonal sensitivity <b>Social functioning</b> –peer relationships, conflict, intimate relationships and family involvement <b>Role functioning</b> – performance and amount of support needed in work or school	PQ	IPSM GF: Social scale GF: Role scale	Statistically significant positive correlation between interpersonal sensitivity and negative symptoms: increase in sensitivity to interpersonal relations, increase in negative symptom level
Corcoran et al. 2011	56 participants 34 clinical high risk 22 healthy controls 77% males Mean age: 20.3 USA participants	Cross sectional	<b>Social function</b> – work, social and leisure activities, relationships with extended family, role within family unit	SOPS	SAS-SR	Statistically significant negative correlation between negative symptoms and social function overall, particularly social and leisure activities: increase in negative symptom level, lower social and activities

Fulford et al. 2013	186 participants 98 clinical high risk 88 first episode psychosis 63% males Mean age: 19.5 Schizophrenia (70.5%), schizoaffective disorder or schizophreniform disorder USA participants	Cross sectional	<b>Social functioning</b> – contact with friends/acquaintances over the past month <b>Occupational functioning</b> - time spent enrolled in school over the past month <b>Role functioning</b> – performance and amount of support needed in work or school	SOPS K-SADS for under 16s  SANS	SCOS-S SCOS-E GFS GFR GAF	Statistically significant negative correlation between negative symptoms and each psychosocial factor for both populations: increase in negative symptoms lower level of functioning
Lee et al. 2017	128 participants 63 clinical high risk 28 first episode psychosis 37 healthy controls 53% males Mean age: 20.3 Schizophrenia South Korean participants	Cross sectional	<b>Social functioning</b> –peer relationships, conflict, intimate relationships and family involvement <b>Role functioning</b> – performance and amount of support needed in work or school	SANS	GF: Social GF: Role	Clinical high risk: Statistically significant negative correlation between social functioning and ‘affective flattening or blunting’ item and ‘avolition-apathy’ item of SANS – decrease in social functioning increase in negative symptom levels  Statistically significant negative correlation between role functioning and ‘avolition-apathy’ item of SANS - – decrease in social functioning increase in negative symptom levels  First episode psychosis: statistically significant negative correlation between social functioning and ‘avolition-apathy’ item of SANS – decrease in social functioning increase in negative symptom levels  statistically significant negative correlation between role functioning and ‘avolition-apathy’ item of SANS – decrease in social functioning increase in negative symptom levels

Addington et al. 2002	306 first episode psychosis participants Gender information provided Age info not provided Diagnosis of schizophrenia spectrum disorder (40.2% schizophrenia) Canadian participants	Cross sectional	<b>Premorbid social functioning:</b> Social withdrawal Peer relationships Ability to function outside nuclear family Sexual relationships	PANSS	PAS	Association between negative symptoms and premorbid social functioning - Individuals with deteriorating premorbid social function had higher levels of negative symptoms
Addington et al. 2003	217 participants 177 first episode psychosis 40 healthy controls Gender information not provided Mean age: 24.5 Diagnosis of schizophrenia spectrum disorder (74% schizophrenia) Canadian participants	Longitudinal – follow up 12 months later	<b>Social functioning:</b> <u>Interpersonal</u> relationships – friends, social activity and initiative <u>Role functioning</u> – work and study <u>Intrapsychic</u> foundations – (sense of purpose, motivation and anhedonia) <u>Common objects and</u> activities - Use of objects and participation in activities	PANSS	QLS	Statistically significant negative correlation between negative symptoms and social functioning at baseline and after one year : increase in negative symptoms, decrease in social functioning  Change in negative symptoms associated with change in QLS score : As negative symptoms increased social functioning decreased  High levels of neg. symptoms predicted low QLS scores after 12 months: Role functioning scores retained or changed to unsuccessful with increase in negative symptoms after 12 months
Milev et al. 2005	99 first episode psychosis patients 70% males Mean age: 24 Diagnosis of schizophrenia, schizophreniform	Longitudinal - follow up for 7 years at 6 month intervals	work satisfaction interpersonal relations and sex relational impairment relationship with family and friends participation and enjoyment of recreational activities	SANS	Psychiatric Status You Currently Have	Negative symptom severity in conjunction with verbal memory statistically significant predictor of the degree of relational impairment  Negative symptoms, shared with processing speed and attention predicted degree of

	or schizoaffective disorder USA participants					impairment in work performance
Stouten et al. 2014	153 first episode psychosis participants 77% males Mean age: 27.8 Diagnosed of non-affective disordered psychosis (81% schizophrenia) Dutch participants	Longitudinal – follow up after 12 months	<b>Psychosocial functioning:</b> Work and study Personal and social relationships Self-care and care for personal environment Disturbing or aggressive behaviour	PANSS	PSP	Negative symptom scores at baseline were related to lower scores in general psychosocial functioning, problems in social relationships, work and study, and self-care problems  Baseline negative symptoms were significantly negatively correlated to functioning at 12 months for work and study - higher negative symptom scores, lower work and study scores
O'Connor et al. 2013	152 first episode psychosis 69% males Mean age: 29.75 Diagnosis of schizophrenia or related disorder Follow up after 12 months British participants	Longitudinal – follow up after 12 month	<b>Clinical insight:</b> awareness of illness, need for treatment, relabelling symptoms as normal <b>Cognitive insight:</b> self-reflectiveness and self-certainty Occupational, psychological and social functioning	PANSS	GAF SAI-E BCIS	Lower score in PANSS predicted increase in functioning at 12 months
Stouten et al. 2017	162 first episode psychosis participants 72% males Mean age: 27 Diagnosis of schizophrenia Dutch participants	Cross sectional	<b>Psychosocial functioning:</b> Work and study Personal and social relationships Self-care and care for personal environment Disturbing or aggressive behaviour	PANSS	PSP	Negative symptoms predicted problems in work and/or study  Negative symptoms predicted problems with self-care  Statistically significant negative correlation between problems in social relationships associated with higher levels of negative symptoms
Lincoln et al.	150 participants	Cross sectional	<b>Social cognition:</b>	PANSS	Movie task of	Statistically significant negative correlation

2011	75 first episode psychosis 75 healthy controls 63% males Mean age: 33.9 Diagnosis of schizophrenia (66%) and schizoaffective disorder German participants		inferring emotions and intentions (theory of mind), empathy, attribution style, self-esteem, interpersonal self-concepts, dysfunctional beliefs		social situations Empathy Scale IPSAQ RSE FSKN DAS-acceptance	with and social cognition. Higher level of negative symptoms, difficulties in abilities to infer emotions and intentions, less readiness to be empathic, less self-serving bias, lower self-esteem, negative self-concepts related to contact and interpersonal abilities, and dysfunctional acceptance beliefs.  Difficulties in inferring emotions associated with higher levels negative symptoms in people with low self-esteem
Butjosa et al. 2016	68 first episode psychosis participants 54% males Mean age: 20.8 Diagnosis of schizophrenia Spanish participants	Cross sectional	<b>Stressful life events one year before first episode psychosis:</b> Functional discomfort Work related stress Health problems Relationship problems Academia Work Love and marriage Children Residence Legal affairs	KIDDIE-PANSS PANSS CGI-S	Peri-M Life Events Scale	Negative symptoms statistically significantly correlated with children and finance significant life events – higher levels of negative symptoms, less significant life events related to children or finance
Lysaker et al. 2005	42 participants with severe and enduring psychosis 93% males Mean age: 46.5 Diagnosis of schizophrenia (55%) or schizoaffective disorder USA participants	Cross sectional	Coping	PANSS	WCQ	Statistically significant positive correlation between negative symptoms and resigning coping style – as negative symptoms levels increased resigning coping style also increased
Suttajit et al. 2015	199 participants with severe and	Cross sectional	<b>Psychosocial functioning:</b> Work and study	PANSS	PSP	Statistically significant negative correlation between negative symptoms and PSP total

	enduring psychosis 52% males Mean age: 37.97 Diagnosis of schizophrenia Thai participants		Personal and social relationships Self-care and care for personal environment Disturbing or aggressive behaviour			and all four domains – as negative symptom levels increase, psychosocial factors decrease  Negative symptoms were predictors of PSP socially useful activities and personal and social relationships scores
Gallagher and Jones 2016	641 participants with severe and enduring psychosis Gender information not provided Age information not provided Diagnosis with schizophrenia USA participants	Cross sectional	Severe childhood neglect	SANS PANSS	Social Service Assessment section of hospital records	Statistically significant difference between those who had experienced childhood neglect and those who did not and the presence of negative symptoms – those who had experienced childhood neglect had higher levels of negative symptoms
Rocca et al. 2014	92 participants with severe and enduring psychosis 54% males Mean age: 42.9 Diagnosis of schizophrenia Italian participants	Cross sectional	<b>Functioning:</b> <u>Interpersonal relationships</u> – friends, social activity and initiative <u>Role functioning</u> – work and study <u>Socially useful activities</u> - Work and study Personal and social relationships Self-care and care for personal environment Disturbing or aggressive behaviour Marital status	SANS	QLS PSP	Statistically significant negative correlation between negative symptoms and interpersonal relations and social network and role functioning – as negative symptom levels increased psychosocial factor levels decreased  Avolition-asociality (AA), affective flattening and alogia domains of SANS correlated with interpersonal relationships, role functioning and socially useful activities – higher score, lower psychosocial factor level  Employment predicted lower AA score  Single marital status positively associated with higher score in AA
Leifker et al. 2009	194 participants with severe and enduring psychosis Gender	Cross sectional	Finance Communication Social skills Physical functioning	PANSS	UPSA-B SSPA SLOF	‘Blunted affect’ and ‘passive apathetic social withdrawal’ domains on PANSS significantly correlated with interpersonal functioning – higher PANSS scores lower levels of

	information not provided Age information not provided Diagnosis of schizophrenia or schizoaffective disorder USA participants		Personal care Interpersonal relationships Social acceptability Participation in community activities Work skills			interpersonal functioning
Rocca et al. 2009	168 participants with severe and enduring psychosis 59% males Mean age: 38.4 Diagnosis of schizophrenia Italian participants	Cross sectional	<b>Social functioning:</b> Social, psychological, occupational functioning	PANSS	GAF	Higher negative symptoms predicted lower social functioning
Fervaha et al. 2014	1427 participants 1209 severe and enduring psychosis 215 healthy controls 74% males Mean age: 40.6 Diagnosis of schizophrenia USA participants	Cross sectional	<b>Functioning:</b> <u>Interpersonal</u> relationships – friends, social activity and initiative <u>Role functioning</u> – work and study <u>Intrapsychic foundations</u> – (sense of purpose, motivation and anhedonia) <u>Common objects and activities</u> - Use of objects and participation in activities	PANSS	QLS	Statistically significant negative correlation between negative symptoms and all domains on the QLS – higher levels of negative symptoms, lower levels of interpersonal relationships, role functioning, intrapsychic foundations and common objects and activities
Oshima et al. 2005	549 participants with severe and enduring psychosis 59% males Median age: 52 Diagnosis of schizophrenia Japanese participants	Cross sectional	<b>Environmental deprivation:</b> Social environment Number of personal possessions Occupation Contact with outside world <u>Ward restrictiveness</u> – autonomy and self-determination	Japanese version of the SANS	Social environment scales	Statistically significant negative correlation between negative symptoms and all domains of environmental deprivation – increase in negative symptoms related to decrease in psychosocial variables
Patkar et al.	87 participants	Cross sectional	Smoking	PANSS	FTND	Significant positive correlations found

2002	66 severe and enduring psychosis 21 healthy controls 56% males Mean age: 40.3 Diagnosis of schizophrenia USA participants					between smoking and scores on negative symptom subscales 'blunted affect' and 'social withdrawal'
Siegrist et al. 2015	1208 participants with severe and enduring psychosis 62% males Mean age: 41 Diagnosis of schizophrenia (75% paranoid schizophrenia) 2 years 5 visits at 6 month intervals French, German and British participants	Longitudinal – 2 years, 5 visits at 6 month intervals	Social contact	PANSS	GAF Interview	Statistically significant correlation between negative symptoms and social contact frequency – increased levels of negative symptoms, decreased levels of social contact  Change across two years: lower baseline contact frequency significantly associated with deterioration in negative symptoms (higher level of negative symptoms)  Change between visits: higher social contact associated with lower severity of negative symptoms
Rabinowitz et al. 2012	1447 participants with severe and enduring psychosis 26% males Mean age: 40.5 Diagnosis of schizophrenia USA participants	Longitudinal – follow up at 2 year intervals over 18 months	<b>Functioning:</b> Education/ occupation Leisure activities Activities of daily living	PANSS	Heinrich and Lehman Quality of Life Scales – excluding items not measuring PANSS negative factor symptoms	Statistically significant negative correlation with total functioning  Negative symptoms predictor of change in functioning from baseline at 18 months
Makinen et al. 2010	46 participants with severe and enduring psychosis 61% males Median age (first hospitalisation):	Retrospective cohort	<u>Analysed at age 14 (before onset):</u> Smoking Alcohol use School performance <u>At onset of illness:</u> Work adjustment	OCCPI (used at first assessment hospitalisation for first episode)	National registry of statistics Self-report Review of hospital notes	Smoking at age 14 and psychosocial stressor predicted more negative symptoms in first episode psychosis  Marital status predicted negative symptoms at follow up stage – married had fewer

	24.3 Mean age at follow up: 33.7 Schizophrenia Finnish participants		Substance misuse Psychosocial stressor Marital status	psychosis) PANSS (follow up phase 1999- 2001)	using the OCPPI	negative symptoms at follow up  Alcohol use age 14 and good school performance predicted less persistent negative symptoms. Also predicted less persistent negative symptoms in follow up  Substance misuse within first year of psychotic symptoms predicted deficit syndrome (severe, enduring symptoms)
<p><i>Note.</i> BCIS = Beck Cognitive Insight Scale, CAI-S= Clinical Global Impression Scale, DAS= Dysfunctional Attitude Scale – Acceptance, FSKN= Frankfurt Self-Concept Scales, GAF= Global Assessment of Functioning, FTND= Fagerstrom Test of Nicotine Dependence, GFR=Global Functioning: Role, GFS= Global Functioning: Social, IPSAQ=Internal Personal and Situational Attributions Questionnaire, IPSM = The Interpersonal Sensitivity Measure, K-SADS – Kiddie Schedule for Affective Disorders and Schizophrenia, KIDDIE-PANSS= A Positive and Negative Symptom Scale for Children and Adolescents, OCPPI = Operational Checklist for Psychotic Illness, PANSS = The Positive and Negative Syndrome Scale, PAS = Premorbid Adjustment Scale, PQ = Prodromal Questionnaire, PSP= The Personal and Social Performance Scale, QLS = Quality of Life Scale, RSE = Rosenberg Self-Esteem Scale, SAI= Schedule of the Assessment of Insight, SANS = Scale for the Assessment of Negative Symptoms, SAS-SR = Social Adjustment Scale = Self Report, SCOS –E = Strauss Carpenter Outcome Scales: Useful Employment, SCOS-S = Strauss Carpenter Outcome Scales: Social Contact, SLOF=Specific Level of Function, SSPA = Social Skills Performance Assessment, UPSA = Performance Based Skills Assessment – Brief Version, WCQ = The Ways of Coping Questionnaire</p>						

#### **4.1.1 Study and participant characteristics.**

A total of 25 quantitative studies, comprising 7420 individuals presenting with negative symptoms and 565 healthy control participants were included in this systematic review. The publication year ranged from 2002 to 2017. Seventeen articles employed a cross sectional design, seven used a longitudinal design, including one study using a retrospective cohort design. Twenty-three of the studies reported the gender and age of participants recruited. Overall, 61% of participants reported were male and the mean age of participants was 29.4 years. Data were collected from participants in 12 countries, nine of 23 studies recruited participants from the USA. All studies examining first episode psychosis and enduring negative symptoms included participants with a diagnosis of schizophrenia, this was the most represented schizophrenia related diagnosis in participants (90% individuals who had received a diagnosis had a diagnosis of schizophrenia).

#### **4.2 Narrative Synthesis**

This narrative synthesis combines and analyses the findings of all 25 studies included in the systematic review.

##### **4.2.1 Negative symptoms definition and measurement.**

Of the 25 articles included in the synthesis, 16 used the PANSS to measure negative symptoms in participants. The PANSS consists of four scales measuring positive and negative symptoms, the difference between the two types of symptoms, and global psychopathology. The PANSS consists of a 30 item, 7-point scale (where 1 = absent and 7 = extreme). Two ratings are assigned for each item, one for the presence of a symptom and another for the symptom's severity. For the negative symptom scale a total score is generated from the combined ratings of seven items: 1. blunted affect, 2.

emotional withdrawal, 3. poor rapport, 4. passive-apathetic social withdrawal, 5. difficulty in abstract thinking, 6. lack of spontaneity and flow of conversation and 7. stereotyped thinking (Kay et al., 1987).

PANSS has shown reliability in scoring over the course of an illness (Mortimer, 2007). Peralta and Cuesta (1994) reported on the inter-rater reliability of the PANSS from a sample of 100 individuals admitted to hospital with a diagnosis of schizophrenia. Both the positive and negative scales showed good inter-rater reliability (interclass correlation coefficients of 0.72 and 0.80; Peralta & Cuesta, 1994).

Six studies utilised the SANS. This evaluates observable behaviours which are listed under 1 of 5 items representing negative symptoms: affective flattening, avolition, alogia, anhedonia, and attentional impairment. Each observable behaviour is rated according to severity (0 = none, 5= severe). For example, “grooming and hygiene” is an observable behaviour listed under the measure “avolition” and can be scored 2 (out of 5), which is equal to “mild” in terms of its severity (Andreasen, 1984).

Inter-rater reliability has been found to be consistent for the SANS, even in cross cultural settings (Andresen, Flaum, Arndt, Alliger, & Swayze, 1991), which perhaps illustrates why a number of the studies in this review chose this assessment tool to measure negative symptoms. Malia, Norman and Williamson (1993) did find that while SANS is stable over a 12-month time frame, subscale scores of “apathy” and “bizarre behaviour” did not have much stability. In this review the articles that used the SANS to measure negative symptoms were cross sectional so may be unaffected by this criticism of its reliability.

However, the PANSS and SANS have been criticised due to the inclusion of items that measure cognitive functioning (Blanchard, Kring, Horan, & Gur, 2011), for

example, attention bias or abstract thinking, which is now thought to be separate from the features of negative symptoms (Harvey, Koren, Reichenberg, & Bowie, 2006). This may have implications for the conclusions drawn by the articles in this review in terms of validity. If Harvey et al.'s (2006) evidence is supported it is possible that the observed negative symptoms in participants were more relevant to cognitive functioning than a syndrome associated with psychiatric condition.

One article (Makinen et al., 2010) used the Operational Criteria Checklist for Psychotic Illness (OCCPI; McGuffin, Farmer, & Harvey, 1991) as a measure of negative symptoms. The OCCPI consists of 90 items measuring clinical characteristics and symptoms across diagnoses. This appears to have been an appropriate assessment tool for Makinen et al. (2010) to use in their study due to its retrospective cohort design. The OCCPI assesses symptoms that have occurred at some point in the individual's life and makes use of data from different interviews (McGuffin et al., 1991), which fits Makinen et al.'s (2010) method of collecting information from the individual's hospital notes. The inter-rater reliability of the OCCPI was assessed for 30 test cases and found to be good (Sarrazin, Louppe, Doukhan, & Schurhoff, 2015).

Two studies investigating a CHR population (Corcoran et al., 2011; Masilo et al., 2013) were the only studies that did not utilise the SANS or PANSS as a measurement of negative symptoms. The Scale of Prodromal Symptoms (SOPS; McGlashan, Miller, & Woods, 2001) and the Prodromal Questionnaire (PQ; Loewy, Bearden, Johnson, Raine, & Cannon, 2005) were used for these studies. The SOPS is a 19-item scale measuring the severity of prodromal symptoms and changes over time. It contains four subscales related to "Positive, Negative, Disorganization and General Symptoms" (McGlashan et al., 2001). Miller et al. (2003) presented results for the

SOPS interrater reliability and found agreement to be in the excellent range for 17 out of 19 items and near the excellent range for the other two items (Miller et al., 2003). Lemos et al. (2006) determined the construct and predictive validity of the subscales of the SOPS in 30 participants. An excellent positive predictive value of the SOPS subscales was found, with negative symptoms having the best specificity (95.5%) and sensitivity (100%) indices. When the factors obtained for negative symptoms were compared with those observed in schizophrenia they were found to have a close relationship, demonstrating continuity from the prodromal phase of negative symptoms to psychosis (Lemos et al. 2006). The 92-item PQ is a self-report questionnaire where items are answered 'true' or 'false' to questions listed under four major subscales: 1) Positive symptoms (e.g., unusual thinking and perceptual abnormalities), 2) Negative symptoms (e.g., flat affect and social isolation), 3) Disorganized symptoms (e.g., odd behaviour) and 4) General symptoms (e.g., depression and role functioning). Sample items include "Sometimes I think that people can read my mind," and "I tend to avoid social activities with other people" (Loewy et al., 2005). In a study measuring its predictive validity, the PQ was found to be good for detecting prodromal or psychotic syndromes (Loewy et al., 2005), however there are no reports on its reliability, limiting its strengths as a questionnaire.

#### **4.2.2 Functioning.**

Across the articles psychosocial factors are consistently mentioned and investigated in the context of "psychosocial functioning," however few studies provide a concrete definition of "functioning." For *impaired* psychosocial functioning a definition was provided in three studies. Lee, Kim, Lee and An (2017) suggested that impaired functioning is defined as "impairment in one or more areas of functioning e.g.

work, interpersonal relations” (Lee et al., 2017, p. 186). Masillo et al.’s (2016) definition of impaired functioning stated the additional impairment of role and social functioning to Lee et al.’s (2017) interpersonal and work functioning. Kim et al. (2013) reported “deficits in social and interpersonal function, occupational and role function, and independent living” as factors encompassing psychosocial functional impairment (Kim et al., 2013, p.762). This could leave the assumption that functioning is related to interpersonal, social, work and role factors, however this is not clarified in the remaining articles included in the systematic review as they did not clearly define this.

For the studies included in this review that were analysing psychosocial factors in the context of psychosocial functioning, this was assessed via outcome measures. The measures used could provide insight into how psychosocial functioning was defined and assessed. The Global Assessment of Functioning (GAF; American Psychiatric Association, 1987) defines functioning by the degree to which an individual is able to perform social roles free of mental or physical limitations (American Psychiatric Association, 1987). The GAF (or a modified version of the GAF) was used most frequently to measure function in seven of the studies included in the review. The GAF is an observational tool that subjectively measures social, psychological and occupational functioning at a point in time, and is scored globally (overall) on a scale of 1-10, 10 indicating “superior” functioning. The reliability and validity of the GAF should be evaluated to determine its usefulness in successfully measuring psychosocial functioning. The method of scoring the lowest function amongst social, psychological and occupational functioning may misrepresent the individual’s global functioning. It is possible that an individual is low functioning occupationally but not socially or psychologically, but the higher functioning in these areas will not be reflected in the

global score (Ryu et al., 2009). Therefore, of the studies in the review, there could be a bias towards low scores and lack of accuracy about what factors of psychosocial functioning are affected by negative symptoms. Bacon, Collins and Plake (2002) also found that clinicians' GAF ratings can be influenced most strongly by symptom severity, followed by functional impairment and the combination of the two, which questions the construct validity of the GAF (Bacon, Collins, & Plake, 2002).

Few studies have investigated the scale's reliability, a limitation of this scale. It is therefore difficult to conclude with confidence whether a change in score reflects a change in presentation based on the evidence (Soderberg, Tongstrom, & Armelius, 2005). Published studies have showed varied results of the reliability of the GAF; in clinical settings reliability is lower (Yamauchi, Ono, & Ikegami, 2001; Vatnaland, Vatnaland, Friis, & Opjordsmoen, 2007), compared to research settings, ranging between 0.85 and 0.9 (Hilsenroth, Ackerman, & Blagys, 2000; Tracy, Adler, & Rotrosen, Edson, & Lavori, 1997). Furthermore, there is little published data about the differences in validity and reliability between low and high scores of the GAF and it has been suggested that further investigation is necessary to determine optimal reliability and validity of the points of the scale (Aas, 2010; Niv, Cohen, Sullivan, & Young, 2007).

It is important to note that the measures used across the studies may not be relating to psychosocial functioning in the same way. Some measures used are objective, for example, the Strauss Carpenter Outcome Scales (SCOS; Strauss & Carpenter, 1972) were used to measure social and occupational functioning. Fulford et al.'s (2013) study, which used the SCOS, explicitly measured the number of times the participant had social contact with friends or acquaintances and the amount time spent

in employment. The SCOS differs from a subjective measure such as the GAF which calls for observational based ratings. There were also measures of psychosocial functioning tailored specifically for a CHR population, for example, Global Functioning: Social Scale (GF: Social; Auther, Smith, & Cornblatt, 2006) and Global Functioning: Role Scale (GF: Role; Niendam, Bearden, Johnson, & Cannon, 2006), both demonstrating high inter-rater reliability and construct validity data (Cornblatt et al., 2007). Some domains are more sensitive to characteristics relevant to a younger population, so cannot be directly compared to other measures of psychosocial functioning for first episode psychosis or populations who live with severe and enduring schizophrenia.

Generally, the scales used to measure psychosocial functioning did so according to the definitions available (occupational, interpersonal, social functioning and independent living). There does, however, appear to be some inconsistency about how various aspects of psychosocial functioning are assessed. Despite there being a range of measures used to assess psychosocial functioning across the studies, the findings generally indicated that the more severe the negative symptoms, or the higher the negative symptom score, the lower the level of psychosocial function.

#### **4.2.3 Population.**

There appeared to be some differences in the psychosocial factor found to be associated with negative symptoms according to the population investigated.

##### **4.2.3.1 Clinical high risk.**

Three studies investigated the psychosocial factors related to negative symptoms in the clinical high risk (CHR) population, participants who were not diagnosed with any schizophrenia related disorder but were presenting with symptoms (Corcoran et al.,

2011; Kim et al., 2013; Masillo et al., 2016). Overall, there were 133 CHR participants and 177 healthy controls recruited from the USA, South Korea and Italy.

Of the studies investigating the clinical high risk (CHR) population (Corcoran et al., 2011; Kim et al., 2013; Masilo et al. 2016) there was a consistent theme of social factors, particularly interpersonal functioning (for example, friendships, social activity and social initiative) in association with negative symptoms. Kim et al. (2013) found that interpersonal functioning was significantly related to negative symptoms; less severe negative symptoms correlated with a higher level of interpersonal functioning. Similarly, Corcoran et al. (2011) found CHR participants who presented with negative symptoms had impaired social function, particularly in social and leisure activities. Masilo et al. (2016) assessed interpersonal sensitivity (excessive awareness of and sensitivity to the behaviour and feelings of others) in CHR compared to healthy controls and found a significant correlation between interpersonal sensitivity and negative prodromal symptoms for both the CHR and healthy control group; more negative symptoms indicated greater interpersonal sensitivity.

This evidence indicates that social functioning, particularly when considering relationships with others, is related to negative symptoms in people who present at clinically high risk of schizophrenia. However, beyond an association between interpersonal functioning and negative symptoms these studies give no further understanding about why this is a significant relationship, neither why this is relevant to the CHR population or what relevant factors affect interpersonal functioning in relation to negative symptoms.

#### ***4.2.3.2 Clinical high risk and first episode psychosis.***

Fulford et al. (2013) and Lee et al. (2017) compared CHR and first episode psychosis (FEP) populations, giving some insight into whether the stage of psychosis (CHR or FEP) was related to the level of psychosocial functioning in individuals and if so to what extent. Overall, there were 128 CHR participants, 116 FEP participants diagnosed with either schizophrenia, schizoaffective or schizophreniform disorder and 37 healthy controls recruited from the USA and South Korea.

Both studies found that interpersonal functioning (for these studies: relationships with others) significantly correlated with negative symptoms; more severe negative symptoms was associated with lower levels of interpersonal functioning. Additionally, levels of role functioning (i.e., time spent in school/work) significantly lowered as the level of negative symptoms increased in both populations. There did not appear to be significant differences in the presentation of CHR and FEP populations in the context of psychosocial factors associated with negative symptoms, so this may help to reliably conclude association between interpersonal skills and negative symptoms at various stages of psychotic presentation. Lee et al. (2017) did additionally describe which subscale of negative symptoms was related to which psychosocial factor. For both the CHR and FEP samples social functioning negatively correlated with the “avolition-apathy” item of the SANS (as “affective flattening” scores increased social functioning scores decreased), and role functioning negatively correlated with the “avolition-apathy” items of the SANS, (as “avolition-apathy” scores increased occupational functioning scores decreased). “Affective flattening or blunting” scores also increased as interpersonal functioning decreased in the CHR sample. The description of which

properties of negative symptoms correlated with which psychosocial factor was a strength of this article and one of only three studies included in this review to do so.

#### **4.2.3.3 *First episode psychosis.***

Eight studies investigated the FEP population (Addington., van Mastrigt, & Addington, 2002; Addington, Young, & Addington, 2003; Butjosa et al, 2016; Lincoln, Mehl, Kesting, & Rief, 2011; Milev, Beng-Choon, Arndt, Andreasen, & 2005; O'Connor et al., 2013; Stouten, Veling, Laan, van der Helm, & van der Gaag, 2014; Stouten, Veling, Laan, van der Helm, & van der Gaag, 2017). Overall, there were 1192 FEP participants and 75 healthy control participants diagnosed with a schizophrenia spectrum disorder (mainly schizophrenia), and recruited from Canada, the USA, Holland, Germany, the UK, and Spain.

The studies related to FEP varied the most in terms of psychosocial factor being assessed and may give the most insight into the range of psychosocial factors that could be related to negative symptoms. A variety of psychosocial factors were found to be significantly associated with negative symptoms at the first episode of psychosis. Inferring emotions and intentions, less readiness to be empathic, lower self-esteem, negative self-concepts related to interpersonal abilities (Lincoln et al., 2011), problems with self-care, work and study (Stouten et al., 2014; Stouten et al., 2017) and social functioning (Addington et al., 2002; Addington et al., 2003) were all found to be statistically significant in their association with negative symptoms – as negative symptoms increased levels of the psychosocial factor decreased. Butjosa et al. (2016)'s was the only study that indicated what factors might be related with negative symptoms in the context of negative symptoms being a protective factor. They found that more negative symptomology at the stage of diagnosis is associated with fewer significant life

events related to children or finances in the 12 months prior to diagnosis. It may be that prodromal symptoms prevents individuals engaging in activities related to children or finances, or due to the population's mean age (20.8) there are less likely to be significant life events related to children or finances, however this cannot be determined based on correlational data. Although there was little consistency in the results in terms of identified psychosocial factors, generally it appeared that lower scores related to these factors correlated with higher levels of negative symptoms in FEP participants.

#### ***4.2.3.4 Enduring negative symptoms.***

Twelve studies investigated participants who had long standing negative symptoms. The definition of enduring psychosis was defined inconsistently across this set of studies, including one or more episodes of schizophrenia (Fervaha, Foussias, Agid, & Remington, 2014; Rabinowitz et al., 2012), no hospitalisations or changes in medication or housing in the past month (Lysaker, Davis, Lightfoot, Hunter, & Stasburger, 2005), hospitalised for at least a year after diagnosis (Oshima, Mino, & Yoshima, 2005), no changes in symptoms (Rocca et al., 2014) and a diagnosis of schizophrenia for more than two years (Makinen et al., 2010). Overall, this population reported the highest number of participants with a schizophrenia related disorder (5851 and 236 healthy controls). Leifker et al.'s (2009) was the only study to include participants with a diagnosis of schizoaffective disorder, all other studies only recruited participants with a diagnosis of schizophrenia. Participants were recruited from Thailand, the USA, Italy, France, Germany, the UK and Japan.

Like the CHR population, for studies investigating participants who had enduring negative symptoms there was a theme of an association with social factors in terms of inclusion and contact with others, despite measuring a number of psychosocial

factors. Suttajit et al. (2015) and Leifker et al. (2009) found a significant association between increased levels of negative symptoms and less inclusion in activities. Siegrist et al. (2015) and Suttajit et al. (2015) both found a negative correlation between frequency of social contact and negative symptoms for people who have a longstanding diagnosis of schizophrenia. Rocca et al. (2014)'s study illustrated that being single is associated with features of negative symptoms related to avolition and asociality, corresponding with Makinen et al.'s (2010) study which found that being married protected participants from negative symptoms over time.

Smoking also emerged as a variable associated with negative symptoms in people with severe and enduring psychosis. Patkar et al. (2002) examined smoking in relation to negative symptoms and found significant positive correlations with smoking and scores on the PANSS subscales 'blunted affect' and 'social withdrawal'. This is in line with Makinen et al. (2010), whose findings indicated that smoking at age 14 was a significant predictor of the development of negative symptoms in adulthood, and substance misuse within the first year of psychotic symptoms predicted deficit syndrome.

#### ***4.2.3.5 Longitudinal studies.***

Seven longitudinal studies were included in the systematic review, of which four articles examined first episode psychosis participants (n=627) (Addington et al., 2003; Milev et al., 2005; O'Connor et al., 2013; Stouten et al., 2014) and three examined participants with enduring psychosis (n=2655) (Makinen et al. 2010; Rabinowitz et al., 2012; Siegrist et al., 2015).

There appeared to be some uniformity in the findings from the longitudinal studies with studies reporting an association between severity of negative symptoms

and the psychosocial factor measured. This was evaluated in various ways: Addington et al. (2003) measured change in social functioning over a year and found an increase in negative symptoms is associated with a decrease in social functioning. Similarly, Siegrist et al. (2015) analysed change between follow up visits and found higher social contact frequency to be significantly associated with lower negative symptoms. All studies reported on negative symptoms as predictors of psychosocial functioning, with all reporting either higher negative symptoms scores predicting impairment of psychosocial functioning over time or lower negative symptoms scores predicting an increase in psychosocial functioning at 12 months. (Addington et al., 2003; Makkinen et al., 2010; Milev et al., 2005; O'Connor et al., 2013; Siegrist et al., 2015; Stouten et al., 2014; Rabinowitz et al. 2012).

These studies are useful for establishing a sequence of the relationship between various factors and negative symptoms. These studies also arguably allow us to make more confident conclusions about the associations between psychosocial factors and negative symptoms, as data is collected at various time points. However, it should be considered that although more data is collected over time, it has been found that the longer the period, the less the outcome can be explained by negative symptoms, possibly due to long term confounding factors such as medication effects, changes in reaction to illness, self-perception, physical illness, effects of medication and significant life events (Robinson et al., 1999; Wing, 1989).

#### **4.2.3.6 Overview.**

Across the papers it was found that there was an association between negative symptoms and various psychosocial factors. The presence of negative symptoms was normally associated with psychosocial factors, and in the longitudinal studies negative symptoms were predictive of psychosocial functioning. Only Makinen et al. (2010) presented findings demonstrating psychosocial factors that were protective against the development of negative symptoms. They found good school performance, alcohol use and being married significantly predicted a decrease or prevention of negative symptoms over time. It is important to note that 17 out of 25 studies measured the association of psychosocial factors according to functioning. This was largely directed by the questionnaires used to assess this. There was more variation in the psychosocial factors measured and the questionnaires used when functioning was removed from the definition of psychosocial factors.

## **5. Discussion**

This review of 25 articles focused on the psychosocial factors associated with negative symptoms occurring in schizophrenia and related disorders. The rationale of this review was based on the limited research surrounding this topic, where there is evolving evidence for biological and genetic explanations of negative symptoms, and data outlining psychosocial factors associated with schizophrenia in instances of positive symptom presentation.

### **5.1 Main Findings**

This review has presented evidence to suggest that the following psychosocial factors are associated with negative symptoms: interpersonal relationships (Addington et al., 2002; Addington et al., 2003; Fervaha et al., 2014; Kim et al., 2013; Lee et al., 2017; Leifker et al., 2009; Lincoln et al., 2011; Rocca et al., 2014; Stouten et al., 2014; Suttajit et al., 2015), intrapsychic foundations (Kim et al., 2013) interpersonal sensitivity (Masillo et al., 2016), social and leisure activities (Corcoran et al., 2011), role functioning (Fulford et al., 2013; Lee et al., 2017; Milev et al., 2005; Oshima et al., 2005; Rocca et al., 2014; Stouten et al., 2014; Stouten et al., 2017; Suttajit et al., 2015), smoking, alcohol use (Makinen et al., 2010; Patkar et al., 2002), self-care (Lincoln et al., 2011; Suttajit et al., 2015), inferring emotions and intentions, empathy, self-esteem, self-concepts (Lincoln et al., 2011), coping style (Lysaker et al., 2005), childhood neglect (Gallagher & Jones, 2016), social contact (Fulford et al., 2013; Oshima et al., 2005; Siegrist et al., 2015), finance and children (Butjosa et al., 2016), marital status (Makinen et al., 2010; Rocca et al., 2014), school performance (Makinen et al., 2010) and psychological functioning (Oshima et al., 2005; Rocca et al., 2009).

Overall, these studies illustrate that there is theme of a relationship between negative symptoms and socialising with others or being included in social activities, where an increase or the presence of negative symptoms indicates that social functioning will be negatively impacted. Of note are the findings regarding interpersonal functioning, particularly at the CHR and FEP stage of psychosis, where there were consistent reports of higher levels of negative symptoms being associated with lower levels of interpersonal functioning. For the studies investigating participants with enduring psychosis there appeared to be more of a relationship between negative symptoms and lack of inclusion or social withdrawal, rather than interpersonal relationships. Mwansisya et al. (2013)'s evidence suggests that people who show negative symptoms at the chronic stage of schizophrenia are less likely than the FEP population to receive social support. This is a possible explanation as to why withdrawal was more prevalent in the enduring population compared to the FEP populations included in the systematic review.

The findings related to social behaviour could also be explained by the features of negative symptoms. Avolition or social withdrawal are examples of defined negative symptoms that could make relationships with others more challenging, as demonstrated by Rocca et al. (2014). Only two studies of those included in the review (Kim et al., 2013; Rabinowitz et al., 2012) acknowledged the potential overlap between features of negative symptoms and the psychosocial factors. They removed measures that included features of negative symptoms as a psychosocial factor. This helped to determine what factors unrelated to fundamental negative symptoms were associated with negative symptoms.

## **5.2 Methodological Issues and Weaknesses**

Many of the studies considered psychosocial factors in the context of psychosocial function, however few articles provided a clear definition for this or reasoning for framing psychosocial factors within functioning. It appeared that the tool used to measure psychosocial functioning governed the psychosocial factor measured, for example, the GAF measures social, occupational and psychological functioning, so these were the psychosocial factors investigated. It is possible that the range of psychosocial factors investigated was limited by the availability of valid and reliable tools to measure possible psychosocial factors.

The number of studies using a cross-sectional design could be seen as a limitation of the literature reviewed. Although this review was able to conclude an association between negative symptoms and psychosocial factors, a cross-sectional design limits the ability to draw any solid conclusions about the associations found as variables are measured at the same time. It is difficult therefore to determine which variable was the causing or affecting factor. The longitudinal studies included in this review were able to describe the effect of negative symptoms on psychosocial functioning over time, which allows for more affirmative conclusion that the presence of negative symptoms is at least contributing to a decline in psychosocial functioning. It would be beneficial in future studies to use a longitudinal design to assess negative symptoms in relation to psychosocial factors over the span of psychosis and develop understanding of possible causation. Retrospective cohort studies, similar to Makinen et al., (2010)'s study, despite conclusions of the findings being limited by its lack of generalisability and vulnerability to gathering inaccurate information, may be useful in determining what

early life factors are associated with negative symptoms. In terms of clinical relevance, knowledge of early psychosocial factors could be used to target early interventions as a preventative method, though it should be considered that cohort designs are generally considered as inferior to prospective designed studies (Hess, 2004). Unfortunately, all the studies included in this review were limited by their design. Cohort, cross-sectional and longitudinal design studies do not manipulate variables, and whilst they can demonstrate a relationship between factors, they have reduced statistical power to determine causality (Tooth, Bain, Purdie, & Dobson, 2005).

As described by Kirkpatrick et al., (2005) and Blanchard et al. (2006) “negative symptoms” is an umbrella term. Few studies attempted to separate the properties of negative symptoms determine whether they related to psychological factors. This may be due to the tools used to assess negative symptoms, however many measures had subscales related to the negative symptoms that could be reported in the findings. The conclusions may have been strengthened by more nuanced data about which features of negative symptoms were related to which psychosocial factor.

Other less pertinent weaknesses identified in the reviews, outside of those discussed in relation to the quality review, included losses to follow up and differences in follow up times.

### **5.3 Limitations of the Systematic Review**

Articles included in this paper were generally of a high standard, with quality scores ranging between 68 and 100%, so there can be some confidence about the methodological process and reporting of findings. Currently, there is no single quality assessment tool identified for widespread use for systematic reviews of observational studies (Sanderson et al., 2007). Kmet et al. (2007)’s tool may be limited by its lack of

specificity to observational studies. This quality assessment tool functions on the premise that each question has an equal implication and weighting. For example, reporting of a clear research question is allocated the same weighting as controlling for confounding factors. This tool fails to account for the fact that controlling confounding factors may be more significant to the outcome of the study than whether the research question had been stated. This may have led to a misrepresentation of the degree of methodological strengths and weaknesses in the studies.

Additionally, some authors included in this review are authors of more than one paper. It is possible that replicated data may have been analysed and reported, resulting in a misrepresentation of the overall findings of this review.

#### **5.4 Future Research**

Outside of social factors, there was little cohesion in the identified factors associated with negative symptoms. Future research could focus on factors outside of sociality that were identified in this literature review, such as self-esteem, childhood neglect, coping and substance misuse, to determine whether similar results are reported with replicated studies or with changes to the sample or diagnosis of participants.

One study reported psychosocial factors (alcohol use and marital status) that were associated with lower levels of negative symptoms over time (Makinen et al., 2010), and Siegrist et al. (2015) reported that an increase in social contact between follow up visits was associated with a reduction in negative symptoms. Further research could aim to identify additional variables that are associated with reducing levels of negative symptoms or psychosocial factors that prevent the development of negative symptoms over time to support clinical intervention and prevention.

Further research to identify what features of negative symptoms (such as blunting or avolition) are associated with particular psychosocial factors may offer more nuanced data about negative symptoms and their mechanisms. This may be useful in terms of clinical intervention, by matching a negative symptom presentation to a potential associative psychosocial factor and intervening based on this.

Associations between psychosocial factors and negative symptoms at the CHR stage could be used as a rationale for early detection and intervention that could be effective in ameliorating the course of negative symptoms. There is no evidence based standardised treatment for negative symptoms (Melle et al., 2008), however there is developing evidence to suggest that specially adapted forms of Cognitive Behavioural Therapy (CBT) may be effective in addressing negative symptoms (Jauhar, McKenna, Radua, Fung, Salvador, & Laws, 2014). Controlled studies examining the effects of an intervention like CBT at the CHR stage, adapted to address psychosocial factors associated with negative symptoms, such as interpersonal relationships, social and leisure activities, academia and work (as identified in this literature review), could be useful in determining the effects of directly intervening with negative symptoms based on associated psychosocial factors amongst the CHR population.

Whilst outside of the scope of the current review, the findings raise questions about the underlying mechanisms of the associations between psychosocial factors and negative symptoms, and why specific psychosocial factors are related to negative symptoms. As mentioned above, Bentall (2004) proposed that lack of social reinforcement may lead to lower levels of self-care. In this review Lincoln et al. (2011) reported that difficulties in inferring emotions was related to negative symptoms in people with low self-esteem. It is possible that when negative symptoms are combined

with one psychosocial factor this combination relates to another psychosocial factor.

The relationship between a combination of psychosocial factors and negative symptoms could be examined in more depth in future research.

## **5.5 Clinical Implications**

The clinical implications of a relationship between psychosocial factors and negative symptoms indicate that a range of treatment options should be available for individuals presenting with negative symptoms. It is possible that approaches based on a social model might be more effective than other treatment options, based on the finding that social factors such as exclusion and difficulty with social relationships were particularly present in CHR and severe, enduring negative symptom populations.

A recent meta-analysis conducted by Turner, McGlanaghy, Cuijpers, van der Gaag, Karyotaki and MacBeth (2018) found social skills training (SST), a psychological intervention based on developing or improving social interaction (Wallace et al., 1980), to be more effective than treatment as usual, controls (no intervention) and other compared interventions such as CBT. Currently, SST is not recommended as an intervention for negative symptoms, however the findings of this systematic review and Turner et al. (2018)'s evidence may highlight potential for wider implementation of SST amongst individuals presenting with negative symptoms.

## **5.6 Conclusions**

This current review contributes to the emerging body of research examining psychosocial factors in relation to negative symptoms in schizophrenia and related disorders. A number of psychosocial factors were found to be associated with negative symptoms, with most studies reporting a decrease in the psychosocial factor when negative symptoms increased. No conclusions of causation or effect can be made due to

the observational designs of the studies. Further research is required in this area to determine effect of particular psychosocial factors on negative symptoms. There is also a need to focus on psychosocial factors outside of social behaviour, particularly those closely aligned with features included in negative symptom presentation such as social withdrawal. It may also be useful to determine which components of negative symptoms are related to specific psychosocial factors, to further understand the risk factors and implement early, appropriate intervention for prevention and amelioration.

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**Empirical Research Paper:**

**HOW DO MENTAL HEALTH STAFF MAKE SENSE OF SELF-NEGLECT IN  
SEVERE AND ENDURING PSYCHOSIS?**

## **Abstract**

**Background:** Despite an increase in recognition and need for intervention, there is limited knowledge about self-neglect, particularly in relation to mental health conditions.

**Aims:** This study aimed to investigate clinical mental health staff's understanding of self-neglect in people living with severe and enduring psychosis.

**Method:** Semi structured interviews were conducted with eight members of staff who worked in assertive outreach teams and rehabilitation teams. The data was thematically analysed using Template Analysis.

**Results:** Four overarching themes were extracted from the data: Definition of self-neglect, Intervention, Experience of working with self-neglect and Perceptions of origins and maintenance of self-neglect. Overall, staff believed self-neglect was a problem identified by behaviours such as poor hygiene and unkempt appearance. Staff believed self-neglect developed due to the impact of their mental health condition.

**Conclusions:** The findings of this study support the developing knowledge of self-neglect. Further research is needed to establish a standardised definition of self-neglect to improve identification and risk management in cases of self-neglect in severe and enduring psychosis.

## **1. Introduction**

### **1.1 Overview**

Self-neglect occurs across populations and has increasingly become recognised as an issue requiring intervention (Gunstone, 2003). In the United Kingdom it is now viewed as a potential safeguarding issue, with the impact of self-neglect potentially risking the individual and others' physical and mental health and safety (Department of Health and Social Care, 2014). Self-neglect has been included as a feature of negative symptoms based on factor analysis of the 24-item version of the Brief Psychiatric Rating Scale (BPRS; Lukoff, Nuechterlein & Ventura, 1986) conducted by Ventura, Nuechterlein, Subotnik, Gutkind and Gilbert (2000). They analysed the 24 items of the BPRS to identify symptom dimensions in psychiatric disorders from a sample of individuals with schizophrenia and bipolar disorder. Self-neglect was found to positively correlate with the "negative symptoms" factor – as levels of self-neglect increased negative symptoms also increased (Ventura, Nuechterlein, Subotnik, Gutkind & Gilbert, 2000). There has since been little research on the development or risks of self-neglect in negative symptoms. This study will therefore aim to shed some light on self-neglect in the context of severe and enduring psychosis, where there are is a higher number of people reporting negative symptoms compared to positive symptoms (Tamminga, Buchanan, & Gold, 1998).

Most research has focused on self-neglect in older adult populations. After conducting a literature review, Pavlou and Lachs (2008) defined self-neglect in older adults as, "(1) persistent inattention to personal hygiene and/or environment, (2) repeated refusal of services which can reasonably be expected to improve quality of life, and (3) self-endangerment through the manifestation of unsafe behaviours" (Pavlou &

Lachs, 2008, p.1842). Morgan (1998) attempted to separate self-neglect from severe self-neglect in the elderly, proposing the following definition:

- (1) The development of serious disability of illness, as a result of neglect, (2) a relapse into a serious mental state that would endanger general health and well-being, clearly identified as caused by neglect of self and/or treatment, (3) the development of a serious environmental health problem that may endanger the individual, carers or other visitors (p.281)

Morgan (1998) suggested these additional factors, alongside self-neglect, arising from denial or avoidance of social norms, would indicate the presence of severe self-neglect: “Deteriorating physical condition, non-compliance with treatment, hoarding of rubbish and neglect of rotting food, denial of danger from malfunctioning appliances, disconnection of essential services, and leaving home with the doors unlocked and open” (Morgan, 1998, p.282). Both definitions outline the danger and negative impact of self-neglect for the individual and illustrate the importance of understanding its presentation so that it can be effectively addressed.

When the self-neglecting client’s perspective is taken into account, although there is agreement with researchers’ and clinicians’ views on the presentation of self-neglect (e.g., poor self-care, poor living conditions and unkempt appearance), clients sometimes do not see their life circumstances as a problem. This raises questions about who self-neglect is a problem for and when it is appropriate to intervene (Day, Leahy-Warren, & McCarthy, 2013).

Assessment tools for self-neglect in older adults have also been published (Abrams et al., 2018; Dyer, Kelly, Pavlik, Lee, Doody, & Regev, 2006), indicating the presence of some consensus of the characteristics of self-neglect in older adults. Recently, Abrams et al. (2018) established the Abrams Geriatric Self-Neglect Scale (AGSS; Abrams et al., 2018), a clinician-rated scale partially based on the definition of self-neglect proposed by Pavlou and Lachs (2008), to identify clinical characteristics of

older adults who are self-neglecting. Development of assessment tools to aid observation and identification of self-neglect demonstrates a degree of progress for self-neglect research in geriatric populations.

Despite the comparative wealth of research into self-neglect in older adults there are still barriers to research in this group due to the complexity of how self-neglect is identified, assessed and intervened (Fulmer, 2008). Whilst several definitions for self-neglect have been proposed in geriatric populations, it should be noted that as yet there is not a standardised national or international definition of self-neglect. Research into geriatric self-neglect provides some insight into how self-neglect is understood and assessed, however, its basis on older adults limits the ability for generalisation to wider populations.

## **1.2 Self-Neglect and Mental Health**

It has been suggested that a number of cases of self-neglect results from an underlying mental illness (Lauder, 1999; Radebaugh, Hooper, & Gruenberg, 1987). Dong and Simon (2016) used the PHQ-9 (PHQ-9; Kroenke, Spitzer, & Williams, 2001) to assess depression in 3159 Chinese adults aged 60 or over. The prevalence of self-neglect of all severities was higher amongst participants displaying depressive symptoms. In another study, Preston-Shoot (2018) thematically analysed self-neglect safeguarding reviews and concluded that self-neglect is complicated by the presence of mental health problems. Despite the assertion that mental illness is associated with self-neglect, there has been little literary attention awarded to self-neglect in relation to mental health problems. There have been attempts to label self-neglect under a psychiatric diagnosis. “Diogenes Syndrome” is a medical diagnosis often labelled to supposed presentations of self-neglect (Clark, Mankikar, & Gray, 1975; Lauder,

Anderson & Barclay, 2002), and was initially described as severe domestic squalor (i.e., a person's home becoming so unclean and unhygienic that people of a similar culture and background would consider extensive cleaning to be necessary) (Pertusa et al., 2010; Snowden, Halliday, & Banerjee, 2012). This definition has since widened; Reyes-Ortiz, (2001) suggested that social withdrawal and treatment refusal were also features of Diogenes Syndrome, however this definition has not been fully applied in later cases of elderly self-neglect (Lauder et al., 2002), perhaps displaying that the understanding of self-neglect is not resolved by a diagnostic label and requires further research.

Gunstone (2003) conducted semi structured interviews with clinical mental health staff (n=7) and found there to be a lack of understanding of a clear definition or conceptualisation of self-neglect and severe self-neglect for individuals with mental health difficulties. There was a consistent response as to what staff recognised as constituting self-neglect, such as low food and drink intake, failure to maintain personal hygiene and clothing, the home environment, finances and social contact, non-compliance with treatment, and failure to protect themselves from abuse (Gunstone, 2003), considering the person's culture and premorbid standards of living. However, staff did not agree on the definition of severe self-neglect, displaying the lack of understanding around the extremities of self-neglect presentations. However, this study did demonstrate that self-neglect is considered, by clinical staff, to extend beyond hoarding and poor hygiene in an individual's home, as defined by a diagnosis of Diogenes Syndrome. The study also accounted for additional factors such as finance and treatment refusal, which supported previous self-neglect research in older adults.

Lamkin, Nguyen, Coverdale and Gordon (2017) presented a set of case examples of self-neglect across various mental health diagnoses, including borderline personality disorder, depression, bipolar disorder and schizophrenia. The common self-neglecting behaviours were similar to those found in Gunstone (2003)'s study and subsequently they proposed a definition of self-neglect as "A set of unhealthy behaviours as well as an unhealthy behavioural and socio-environmental condition" (Lamkin et al., 2017, p. 557), with behaviours including "poor hygiene, non-compliance with treatment, failure to attend appointments, unsafe home environment, selective mutism and disrobing" (Lamkin et al., 2017, p.557). Unlike self-neglect in the geriatric population, where it is conceptualised as a condition that is irreversible in its connection with organic decline, for psychiatric service users self-neglecting behaviours or environments are treatable conditions or states, and therefore its identification and treatment is necessary (Lamkin et al., 2017). The study was limited by its design: reporting single case studies at a single point in time. Nevertheless, as one of the few studies to explore self-neglect across psychiatric diagnoses, this study is a useful foundation for developing the understanding of self-neglect in psychiatric populations.

### **1.3 Self-Neglect and Severe and Enduring Psychosis**

The limited understanding of *severe* self-neglect found by Gunstone (2003) is significant for individuals with severe and enduring schizophrenia and their carers. Self-neglect presents more severely in service users with chronic schizophrenia compared to other mental health disorders (Lamkin et al., 2017). Additionally, self-neglect, as defined by Pavlou and Lachs (2008), is a significant risk factor in people with schizophrenia; disorganisation, poor insight and psychotic symptoms (such as delusions) may prevent the individual from seeking help for this (Pavlou & Lachs,

2008). Lamkin et al., (2017) also suggested that there is a higher safety risk for individuals with chronic schizophrenia and a less favourable treatment prognosis if self-neglect persists.

Symptoms of psychosis, such as those experienced in people with a diagnosis of schizophrenia, can be categorised as either ‘positive’ (e.g., delusions, hallucinations) or ‘negative’ symptoms (e.g., lack of emotions, slow speech) (Andreasen & Olsen, 1982). Negative symptoms of psychosis can be understood as thoughts, feelings or behaviours normally present in an individual that are diminished or absent in people with psychosis (e.g., maintaining hygiene or social withdrawal; Meaden & Hacker, 2010). Within schizophrenia self-neglect is viewed as a negative symptom (Lukoff et al., 1992), and although there is evidence for effective treatments for positive symptoms (Addington et al., 2011) there is very limited evidence about what works for negative symptoms in psychosis (Remington et al., 2016), despite the fact that negative symptoms, compared to positive symptoms, are linked to much poorer function in people with psychosis (Milev, Beng-Choon, Arndt, & Andreasen, 2005). Currently, it is unclear to what degree self-neglect contributes to psychosis and the vulnerabilities associated with this (Lamkin et al. 2016). Although self-neglect is viewed as a negative symptom there is limited agreement about the definition and presentation of self-neglect. The term self-neglect is not widespread in psychiatric literature despite often being referred to in relation to schizophrenia and is based on scientific theory rather than a clearly developed evidence base (Pavlou & Lachs, 2008).

Research has highlighted this lack of knowledge about self-neglect, particularly in psychiatric populations. Developing a clear definition of self-neglect will help to develop further research programmes, assess risk and clinically train staff in effective

identification and early intervention. The current research aims to develop understanding of self-neglect in individuals with severe and enduring psychosis, where self-neglect is suggested to be particularly severe, and the complex needs this client group presents, such as social exclusion, leaves many at risk of self-neglect (Cook & Howe, 2003). Clinical staff members who have regular contact with this group and are likely to have insight into how self-neglect is understood in instances of severe and enduring psychosis will be interviewed for this study. The aim is to provide a greater understanding of the characteristics of self-neglect in people with severe and enduring psychosis, which can be used to contribute to the development of a definition of self-neglect in severe and enduring psychosis. This can then be used to develop further research programmes in this area and facilitate staff who work with this clinical group to notice and address risk of self-neglect.

Specifically, this research aims to answer the research questions:

**Research Question 1:** How do staff make sense of self-neglect in service users with severe and enduring psychosis (for example, how it presents)?

**Research Question 2:** What factors do staff believe may be associated with self-neglect in severe and enduring psychosis?

## **2. Method**

### **2.1 Ethical Approval**

This research study was reviewed and received full ethical approval from the University of Birmingham Research and Governance committee, Health Research Authority and the Research and Innovation department of the Trust from which participants were recruited. See Appendices I, II and III.

### **2.2 Recruitment and Sample Description**

Mental health staff (e.g., psychiatrists, community psychiatric nurses, occupational therapists, psychologists and support workers) who had worked clinically with service users with psychosis for at least 12 months, in either an Assertive Outreach Team (AOT) or Inpatient Rehabilitation Team were eligible to participate in this study. Participants were recruited from a large NHS mental health trust in the West Midlands of the UK that provides specialist services for people affected by psychosis. Mental health staff were chosen as participants as their daily contact with service users with negative symptoms might offer some understanding of how self-neglect presents in this population. Clinicians were excluded if they did not work in AOT or inpatient rehabilitation services. Potential participants were identified by the project supervisors (A.F. and S.R.) who had knowledge of clinical staff who worked in these settings. Those identified were then distributed information regarding the research study by the researchers via face to face meetings and emails. The recruitment strategy is illustrated in Figure 1. Participants were recruited across disciplines, with the view that various training backgrounds would allow for diverse perspectives of self-neglect to emerge from the data, more than would be possible with a homogenous sample. A total of eight participants included two psychiatrists, two community psychiatric nurses, one

occupational therapist, two support workers and one clinical psychologist. Ten participants were originally recruited, however, due to service restraints, two participants withdrew from the research study.

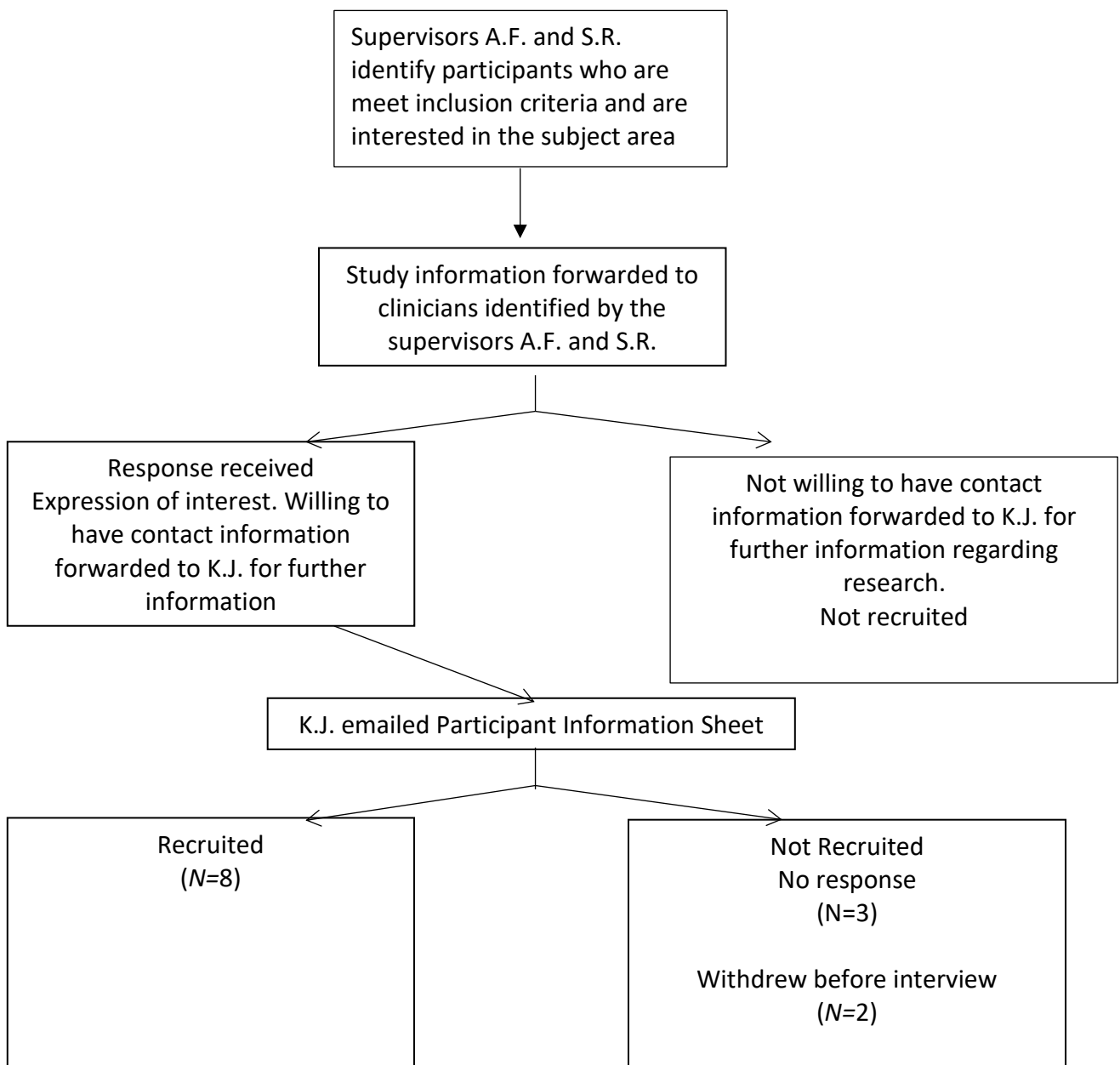


Figure 1. Recruitment strategy

### **2.3 Data Collection**

In accordance with the British Psychological Society Code of Ethics and Conduct (British Psychological Society, 2014) participants were asked to provide written informed consent which contained information of the study aims and methodology. Following this, data were collected in semi structured, digitally recorded, face to face interviews at the participant's work base. Interviews were conducted by the researcher (K.J.) between January and April 2018. Interview length ranged from 35 to 75 minutes, after which each interview was transcribed verbatim and analysed using Template Analysis (TA). The lack of previous research (including a lack of definition of self-neglect) meant that hypotheses could not be generated for testing. Exploratory, inductive research is needed to provide an initial definition that can then be explored through further research (including deductive testing).

### **2.4 Approach to Data Analysis**

TA is a method for analysing qualitative data; themes emerging from a data set are summarised and extracted into a coding template relevant to the research question (King, 1998). Some codes are usually identified a priori, they are then modified and additional codes are added as the researcher reads and interprets the textual data (King, 1998). The research was conducted as part of a professional doctorate training in clinical psychology, and the primary researcher (KJ) received regular supervision from a clinical psychologist with experience in using qualitative methods (AF).

The aim for the findings of this study was to contribute to knowledge of self-neglect in the context of psychosis, both generally and specifically. Grounded theory was considered as an approach for this study in terms of developing an understanding of a phenomenon based on the data. However, despite not being strictly attached to one

epistemological approach (Charmaz, 1995) it has been developed as a realist methodology (aiming to undercover the “real” beliefs, attitudes and values of participants). The researchers acknowledged that there are multiple interpretations to be made of self-neglect. From a contextual constructivist stance (Madill, Jordan, & Shirley, 2000) it is understood that understanding of self-neglect can be influenced by the participant’s context i.e. training, gender, previous experience with service users. For the purposes of this study we asked clinical staff of different professions as we thought they would have varying perspectives and understanding of self-neglect.

Furthermore, grounded theory was also thought to be unsuitable as there was already existing knowledge of self-neglect in the context of elderly populations and some mental health disorders. The researchers also had some experience of working with service users with psychosis in rehab settings. For these reasons a-priori codes were included to provide structure and incorporate knowledge from previous research, whilst maintaining an inductive approach by using the data to generate codes. Template analysis was felt to be an appropriate tool for this purpose due to explicitly incorporating an inductive approach whilst also representing a-priori knowledge within the analysis.

Hierarchical coding is applied to the text; broad themes are identified as the highest-level codes before lower level codes, which are narrower, more specific themes connected to the broader themes are identified (King, 1998). Hierarchical coding allows analysis at varying levels of specificity. Higher-order codes provide a general overview of the content of the interview, while more detailed lower-order codes display finer distinctions, both between and within cases. TA was the selected qualitative data analysis method as it allowed for a clear yet flexible approach to analysis which

supported answering the research questions (Brooks, McCluskey, Turley, & King, 2015).

Following TA protocol, four a priori codes were identified based on the academic literature and the researchers' own personal clinical experience (King, 1994). These codes formed the interview topics and subsequent initial template. Main questions reflected the higher-order codes, with secondary questions and probes as the potential lower-order codes, although they could be modified throughout the analysis process.

The researcher (K.J.) developed an initial template by examining a subset of the transcript data (two interviews) based on the a priori codes and including new codes based on the research questions (see Appendices V and VI). The initial template consisted of 29 'first level' codes, sub-divided into one level of lower order codes. The extent of sub-division reflects the depth of analysis. The text was colour coded by hand (see Appendix IV).

Once the initial template was constructed, K.J. systematically examined the full set of transcripts, identifying sections of text related to the research questions, and marked them with one or more codes from the initial template.

The initial template was refined through a systematic process guided by previous TA research (Brooks et al., 2015):

- a) inserting a new code when the researcher identified a relevant issue in the text which was not already covered by an existing code. For example, in this analysis 'Approach' was added as a 'second level' code in Version 2 of the template (see Appendix VII), which led to a new set of lower level codes that were new or had initially appeared somewhere else in the template. This developed as a result of

the increasing awareness over the course of the analysis that the way staff intervened was a key theme in much of the staff members' discussion.

- b) deleting a code because it overlapped with other established codes. On our template Version 2 (see Appendix VII), we distinguished between 'Not engaging' and 'Using very little'. On reflection it was decided there was too much overlap in the comments arising from these two codes, so it was not useful to keep both codes. The code 'Using very little' was deleted and amalgamated the related comments to 'Not engaging'.
- c) codes were also deleted if they were not supported by more than one participant
- d) if a theme was too narrowly or broadly defined to be useful the code was either redefined and joined with other themes at a higher level or divided into lower levels – for example 'Definition of self-neglect' was divided into lower levels in Version 2 of the template (see Appendix VII) as this was too broadly defined to reflect the depth of analysis for this theme.
- e) on occasion, lower level codes were shifted between higher order codes when the researcher thought a different higher code was more appropriate, for example 'When service user does not see self-care as a priority' was shifted from the higher order code 'Point of intervention' in Version 3 of the template (see Appendix VIII) to 'A problem' in Version 4 of the template as it was felt to be more appropriate to this code.

In total four versions of the template were progressively developed through revision and refinement. Version 4 (Appendices IX and X) was considered the final template, as all sections of data were related to the research questions and well defined by three or more team members. Appendices V-X map the development of the codes to Version 4.

#### **2.4.1 Rigour of analysis.**

Quality control of TA was based on the methods recommended by King (1998). At each stage of analysis, the template was evaluated by the supervisor (AF) who coded sections of text for similarities and differences within the analyses. The researchers considered each other's suggestions and agreed modifications accordingly. This collaborative process forced the justification of each code's inclusion and how it should be used. Once the researchers completed the final template, all themes were sent via email to the participants for feedback on the findings. An audit trail was also maintained demonstrating each stage of analysis, from raw transcripts to the final template of the data.

### 3. Results

#### 3.1 Themes

Four ‘first-level’, nineteen ‘second-level’ and eighty-nine ‘third-level’ themes were identified. Figure 2 displays the final coding template (Version 4). First-level themes are generally outlined below whilst lower level themes of most central relevance to the research questions are explained and described including extracts of interview data to evidence and illustrate the themes.

##### 1.0 Definition of self-neglect

###### 1.1 Properties of self-neglect

- 1.1.1 Undesirable
- 1.1.2 Multidimensional
- 1.1.3 Consequential
- 1.1.4 Noticeable
- 1.1.5 An individual experience
- 1.1.6 Choice
- 1.1.7 Persistence
- 1.1.8 Varies in severity
- 1.1.9 Deteriorates

###### 1.2 A problem

- 1.2.1 Change from usual presentation
- 1.2.2 When service user does not see self-care as a priority
- 1.2.3 Negative impact of self-neglect

###### 1.3 Noticing Self-Neglect

- 1.3.1 Friends and family
- 1.3.2 The service user
- 1.3.3 Staff
- 1.3.4 Use of senses
- 1.3.5 Gender

###### 1.4 Presentation

- 1.4.1 Poor hygiene
- 1.4.2 Lack of function
- 1.4.3 Individual looks unkempt
- 1.4.4 Poor living conditions
- 1.4.5 Not attending to finances
- 1.4.6 Poor diet
- 1.4.7 Social isolation
- 1.4.8 Unmanaged physical health
- 1.4.9 What self-neglect is not

###### 1.5 Determinants of severity of self-neglect

- 1.5.1 Awareness
- 1.5.2 Negative symptoms

###### 1.6 Diagnoses associated with self-neglect

- 1.6.1 Depression
- 1.6.2 Psychosis
- 1.6.3 Schizophrenia
- 1.6.4 Bipolar Disorder
- 1.6.5 Co-morbid substance misuse

- 1.6.6 Anxiety
- 2.0 Intervention
  - 2.1 Approach
    - 2.1.1 Planned intervention
    - 2.1.2 Working as a team using a biopsychosocial approach
    - 2.1.3 Adapting to individual's needs
    - 2.1.4 Consistent intervention
    - 2.1.5 Persistence
    - 2.1.6 Staged intervention
    - 2.1.7 Trial and error
    - 2.1.8 Care
    - 2.1.9 Creativity
    - 2.1.10 Different services for males and females
  - 2.2 What staff do
    - 2.2.1 Talking
    - 2.2.2 Care planning
    - 2.2.3 Service user involvement
    - 2.2.4 Recognise self-neglect
    - 2.2.5 Giving service users choice
    - 2.2.6 Proximity to service user
    - 2.2.7 Staff taking responsibility for daily tasks
    - 2.2.8 Monitoring activities
    - 2.2.9 Prompts
    - 2.2.10 Allocated staff members
    - 2.2.11 Establishing routine
    - 2.2.12 Developing a relationship with service user
    - 2.2.13 Involving tertiary services
    - 2.2.14 Assessment and formulation
  - 2.3 What does not work for self-neglect
    - 2.3.1 Authoritarian approach
    - 2.3.2 No intervention
  - 2.4 Outcome of intervention
    - 2.4.1 Moderate improvement
    - 2.4.2 Self-neglect returns
    - 2.4.3 Unsuccessful intervention
- 3.0 Experience of working with people who self-neglect
  - 3.1 Negative emotions
    - 3.1.1 Difficulty
    - 3.1.2 Discomfort for male staff
    - 3.1.3 Frustration
    - 3.1.4 Draining
  - 3.2 Positive emotions
    - 3.2.1 Exciting
    - 3.2.2 Proud
  - 3.3 Cause of emotion
    - 3.3.1 Value of staff member determined by extent of service user's progress
  - 3.4 Challenges
    - 3.4.1 Compliance
    - 3.4.2 Engagement
    - 3.4.3 Autonomy
    - 3.4.4 Lack of resources
    - 3.4.5 Service user capacity
    - 3.4.6 Staff inconsistency
  - 3.5 Staff attitudes to self-neglect
    - 3.5.1 Self-neglect presentation does not affect staff
    - 3.5.2 Gender

- 3.6 Staff priorities
  - 3.6.1 Physical health prioritises self-neglect
  - 3.6.2 Safety
- 4.0 Perceptions of origins and maintenance of self-neglect
  - 4.1 Origins
    - 4.1.1 Practicality
    - 4.1.2 Medication side effects
    - 4.1.3 Lack of awareness
    - 4.1.4 Consequence of impact of mental health difficulty
    - 4.1.5 Abuse
    - 4.1.6 Organic causes
  - 4.2 Maintaining factors of self-neglect
    - 4.2.1 Resignation
    - 4.2.2 Losing control
    - 4.2.3 Avoidance
  - 4.3 Origin and maintaining factors
    - 4.3.1 Command hallucinations
    - 4.3.2 Negative symptoms

*Figure 2. Final set of themes*

### **3.1.1 Higher order theme one: Definition of self-neglect.**

This ‘first-level’ theme referred to what staff understood to be some of the key properties of self-neglect, how the self-neglect was noticed and by whom. It also included what staff felt self-neglect was not, the factors believed to determine the severity of self-neglect and the diagnoses staff believed were usually associated with self-neglect in their experience.

#### ***3.1.1.1 Properties of self-neglect.***

This ‘second-level’ theme outlined what features respondents believed characterised self-neglect. Whilst participants spoke of what properties they thought were typical of self-neglect, they did acknowledge that each service user’s experience with self-neglect was unique.

##### ***3.1.1.1.1 Choice.***

Four respondents described self-neglect as a choice: a refusal or unwillingness to engage with daily activities.

“...they are unwilling to apply for benefits they are entitled to” (“Tracey”, Support Worker)

“...what would probably come to mind would be more on the personal side of it. Um, probably somebody who is declining or willing to look after themselves” (Tracey, Support Worker)

“...you can have people who are a little bit eccentric, a little bit bizarre and they might want to neglect out of choice.” (“Harvinder”, Psychiatrist)

When staff were asked about their understanding of self-neglect, staff used words like “unwilling” and “declining”, suggesting they believed service users had actively declined or did not want to engage in behaviours that would prevent the development of self-neglect.

However, a number of the participants who described self-neglect as an active choice also described self-neglect as being devoid of choice, but only in the context of a service user being mentally unwell or lacking capacity to make decisions for his or herself.

“...people will not self-neglect out of choice, usually.” (Harvinder, Psychiatrist)

“...it’s definitely not a choice, it’s a core feature of schizophrenia... So, people don’t have a choice.” (“Jim”, Clinical Psychologist)

This indicates that staff understood that self-neglect could develop from different mental states. If an individual is mentally well, has capacity and presents with self-neglect this is usually his or her choice, but if the service user is mentally unwell it may be outside of the service user’s ability to avoid self-neglecting.

#### *3.1.1.1.2 Persistence.*

Staff used the length of time a service user was displaying a behaviour as an indicator of when self-neglect was becoming an issue requiring intervention.

“...if it might be you or me in our jim jams [pyjamas] at the weekend, it might not be a big deal, ‘I’m just going to wear my pyjamas’. If we self-neglected at

the weekend and then it got longer people would be thinking, ‘What’s going on?’” (“Jane,” Support Worker)

Staff described behaviours that they believed were not unusual or problematic unless maintained over time. Behaviours like wearing the same clothes or not washing were only deemed as self-neglect by participants if they were unchanged over several days.

“We might sort of start by noticing, you know, probably the same clothes on for 3 days, 4 days.” (“Martha”, Occupational Therapist)

“...wearing the same clothes day after day” (Tracey, Support Worker)

#### *3.1.1.1.3 Deterioration.*

Staff suggested that self-neglect also progressed by deteriorating over time.

Deterioration in presentation was an indication of the need to intervene.

“If you don’t wash yourself for a prolonged period of time, um, that progresses. To begin with you might be ok, but there will become more and more of a smell and your clothes will become dirtier and dirtier.” (“Tom”, Psychiatrist)

Staff did not describe the underlying cause of the deterioration but spoke about recognising self-neglect due to its progression. It is possible that self-neglect worsens as a result of the negative impact of social isolation or physical and health deterioration, as reflected in other themes below.

#### *3.1.1.2 A problem.*

This ‘second-level’ theme describes when staff believe self-neglect becomes a problem. It also outlines how it becomes a problem for the individual, his or her family and friends and the wider community. Staff took into account the service user’s usual standard of care, which might have been low, but as this was usual for him or her and not negatively impacting the service user this was not seen as self-neglect amongst staff.

#### *3.1.1.2.1 Change from usual presentation.*

Self-neglect appeared to be a problem when the service user significantly deviated from his or her usual standard of care.

“...not attending to things that the person would usually attend to in their day to day life. I suppose that’s all relative... but certainly with a lot of our clients there’s been family members who have noticed changes in their routines and habits” (“Charles”, Community Psychiatric Nurse)

“...hadn’t seen him for a long time...came back and sees a very marked difference, she was obviously, you know, very concerned at that point” (Tom, Psychiatrist)

Staff described this change occurring sometimes between long periods of seeing service users, but this was sometimes noticed within the space of a few days, whilst staff were working alongside service users. This may be connected to the service that the staff member worked in. Tom (Psychiatrist), for example, worked in AOT services as well as rehabilitation services, and spoke of service users’ change in presentation where he had less frequent contact, compared to Charles (Community Psychiatric Nurse) who worked intensely with service users in the rehabilitation setting and would see service users on a near daily basis. How staff describe this change might be influenced by the model of working, nevertheless it does indicate that a change in presentation does occur, whether over a space of days or a longer period of time.

#### *3.1.1.2.2 Negative impact of self-neglect*

Self-neglect was also viewed as concerning for staff due to the risk of harm it causes to the service user.

“...someone neglecting themselves potentially is a safeguarding issue” (Tom, Psychiatrist)

Participants described self-neglect as a risk factor for both physical and mental health

“I think it can impact on their mental health because if you’re not feeling great...we all know if you’re washing and dressing, you’re looking nice, you tend to...feel better, so obviously for their wellbeing” (Tracey, Support Worker)

“Interviewer: If it’s not an issue for them then why would you address it?  
Participant: Sometimes personal safety...infections...illness...ingrown toenails”  
 (“Regina”, Community Psychiatric Nurse)

Self-neglect was also viewed as having a negative impact, from the personal level of the service user to members of society. Staff explained that self-neglect contributed to social isolation, they also identified physical withdrawal from others and difficulty to maintain social networks as potential markers of self-neglect. Self-neglect was also thought to be associated with social isolation due to its effects – for example, poor odour and dishevelled presentation, which meant people formed negative assumptions about the service user and distanced themselves.

“...they (family and partners) might be planning to take them out, but they might not want to take them out.” (Tracey, Support Worker)

“...people move away from them, won’t touch them” (Tom. Psychiatrist)

Thus, staff felt it inappropriate for the service user to leave the rehabilitation unit or home for activities.

### ***3.1.1.3 Noticing self-neglect.***

This ‘second-level’ theme illustrates how self-neglect is noticed and identified.

#### ***3.1.1.3.1 Use of senses.***

Most staff talked about using their senses, for example, sight and smell, to notice self-neglect. When staff were explaining how they noticed self-neglect they were linking the use of senses to the service user’s presentation - many staff members spoke of what they could smell in the service user’s environment or what they saw related to the service user and used this as a way of identifying self-neglect.

“...we see, smell, use all sorts of senses” (Tom, Psychiatrist)

“...it’s not just way you see it’s what you smell” (Tom, Psychiatrist)

“I think you can always see if people haven’t attended to things like personal hygiene” (Regina, Community Psychiatric Nurse)

It appeared to be crucial to staff to notice self-neglect and for it to be identified in order to intervene. The use of senses appeared to be used as a helpful assessment tool in identifying self-neglect in service users. Often, staff spoke of using more than one sense, for example sight and smell, to confirm the presence of self-neglect in individuals.

#### ***3.1.1.4 Presentation.***

This ‘second-level’ theme details respondents’ descriptions of what they noticed in identifying self-neglect and how staff thought self-neglect presented.

##### ***3.1.1.4.1 Poor hygiene.***

All participants regarded poor hygiene as a significant indicator of self-neglect. One staff member used the term “poor hygiene” interchangeably with “self-neglect” and most often gave clinical examples of service users who had a low level of hygiene as examples of self-neglect.

“...you see that they...don’t take a bath, don’t brush their teeth” (Harvinder, Psychiatrist)

“...in regards to personal hygiene, you can smell body odour with some people, especially when it’s been a number of days” (Charles, Community Psychiatric Nurse)

Most staff also offered poor hygiene as the first response to questions related to how self-neglect presented, perhaps indicating that poor hygiene frequently occurs in self-neglect presentations or is a commonly recognised marker of self-neglect amongst staff. Staff spoke of difficulties service users had with maintaining good hygiene

throughout the interviews and mentioned features of poor hygiene in answer to both direct and indirect questions.

#### *3.1.1.4.2 Lack of function.*

Staff also reported lack of function as an indication that someone might be self-neglecting. Staff gave examples of service users not engaging with every day activities such as waking up, showering or eating. This was often explained in the context of service users not having the ability to function, although one participant did speak of a service user declining to do tasks asked of them. This might correspond to the theme regarding choice, where staff considered self-neglect in the context of a service user's state of mind.

“I have noticed people saying they're showering and being quite convinced they've had a shower but really just standing and not using any soap or any action to wash their body, just standing under the shower” (Regina, Community Psychiatric Nurse)

“...somebody just staying in bed, not wanting to get up.” (Tracey, Support Worker)

“...it might be that they're not eating at all...if someone was actually, you know, stopped...had actually, um, lost the motivation to even prepare themselves a meal.” (Martha, Occupational Therapist)

#### *3.1.1.4.3 Individual looks unkempt.*

All participants also spoke about the individual's appearance as a marker for self-neglect. Staff explained that if an individual appeared ungroomed, his or her clothes looked dishevelled or stained or generally unkempt then they may be self-neglecting. If the service user had lost weight this was also mentioned as a visual sign of self-neglect caused by maintaining a poor diet.

“...they might be dishevelled looking, wearing clothes that aren't worn in an appropriate manner: collars sticking up, shirts all creased and this sort of thing” (Charles, Community Psychiatric Nurse)

“...so most noticeable, um... being unkempt in appearance” (Jim, Clinical Psychologist)

#### *3.1.1.4.4 Poor living conditions.*

The service user’s living conditions were also used as a visual measure of self-neglect. Participants reported that untidy homes or unsanitary conditions indicated difficulties with self-neglect.

“I have a number of patients at their home... and their home environment is in a terrible state: untidy, disorganised.” (Tom, Psychiatrist)

“...their parcels and stuff in the house are just lying around, things are just becoming messy. If you have beds, you’ll have beds all over the place” (Harvinder, Psychiatrist)

Tom referred to Diogenes Syndrome to explain hoarding behaviours he had noticed in cases of self-neglect.

“...you can get hoarding; you see, um, – I mean it’s on TV isn’t it? You see people with um... who live in homes that are piled high with newspapers, they never throw things out, they, you know, store faeces and stuff like that. That’s sort of – you can describe that as Diogenes Syndrome which is just a term that describes the behaviour of hoarding.” (Tom, Psychiatrist)

Referring to Diogenes Syndrome to describe an individual’s living environment may indicate that previous conceptualisations of self-neglect used in older adult populations are also applied to service users with severe and enduring psychosis to understand self-neglect. It is possible that the person who referred to Diogenes Syndrome did so due to the nature of their job as a psychiatrist, where a service user’s presentation is sometimes understood based on a diagnosis. Previous references to Diogenes Syndrome may therefore have assisted his understanding of how self-neglect presents.

#### *3.1.1.4.5 What self-neglect is not.*

Participants reflected on examples of service users whose self-neglect improved after intervention to illustrate when a service user was not self-neglecting. The antithesis of how service users presented when they were self-neglecting represented what staff believed was not self-neglect.

“...it is good when you see someone all nicely dressed and their hair done”  
(Tracey, Support Worker)

“...making sure that you’re up in the morning, you’re showered, you’re getting dressed, you’re actually engaging” (Martha, Occupational Therapist)

When staff spoke about behaviours that were not aligned to self-neglect they often referred to examples of service users who had received some level of intervention to address their self-neglect and improved in presentation, rather than service users who had no history of self-neglect. It may be that staff made sense of self-neglect based on the contrast between the presence and then reversal of a maladaptive behaviour or condition.

#### *3.1.1.5 Diagnoses associated with self-neglect.*

This theme outlines what diagnoses staff considered in relation to self-neglect. Schizophrenia, psychosis and depression were the main diagnoses staff thought were associated with self-neglect. Staff also spoke of substance misuse in connection with self-neglect, but only when co-morbid with schizophrenia. In fewer examples, staff also mentioned bipolar disorder and anxiety in relation to self-neglect.

“...the common diagnosis is paranoid schizophrenia” (Tom, Psychiatrist)

“I focus much more on psychosis but obviously the substance issue, which is a significant factor for our population that can lead to significant self-neglect as well, so it’s almost a double whammy in some cases with both” (Jim, Clinical Psychologist)

“Here there tends to be more people having had episodes of psychosis and sort of long-term schizophrenia” (Charles, Community Psychiatric Nurse)

This demonstrated that self-neglect was a concept that featured quite prominently in certain psychiatric conditions, particularly psychosis and depression, however this could also be a direct reflection of the service population staff worked alongside.

### **3.1.2 Higher order theme two: Intervention.**

This ‘first-level’ theme explored staff’s approach to intervening in self-neglect and what they did to address self-neglect. Staff reflected on the interventions used, what interventions do not work and the range of outcomes as a result of interventions for self-neglect.

#### ***3.1.2.1 Approach to self-neglect.***

When reporting incidents in which staff intervened in cases of self-neglect, many participants described their general approach to intervention in addition to the particular skills and techniques used (which is demonstrated in the theme *what staff do*).

##### ***3.1.2.1.1 Working as a team using a biopsychosocial approach.***

All participants were members of a multidisciplinary team and actively functioned as such, with contributions from all disciplines. Staff frequently discussed the need to work together and offer variation in expertise to address self-neglect.

“Everything else in their nursing package is actually a team approach so I think addressing neglect should be a team approach too” (Regina, Community Psychiatric Nurse)

“I think that opportunity to sit down, talk about things, say “What do you think if we try this?” Quite often I’ll have a chat with the psychologist, um, throw some ideas around.” (Martha, Occupational Therapist)

Meetings between staff happened both formally and informally. Staff considered the support of other team members to be helpful in addressing the issues associated with

self-neglect, perhaps indicating that working in isolation is a less successful approach to working with self-neglect. According to participants, the use of a biopsychosocial approach was beneficial in addressing self-neglect as it provided a variety of perspectives and a mix of skills.

“...it’s a multifactorial, multipronged approach, so you need lots of input from – first of all you need to look at the person’s medications, treatment, psychotherapy, so required, social services, family, what other... services are available, charities. So, it requires a lot of things, because this what we call the biopsychosocial approach... you have to approach all three because one in isolation is not going to work.” (Harvinder, Psychiatrist)

The need for biopsychosocial contributions might indicate that a variety of approaches are necessary to successfully address self-neglect, it is possible that the need for a biopsychosocial approach is connected to underlying biological, psychological or social contributing factors. Self-neglect had been described as a broad concept by some staff and the importance of a mix of approaches was useful for addressing different aspects of its presentation.

Tracey spoke of the success of working as a team due to the absence of significant power differences between staff members; everyone’s input was valued equally.

“There’s no ‘who’s the boss? Who’s in charge? Who’s an HCA?’ It’s not that here.” (Tracey, Support Worker)

The lack of power differences may have helped to ensure that all staff members’ voices were heard and acknowledged as a possible idea for intervention.

#### *3.1.2.1.2 Consistent intervention.*

Staff frequently recounted that working together as a team helped to keep the staff’s approach cohesive when working with service users who are self-neglecting.

When elaborating on this point it appeared that staff found it useful for everybody to be working in the same way in relation to each service user.

“...that’s how we really learnt a lot that we had to have things very tight and everybody had to do the same thing... and it does seem to work for us... but we have to have everybody doing the same thing” (Tracey, Support Worker)

One staff member noted that staff even responded to service users’ questions and remarks in a uniform manner, with the aim of helping the service user to learn what to expect from staff and for the service user to understand staff’s expectations, in terms of engaging with his or her treatment plan. Staff explained that the absence of a consistent approach could result in an unsuccessful intervention outcome.

“...it is important that if we’re doing that we’re doing it for a reason, it’s followed. And for the most part it is but there will be times when you’ll find it’s falling apart again...I think it potentially has an impact of confusion (laughter) - confusing our clients” (Martha, Occupational Therapist)

The possibility of an unsuccessful outcome due to a lack of consistency may demonstrate the importance of a cohesive approach amongst the staff team. For staff working in AOT, consistent intervention was also explained as staff having regular face to face contact with service users.

“Most of the people we see once a week, so we would pick things up” (Jim, Clinical Psychologist)

Consistency was thought to be useful in helping the service user to develop and maintain a routine (establishing a routine for service users emerged as a theme for what staff did to address self-neglect).

#### *3.1.2.1.3 Trial and error.*

Staff recognised that due to the individual nature of self-neglect sometimes a trial and error approach was necessary for intervention. Participants gave examples of working with service users who were self-neglecting and often recalled adjusting plans

to meet the needs of the service user, particularly if the current intervention was not helpful for him or her.

“...a particular routine was being followed and for a while it worked and then it stopped working. There were still elements of it that continued to be used but it’s just having to adapt... You’re constantly having to be, um, wanting, um, willing to adapt around people.” (Martha, Occupational Therapist)

Staff described sharing new ideas with each other, or as a team. Continuously adjusting intervention plans may reflect how different interventions may be useful at different stages of the development or recovery of self-neglect.

### ***3.1.2.2 What staff do to address self-neglect.***

This ‘second-level’ theme offers descriptions and explanations of the skills and techniques staff used to address self-neglect. These ranged extensively and included prompts, monitoring activities, assessment, formulation and involving the service user in decision making.

#### ***3.1.2.2.1 Service user involvement.***

Many participants noted that involving the service user in developing an intervention plan was crucial for successful intervention.

“...we’d identify risks or areas where they might need support and they can also self-identify. Sometimes they say, ‘I need a bit of help with this, that, the other’” (Jane, Support Worker)

“...when we’ve...decided what we think might be helpful obviously we involve the patient and try and, you know, motivate them to become part of the process of solving it” (Tom, Psychiatrist)

As displayed above, participants noted that including service users increased the likelihood of engagement with the treatment plan and made service users take ownership of decisions regarding his or her care. When elaborating on the decision to involve service users in developing care plans, it appeared to be linked to giving service

users choice, with the notion that if service users agreed with their plan they were more likely to engage with it.

#### *3.1.2.2.2 Giving service users choice.*

Staff explained that in their services some choices are made on the service user's behalf. During the interviews staff expressed the need to give service users choice about certain decisions, particularly those connected to daily routines, such as what time to wake up and the time of day to wash.

“I think it's just about getting to know that individual again and asking. You can always say, ‘Would you like me to dry your hair?’ Or ‘Would you like me to spend a bit longer with you?’” (Jane, Support worker)

“I go in and say, ‘What time would you like to wake up this morning?’ I don't want to take all of her choices away, um, just to give her some control over it as well.” (Tracey, Support Worker)

These quotes appear to demonstrate that in the process of intervention some control is taken away from service users. Giving service users some choice about tasks that will not affect their wider intervention plan was considered by staff to be useful in increasing autonomy and sense of control, at the same time as improving the behaviours associated with self-neglect.

#### *3.1.2.2.3 Taking responsibility of tasks.*

In instances that staff felt service users were not able to make choices and were practically unable to attend to their self-care needs staff took responsibility of their daily tasks.

“...we've got a few patients where there is a care package aimed at helping them with tidying or making sure they've had something to eat” (Tom, Psychiatrist)

This was described with the aim of service users eventually taking over the tasks his or herself, once staff felt that a service user was able. This demonstrates that staff

saw the need to support service users with tasks related to self-care if the service user did not see it as a priority or was unable to tend to this need.

#### *3.1.2.2.4 Prompts.*

Once staff felt that service users were able to take responsibility for caring to their care needs, they used prompts to support them to complete tasks.

“We’ll also work off the service user as well to, as much as possible, help them house their ability to attend to their basic needs, so obviously prompts and... also lots of reminders” (Jim, Clinical Psychologist)

“...we could be in the bathroom with her in the morning...prompting her to have a shower, prompting her every step of the way, and we’d do that so it doesn’t get any worse.” (Tracey, Support Worker)

This appeared to be an intervention that was implemented in daily face to face interactions with service users. Prompts were explained by staff as a less intense intervention option than staff taking full responsibility for tasks and demonstrates the graded approach to working with service users who are self-neglecting. Again, prompts were thought to be connected to helping service users develop skills and learn to maintain his or her own routines and avoid self-neglect reoccurring.

#### *3.1.2.2.5 Developing a relationship with service user.*

Developing a relationship with service users was described as important to most staff in successfully addressing self-neglect.

“I think the key to a lot of what we do is the way we relate to people and the relationships we build.” (Martha, Occupational Therapist)

Self-neglect was perceived as a sensitive topic for staff to discuss with service users. Participants represented in this theme concluded that issues surrounding self-neglect were better received by service users if communicated by staff members who had built up a relationship with the service user.

“Conversations are more palatable, and they put up with you a bit more...so, your suggestions are probably more sugar coated in a way, and you’re finding it’s probably easier to say yes to things.” (Regina, Community Psychiatric Nurse)

Building a relationship was assisted by allocating staff members to specific service users.

“...each patient has a named nurse and a co-worker as well so there’s two named nurses, so they mainly do the care plans with the service user” (Tracey, Support Worker)

Having assigned staff members was thought by respondents to be beneficial for staff and the service user. It allowed development of a relationship between service user and staff member, increased knowledge of the service user and his or her behaviours, attitudes, likes and dislikes, and increased the trust between service user and staff member. This made it easier for the staff member to address sensitive topics with the service user and sometimes challenge current behaviours that were contributing to self-neglect. It also allowed for an even spread of workload across the workforce.

### ***3.1.2.3 What does not work for self-neglect.***

This ‘second level’ theme outlines what staff believed was ineffective when intervening with self-neglect.

#### ***3.1.2.3.1 No intervention.***

Staff acknowledged that without intervention self-neglect will worsen. One participant framed this belief within a wider context, suggesting that everything, including self-neglect, naturally deteriorates into a state of chaos if energy is not used to counteract this.

“That’s a feature of thermodynamics, you don’t have to expend energy to maintain order, it’s the natural order of the universe to become more chaotic. Um, so entropy, disorganisation, always kind of takes over unless you do something.” (Tom, Psychiatrist)

This quote illustrates the belief that it is not possible for self-neglect to resolve of its own accord, a belief that appeared to be supported by other participants.

“Interviewer: And what interventions do you think haven’t worked so well?  
Participant: Not doing anything is probably one of them. You should do something, I think”. (Jane, Support Worker)

Staff did not believe that unassisted recovery would be sufficient for self-neglect to ameliorate. It was considered by staff that self-neglect will not naturally resolve and therefore required some level of intervention.

#### **3.1.2.4 Outcome of intervention.**

This ‘second-level’ theme represented staff’s beliefs about the outcomes of interventions for self-neglect.

##### *3.1.2.4.1 Moderate improvement.*

Staff reflected on the need to manage their expectations about what improvements will be seen post-intervention.

“...we have another person who engaged, well in a very limited way, during his time here. So, I suppose it’s being realistic in some instances and not expecting that, you know, life is going to be completely transformed, you’re going to leave here completely independent and continue on their journey without any further need for support” (Martha, Occupational Therapist)

Moderate changes were deemed to be a success for staff addressing self-neglect, perhaps due to the severe and enduring nature of the mental health illnesses that service users were living with, which limited the extent of change staff usually observed.

##### *3.1.2.4.2 Self-neglect returns.*

In instances where self-neglect did improve staff described this improvement as temporary.

“...give people scope to try and support them to be as independent as they can, but often it becomes apparent that there’s a limit to how much you’re going to

do and maybe fall back into some of the patterns of self-neglect” (Jim, Psychologist)

From the respondents’ experience of self-neglect in this group of service users, it appeared that self-neglect almost occurred cyclically and therefore would return despite intervention.

When exploring the reasons for this, one staff member hypothesised that the return of issues with self-neglect was related to not treating the underlying cause.

“...these things take time, they’re difficult, because, um, whether it’s hard to change the causes, even if you do kind of get in and make a change it often does kind of gravitate back to a bad situation.” (Tom, Psychiatrist)

These accounts from staff may illustrate that although the aim of intervention is recovery, there was some knowledge that in terms of self-neglect if recovery was achieved this may only be a temporary relief. Some aspects of self-neglect may be targeted and addressed, however if the underlying, contributing factors were not also attended to then it is unlikely improvements will be seen long term.

### **3.1.3 Higher order theme three: Experience of working with people who self-neglect.**

This ‘first-level’ theme explored participants’ negative and positive emotions and what factors contributed to these emotions. It also includes the challenges staff thought they faced whilst working with service users who are self-neglecting, staff’s attitudes to self-neglect and what staff prioritised in cases of self-neglect.

#### ***3.1.3.1 Negative emotions.***

Staff mainly expressed negative emotions when talking about working with service users who self-neglect. Every participant spoke of the difficulty of working with this group of service users.

“I find it quite hard to be honest. I do find it hard and, um, it’s upsetting seeing someone whose basic needs are not being met” (Jim, Clinical Psychologist)

Participants identified the difficulty of working with service users who self-neglect when reflecting on cases of self-neglect rather than in response to the question directly related to the experience of working with self-neglect. This might demonstrate the effect the staff members’ emotional experiences have on a number of aspects of working with service users who self-neglect, for example what shapes their understanding and how they address self-neglect. It may also represent the profound effect of service users who self-neglect on the staff member’s wellbeing. Participants frequently spoke about the work associated with self-neglect having an impact on their emotional wellbeing.

“I think it can be quite draining for staff... I think the fact that it’s just so personal, and that creates a certain...whether people say it or not, I think it creates a certain amount of anxiety because you just don’t feel comfortable” (Charles, Community Psychiatric Nurse)

On exploration, this seemed to be associated with the level of intimacy and close relationship when working with this client group, which perhaps made it difficult to separate the emotions of building and maintaining a relationship with the service user from the emotional impact of the professional role. Theme *developing a relationship* spoke of the importance of building a relationship, but the emotional toll of working with this group of service users may be a consequence of this.

### **3.1.3.2 Cause of emotion.**

Staff rarely spoke of positive emotions over the course of the interviews. If staff identified positive emotions when working in cases of self-neglect this was associated with noticing improvement in service users. Several staff members spoke of achievement and pride when individuals were progressing in regard to their self-neglect.

“I’m thinking of another chap actually he’s moved on, where he was before he came here and where he was in terms of his progress when he left here, it was a very proud moment for me actually, a proud moment for us all.” (Martha, Occupational Therapist)

“I get quite proud of myself when I’ve actually achieved it” (Tracey, Support Worker)

“Frustrated, but then made up when they get there, the level they’re happy with” (Jane, Support Worker)

On the contrary if a service user appeared to not be doing well with their treatment then this had a negative impact on the staff member.

“...it does make me feel like I haven’t done my job very well and it is hard to think ‘Well it’s not the end of the world, ok she didn’t have a wash today, or wash her hair, or brush her teeth’” (Tracey, Support Worker)

It appeared that participants directly associated their value as a staff member by how well the service user was doing - this determined their emotional experience when working with this clinical group.

### **3.1.3.3 Challenges.**

Staff reported many challenges of working with service users who self-neglect. These included engaging service users in the treatment process and determining the degree of autonomy afforded to service users. Staff also found the lack of resources to support with clinical practice challenging, as explained below. As described in earlier themes, giving choice to the service user was stated as one of the tools used as an intervention for self-neglect. However, deciding how much choice should be afforded to service users was posed as a difficulty for staff.

#### ***3.1.3.3.1 Engagement.***

Engaging service users in interacting with their care plans appeared to be challenging for participants, despite encouraging service users to collaborate with the process of its development

“...patients can be difficult to engage” (Martha, Occupational Therapist)

This appeared to be connected to the wider service user group. When participants were talking about the difficulties with engagement, this was in the context of self-neglect presenting in service users diagnosed with schizophrenia and living with negative symptoms. Engagement appeared to be a facilitator for improvement in self-neglect but a difficult challenge for staff.

#### *3.1.3.3.2 Autonomy.*

Staff explained that they found it difficult to balance dependence on staff at the same time as meeting service users’ needs and helping the service user to develop his or her own skills to manage self-care.

“...you would try to then ameliorate the impact of the self-neglect, um, and this is where it gets really hard because, um, to what extent – you know, you’re always kind of worried that you’re going to seem paternalistic about, you know, taking over someone’s life and trying to get them cleaned up or their place tidier” (Tom, Psychiatrist)

There appeared to be some tension amongst staff about self-directed recovery compared to clinician directed recovery and which approach was most likely to ensure a successful outcome.

“...we are trying to stop them being too dependent on us for doing things as well, so that’s another dynamic” (Tom, Psychiatrist)

Staff also spoke of the difficulty of working in the service user’s best interest - determining when self-neglect was a problem that required intervention or a lifestyle choice. Giving service users the option to make (what staff believed were) unwise decisions appeared to be a struggle for staff.

“...they go and have snacks in their room and they have their own cupboards. There’s lots of pop, there’s a lot of takeaways, and you can keep asking and you can keep guiding but you don’t necessarily get through, because that’s their choice” (Jane, Support Worker)

When speaking about the difficulties of service user autonomy this was tied into staff's value of supporting service users and what that meant, for example whether they were doing their job correctly by allowing service users to make decisions that they thought might be unwise, and whether they were meeting the service user's health needs if they did not intervene. Using a trial and error approach (as described in Theme 2.1.7) might have been helpful in managing this tension within staff. If staff felt that a paternalistic or autonomous approach was ineffective they were able to make changes according to the individual's needs.

#### *3.1.3.3.3 Lack of resources.*

Three participants found the lack of evidence base for appropriate interventions for self-neglect challenging.

“...if there was an evidence based, very effective intervention that would address that, that would be very helpful” (Tom, Psychiatrist)

“I'm sure there's some interesting literature but clinically...I don't think that's what's widely recognised.” (Jim, Clinical Psychologist)

The respondents who mentioned the limitations of not having an evidence base were medical doctors and clinical psychologists. It is likely that working based on evidence could be particularly important for these participants with their professions being rooted in a scientist-practitioner model. To some extent, limited evidence for how to intervene with self-neglect might be helpful for these participants, despite its challenges— if service users are not progressing how they hoped, they may be able to rationalise these feelings by acknowledging that the lack of evidence into self-neglect reflects its complex nature.

#### **3.1.3.4 Staff attitudes to self-neglect.**

This ‘second-level’ theme reflected the beliefs staff had about people who self-neglect and the attitudes staff had when working with people who self-neglect.

##### *3.1.3.4.1 Self-neglect presentation does not affect staff.*

Although staff spoke frequently of the challenges and emotional impact of working with service users who were self-neglecting, interestingly, when asked directly some participants described working with service users as having no effect on their emotions.

“I mean for staff if we’ve got to go out with somebody who doesn’t want to attend to their personal care it’s not really an issue for us because that’s their choice, it’s really difficult for families to see that” (Tracey, Support Worker)

It may be that staff are not explicitly aware of the impact of working with service users who self-neglect or compared to other difficulties within this group (e.g., positive symptoms, challenging risk behaviour) self-neglect has less of an emotional impact.

##### *3.1.3.4.2 Gender.*

Some staff spoke about the difference the gender of either the service user or staff member had on the attitude towards self-neglect. Staff spoke of there being a more relaxed attitude towards poor hygiene and grooming for men, which made it difficult for individual staff members to intervene with male service users.

“The pressure seems to be on the women, you must adhere to a, ‘You have your bath, you have your hair washed, you smell nice, you look nice and dressed.’ We spend hours in the room with women, ladies, and then the gents less so. No one wants to approach that and that’s really sad and that’s very frustrating as well.” (Jane, Support Worker)

Staff attitudes also appeared to differ according to the gender of the staff member. Respondents explained that female staff members seemed more gungy about managing self-neglect in comparison to male staff members.

“I don’t know if the male staff find it a little bit – whereas the females, we sort of get on with it” (Tracey, Support Worker)

A few participants also noted that male staff tended to have a more relaxed approach towards intervening for self-neglect. This was attributed to male staff feeling a greater level of discomfort in addressing this issue with service users.

“I do notice some patients that are being nursed by males not always supported in the same way. Some female staff will be more hands on with patients and male staff not so – it doesn’t feel as though they’re as comfortable, kind of, getting in and physically helping them, physically supporting them” (Regina, Community Psychiatric Nurse)

This was suggested more as a query than a statement by the members of staff who spoke of this observation in their team. Issues related to gender were described by staff members who worked more practically with service users, for example community psychiatric nurses and support workers. It is possible that gender differences related to self-neglect are noticed more often in instances where staff have daily contact with service users and might be required to support in a more physical manner.

#### **3.1.4 Higher order theme four: Perceptions of origins and maintenance of self-neglect.**

This ‘first-level’ theme explored staff members’ beliefs about what factors they thought were causing self-neglect, which factors were maintaining self-neglect in service users and which factors were both an underlying cause of self-neglect and also contributed to its maintenance.

#### ***3.1.4.1 Origins.***

When staff described what factors they thought were associated with self-neglect they spoke of what they thought to be the underlying causes. These factors included lack of awareness and self-neglect developing as a consequence of the impact of the individual's mental health difficulty.

##### ***3.1.4.1.1 Lack of awareness.***

The service users' lack of awareness of the extent of their self-neglect or that self-neglect was a problem at all was proposed by staff as an underlying cause of self-neglect.

“...engagement can be quite – really challenging, because of lack of awareness, or in the past we'd say lack of insight, so lack of awareness around the nature of their difficulties and what their needs are” (Jim, Clinical Psychologist)

Staff spoke about participants who present with psychotic symptoms when referring to this theme. This could indicate that this originating factor is something specific to conditions where the individual experiences some degree of psychosis.

##### ***3.1.4.1.2 Consequence of the impact the mental health difficulty.***

Self-neglect as a consequence of a mental health difficulty was believed by all staff to be at least a contributing factor to self-neglect in service users with severe and enduring mental illness. Most staff referred to self-neglect as a by-product of the service users' primary mental health difficulty, particularly in relation to schizophrenia and depression.

For schizophrenia, staff suggested that being distracted by positive symptoms meant engagement in daily activities that might prevent self-neglect was not prioritised.

“Here, we do deal tend to deal more with negative symptoms, but we've also got people who really struggle with persecutory voices and that will impact on their ability to look after themselves because quite often they're very distracted and

very, at times, distressed by what they're experiencing" (Martha, Occupational Therapist)

Some participants represented in this theme questioned whether self-neglect was a consequence of depression. Respondents proposed that the negative thoughts experienced with depression made it difficult for service users to care for themselves.

"Is it due to negative cognitions that come from depression, so they're then looking at not feeling worth looking after themselves?" (Tom, Psychiatrist)

These examples demonstrated that staff members' ideas of the causes of self-neglect were related to the difficulties of living with a mental health problem and how this might have a negative effect on the ability to prevent self-neglecting behaviours.

#### ***3.1.4.2 Maintaining factors of self-neglect.***

This theme demonstrates what factors, such as avoidance of addressing difficulties, staff believed contributed to the maintenance of self-neglect.

##### ***3.1.4.2.1 Avoidance.***

The difficulty of confronting issues related or unrelated to their mental health was suggested as a maintaining factor of self-neglect.

"People who suffer from anxiety... probably they're going to stay in bed anyway because they don't have to come down and face anything. So, it will lead to that cycle then" (Tracey, Support Worker)

Participants suggested that some behaviours associated with self-neglecting helped service users avoid addressing their mental, physical and social difficulties, consequently as the difficulties continued so did self-neglect.

#### ***3.1.4.3 Origin and maintaining factors.***

This 'second-level' theme describes factors staff believed was both an underlying cause and maintaining factor of self-neglect. This included command hallucinations and lacking motivation.

#### *3.1.4.3.1 Command hallucinations.*

Staff suggested that service users' focus on listening to command hallucinations was both an originating and maintaining factor in cases of self-neglect.

"In psychosis... if someone's hearing voices and they're telling him not to listen, not to have a wash then that's really difficult because whatever the voices are saying is paramount for that person" (Tracey, Support Worker)

Staff suggested that obeying voices was not only distracting, but that command hallucinations may prevent service users from engaging in behaviours involving self-care. By commanding the service user not to partake in these activities and/or predicting negative consequences if the individual engages in these activities, thus leading to self-neglect. Focus on symptoms was also proposed in instances of substance misuse.

"If you have someone who's dependent on substances the substance becomes their focus. That's the sort of salience in terms of their dependence, so they neglect other aspects of their life... if they're maybe intoxicated all of the time they're not focusing on other things like their diet, they're not looking after themselves" (Tom, Psychiatrist)

#### *3.1.4.3.2 Lacking motivation.*

Participants also described the effects of negative symptoms on the development and maintenance of self-neglect.

"...the patient lacks motivation, they're apathetic, they lack the drive to do things" (Tom, Psychiatrist)

One staff member suggested that the symptoms associated with negative symptoms, for example apathy and lack of motivation, caused problems with maintaining self-care and developed into significant issues with self-neglect. Lack of motivation was highlighted by a number of participants as a significant factor in cases of self-neglect.

"The other one is low motivation; apathy, that's got to be the hardest actually in some ways." (Martha, Occupational Therapist)

“...lack of motivation to engage with the team and lack of motivation to actually, you know, engage with their treatment plan” (Jim, Psychologist)

This appeared to be a factor that both caused self-neglect but also continued and therefore brought about a continuation in self-neglect.

These quotes illustrate that staff believed self-neglect was an experience that might not occur if mental health difficulties were absent. Self-neglect as a consequence of a mental health difficulty was believed by all staff to be at least a contributing factor to self-neglect in service users with severe and enduring mental illness.

## **4. Discussion**

### **4.1 Main findings**

This study examined clinical staff's understanding of self-neglect and its associated factors amongst service users with severe and enduring psychosis. Template Analysis was used to analyse interviews with clinical staff who work daily with people with a psychotic diagnosis who also display self-neglect (as it is currently understood). The findings indicate that self-neglect is a complex and broad problem in cases of severe and enduring psychosis, comprising of harmful behaviours and/or unhealthy social or environmental conditions that have a negative impact on the individual if persistent. This study illustrated the individual nature of self-neglect and suggests that self-neglect needs to be understood within the context of personal and environmental living circumstances, culture, relationships and health needs.

Pertaining to the first research question, which centred on staff members' understanding of self-neglect, it appeared that despite the lack of a formal definition of self-neglect all participants had ideas about what they believed self-neglect to be. All participants described self-neglect, if not directly, at least in the context of it being a problem that requires intervention for improvement. This was marked by concern from staff and evidenced by the negative impact self-neglect had on the service user and those around him or her. Although it was acknowledged that self-neglect presents and is experienced differently with each case, staff reported properties they thought helped to identify self-neglect in service users, including its presentation being maintained over time and deterioration.

Participants also believed that unkempt appearance of the service user and his or her environment was a sign of difficulties with self-neglect. Other factors included in

this theme described poor living conditions, the individual's unkempt appearance and lack of function. The antithesis of the presentation of self-neglect (i.e., engaging with daily activities and grooming behaviours) was the signal for staff that a service user was no longer self-neglecting.

When conceptualisations of self-neglect from this data are compared with existing literature (Gunstone, 2003; Lamkin et al., 2017; Pavlou & Lachs, 2008), there are similarities and differences. Pavlou and Lachs (2008), Gunstone (2003) and Lamkin et al. (2017) reported that poor hygiene was a feature of self-neglect, which aligned with the findings of this study. Staff considered poor hygiene as significant to the presentation of self-neglect, with all participants offering examples of this. Participants also believed that unkempt appearance of the service user and his or her environment was a sign of difficulties with self-neglect which replicated findings of Gunstone (2003) and Pavlou and Lachs (2008). Poor management of finances and social isolation were also included as themes of presentation of self-neglect in this study and is consistent with Gunstone (2003).

Interestingly, Gunstone (2003) included "a failure to protect themselves from sexual abuse, financial abuse and abuse of their goods and properties by others" (Gunstone, 2003, p. 291) as a feature of self-neglect. Childhood neglect was described as an originating cause of self-neglect, but exploitation was not mentioned as a presenting feature of self-neglect by any participant interviewed for this study. For the service users referred to in this study it may be that there are robust safeguarding structures in place and frequent contact with the service user that may reduce the risk of abuse or engaging in behaviours that significantly affect the individual's safety.

Failure to comply with treatment was also included in Lamkin et al. (2017), Gunstone (2003) and Pavlou and Lach (2008)'s definitions of self-neglect; however, this was not mentioned in any great detail in this study. It is possible that the culture of the services or the later stage of recovery of the service users means treatment noncompliance is seen less often by staff.

Self-neglect appeared to be seen by staff most often in cases of schizophrenia and depression, although it is important to note that this could be related to the service population (severe and enduring mental illness) where a high percentage of the service users were diagnosed with schizophrenia. This substantiates Lamkin et al.'s (2017) suggestions that severe self-neglect is prevalent in people with schizophrenia and mirrors findings in the older adult population connecting depression with self-neglect. Snowden, Shah, and Halliday (2007) also concluded that living in squalor ("...neglect of hygiene and of attention to cleanliness of environment"; Snowden, Shah, & Halliday, 2007, p. 37), as observed by participants in this study, is frequently accompanied by a diagnosis of schizophrenia. It is possible that there are unique markers for self-neglect in people with schizophrenia. Pavlou and Lachs (2008) and Lamkin et al. (2017) highlighted the risk of self-neglect occurring in instances of schizophrenia when the individual lacks awareness. This was also reported by staff in this study as a cause of self-neglect – individuals being unaware that they are not maintaining self-care behaviours. Lack of insight may be more relevant to self-neglect in cases of schizophrenia and may need to be considered when assessing the risk of self-neglect in individuals.

Overall, staff defined self-neglect in individuals with severe and enduring psychosis as a persistent problem often characterised by, but not limited to, unkempt

appearance, a failure to attend to hygiene, and poor living conditions. These factors are considered in the context of the negative impact on the individual, usual lifestyle choices and the individual's mental health. Lack of awareness might be a unique cause of self-neglect in service users who live with severe and enduring psychosis.

Considering what staff believed defined self-neglect and its presentation, addressing self-neglect included working from a team approach, using a variety of skills based on team members' expertise, including prompts, building a relationship with the service user and including the service user in the process of intervention, with the aim of improving engagement with the process and giving the service user choice. Research suggests that including service users with schizophrenia in the rehabilitation process allows management of symptoms and understanding of the details of their difficulties (Winton & Robinson, 2005). Staff also worked to help the service user to take responsibility for his or her own care and develop the skills necessary to do this. The emphasis on service users taking responsibility may be underpinned by the "recovery culture" of the clinical teams. According to the recovery model, if an individual reaches a level of self-sufficiency this reflects a progression and move towards a less dependent lifestyle (Winton & Robinson, 2005). Overall, current methods were considered by staff to be useful in addressing self-neglect as staff reported moderate improvements in service users. It should be highlighted however that some staff recognised that despite moderate improvements, often self-neglect does reoccur.

Regarding the second research question, exploring the factors associated with self-neglect in severe and enduring psychosis, participants offered suggestions of what they thought caused self-neglect and what factors maintained it. Respondents mainly concluded that the impact of the mental health problem, in terms of the direct effects of

the symptoms and the associated distress, meant that self-care was not a priority for service users. It is possible that the adverse symptoms of a mental health difficulty directly leads to self-neglect, supporting Lauder (1999) and Radebaugh et al. (1987)'s findings. Alternatively, it has been suggested that the psychological conditions associated with the mental health conditions such as hopelessness, apathy, lack of power and meaning and agency are more significant than symptoms in the development self-neglect (Deegan, 1993; Strauss 1994).

Participants also suggested that symptoms associated with negative symptoms, such as lack of motivation and apathy, in schizophrenia contributed to the presentation of self-neglect. Some factors were thought to contribute to the cause and maintenance of self-neglect, for example lacking motivation or routine. Suttajit et al. (2015) reports a similar finding; they suggested that within schizophrenia negative symptoms is a main predictor of impairment of self-care. Furthermore, Rocca, Montemagni, Zappia, Pitera, Sigaudo and Bogetto (2015) specifically identified avolition (lack of motivation) as the strongest predictor of self-care functioning within negative symptoms. They found self-care decreased as levels of negative symptoms increased. Currently, there is no clear evidence to indicate that a particular medical diagnosis or pattern of medical diagnoses causes self-neglect or whether self-neglect exacerbates the symptoms of mental health diagnoses (Dong, Simon & Mendes de Leon, 2009; Lauder, 2001). This may be due to the lack of formal definition of self-neglect to base causal research upon.

Additional information about the challenges of working with self-neglect emerged from the data. There appeared to be a tension between giving service users autonomy over their own recovery and the way staff felt that they had to intervene with self-neglect: taking over tasks, monitoring their activities and being directive. Published

data indicates that recovery must be self-directed, with the person's own goals for their lives guiding interventions (Davidson & Roe, 2007; Deegan, 2002). The emphasis on self-direction aligns with broader theories specifying the importance of autonomy for behaviour change (Rollnick & Miller, 1995). However, a potential limitation of this approach to recovery is that evidence may not account for individuals who may have some difficulty in determining their recovery goals, particularly in people with schizophrenia who might lack insight into their problems and might find it difficult to develop ideas to change their circumstances. These difficulties might impact a person's motivation or ability to self-direct (Hamm, Buck, Leonhardt, Luther, & Lysaker, 2018). It is also possible that clinicians want to promote self-direction but may be unsure how to do so (Hamm et al., 2018), so may resort to clinician-directed interventions to facilitate recovery, a conflict reflected in the interviews with participants of this study. The balance between self-directed and clinician-directed recovery appeared to be managed well by clinicians at the stage of care planning, where service users' voices were acknowledged and incorporated into goals, but more difficult to implement in day to day working.

In terms of the emotional experience of working with self-neglect, staff mainly described negative emotions, such as "difficult" and "draining" when talking about working with cases of self-neglect, indicating that working with self-neglect can be a negative experience. When participants mentioned positive emotions this was in the context of a successful intervention, indicating that participants' value as staff members was directly linked to the outcome of an intervention with service users. The emotional impact of working with individuals with self-neglect might highlight the need for structures to prevent burnout when working with this group. Participants spoke of

sharing responsibilities to manage the risk of burnout, a strategy supported by Harry Lamb (1978). He suggested that when working with service users on a long-term basis, relationships between staff and service users should be spread across the team to reduce dependency on individual staff members (Lamb, 1978). It has also been recommended that staff take breaks from directly working with service users to reduce the risk of burnout (Pines & Maslach, 1978). Staff also spoke of the feelings of failure when self-neglect did not ameliorate. The tendency to appraise work performance in a negative manner has been presented as a long-term job stressor that leads to staff burnout (Maslach & Jackson, 1981; Pines & Maslach, 1978). It is possible that the feelings of failure stem from difficulty in recognising the range of outcomes for recovery (Lamb, 1979). Clinical supervision may also manage and reflect on the emotional and professional demands of working with this group. One-to-one clinical supervision has been described as being useful in improving self-awareness and helpful in informing the staff member's needs (Bryant, 2010). Melchior, Bours, Schmitz and Wittich (1997) suggested that peer supervision may be useful in managing the emotional toll of working with difficult clinical groups (Melchior, Bours, Schmitz, & Wittich, 1997). This support can be emotional, such as listening sympathetically, or practical, such as offering suggestions or helping with a work task (Fenlason & Beehr, 1994). High levels of support have been associated with low levels of burnout (Kilfedder, Power & Wells, 2001) and might be a useful solution for the emotional impact of working with self-neglect in severe and enduring mental illness.

Gender also appeared to factor in the attitude towards self-neglect. Self-neglect was perceived to be less of a problem if the service user was male, and male staff were perceived to be less likely to intervene. This difference could be attributed to culture,

both of the service and on a wider societal level (i.e., females are more likely to intervene in regard to issues related to self-care). There is also evidence to suggest that a staff member's gender is noteworthy in assessing the risks associated with health. Research has demonstrated that females perceive risks to a greater extent than male staff members (Kristiansen, 1990). It is possible that female staff members perceive self-neglect as more of a risk than male staff and therefore tend to intervene at an earlier stage.

#### **4.2 Evaluation of Themes**

The first level code "Definition of self-neglect" helped to answer both research questions regarding how self-neglect presents in severe and enduring psychosis and its associated factors. Arguably, this theme related to the research questions most directly, with clear examples of how self-neglect presented to staff members interviewed and what factors they thought were associated with self-neglect. Staff spoke about these factors in much depth throughout the interviews and the codes generated from this theme were in line with previous research findings. It could be suggested that this theme also connected most readily with the other three themes. Staff members' understanding of how self-neglect presents and its associated factors may have influenced how they addressed self-neglect ("Intervention"), their experience of working with self-neglect ("Experience of working with people who self-neglect") and their perceptions of what caused and maintained self-neglect in severe and enduring psychosis ("Perceptions of origins and maintenance of self-neglect").

The first level codes "Intervention" and "Experience of working with people who self-neglect" were less relevant to the research questions compared to the other first level codes, however both themes are clinically useful in illustrating how staff address

self-neglect and the impact it has on clinical practice. “Intervention” might not have required three levels of coding however it appeared significant through analysis to separate the approach to managing self-neglect from what practical skills staff used to address self-neglect.

The first level code “Perceptions of origins and maintenance of self-neglect” helped to directly answer the research question about the associated factors for self-neglect in terms of its aetiology and maintaining factors, however this was less supported in terms of the amount of data emerging from participants’ interviews compared to other themes. This could be explored further in future research.

#### **4.3 Limitations**

This study offers insights into self-neglect in individuals with severe and enduring psychosis, although there are some methodological limitations. The use of Template Analysis allows for a streamlined view of varied perspectives, which captures the significant answers to research questions. The coding process does help to identify themes across the data set however the extraction of quotes might result in some loss of holistic understanding of each individual’s account. The small sample size of this study, recruited from a self-selected sample of staff working for the same service, limits generalisations of findings to all cases of self-neglect in service users with psychosis. As such, future research would benefit from recruiting from a wider, more varied population to address this limitation.

#### **4.4 Research Implications**

The present understanding of self-neglect has emerged from staff members, potentially excluding the perspectives of other invested groups who may also have supporting or contrasting views of self-neglect. Future studies could explore feelings of

service users or service users' family or friends for a broader perspective, including lived experience of self-neglect. This research paper was mainly focused on self-neglect once it had developed and required intervention, it may be that exploring factors that protect against self-neglect may be helpful in prevention and promoting recovery. This study aimed to add to current information of self-neglect in psychiatric populations, specifically in individuals with severe and enduring psychosis. Although this research provides further information of how self-neglect is conceptualised for people with mental health conditions, a standardised definition or theory-based model that can be applied to all cases of psychosis would be useful to help clinicians develop interventions to successfully address self-neglect.

#### **4.5 Clinical Implications**

Participants in this study were cohesive in describing what they recognised as self-neglect in people with severe and enduring psychosis. A formal assessment tool as a supplement to clinical observation might be useful in early identification self-neglect and its risks and subsequent intervention.

Staff may also benefit from training on current legislation and policy surrounding the management of self-neglect, particularly considering its increasing relevance to clinical practice. Staff spoke of a number of challenges when working with service users with severe and enduring psychosis who are self-neglecting. Staff may require additional support, for example specific supervision for this group, optimum shift patterns, or joint working to alleviate the emotional impact of working alongside this group of service users.

## **4.6 Conclusions**

In conclusion, this research paper expands the current knowledge of how self-neglect presents and its associated factors when applied to individuals with severe and enduring psychosis. It appears that to some extent self-neglect in cases of severe and enduring psychosis does mirror previous understanding in terms of its presentation, such as inattention to hygiene and poor living conditions. However, there are some additional factors associated with self-neglect in people with severe and enduring psychosis, such as negative symptoms and lack of awareness, which might complicate the presentation and intervention of self-neglect. Participants identified successful approaches, such as team working, and techniques, such as prompts, that were used to address self-neglect. Individuals were able to identify and discuss the challenges of working with this population, such as the degree of autonomy afforded to service users and the difficult emotions that emerge whilst working with service users who self-neglect.

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## **Public Dissemination Document**

This document offers an overview an overview of the thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (ClinPsyD) at the University of Birmingham. This research consists of two papers. The first paper is a review of the existing academic literature examining psychosocial factors related to negative symptoms (most often seen in cases of schizophrenia). The second paper explores mental health staff's understanding of self-neglect in people living with severe and enduring psychosis.

### **1. Literature review: What psychosocial factors are associated with negative symptoms? A systematic review of the literature**

This review aimed to combine and assess all previous literature that has investigated psychosocial factors associated with negative symptoms in schizophrenia and related disorders. “Psychosocial factors” was defined as any environmental factor (such as relationships, self-esteem or living environment) not related to biological or genetic factors.

Negative symptoms are a group of symptoms, including lack of motivation, flattened emotion and social withdrawal (Kirkpatrick, Fenton, Carpenter & Marder, 2006) that are important to research as currently little is known about the best way to treat these symptoms (Remington et al., 2016). Determining the underlying causes of negative symptoms may be useful in developing knowledge of effective treatment. There is evidence to support associations between biological factors such as enlarged ventricles (Cuesta et al., 2017) and genetic factors such as heritability (Edwards et al.,

2016) and negative symptoms. There is comparably less evidence outlining what psychosocial factors are associated with negative symptoms. This study therefore aimed to investigate what psychosocial factors are related to negative symptoms.

Previous research papers which have examined the relationship between negative symptoms and psychosocial factors were searched electronically and then assessed to determine how well the research has been executed and reported. The findings of each study were combined and examined collectively.

A number of psychosocial factors were found to be associated with negative symptoms. There was a theme of social behaviours, for example, social withdrawal, maintaining friendships and involvement in activities, being associated with negative symptoms, particularly before an individual had received a diagnosis and once an individual's negative symptoms were severe and enduring. Typically, when negative symptom levels increased social behaviours tended to decrease. Some social behaviours are considered as negative symptoms so further research may be necessary to determine what psychosocial factors outside of social behaviours are related to negative symptoms. This will assist clinicians in identifying psychosocial factors that might related to negative symptoms and put treatment in place for prevention and decrease of symptoms.

## **2. Empirical paper: How do mental health staff make sense of self-neglect in people with severe and enduring psychosis?**

Self-neglect is a concept that is increasing in recognition due to its negative impact on the individual and those around them (Department of Health and Social Care,

2014). Most research has focused on self-neglect in older adults, despite it being seen often in people with mental health problems, regardless of age (Lamkin, Nguyen, Coverdale, & Gordon, 2017). Recent research published by Lamkin et al. (2017) claimed that self-neglect is particularly severe in people with schizophrenia. This research aimed to build on Lamkin et al.'s (2017) findings and develop understanding of self-neglect in people with severe and enduring psychosis.

Interviews were conducted with eight members of clinical mental health staff who came across self-neglect (as it is currently understood) in people who used the services they worked in. Information from their interviews were then transcribed and extracts from the interviews that helped to further the understanding of self-neglect in severe and enduring psychosis were grouped together and assessed to determine themes.

Following assessment, four themes emerged from the data: Definition of Self-Neglect, Intervention, Experience of Working with Self-neglect and Perceptions of Origins and Maintenance of Self-Neglect.

Staff's descriptions of self-neglect in cases of severe and enduring psychosis were found to be similar to previous research (Gunstone, 2003; Lamkin et al. (2017); Pavlou and Lachs, 2008). Staff described behaviour such as poor hygiene and being unkempt as typical of individuals with severe and enduring psychosis who self-neglect. Sometimes in cases of schizophrenia people can lose insight into their problems, this appeared to be a factor that staff recognised as unique to people who used their services. Participants in this study also shared information regarding the challenges of working with this clinical group when they are self-neglecting and the approaches and skills used to treat self-neglect. Further research is required to develop a standardised definition of

self-neglect to facilitate intervention and managing the harmful effects of self-neglect in people with severe and enduring psychosis.

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## Appendices











## Appendix V. Initial Template of Themes – 2 Participants (Version 1)

First level code	Second level code	Quote	Where in text?
Definition of self-neglect	Lacking care routines	“Self-neglect would be things like not washing, not dressing, not taking care of themselves, not eating.” “self-care”	P1 lines 2-3  P2 146
	Impairment	“self-care may be impaired. All aspects of that can be impaired”	P2 lines 12-14
	A problem	“personal hygiene may be problematic” “you have a problem”	P2 line 13 P2 556-7
	Undesirable	“people smelling is a bad thing” “bad living circumstances” “unpleasant” “a bad situation” “unsavoury”	P2 160 P2 170-71 P2 211 P2 446 P2 625
	Multidimensional	“you can look at a particular aspect of something and go into a lot of detail.” “that’s just one kind of tiny aspect”	P2 line 14  P2 71
	Consequential	“arising because of active symptoms” “never had any money, therefore he never had any food”	P2 102 P2 456
	An individual experience	“for one person, they’re afraid to go to the dentist.”	P2 lines 15-16
	Choice	“unwilling to apply for benefits” “declining on willing to look after themselves” “declining to eat” “Not coming for meals or they’re avoiding meals”	P1 line 6  P1 line 15  P1 line 21 P1 line 22  P1 line 96

		“she won’t get up” “not wanting to”	P1 line 130
	Not attending to finances	“unwilling to apply for benefits that they might be entitled to”	P1 line 6
	Lack of function	“they’re not able to look after themselves.” “concerns about how well they are able to care for themselves” “(concerns about) how well they’re able to function” “not doing”	P1 line 10 P2 lines 7-8 P2 line 8 P2 39-40
	Lack of function in environment	“function in their accommodation, in the community or institutional settings.”	P2 line 8 -9
	Worrying	“concerns” “we really worry” “very concerned”	P2 line 7 P2 192 P2 201
	Broad	“quite a broad concept” “it’s a broad area”	P2 line 10 P2 647
	Maintained over time	“it will lead to that cycle” “Prolonged period of time” “slowly”	P1 line 124-125 P2 219 P2 417
	Sometimes associated with mental illness	“people label self-neglect as part of mental health illness but it’s not always”  “people think because you’ve got a mental illness that’s an automatic self-neglect and it’s not”	P1 440-41  P1 450-51
	Frequency	“don’t brush their teeth very often”	P2 line 16
	Not maintaining daily routines	“they don’t do the usual things people do to maintain oral hygiene” “you have to expend energy to maintain order”	P2 16-17  P2 226-7

	Risk	<p>“self-neglect is one feature in terms of their risks”</p> <p>“self-neglect come sunder risks to self”</p> <p>“someone neglecting themselves potentially is a safeguarding issue”</p>	<p>P2 25-26</p> <p>P2 30-31</p> <p>P2 193</p>
	Spectrum of severity	<p>“it can be a relatively mild thing”</p> <p>“extreme forms of self-neglect”</p> <p>“profoundly neglected”</p> <p>“if things are really bad”</p> <p>“extreme cases”</p>	<p>P2 31</p> <p>P2 33</p> <p>P2 382</p> <p>P2 403</p> <p>P2 546</p>
	Change from usual	<p>“individual’s usual activities”</p> <p>“they may usually appear unkempt”</p> <p>“they may look thinner than you last saw them”</p> <p>“sees a very marked difference”</p>	<p>P2 45</p> <p>P2 59</p> <p>P2 74</p> <p>P2 200-201</p>
	Deteriorates	<p>“very gradual decline”</p> <p>“a deterioration in things”</p> <p>“his home environment has deteriorated”</p> <p>“that progresses. To begin with you might be ok, but there will become more and more of a smell, your clothes will become dirtier and dirtier”</p> <p>“whole house was deteriorated into a messy place”</p> <p>“it always deteriorates again”</p>	<p>P2 96</p> <p>P2 133-4</p> <p>P2 197-8</p> <p>P2 219-221</p> <p>P2 235</p> <p>P2 343</p>
	Self-neglect can be circumscribed	<p>“his whole house was deteriorated into a very, very messy place apart from his</p>	<p>P2 235-6</p>

		living room"	
Presentation	Poor hygiene	"dirty clothes, not brushing of teeth" "they don't brush their teeth" "not washing, not bathing" "don't change their clothes, launder clothes" "wearing very dirty clothes" "clothes become stained" "breath may smell, through oral hygiene"	P1 line 17/ 30  P2 line 16  P1 line 18  P2 21-2  P2 61  P2 66  P2 73
	Appearance of the person	"unkempt really" "appear unkempt" "unshaven" "poorly maintained clothes" "stain things" "they may look thinner" "clothes look looser, belt's tighter, or they just look thinner overall" "if they've lost weight" "they are also in a terrible state" "they look odd"	P1 line 17 P2 59 P2 61 P2 62  P2 64 P2 74  P2 75-76  P2 146-7 P2 156-7  160
	Appearance of the home	"home environment is in a terrible state; untidy, disorganised." "home environment may not be organised; dirty" "unpleasant environment" "hoarding"	P2 line 11-12  P2 132-33  P2 211  P2 396
	Not engaging in daily activities	"somebody just staying in bed, not wanting to get up."  "tend to stay in bed"	P1 lines 18-19  P1 line 108

		<p>“not eating, declining to eat.”</p> <p>“not getting up and getting dressed and doing the daily things they should be doing”</p> <p>“in bed 20 hours a day”</p>	<p>P1 line 21</p> <p>P1 line 42</p> <p>P1 368</p>
	Noticeable	<p>“it can be obvious to see”</p> <p>“in a marked way”</p>	<p>P1 line 34</p> <p>P2 67</p>
	Unchanging over days	<p>“wearing the same clothes day after day”</p> <p>“you’d notice the clothes being on every single day or sleep in their clothes”</p> <p>“doesn’t want to get up say three or four days a week.”</p>	<p>P1 line 35</p> <p>P1 line 68=69</p> <p>P1 line 52-53</p>
	Use of senses important for noticing self-neglect	<p>“we see, smell, use all sorts of senses”</p> <p>“it’s not just way you see it’s what you smell”</p> <p>“patients may smell of urine”</p> <p>“breath may smell”</p> <p>“so where you see them”</p> <p>“you see everything”</p> <p>“looking like that, or smelling like that”</p> <p>“we always get to see their environment”</p>	<p>P2 53-54</p> <p>P2 71-72</p> <p>P2 72</p> <p>P2 73</p> <p>P2 151-52</p> <p>P2 159</p> <p>P2 639</p>
	Using very little	<p>“patients who have nothing, mattress on the floor and very little else”</p> <p>“Spartan existence”</p> <p>“he doesn’t have as much food”</p>	<p>P2 134-5</p> <p>P2 141-42</p> <p>P2 198</p>
	Not engaging	<p>“didn’t get out of bed at all”</p> <p>“wearing</p>	<p>390</p> <p>390-91</p>

		pads/nappies"	
Intervention	Planned intervention	"we put plans in place." "timetabled" "put some sort of care plan into place" "there is a care package" "support packages" "you can plan your interventions" "target an intervention with the care plan"	P1 line 51  P1 145 P1 184  P2 356  P2 381  P2 376  P2 531-2
	Talking	"we speak to the psychologist" "team discussion" "discuss every patient on the caseload"	P1 318  P2 344  P2 526
	Care plan used as a point of reference	"if they're still not happy, if they're still not doing things, we can refer back to the care plan"	P1 186-7
	Current interventions work	"a lot of the time it does work (care plans)" "it does seem to work for us (consistency)" "it works"	P1 187-8  P1 216-17  P1 226
	Plans are visible	"it's up on the wall"	P1 144
	Service user involvement	"they know what they're doing" "involve the patient and try and motivate them to become part of the process"	P1 144  P2 563
	Make service user aware	"addressing it with the patient or sensitively raising it with the patient"	P2 314-5
	Recognise self-neglect	"recognising it"	P2 314
	Service user agreement used as boundary	"You agreed to get up at ten, it's ten o'clock now so come on"	P1 403
	Giving service user choice	"we're not forcing them to do things they don't want to"	P1 145-146

		<p>do”</p> <p>“what they want to do”</p> <p>“we can’t force people to do anything”</p> <p>“something they’ve chosen to do”</p> <p>“they agree to”</p> <p>“time agreed to be knocked/woken up”</p> <p>“” What time would you like to wake up this morning? “I don’t want to take all of her choices away”</p> <p>“ok well this is the options”</p> <p>“Are you ready to get up?”</p> <p>“Instead of telling them, asking. Giving them the choice, giving them the control back.”</p> <p>“maximise their autonomy”</p>	<p>P1 145</p> <p>P1 149</p> <p>P1 150</p> <p>P1 184/ 185-186</p> <p>P1 201</p> <p>P1 276-7</p> <p>P1 278</p> <p>P1 394</p> <p>P1 394</p> <p>P2 330</p>
	Proximity to service user	<p>“we could be in the bedroom with her in the morning for two hours”</p> <p>“staff would sit in somebody’s room”</p> <p>“we would sort of back off, then we back off a little bit more”</p> <p>“because you’re there it’s quite intimate”</p>	<p>P1 line 92-93</p> <p>P1 202</p> <p>P1 223-24</p> <p>P1 310</p>
	Staff taking responsibility for daily tasks	<p>“we’re running her a bath and we’re washing her hair for her.”</p> <p>“knocked/woken up”</p> <p>“helping them”</p>	<p>P1 line 54</p> <p>P1 201</p> <p>P2 356</p>
	Monitoring activities	<p>“check that he’s had a bath every day”</p> <p>“food and fluid charts just to help them.”</p>	<p>P1 line 55</p> <p>P1 line 27-28</p>

		<p>"we'd do checks"</p> <p>"we'd still be on top of it"</p> <p>"things documented"</p> <p>"ward review"</p> <p>"we can monitor that on a daily basis"</p> <p>"it's all recorded and monitored... everything"</p> <p>"she needs to be downstairs so we can monitor her quite a lot"</p>	<p>P1 line 71</p> <p>P1 line 102</p> <p>P1 326</p> <p>P1 359</p> <p>P1 379</p> <p>P1 381</p> <p>P1 412</p>
	Reminders	<p>"we bring it up lots"</p> <p>"we prompt her"</p> <p>"we tend to prompt them"</p> <p>"prompting her to have a shower, prompting her every step of the way"</p> <p>"encourage them"</p>	<p>P1 line 51</p> <p>P1 line 53</p> <p>P1 line 72</p> <p>P1 line 93-94</p> <p>P1 150</p>
	Allocated staff members	<p>"we have got somebody in place."</p> <p>"each patient has a named nurse and a co-worker as well so there's two named nurses"</p> <p>"the care coordinator"</p> <p>"people are allocated to do a particular piece of work"</p>	<p>P1 line 55</p> <p>P1 192</p> <p>P2 532</p> <p>P2 534</p>
	Team approach	<p>"the whole team"</p> <p>"we all get together as a team"</p> <p>"team discussions"</p> <p>"talking it through with whole team"</p> <p>"there's no "who's the boss? Who's in charge? Who's an HCA? If anything. It's not that here."</p> <p>"everything's decided as a team"</p> <p>"multidisciplinary"</p>	<p>P1 190</p> <p>P1 194-5</p> <p>P1 314</p> <p>P1 315-16</p> <p>P1 357-58</p> <p>P1 359</p> <p>P2 372</p>

		team" "it's within a team" "everybody contributes their expertise"	P2 523 P2 524
	Staff meet frequently	"we all get together as a team quite often" "we have supervision every week" "we meet once a week"	P1 195-5  P1 197  P2 526
	Intervention is consistent	"we're sort of on somebody's case all the time" "all the staff doing the same sort of routine" "very tight" "everybody had to do the same thing" "everybody's doing the same and we know everybody's doing the same" "we have to have everybody doing the same thing" "same approach" "every day" "seeing him regularly"	P1 line 109-110  P1 205  P1 212 P1 212-13  P1 215    P1 217  P1 219 P1 221  P2 476
	Observation	"watch somebody have a bath, watch somebody have a bath"	P1 311
	Amount of input	"a lot of work with the psychologist" "detailed care plan" "it would be very, very detailed" "a lot of care planning"	P1 line 119  P1 185 P1 204  P1 314
	Reasonable boundaries	CONTEXT "we try to here to be what we call "least restrictive" CONTEXT "people can go in and out as they please as long as they're signing in and	P1 line 135  P1 138

		out" "would staff come out while somebody's getting dressed" "firm boundaries"	P1 203  P1 384
	Based on individual's needs	"everything is done on an individual's needs, everybody has their own plan for each day" "timetabled around them"	P1 143 – 144  P1 145
	Duration	"it's a long process" "it took us a long time, about two years to get to grips with her" "A year, every day" "very gradually" "it's a long, long process" "that can take years. It can take years" "that took us three years"	P1 line 183 P1 210-11  P1 221 P1 224 P1 226  P1 367  P1 377
	Intervention takes place in stages	"firstly" "then" "initially"	P1 182 P1 183 P1 364
	Re-establishing routine	"we'd go through a routine" "becomes a routine" "it would be routine" "having routine"	P1 201  P1 230 P1 326 P1 384
	Highlighting consequences of non-compliance	"I've never threatened that she can't go on leave, but some people do"	P1 285-6
	Developing relationship	"bit of a bond with them" "more of a trust with somebody" "we have lots of one-to-one time" "someone who knows the patient very well"	P1 309  P1 309-10  P1 339  P2 313
	Involving family as a last resort	"involve family if we're really, really struggling"	P1 331
	Medication for	"with depression we	P1 354-55

	underlying mental health related symptoms	can help with medication or the anxieties and stuff." "antipsychotic medication"	P2 323
	Medication does not address self-neglect wholly	"apart from (depression and anxiety), probably not"	P1 354-55
	Trial and error	"Ok, this is not working let's have another plan" "Keep trying and keep trying and try again" "suggestions" "generate ideas"	P1 360-61  P2 377  P2 527 P2 559
		"Ok, what worked? What didn't work? Well how can we change that? And we just keep going and keep going swapping and changing until we get it right"	P1 365-
	Staff use approach most useful for them	"that does not work. It wouldn't work for me"	P1 387
	Tertiary services	"environmental health and social services" "dentist"	P2 175-80  P2 541
	With care	"carefully, hopefully tactfully" "sensitively" "has to be done carefully"	P2 313  P2 315/365 P2 341
	Cause of self-neglect determines intervention	"it really kind of comes down to what the cause is"	P2 315-6
	With effort	"try"	P2 330
	Active	"active treatment"	P2 412
	Separated into psychological, practical and medical interventions	"whether it's psychological, whether it's practical or me mucking about with their medication"	P2 534

	Psychology	"psychological interventions"	P2 323
	Address the cause of self-neglect	"we will try and address whatever the cause is"	P2 324-5
	Reduce impact of self-neglect	"ameliorate the impact of self-neglect"	P2 327
	Improve hygiene	"cleaned up or their place tidier" "getting someone to tidy up"	P2 329-30 P2 340
	Assessment	"assess what is going on"	P2 372
	Formulate the issue	"understanding, a formulation if you will" "Based on the formulation you can plan" "Go back to the formulation" "once you've decided what you're dealing with" "you have a good think about why this might be"	P2 374-5 P2 375-6 P2 519 P2 531 P2 557
	Change service user environment	"bring them into hospital"	P2 383
	Using legislation	"you can use legislation"	P2 404
	Diet supplements	"dietary supplementation, build up drinks, vitamin supplements"	P2 545
Diagnoses	depression	"self-neglect can lead to depression"  "something due to depression?" "mood symptoms, particularly depression"	P1 line 107 (said opposite in section below) P2 92  P2 109
	Self-neglect is a consequence of mental health	"I think it probably comes after" "I think the self-	P1 line 128 P1 line 129

	disorder	neglect would come after"	
	Psychosis	"in psychosis obviously" "psychosis"	P1 117 P2 102
	Schizophrenia (severe and enduring mental illness)	"the common diagnosis is paranoid schizophrenia" "the majority of my patients have schizophrenia or schizoaffective disorder"	P2 247
	Bipolar disorder	"we have a few patients who have severe bipolar disorder"	P2 256-7
	Substance misuse	"there's a lot of co-morbid substance misuse"	P2 263
Function of self-neglect	Avoidance	"they're going to stay in bed anyway because they don't have to come down and face anything"	P1 line 123-124
	Useful	"may serve a purpose"	P2 95
Experience for staff	Unenjoyable	"it's not very nice"	P1 line 134
	Difficult	"it is difficult" "struggling with somebody" "struggled and struggled and struggled" "it's hard" "difficult it is"	P1 242/261/272 P1 315 P1 323 P1 388 P2 444
	Discomfort	"maybe it's the staff who feel uncomfortable doing it (male staff)" "difficult conversation to have"	P1 243-44 P2 302
Deleted	Embarrassing	"maybe the male staff feel embarrassed about it"	P1 244-5
Moved to different code	Being supported helpful	"great"	P1 199

Moved to intervention approach code	Staff working in the same way is helpful	<p>“also helps with all the staff doing the same sort of routine”</p> <p>“it helps because everybody’s doing the same approach”</p>	<p>P1 205</p> <p>P1 230-31</p>
	Exciting	“I feel quite a buzz”	P1 298
	Achievement moderates mood	<p>“I get quite proud of myself when I’ve actually achieved it”</p> <p>“it’s good when you see somebody coming down all nicely dressed and their hair done”</p> <p>“I feel rubbish when I can’t achieve it”</p> <p>“when I do achieve it I feel like yeah, I have achieved something today”</p> <p>“if you’re not successful you can get disheartened”</p> <p>“if you can make a change that’s good for your sense of worth”</p> <p>“get fed up and think you’re not achieving something”</p>	<p>P1 298</p> <p>P1 299-300</p> <p>P1 420</p> <p>P1 421</p> <p>P2 377-8</p> <p>P2 448</p> <p>P2 504-5</p>
	If finding it difficult with service user staff question ability in role	<p>“when I can’t achieve it, because it makes you feel like you haven’t done your job”</p> <p>“I haven’t possibly done my best”</p>	<p>P1 420-21</p> <p>P1 423-24</p>
	Consuming	“it’s hard to put it to one side”	P1 424-25
	No emotional impact	“I don’t think it really has an impact”	P1 436
	Complacency	“you get used to it	P2 210-211

		and as a result our tolerance of someone's self-neglect might be higher" "we may become immune to things like self-neglect" "you do get kind of used to it"	P2 294-5  P2 364
	Guilt if self-neglect is unnoticed	"professional guilt there, that things have got to that state" "if relatives notice something I haven't I'll probably feel more guilty about it"	P2 606  P2 618
	Staff feelings matching service user	"transference and counter transference can give insight into why the patient is feeling like they are" "maybe that's because that's how the patient feels in themselves"	P2 608-9  P2 610-11
	Lacking motivation	"lack motivation and feed fed up"	P2 610
	Powerless	"think that you are powerless"	P2 610
	Feelings depend on circumstance	"lots of different ways you might feel but it depends on the circumstances" "it entirely depends on the individual circumstance"	P2 611-2  P2 617
	Shocking	"it can be quite shocking"	P2 623-4
Challenges	Trust between service user and staff member	"gaining someone's trust whilst you're doing it"	P1 248
	Number of challenges	"there's lots of challenges"	P1 252
	Service user's behaviour	"you can get lots of challenging behaviours from it" "angry behaviour"	P1 252-3  P1 266-7

		"you don't know what the response is going to be"	P1 266
	Aggression	"throwing things at you" "throwing all the water out the bath" "aggression. Mainly aggression"	P1 256  P1 256 P1 270
	Compliance	"they'll do it, but they'll do it under protest"	P1 253
	Risk to staff	"you're up there on a one to one basis" "when do I press my alarm?"	P1 261 P1 262
	Staff response to challenging behaviour	"you might back off, but then if we back off too much it's not going to work"	P1 267-8
	engagement	"part of the problem is engagement" "patients can be difficult to engage"	P2 309 P2 560
	Evidence base	"the evidence base for what works in negative symptoms, is a lot harder" "if there was an evidence based, very effective intervention that would address that, that would be very helpful"	P2 323-4  P2 351-2
	Amount of change with intervention	"something you can't necessarily change"	P2 326
	Degree of autonomy service user has	"you're always kind of worried that you're going to seem paternalistic about, you know, taking over someone's life" "some people might view it as paternalistic" "we are trying to stop being too dependent on us for doing things as well, so that's"	P2 328-9  P2 346 P2 508-9

		another dynamic"	
	Working in service user's best interest	<p>"in what you think is their best interest you can come into problems"</p> <p>"Is it appropriate to do something?"</p> <p>"if you're quote happy losing weight, not eating very much, don't mind that your clothes are in tatters and you're living in squalor"</p> <p>"they can choose unwisely to live in terrible circumstances and neglect themselves"</p>	<p>P2 331-2</p> <p>P2 528</p> <p>P2 566-8</p> <p>P2 570-1</p>
	Lack of resources	<p>"availability of resources as well"</p> <p>"finances for that are increasingly limited"</p>	<p>P2 353</p> <p>P2 357</p>
	Addressing cause of self-neglect	Hard to change the causes	P2 444-5
	Service user capacity	"issues around capacity"	P2 568-9
Barriers	Inconsistency	"different things or approach it differently it doesn't work"	P1 206
Benefits	Staff skill mix	<p>"different sort of professional backgrounds you get a more rounded assessment"</p> <p>"appreciate everybody's contribution"</p>	<p>P2 373-4</p> <p>P2 525</p>
Gender	Differing staff attitudes according to gender	<p>"harder with men than it is with the women."</p> <p>"that side of it"</p>	<p>P1 line 38</p> <p>P1 line 237</p>
	Less focus on men	<p>"we don't tend to notice so much with the men"</p> <p>"with women we tend to notice if the hair</p>	<p>P1 line 39-40</p> <p>P1 line 39</p>

		<p>needs washing.”</p> <p>“with the men it sort of seems to take a back seat and it seems to be ok”</p> <p>“ok for the guys not to do it”</p> <p>“for personal care it just doesn’t seem to get followed up as much”</p> <p>“I’d like to be able to manage the male side of it a bit more”</p> <p>“I don’t know why it goes under the radar”</p>	<p>P1 line 47</p> <p>P1 line 49</p> <p>P1 line 72</p> <p>P1 235-36</p> <p>P1 235</p>
	Different features noticed for males/females	<p>“with the males you’d notice the clothes”</p> <p>“(for the women) unkempt hair”</p> <p>“with women we tend to notice if the hair needs washing.”</p> <p>“unshaven if it’s a male patient”</p>	<p>P1 line 68</p> <p>P1 line 74</p> <p>P1 line 39</p> <p>P2 61</p>
	Gender of staff member has an effect?	<p>“women don’t care if they take their clothes off in front of another woman but if a am was taking his clothes off in front of another male staff”</p> <p>“the females, we sort of get on with it”</p> <p>“maybe the male staff feel embarrassed about it”</p>	<p>P1 241</p> <p>P1 243</p> <p>P1 244-245</p>
	Different groups for males and females	<p>“women’s group... men’s group”</p>	P1 332
Cause of self-neglect	Fear	<p>“they’re afraid to go to the dentist so they don’t brush their teeth very often”</p>	P2 line 16
	(In psychosis) listening to command hallucinations/ importance of listening to voices	<p>“someone’s hearing voices and they’re telling them not to listen”</p> <p>“whatever the voices</p>	<p>P1 line 117</p> <p>P1 line 118</p>

		are saying is paramount for that person" "regardless of what it is, regardless of what they think they still do that"	P1 176
	Resignation	"they'll probably think "why bother?""	P1 line 131
	Reacting to losing control	"being put in hospital, being told what to do, on medication, takes that loss of control" "well this is the only part of me I have control over" "you might see somebody who's really well groomed, but you don't see that side very often, it always seems to be the neglect side of it" "give her some control over it now"	P1 166-167  P1 167  P1 167-169  P1 277-8
	Many reasons why self-neglect occurs	"there may be a whole range of reasons for that" "for a variety of reasons" "there's so many different reasons this may happen"	P2 22  P2 24  P2 94
	Practicality	"it could include the practical aspects of washing" "not able to attend to themselves going to the toilet"	P2 22-23  P2 72-73
	Medication side effects	"side effects of medication which they may not attend to"	
	Lack of awareness	"aren't either aware of it" "is this a conscious process?" "wouldn't necessarily be thinking to do"	P2 65  P2 90-91  P2 284

		"patients may not realise there are problems, issues that need addressing"	P2 298-299
	Lacking motivation	"lacking motivation"	P2 91-92
	Lack of energy	"they'll lack energy"	P2 224
	Consequence of impact of mental health difficulty	<p>"something due to depression?"</p> <p>"negative cognitions that come from depression"</p> <p>"these things are arising usually because of active symptoms"</p> <p>"the patient lacks motivation, they're apathetic, they lack the drive to do things"</p> <p>"it may be due to positive symptoms"</p> <p>"the psychomotor retardation"</p> <p>"profoundly unwell and neglecting themselves"</p> <p>"impact of psychosis or depression"</p> <p>"if you have someone who's dependent on substances the substance becomes their focus"</p> <p>"if they're maybe intoxicated all of the time they're not focusing on other things like their diet, they're not looking after themselves"</p> <p>"positive symptoms, if they're distracting can have an impact on someone's behaviour and therefore self-neglect"</p> <p>"psychosis – thought processes and</p>	<p>P2 92</p> <p>P2 92-93</p> <p>P2 104</p> <p>P2 105</p> <p>P2 109</p> <p>P2 110</p> <p>P2 151</p> <p>P2 158</p> <p>P2 264-5</p> <p>P2 267-9</p> <p>P2 277-8</p> <p>P2 280</p>

		disorganised person"	
	Lack of routine	"they may not be organised in terms of doing shopping"	P2 281
	Not attending to issues	"don't attend to themselves in what they're wearing"	P2 65-66
	Poor diet choices	"not eat efficiently" "not take enough fluid"	P2 24 P2 24
	Low self-worth	"they don't feel worth looking after themselves" "just give things away, they don't value themselves"	P2 93  P2 140-41
	Abuse	"a consequence of people being taken advantage of"	P2 139
Impact of self-neglect	Impact on families	"it does affect families and partners" "it's really difficult for families to see that" "for family and friends they may well be worried about the impact of self-neglect"	P1 line 76  P1 line 80  P2 194-5
	Self-neglect presentation does not affect staff	"I mean for staff if we've got to go out with somebody who doesn't want to attend to their personal care it's not really an issue for us"	P1 line 78-80
	Negative impact on social life	"they (family and partners) might be planning to take them out, but they might not want to take them out" "that impacts on their family life, their social skills" "partner not wanting to take her out" "people move away from them, won't touch them" "disenfranchised from	P1 line 76-77    P1 line 82  P1 284  P2 160-1  P2 169-70

		family and friends"	
	Impacts all aspects of life	"impacts on...everything" "it can impact on a lot really, anything"	P1 line 82 P1 line 83
	Occupation	"right down to job interviews" "if they go to an interview and they're not looking after themselves, first impressions"	P1 line 83 P1 line 84-85
	How others perceive service user	"if... they're not looking after themselves, first impressions, and that's what it is isn't it? It's first impressions"	P1 line 85-86
	Mental health	"it can impact on their mental health" "feeds into issues of self-esteem" "no pride in himself, no self-esteem"	P1 line 112 P2 301 P2 458-9
	Dignity	"dignity"	P2 301
	Risk of physical health decline increases	"you become more prone to infections" "physical health does deteriorate if they're neglecting their diet"	P2 221 P2 544
Mood of service user who self neglects	Anger	"it can lead to anger as well"	P1 line 109
	Low mood	"you'd be in that low mood" "they just get so low" "you're not feeling great"	P1 line 130 P1 171 P1 113
What doesn't work for self-neglect	Authoritarian approach	"heavy handed, "Right you're getting out of bed" does not work" "shouting, quite stern really just doesn't work" ""pull yourself together and get	P1 385 P1 406 P2 582-3

		yourself tidied up.” I can’t imagine that would be very successful”	
	Lack of routine	“I don’t find that helpful, not having a routine”	P1 416
	No intervention	“left without support and intervention patients can be left in a very perilous state” “if you leave any kind of home environment without tidying it up it gets more and more untidy”	P2 32  P2 224-5
	Intervening without addressing underlying cause	“if you haven’t addressed the sort of root – underlying cause of self-neglect it always deteriorates again”	P2 342-3
Staff priorities	Physical health prioritises self-neglect	“her personal care is not really our main concern as such because of her physical health” “physical is more of a concern” “if physical needs take precedence on that it would come kind of lower down” “not going to be prompting her every day when our main concern is just to get her to come down for medication”	P1 line 97  P1 line 97-98  P1 line 101  P1 103-104
How self-neglect progresses	Stuckness	“getting in that rut”	P1
	Everything progresses together	“most things might progress together”	P2
Service user experience	Living with self-neglect is difficult	“difficult”	P1 line 118
	Easier when service user is aware of self-neglect	“That makes it easier”	P2 300

	Treatment can be shocking	"it can be a shock I suppose"	P2 416
Staff support	Staff receive supervision for service users who are self-neglecting	"we have supervision every week with the psychologist" "specialist supervision once a month"	P1 197  P1 318
	External support from psychotherapist	"he sort of came in to help staff"	P1 323-24
What not self-neglecting looks like	Getting out of bed	"once somebody was out of bed that was fine"	P1 225
	Well groomed	"nicely dressed and their hair done"	P1 299-300
	Washing	"washing their clothes, had a shower, been in the bathroom"	P1 380-81
Staff attitudes to self-neglect	Different approaches to intervening	"my approach isn't what some people's approach would be" "whereas somebody might just let her lie in bed"	P1 274  P1 280
	Persistence	"it's perseverance, obviously perseverance" "if we just keep trying" "keep going" "stuck with him"	P1 326  P1 388 P2 378 P2 473
Control	Control is an illusion	"giving them the control back. Although really, you're taking it away from them, but it's making them feel like they have a choice" "they feel like they're in control."	P1 397-98   P1 401
Standards	There is a norm for self-neglect in society	"for us it's normal isn't it; get up, have a shower, come to work" "things that you would ordinarily need"	P1 428-29  P2 284
	There is a norm for self-neglect in service	"strangely get used to it (self-neglect)"	P1 436

	users	<p>“we shouldn’t get used to it. People get complacent about it”</p> <p>“people sort of expect people to self-neglect”</p>	<p>P1 439-40</p> <p>P1 446</p>
	People who self-neglect are deviating from expected norms	<p>“not doing something you should be doing”</p> <p>“the things you would usually do to keep yourself not neglected”</p>	<p>P2 39-44</p> <p>P2 105</p>
Moderating factors	Awareness	“it depends on the level of insight as well”	P2 95
	Adjustment of the service user	“what people get used to”	P2 96
	Psychosis symptoms	<p>“some are more treatable than others. Negative symptoms are particularly difficult to change. Positive symptoms much easier”</p>	P2 321-2
	Service user’s values	“it depends on their values as well”	P2 332
	Service user’s norms	“what the baseline is for someone”	P2 338
Point of intervention	When noticed	<p>“for a long period of time might go unnoticed”</p> <p>“by the time everybody notices”</p> <p>“we need to realise that it’s happening”</p> <p>“if you don’t know it’s happening you wouldn’t necessarily do anything about it”</p>	<p>P2 172</p> <p>P2 207-8</p> <p>P2 293-4</p> <p>P2 296-7</p>
	When others complain	“people to complain about smells”	P2 181-82
Pervasiveness of self-neglect	Self-neglect is seen often	<p>“we get exposed to this quite a lot”</p> <p>“we see maybe too much of it”</p>	<p>P2 209</p> <p>P2 295</p>
Who notices self-neglect?	Friends and family	“they pick up on it, maybe more than we	P2 212-3

		do.” “if relatives notice something I haven’t”	P2 617-8
	The service user	“patient seeks help as well” “patients might recognise it in themselves”	P2 297 P2 299-300
Outcome of intervention	Change for service user	“positive change” “meaningful change fundamentally for the patient”	P2 443 P2 565
	Self-neglect returns	“it often does kind of gravitate back to a bad situation” “temporarily improve things and then they go back” “things often do go back downhill again for a while”	P2 445-6 P2 502 P2 510-11
	Not always successful	“if you can make a change”	P2 448
	Varies according to the individual	“whichever intervention has been successful for a particular person”	P2 533-4
Power	Little power differences between team members	“not a huge hierarchy”	P2 524
Self-neglect in relation to mental illness	A feature of mental health difficulty	“one feature of a lot of my patients” “psychoses that we are dealing with and that links in with self-neglect”	P2 25 P2 257-8

## Appendix VI. Map of Initial Template of Themes: 2 Participants (Version 1)

### Definition of self-neglect D

#### KEY

A: new code inserted – current version

B: code deleted - next version- overlapping

C: code deleted – next version -one participant

D: code redefined – next version

E: code shifted between codes – next version

- Broad **B**
- Consequential
- Lacking care routines
- An individual experience
- Lack of function in environment **B**
- Lack of function **E**
- Frequency
- Not attending to finances
- Undesirable
- Multidimensional
- A problem
- Risk
- Choice
- Sometimes associated with mental illness
- Spectrum of severity
- Risk
- Multidimensional
- Deteriorates
- Self-neglect can be circumscribed
- Worrying **C**

### Presentation D

- Poor hygiene
- Using very little
- Not engaging in daily activities
- Noticeable
- Unchanging over days B
- Use of senses important for noticing self-neglect

### Function of self-neglect B

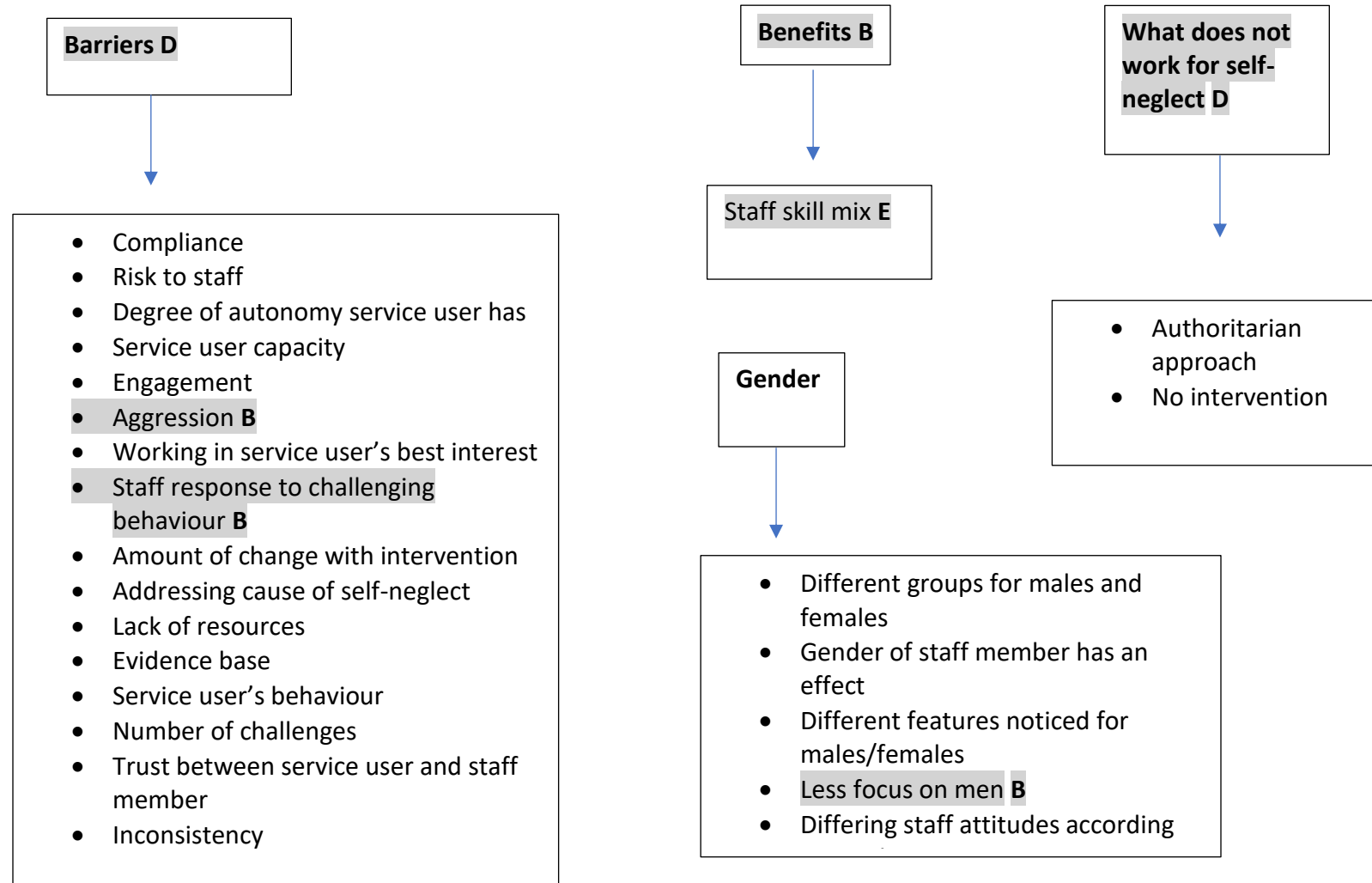
Avoidance E  
Useful E

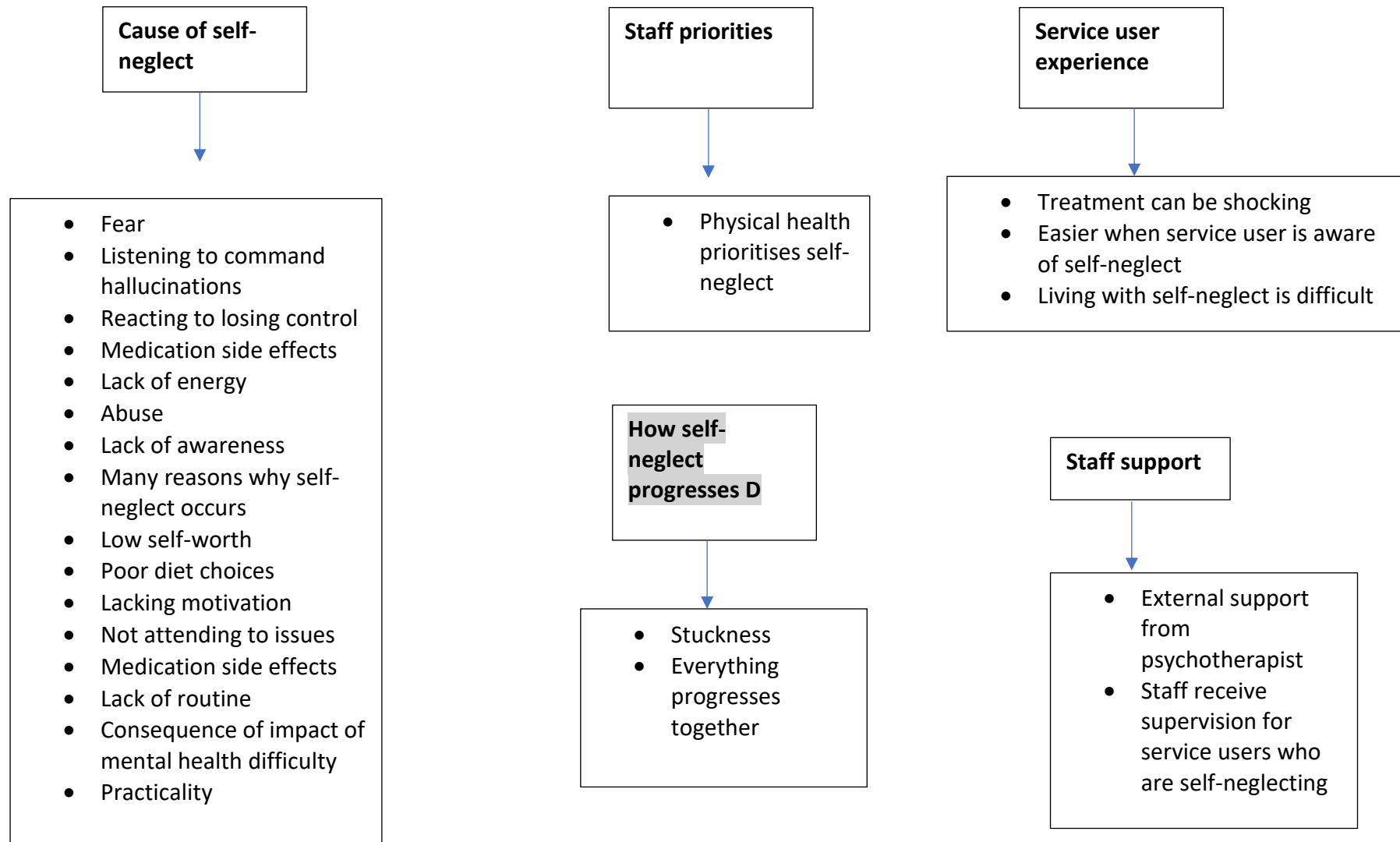
### Mood of service user who self-neglects B

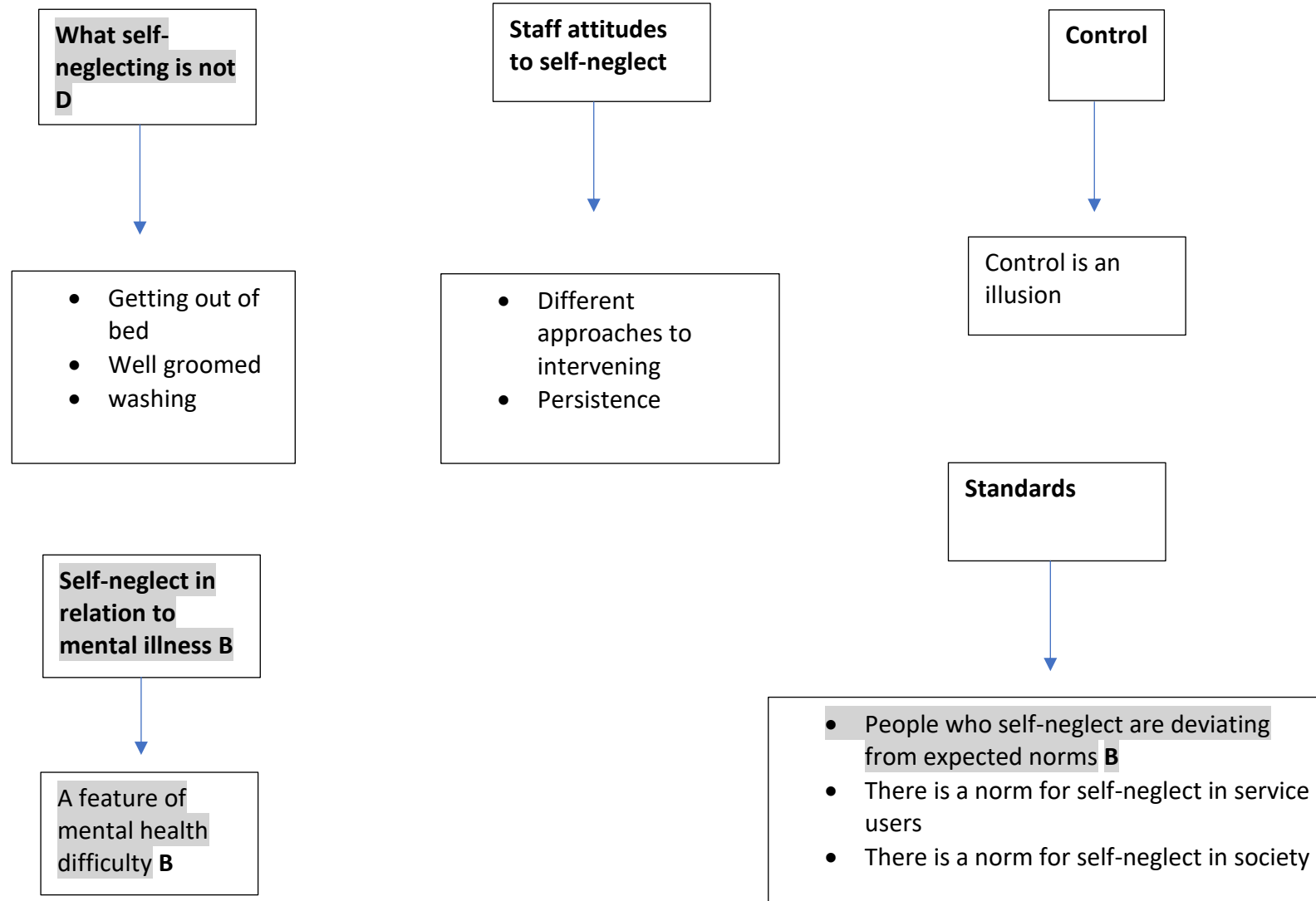
Low mood E  
Anger E

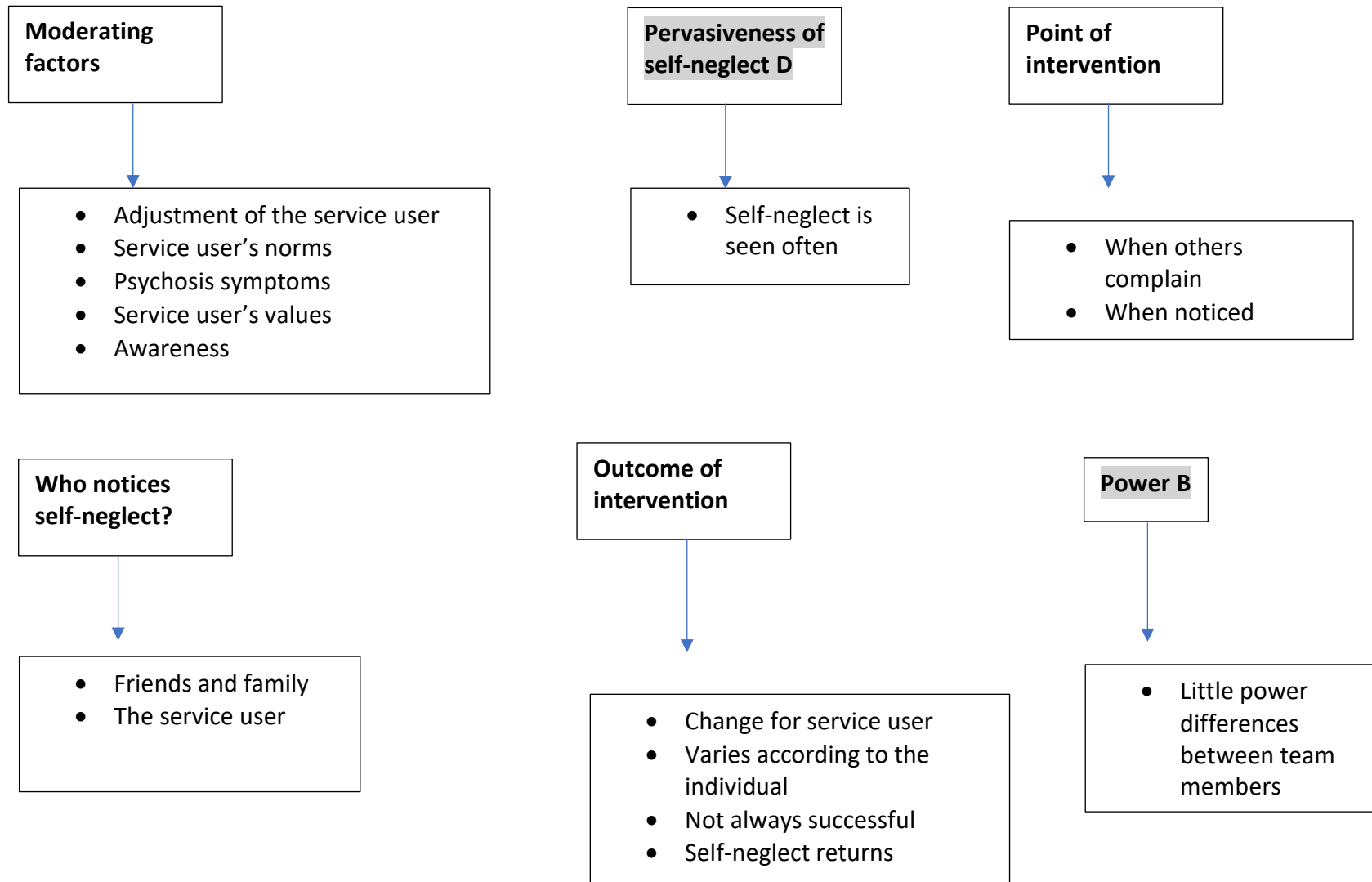
### Impact of self-neglect

- Negative impact on social life
- Self-neglect presentation does not affect staff
- Occupation
- How others perceive service user
- Impacts all aspects of life
- Mental health
- Impact on families
- Dignity
- Risk of physical health decline decreases









## Intervention D



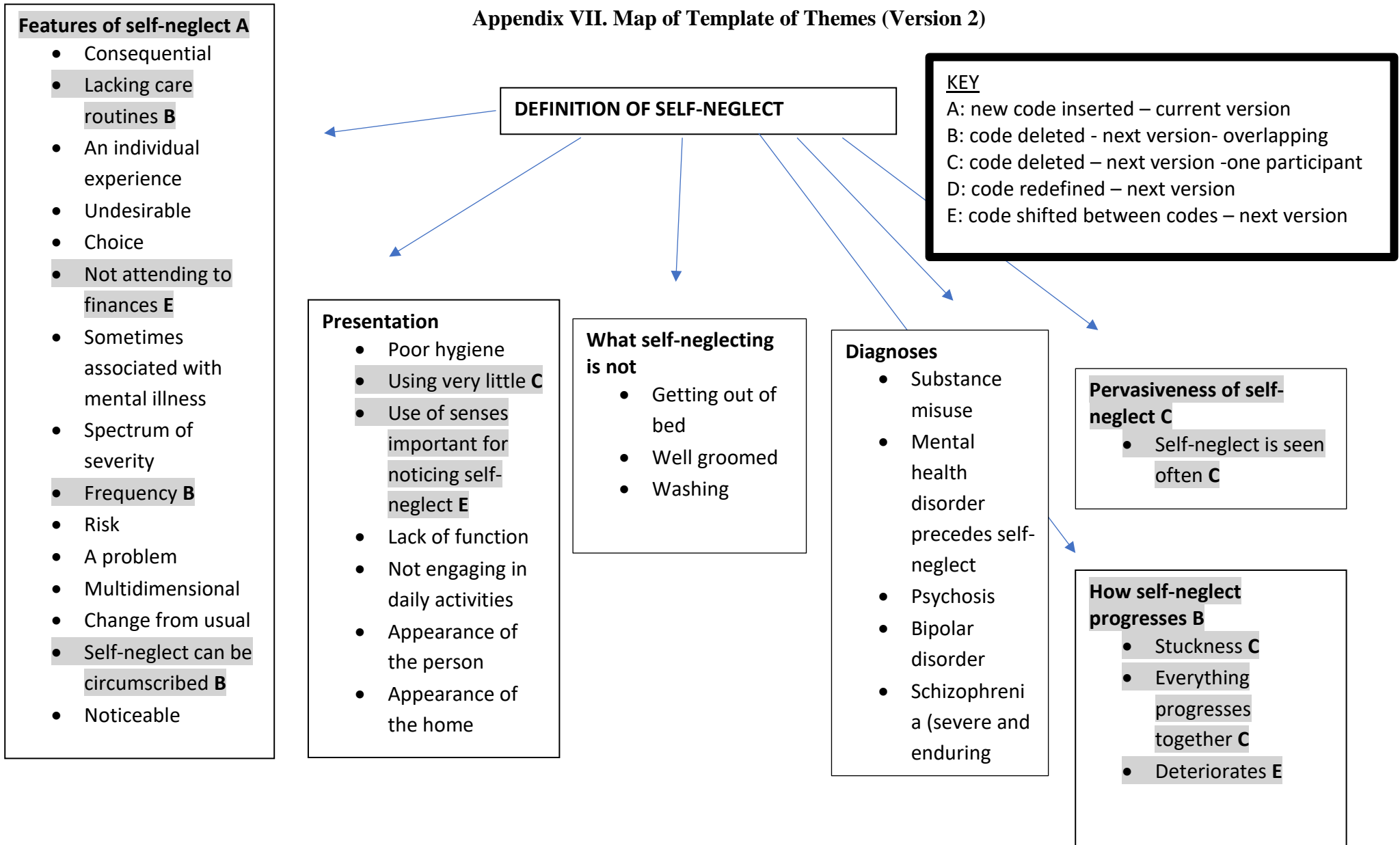
- Plans are visible B
- Psychology B
- Cause of self-neglect determines intervention B
- Observation B
- Duration
- Re-establishing routine
- Highlighting consequences of non-compliance
- Address cause of self-neglect
- Staff taking responsibility for daily tasks
- Giving service user choice
- Service user agreement used as boundary
- Proximity to service user
- Intervention is consistent
- Intervention takes place in stages
- With care
- Tertiary services
- Not engaging in daily activities
- Reduce impact of self-neglect
- Improve hygiene
- Staff use approach most helpful to them
- Developing relationship
- Staff meet regularly
- Make service user aware
- Recognise self-neglect
- Active
- Formulate the issue
- Change service user environment
- With effort
- Trial and error
- Based on individual's needs
- Team approach
- Medication does not address self-neglect wholly
- Diet supplements
- Allocated staff members
- Reasonable boundaries
- Medication for underlying health related symptoms
- Assessment
- Amount of input
- Reminders
- Current interventions work
- Service user involvement
- Talking
- Care plan used as point of reference
- Monitoring activities
- Involving family as a last resort
- Separated into psychological, practical and medical interventions
- Using legislation

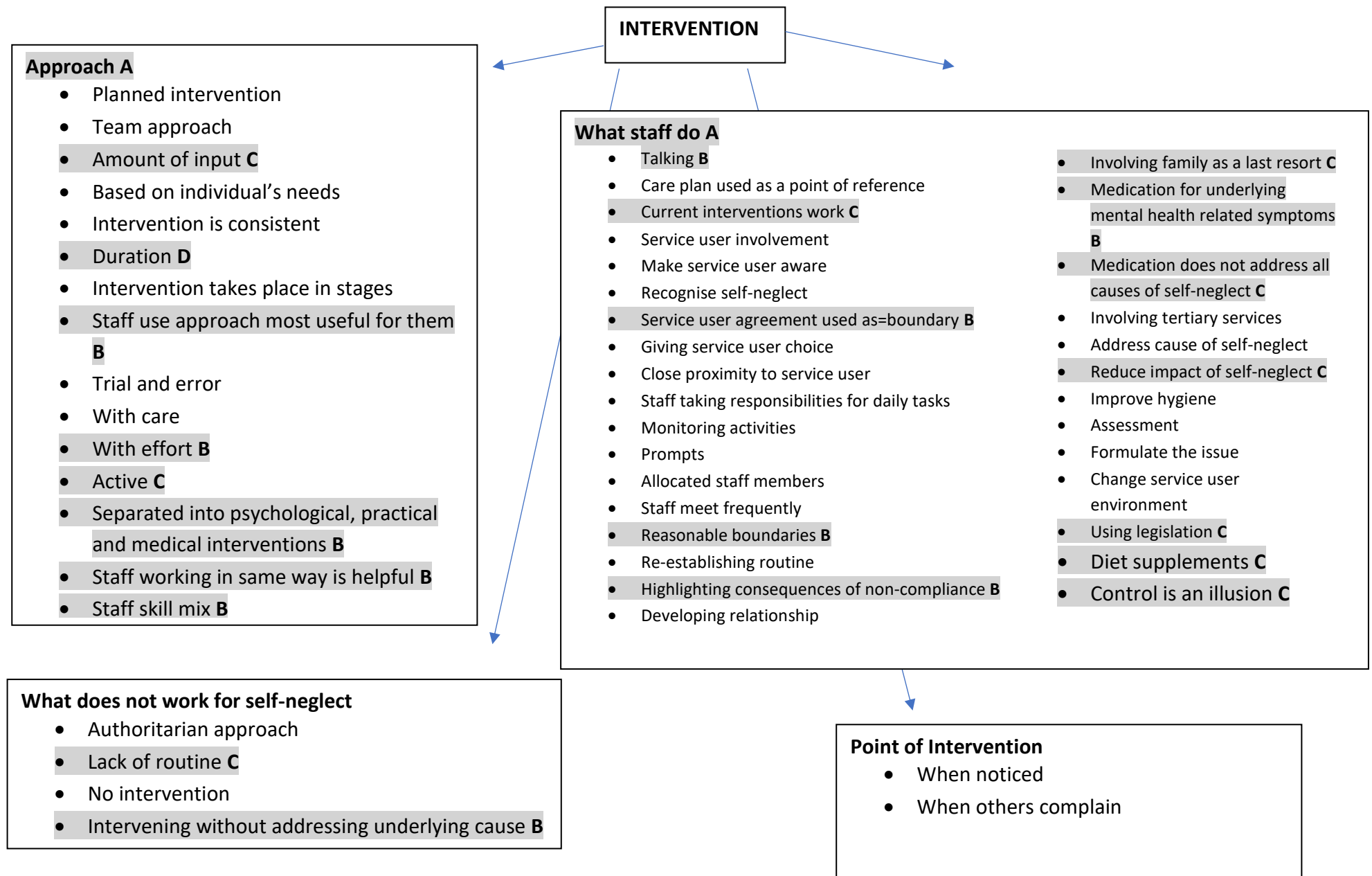
## Diagnoses E

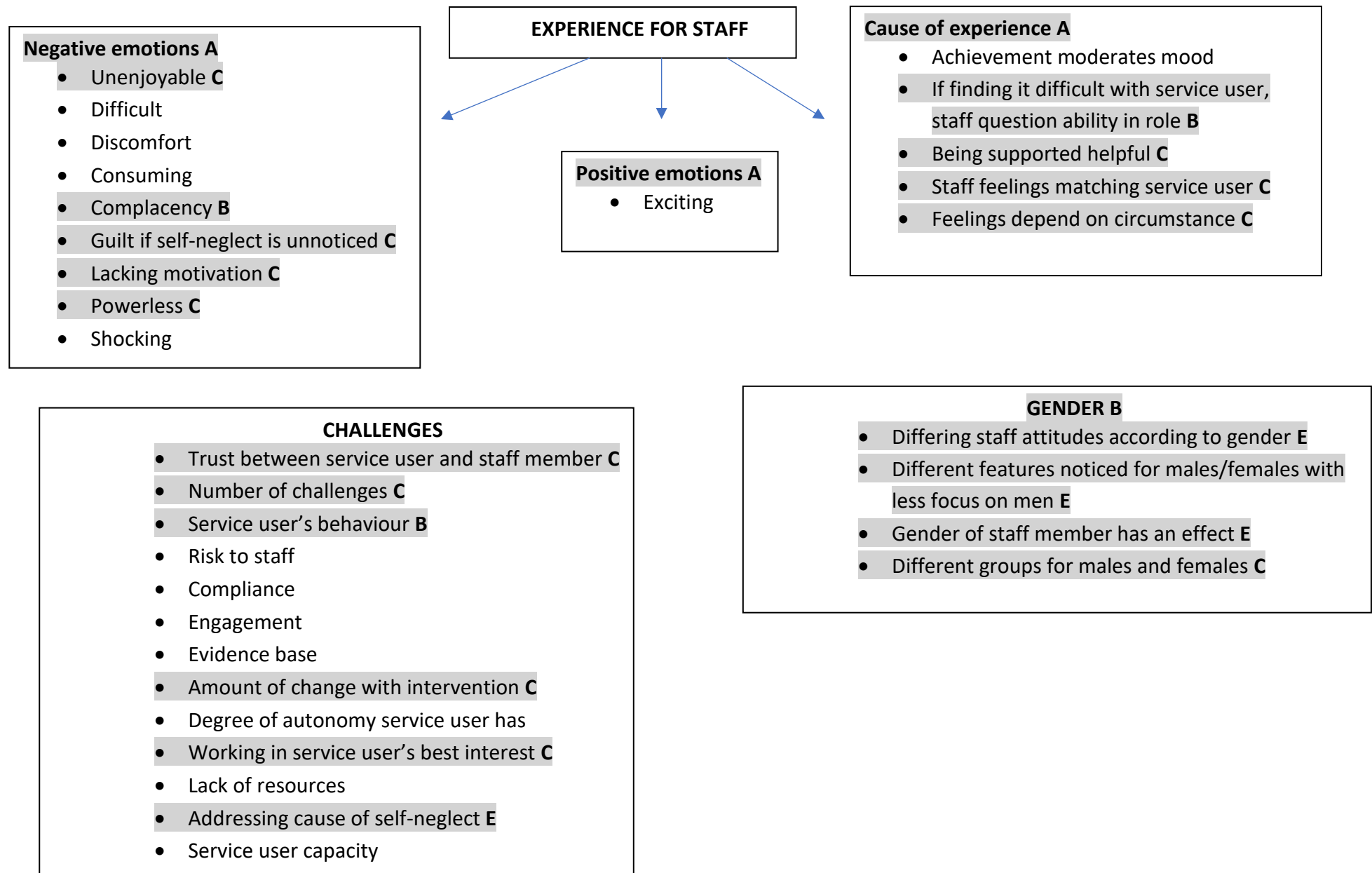


- Self-neglect is a consequence of mental health disorder **B**
- Depression
- Bipolar disorder
- Schizophrenia (severe and enduring illness)
- Psychosis
- Substance misuse
- Mental health disorder precedes self-neglect

## Appendix VII. Map of Template of Themes (Version 2)







### ORIGINS AND MAINTENANCE OF SELF-NEGLECT

- Fear **B**
- Listening to command hallucinations
- Resignation
- Reacting to losing control
- Many reasons why self-neglect occurs
- Practicality
- Medication side effects
- Lack of awareness
- Lacking motivation
- Lack of energy **B**
- Consequence of impact of mental health difficulty
- Lack of routine
- Not attending to issues **B**
- Poor diet choices
- Low self-worth
- Abuse
- Avoidance
- Useful **C**

### STAFF SUPPORT

- Staff receive supervision for service users who are self-neglecting
- External support from psychotherapist **B**

### IMPACT OF SELF-NEGLECT

- Impact on families
- Negative impact on social life
- Impacts all aspects of life **C**
- Occupation **B**
- How others perceive service user
- Mental health
- Dignity **C**
- Risk of physical health decline increases

### STAFF PRIORITIES

- Physical health prioritises self-neglect

### SERVICE USER EXPERIENCE

- Living with self-neglect is difficult
- Easier when service user is aware of self-neglect **C**
- Treatment can be shocking **C**
- Anger **B**
- Low mood **B**
- Loss of control

### **STAFF ATTITUDES TO SELF-NEGLECT**

- Different approaches to intervening
- Persistence **E**
- Self-neglect presentation does not affect staff

### **MODERATING FACTORS D**

- Awareness
- Adjustment of the service user
- Psychosis symptoms
- Service user's values **B**
- Service user's norms

### **STANDARDS**

- There is a norm for self-neglect in society. People who self-neglect deviate from this norm
- There is a norm for self-neglect in service users

### **WHO NOTICES SELF-NEGLECT D**

- Friends and family
- The service user

### **OUTCOME OF INTERVENTION D**

- Change for service user
- Self-neglect returns
- Not always successful
- Varies according to the individual **C**

### Features of self-neglect D

- Consequential
- An individual experience
- Undesirable
- Choice
- Sometimes associated with mental illness
- Spectrum of severity
- Risk
- A problem D
- Multidimensional
- Change from usual D
- Noticeable
- Not a choice when mentally unwell A/B
- Deteriorates

## Appendix VIII. Map of Template of Themes (Version 3)

### DEFINITION OF SELF-NEGLECT

#### KEY

- A: new code inserted – current version
- B: code deleted - next version- overlapping
- C: code deleted – next version -one participant
- D: code redefined – next version
- E: code shifted between codes – next version

### Presentation

- Poor hygiene
- Lack of function
- Not engaging in daily activities
- Appearance of the person D
- Appearance of the home D
- Not attending to finances
- Poor diet A
- Social isolation A
- Unmanaged physical health A
- Symptoms of mental illness A/B

### Who notices self-neglect? B

- Friends and family
- The service user
- Staff A

### What self-neglecting is not D

- Getting out of bed B
- Well groomed B
- Washing B
- Engaging A/B
- Managing physical health A/B
- Maintaining social contact A/B

### How self-neglect is noticed A/D

- Use of senses important for noticing self-neglect
- Different features noticed for males/females with less focus on men B

### Diagnoses

- Substance misuse
- Mental health disorder precedes self-neglect
- Psychosis
- Bipolar disorder
- Schizophrenia (severe and enduring illness)
- Anxiety A
- Depression

### Determinants of severity of self-neglect

- Awareness
- Psychosis symptoms D
- Service user's norms B

## INTERVENTION

### Approach

- Planned intervention
- Team approach
- Based on individual's needs
- Intervention is consistent
- Long term intervention **A/B**
- Persistence
- Intervention takes place in stages
- Trial and error
- With care
- Creative **A**
- Different groups for males and females

### What staff do

- Meet to discuss service users **A/D**
- Care plan used as a point of reference **D**
- Service user involvement
- Make service user aware **B**
- Recognise self-neglect
- Giving service user choice
- Close proximity to service user **D**
- Staff taking responsibilities for daily tasks
- Monitoring activities
- Prompts
- Allocated staff members
- Staff meet frequently **B**
- Re-establishing routine **D**
- Developing relationship
- Involving tertiary services
- Address cause of self-neglect **B**
- Improve hygiene **B**
- Assessment **D**
- Formulate the issue **B**
- Change service user environment **B**
- Rewarding compliant behaviour **A/B**

### Outcome of intervention

- Change for service user **B**
- Self-neglect returns
- Not always successful
- Service user has more control over life **B**
- Moderate improvement

### Point of Intervention **B**

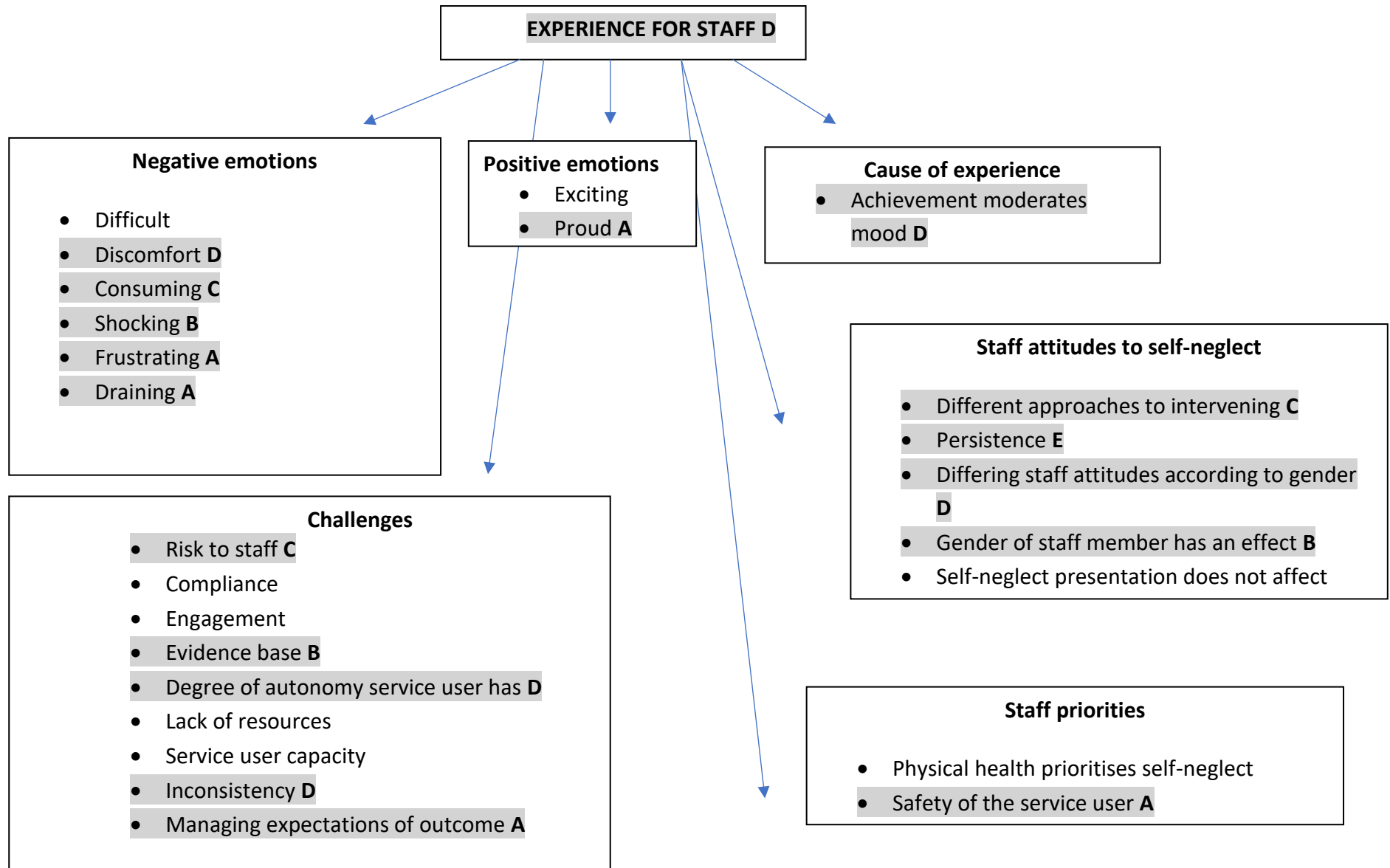
- When noticed **B**
- When others complain **B**
- When service user does not see self-care as a priority **E**

### Staff support **B**

- Staff receive supervision for service users who are self-neglecting **B**

### What does not work for self-neglect

- Authoritarian approach
- No intervention



### ORIGINS AND MAINTENANCE OF SELF-NEGLECT D

- Listening to command hallucinations D
- Resignation
- Reacting to losing control
- Many reasons why self-neglect occurs C
- Practicality
- Medication side effects
- Lack of awareness
- Lacking motivation D
- Consequence of impact of mental health difficulty
- Lack of routine C
- Poor diet choices C
- Low self-worth B
- Abuse
- Avoidance
- A feature of mental health difficulty
- Brain damage A/D

### IMPACT OF SELF-NEGLECT D

- Impact on families B
- Negative impact on social life B
- How others perceive service user B
- Mental health B
- Risk of physical health decline increases B

### SERVICE USER EXPERIENCE

- Living with self-neglect is difficult B
- Loss of control B
- Staff are intrusive A/B

### STANDARDS B

- There is a norm for self-neglect in society. People who self-neglect deviate from this norm B
- There is a norm for self-neglect in service users B

## Appendix IX. Map of Final Template of Themes (Version 4)

### KEY

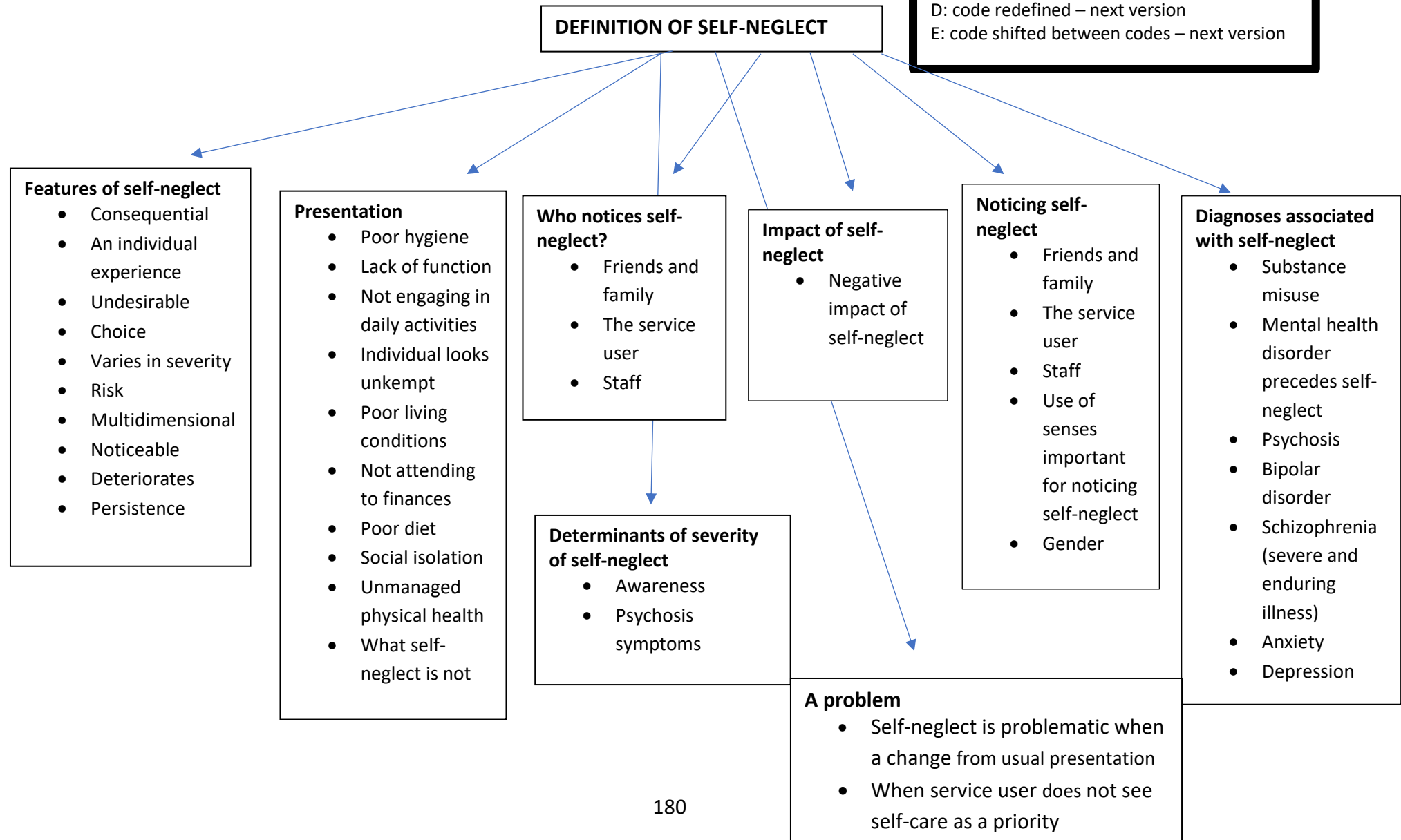
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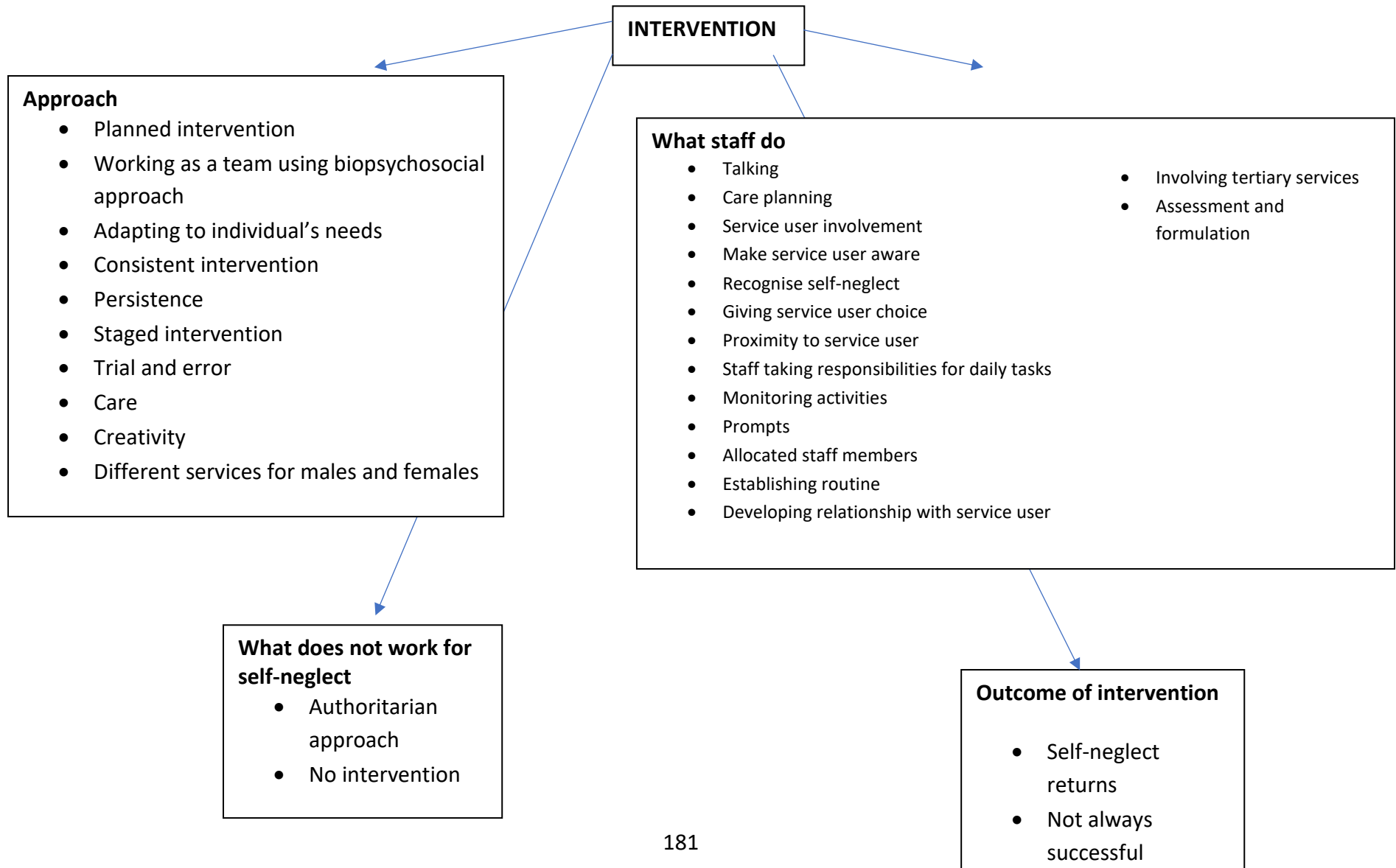
B: code deleted - next version- overlapping

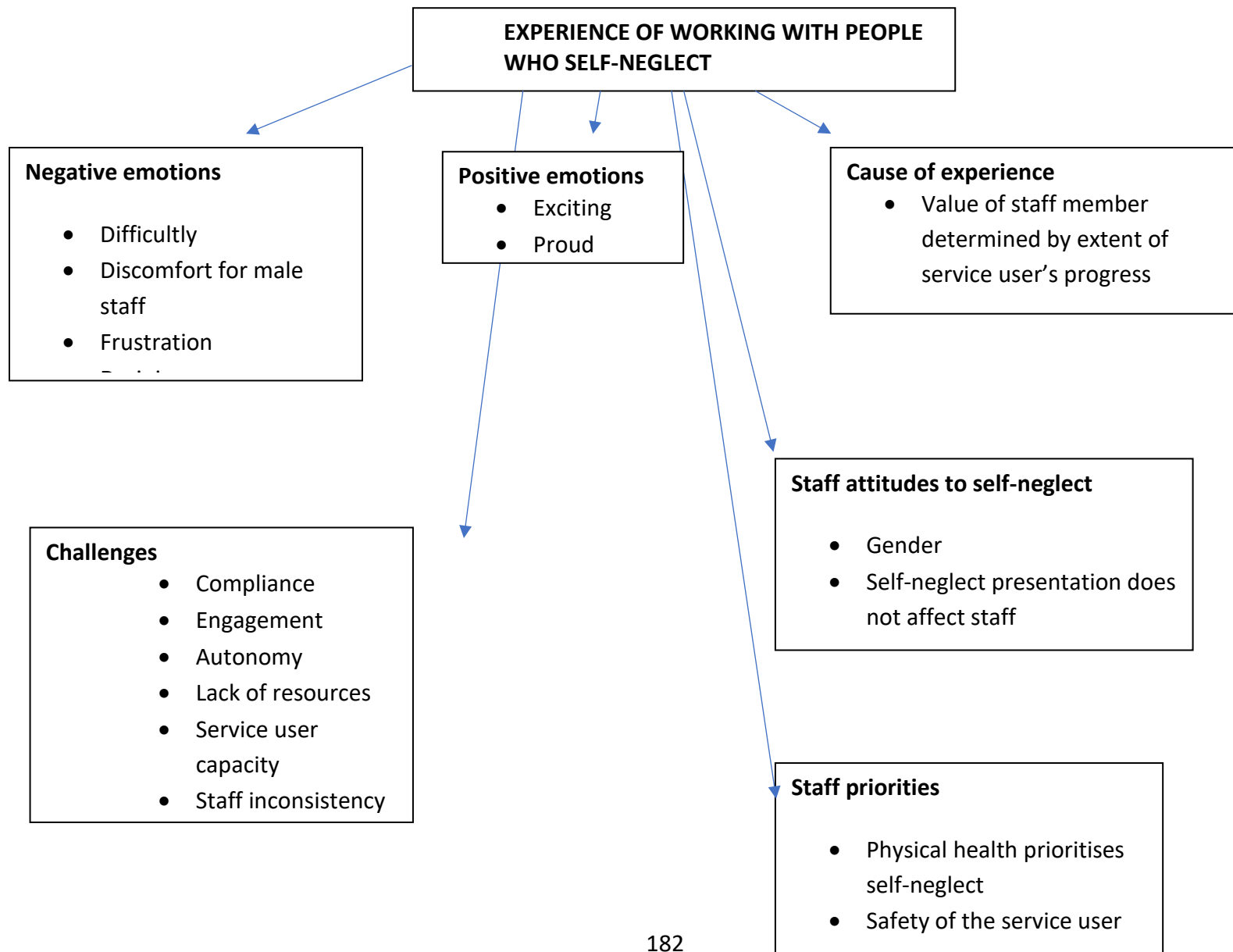
C: code deleted – next version -one participant

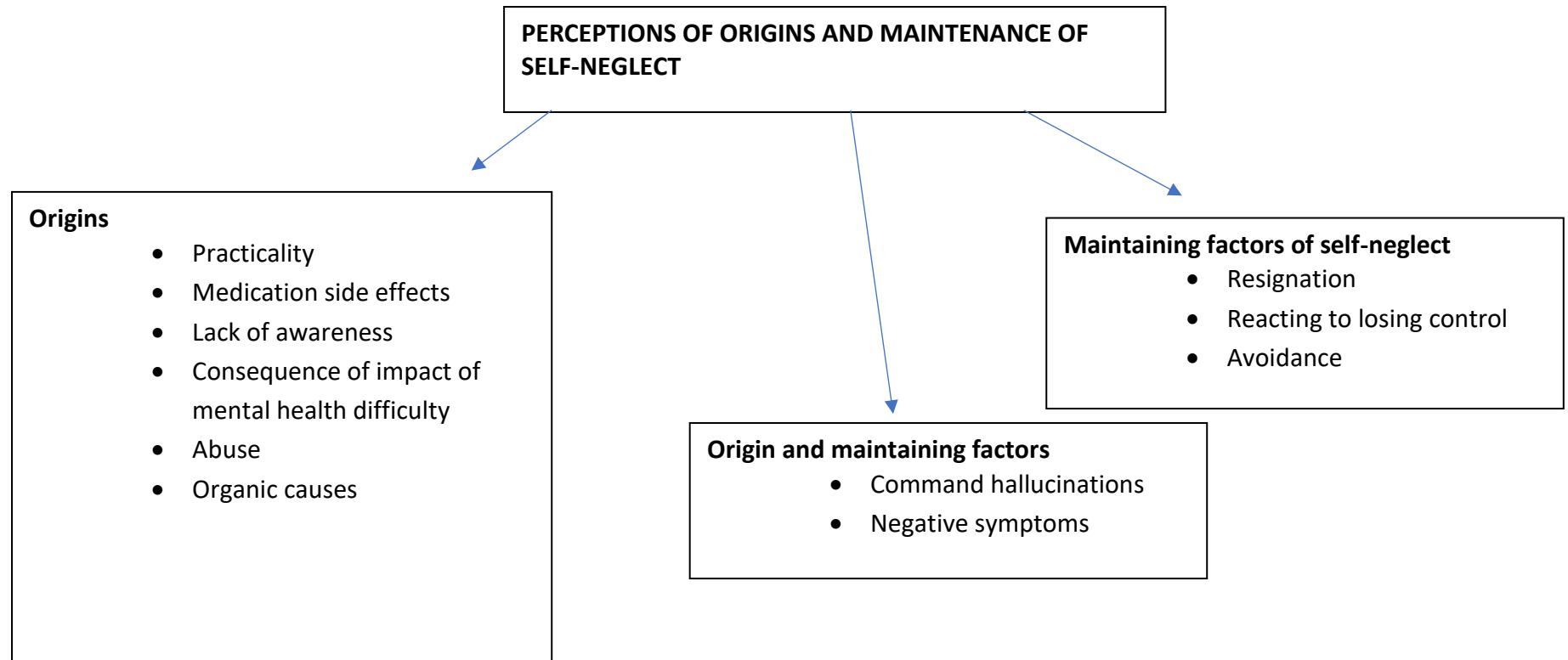
D: code redefined – next version

E: code shifted between codes – next version









### Appendix X. Final Template of Themes (Version 4)

First level code	Second level code	Third level code	Quote	Where in text?
Definition of self-neglect	Properties of self-neglect	Undesirable	“people smelling is a bad thing” “bad living circumstances” “unpleasant” “a bad situation” “unsavoury”	P2 160 P2 170-71 P2 211 P2 446 P2 625 P8
		Multidimensional	“you can look at a particular aspect of something and go into a lot of detail.” “that’s just one kind of tiny aspect” “quite a broad concept” “it’s a broad area”	P2 14  P2 71 P2 10 P2 647 P3 P7
		Consequential	“arising because of active symptoms” “never had any money, therefore he never had any food”	P2 102 P2 456 P3 P5
		Noticeable	“it can be obvious to see” “in a marked way”	P1 34 P2 67 P4 P6 P7 P8
		An individual experience	“for one person, they’re afraid to go to the dentist.”	P2 15-16 P3 P6
		Choice	“unwilling to apply for benefits” “declining on willing to look after themselves” “declining to eat” “Not coming for meals or they’re avoiding meals” “she won’t get up” “not wanting to” “people will not self-neglect out of choice, usually”	P1 6 P1 15 P1 21 P1 22 P1 96 P1 130 P4 80 P6 P7 P8
		Persistence	“it will lead to that cycle” “Prolonged period of time” “slowly” “wearing the same clothes day after day” “you’d notice the clothes being	P1 124-125 P2 219 P2 417 P1 35 P1 68-69

			on every single day or sleep in their clothes" "doesn't want to get up say three or four days a week."	P1 52-53 P3 52-3 P3 160-1 P4 22 P7 P8
		Varies in severity	"it can be a relatively mild thing" "extreme forms of self-neglect" "profoundly neglected" "if things are really bad" "extreme cases"	P2 31 P2 33 P2 382 P2 403 P2 546 P4 P5 P6 P7
		Deteriorates	"very gradual decline" "a deterioration in things" "his home environment has deteriorated" "that progresses. To begin with you might be ok, but there will become more and more of a smell, your clothes will become dirtier and dirtier" "whole house was deteriorated into a messy place" "it always deteriorates again"	P2 96 P2 133-4 P2 197-8 P2 219-221  P2 235 P2 343 P3 P4 P6 P7 P8
	A problem	Self-neglect is problematic when a change from usual presentation	"individual's usual activities" "they may usually appear unkempt" "they may look thinner than you last saw them" "sees a very marked difference"	P2 45 P2 59 P2 74 P2 200-201 P6 1 P8
		When service user does not see self care as a priority	"that's not really important to me right now" and so that's when we hopefully pick up and get back on it.	P8 144-5
	Impact of self-neglect	Negative impact of self-neglect	"it does affect families and partners" "it's really difficult for families to see that" "for family and friends they may well be worried about the impact of self-neglect" "they (family and partners) might be planning to take them out, but they might not want to	P1 76-77 P1 82 P1 85-86 P1 112 P1 130 P1 171 P1 180 P1 284 P1 171 P2 25-26

			<p>take them out”</p> <p>“that impacts on their family life, their social skills”</p> <p>“partner not wanting to take her out”</p> <p>“people move away from them, won’t touch them”</p> <p>“disenfranchised from family and friends”</p> <p>“if... they’re not looking after themselves, first impressions, and that’s what it is isn’t it? It’s first impressions”</p> <p>“it can impact on their mental health”</p> <p>“feeds into issues of self-esteem”</p> <p>“no pride in himself, no self-esteem”</p> <p>“you become more prone to infections”</p> <p>“physical health does deteriorate if they’re neglecting their diet”</p> <p>“self-neglect is one feature in terms of their risks”</p> <p>“self-neglect come under risks to self”</p> <p>“someone neglecting themselves potentially is a safeguarding issue”</p> <p>“you’d be in that low mood”</p> <p>“they just get so low”</p> <p>“you’re not feeling great”</p> <p>“also lead to further distress”</p>	<p>P2 30-31</p> <p>P2 160-1</p> <p>P2 169-70</p> <p>P2 193</p> <p>P2 194-5</p> <p>P2 221</p> <p>P2 301</p> <p>P2 458-9</p> <p>P2 544</p> <p>P3 70-1</p> <p>P4</p> <p>P5 66</p> <p>P5 68-9</p> <p>P5 93-4</p> <p>P6 61-2</p> <p>P7</p> <p>P8</p>
	Noticing self-neglect	Friends and family	<p>“they pick up on it, maybe more than we do.”</p> <p>“if relatives notice something I haven’t”</p>	<p>P2 212-3</p> <p>P2 617-8</p> <p>P3 391-2</p> <p>P6 3-4</p>
		The service user	<p>“patient seeks help as well”</p> <p>“patients might recognise it in themselves”</p>	<p>P2 297</p> <p>P2 299-300</p> <p>P5</p> <p>P8</p>
		Staff	<p>“the whole team does”</p>	<p>P5 201</p> <p>P5 38</p> <p>P6</p> <p>P8</p>
		Use of senses	<p>“we see, smell, use all sorts of</p>	<p>P2 53-54</p>

		important for noticing self-neglect	<p>senses”</p> <p>“it’s not just way you see it’s what you smell”</p> <p>“patients may smell of urine”</p> <p>“breath may smell”</p> <p>“so where you see them”</p> <p>“you see everything”</p> <p>“looking like that, or smelling like that”</p> <p>“we always get to see their environment”</p>	<p>P2 71-72</p> <p>P2 72</p> <p>P2 73</p> <p>P2 151-52</p> <p>P2 159</p> <p>P2 639</p> <p>P3</p> <p>P4</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Gender	<p>“we don’t tend to notice so much with the men”</p> <p>“with women we tend to notice if the hair needs washing.”</p> <p>“with the men it sort of seems to take a back seat and it seems to be ok”</p> <p>“ok for the guys not to do it”</p> <p>“for personal care it just doesn’t seem to get followed up as much”</p> <p>“I’d like to be able to manage the male side of it a bit more”</p> <p>“I don’t know why it goes under the radar”</p> <p>“with the males you’d notice the clothes”</p> <p>“(for the women) unkempt hair”</p> <p>“with women we tend to notice if the hair needs washing.”</p> <p>“unshaven if it’s a male patient”</p>	<p>P1 line 39-40</p> <p>P1 line 39</p> <p>P1 line 47</p> <p>P1 line 49</p> <p>P1 line 72</p> <p>P1 235-36</p> <p>P1 235</p> <p>P1 line 68</p> <p>P1 line 74</p> <p>P1 line 39</p> <p>P2 61</p> <p>P8</p>
	Presentation	Poor hygiene	<p>“dirty clothes, not brushing of teeth”</p> <p>“they don’t brush their teeth”</p> <p>“not washing, not bathing”</p> <p>“don’t change their clothes, launder clothes”</p> <p>“wearing very dirty clothes”</p> <p>“clothes become stained”</p> <p>“breath may smell, through oral hygiene”</p>	<p>P1 17/ 30</p> <p>P2 16</p> <p>P1 18</p> <p>P2 21-2</p> <p>P2 61</p> <p>P2 66</p> <p>P2 73</p> <p>P3</p> <p>P4</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Lack of function	<p>“they’re not able to look after</p>	<p>P1 10</p>

			<p>themselves.”</p> <p>“concerns about how well they are able to care for themselves”</p> <p>“(concerns about) how well they’re able to function”</p> <p>“not doing”</p> <p>“function in their accommodation, in the community or institutional settings.”</p> <p>“somebody just staying in bed, not wanting to get up.”</p> <p>“tend to stay in bed”</p> <p>“not eating, declining to eat.”</p> <p>“not getting up and getting dressed and doing the daily things they should be doing”</p> <p>“in bed 20 hours a day”</p> <p>“didn’t get out of bed at all”</p> <p>“wearing pads/nappies”</p> <p>“they don’t do the usual things people do to maintain oral hygiene”</p> <p>“you have to expend energy to maintain order”</p>	<p>P2 7-8</p> <p>P2 8</p> <p>P2 39-40</p> <p>P2 8 -9</p> <p>P1 18-19</p> <p>P1 108</p> <p>P1 21</p> <p>P1 42</p> <p>P1 368</p> <p>P2 390</p> <p>P2 390-91</p> <p>P2 16-17</p> <p>P2 226-7</p> <p>P3 221-224</p> <p>P4 3</p> <p>P5 3</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Individual looks unkempt	<p>“unkempt really”</p> <p>“appear unkempt”</p> <p>“unshaven”</p> <p>“poorly maintained clothes”</p> <p>“stain things”</p> <p>“they may look thinner”</p> <p>“clothes look looser, belt’s tighter, or they just look thinner overall”</p> <p>“if they’ve lost weight”</p> <p>“they are also in a terrible state”</p> <p>“they look odd”</p>	<p>P1 17</p> <p>P2 59</p> <p>P2 61</p> <p>P2 62</p> <p>P2 64</p> <p>P2 74</p> <p>P2 75-76</p> <p>P2 146-7</p> <p>P2 156-7</p> <p>P3</p> <p>P4</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Poor living conditions	<p>“home environment is in a terrible state; untidy, disorganised.”</p> <p>“home environment may not be organised; dirty”</p> <p>“unpleasant environment”</p>	<p>P2 11-12</p> <p>P2 132-33</p> <p>P2 211</p> <p>P2 396</p> <p>P3</p>

			"hoarding"	P4 P5
		Not attending to finances	"unwilling to apply for benefits that they might be entitled to"	P1 6 P3 94-5 P5 118 P6 22
		Poor diet	"if someone wasn't eating a balanced diet"	P3 6 P3 28 P4 26 P5 4 P5 29 P6 24 P8
		Social isolation	"build and maintain a social network"	P5 4-5 P5 33-4 P7
		Unmanaged physical health	"inability to... attend to your physical health, like attend the GP"	P5 5 P7 P8
		What self-neglect is not	"once somebody was out of bed that was fine" "nicely dressed and their hair done" "washing their clothes, had a shower, been in the bathroom" "you're actually engaging"	P1 225 P1 299-300 P1 380-81 P3 P6 P7 P8
	Determinants of severity of self-neglect	Awareness	"it depends on the level of insight as well"	P2 95 P3 P4 P5 P8
		Negative symptoms	"some are more treatable than others. Negative symptoms are particularly difficult to change. Positive symptoms much easier"	P2 321-2 P3 P5 P7
	Diagnoses associated with self-neglect	Depression	"self-neglect can lead to depression"  "something due to depression?" "mood symptoms, particularly depression"	P1 line 107 P2 92 P2 109 P4 P5 P8
		Psychosis	"in psychosis obviously" "psychosis"	P1 117 P2 102 P3

				P4 P5 P6 P8
		Schizophrenia (severe and enduring mental illness)	"the common diagnosis is paranoid schizophrenia" "the majority of my patients have schizophrenia or schizoaffective disorder"	P2 247 P3 P4 P5 P6 P7 P8
		Bipolar disorder	"we have a few patients who have severe bipolar disorder"	P2 256-7 P4 11 P8
		Co-morbid Substance misuse	"there's a lot of co-morbid substance misuse"	P2 263 P3 104-5 P3 113 P5 98
		Anxiety	"the other sort of significant area that a lot of our clients is anxiety"	P3 113-4 P5 P8
Intervention	Approach	Planned intervention	"we put plans in place." "timetabled" "put some sort of care plan into place" "there is a care package" "support packages" "you can plan your interventions" "target an intervention with the care plan"	P1 51 P1 145 P1 184 P2 356 P2 381 P2 376 P2 531-2 P4 215 P6 P8
		Working as a team using biopsychosocial approach	"the whole team" "we all get together as a team" "team discussions" "talking it through with whole team" "there's no "who's the boss? Who's in charge? Who's a HCA? If anything. It's not that here." "everything's decided as a team" "multidisciplinary team" "it's within a team" "everybody contributes their expertise" "whether it's psychological, whether it's practical or me mucking about with their	P1 190 P1 194-5 P1 314 P1 315-16 P1 357-58  P1 359 P2 372 P2 523 P2 524 P2 534  P2 323 P2 373-4  P2 525 P3

			<p>medication”</p> <p>“psychological interventions”</p> <p>“different sort of professional backgrounds you get a more rounded assessment”</p> <p>“appreciate everybody’s contribution”</p>	<p>P4</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Adapting to individual’s needs	<p>“everything is done on an individual’s needs, everybody has their own plan for each day”</p> <p>“timetabled around them”</p>	<p>P1 143 – 144</p> <p>P1 145</p> <p>P3</p> <p>P4</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Consistent intervention	<p>“we’re sort of on somebody’s case all the time”</p> <p>“all the staff doing the same sort of routine”</p> <p>“very tight”</p> <p>“everybody had to do the same thing”</p> <p>“everybody’s doing the same and we know everybody’s doing the same”</p> <p>“we have to have everybody doing the same thing”</p> <p>“same approach”</p> <p>“every day”</p> <p>“seeing him regularly”</p> <p>“also helps with all the staff doing the same sort of routine”</p> <p>“it helps because everybody’s doing the same approach”</p>	<p>P1 109-110</p> <p>P1 205</p> <p>P1 212</p> <p>P1 212-13</p> <p>P1 215</p> <p>P1 217</p> <p>P1 219</p> <p>P1 221</p> <p>P2 476</p> <p>P1 205</p> <p>P1 230-31</p> <p>P4 260-1</p> <p>P5 208</p>
		Persistence	<p>“it’s perseverance, obviously perseverance”</p> <p>“if we just keep trying”</p> <p>“keep going”</p> <p>“stuck with him”</p>	<p>P1 326</p> <p>P1 388</p> <p>P2 378</p> <p>P2 473</p> <p>P4</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Staged intervention	<p>“firstly”</p> <p>“then”</p> <p>“initially”</p>	<p>P1 182</p> <p>P1 183</p> <p>P1 364</p> <p>P3</p> <p>P4</p>

				P7
		Trial and error	<p>"Ok, this is not working let's have another plan"</p> <p>"Keep trying and keep trying and try again"</p> <p>"suggestions"</p> <p>"generate ideas"</p> <p>"Ok, what worked? What didn't work? Well how can we change that? And we just keep going and keep going swapping and changing until we get it right"</p>	<p>P1 360-61</p> <p>P2 377</p> <p>P2 527</p> <p>P2 559</p> <p>P1 365-367</p> <p>P3</p> <p>P5</p> <p>P7</p>
		Care	<p>"carefully, hopefully tactfully"</p> <p>"sensitively"</p> <p>"has to be done carefully"</p>	<p>P2 313</p> <p>P2 315/365</p> <p>P2 341</p> <p>P3</p> <p>P6</p> <p>P8</p>
		Creativity	"opportunity to be creative"	<p>P3 386</p> <p>P5</p> <p>P8</p>
		Different services for males and females	"women's group... men's group"	<p>P1 332</p> <p>P6</p> <p>P8</p>
	What staff do	Talking	<p>"we all get together as a team quite often"</p> <p>"we have supervision every week"</p> <p>"we meet once a week"</p> <p>"we speak to the psychologist"</p> <p>"team discussion"</p> <p>"discuss every patient on the caseload"</p>	<p>P1 195-5</p> <p>P1 197</p> <p>P2 526</p> <p>P1 318</p> <p>P2 344</p> <p>P2 526</p> <p>P3</p> <p>P5</p> <p>P8</p>
		Care planning	<p>"if they're still not happy, if they're still not doing things, we can refer back to the care plan"</p> <p>"You agreed to get up at ten, it's ten o'clock now so come on"</p>	<p>P1 186-7</p> <p>P1 403</p> <p>P7</p> <p>P8</p>
		Service user involvement	<p>"they know what they're doing"</p> <p>"involve the patient and try and motivate them to become part of the process"</p> <p>"addressing it with the patient or sensitively raising it with the</p>	<p>P1 144</p> <p>P2 314-5</p> <p>P2 563</p> <p>P3</p> <p>P4</p> <p>P5</p> <p>P6</p>

			patient"	P7 P8
		Recognise self-neglect	"recognising it"	P2 314 P3 P5 P8
		Give service user choice	<p>"we're not forcing them to do things they don't want to do"</p> <p>"what they want to do"</p> <p>"we can't force people to do anything"</p> <p>"something they've chosen to do"</p> <p>"they agree to"</p> <p>"time agreed to be knocked/woken up"</p> <p>"" What time would you like to wake up this morning?" I don't want to take all of her choices away"</p> <p>"ok well this is the options"</p> <p>"Are you ready to get up?"</p> <p>"Instead of telling them, asking. Giving them the choice, giving them the control back."</p> <p>"maximise their autonomy"</p>	<p>P1 145-146</p> <p>P1 145</p> <p>P1 149</p> <p>P1 150</p> <p>P1 184/ 185-186</p> <p>P1 201</p> <p>P1 276-7</p> <p>P1 278</p> <p>P1 394</p> <p>P1 394</p> <p>P2 330</p> <p>P6</p> <p>P8</p>
		Proximity to service user	<p>"we could be in the bedroom with her in the morning for two hours"</p> <p>"staff would sit in somebody's room"</p> <p>"we would sort of back off, then we back off a little bit more"</p> <p>"because you're there it's quite intimate"</p>	<p>P1 92-93</p> <p>P1 202</p> <p>P1 223-24</p> <p>P1 310</p> <p>P7</p> <p>P8</p>
		Staff taking responsibility for daily tasks	<p>"we're running her a bath and we're washing her hair for her."</p> <p>"knocked/woken up"</p> <p>"helping them"</p>	<p>P1 54</p> <p>P1 201</p> <p>P2 356</p> <p>P8</p>
		Monitoring activities	<p>"check that he's had a bath every day"</p> <p>"food and fluid charts just to help them."</p> <p>"we'd do checks"</p> <p>"we'd still be on top of it"</p>	<p>P1 55</p> <p>P1 27-28</p> <p>P1 71</p> <p>P1 102</p> <p>P1 326</p> <p>P1 359</p>

			<p>"things documented"</p> <p>"ward review"</p> <p>"we can monitor that on a daily basis"</p> <p>"it's all recorded and monitored... everything"</p> <p>"she needs to be downstairs so we can monitor her quite a lot"</p> <p>"watch somebody have a bath, watch somebody have a shower"</p>	<p>P1 379</p> <p>P1 381</p> <p>P1 412</p> <p>P1 311</p> <p>P3</p> <p>P5</p> <p>P6</p> <p>P8</p>
		Prompts	<p>"we bring it up lots"</p> <p>"we prompt her"</p> <p>"we tend to prompt them"</p> <p>"prompting her to have a shower, prompting her every step of the way"</p> <p>"encourage them"</p> <p>"it's up on the wall"</p>	<p>P1 51</p> <p>P1 53</p> <p>P1 72</p> <p>P1 93-94</p> <p>P1 150</p> <p>P1 144</p> <p>P3</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>p8</p>
		Allocated staff members	<p>"we have got somebody in place."</p> <p>"each patient has a named nurse and a co-worker as well so there's two named nurses"</p> <p>"the care coordinator"</p> <p>"people are allocated to do a particular piece of work"</p>	<p>P1 55</p> <p>P1 192</p> <p>P2 532</p> <p>P2 534</p> <p>P5</p> <p>P6</p> <p>P8</p>
		Establishing routine	<p>"we'd go through a routine"</p> <p>"becomes a routine"</p> <p>"it would be routine"</p> <p>"having routine"</p>	<p>P1 201</p> <p>P1 230</p> <p>P1 326</p> <p>P1 384</p> <p>P3</p> <p>P6</p> <p>P8</p>
		Developing relationship with service user	<p>"bit of a bond with them"</p> <p>"more of a trust with somebody"</p> <p>"we have lots of one-to-one time"</p> <p>"someone who knows the patient very well"</p>	<p>P1 309</p> <p>P1 309-10</p> <p>P1 339</p> <p>P2 313</p> <p>P3</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Involving tertiary	"environmental health and	P2 175-80

		services	social services" "dentist"	P2 541 P3 74-5 P4 96-7 P4 125-6 P4 127-9 P5 177-8
		Assessment and formulation	"assess what is going on" "understanding, a formulation if you will" "Based on the formulation you can plan" "Go back to the formulation" "once you've decided what you're dealing with" "you have a good think about why this might be" "with depression we can help with medication or the anxieties and stuff." "antipsychotic medication" "we will try and address whatever the cause is" "it really kind of comes down to what the cause is"	P1 354-55 P2 315-6 P2 323 P2 324-5 P2 372 P2 374-6 P2 519 P2 531 P2 557 P4 154-5 P5 83-5 P5 175 P5 235 P6 53-4 P8
	What doesn't work for self-neglect	Authoritarian approach	"heavy handed, "Right you're getting out of bed" does not work" "shouting, quite stern really just doesn't work" ""pull yourself together and get yourself tidied up." I can't imagine that would be very successful"	P1 385  P1 406 P2 582-3 P3 P8
		No intervention	"left without support and intervention patients can be left in a very perilous state" "if you leave any kind of home environment without tidying it up it gets more and more untidy"	P2 32  P2 224-5 P5 298-300 P4 P7 P8
	Outcome of intervention	Moderate improvement	"positive change" "meaningful change fundamentally for the patient" "not expecting that, you know, life is going to be completely transformed"	P2 443 P2 565 P3 262 P5 P6 P8

		Self-neglect returns	<p>"it often does kind of gravitate back to a bad situation"</p> <p>"temporarily improve things and then they go back"</p> <p>"things often do go back downhill again for a while"</p> <p>"if you haven't addressed the sort of root – underlying cause of self-neglect it always deteriorates again"</p>	<p>P2 445-6</p> <p>P2 502</p> <p>P2 510-11</p> <p>P2 342-3</p> <p>P5</p> <p>P8</p>
		Not always successful	<p>"if you can make a change"</p> <p>"something you can't necessarily change"</p>	<p>P2 448</p> <p>P2 326</p> <p>P4 144-5</p> <p>P4 273-4</p> <p>P4 295-6</p>
Experience of working with people who self-neglect	Negative emotions	Difficulty	<p>"it is difficult"</p> <p>"struggling with somebody"</p> <p>"struggled and struggled and struggled"</p> <p>"it's hard"</p> <p>"difficult it is"</p>	<p>P1</p> <p>242/261/272</p> <p>P1 315</p> <p>P1 323</p> <p>P1 388</p> <p>P2 444</p> <p>P3</p> <p>P4</p> <p>P5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Discomfort for male staff	<p>"maybe it's the staff who feel uncomfortable doing it (male staff)"</p> <p>"difficult conversation to have"</p> <p>"maybe the male staff feel embarrassed about it"</p>	<p>P1 243-44</p> <p>P2 302</p> <p>P1 244-5</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Frustration	<p>"difficult dealing with some of the areas of frustration"</p>	<p>P3 376</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Draining	<p>"it is quite emotionally draining"</p>	<p>P4 282</p> <p>P6</p> <p>P7</p> <p>P8</p>
	Positive emotions	Exciting	<p>"I feel quite a buzz"</p>	<p>P1 298</p> <p>P3</p> <p>P8</p>
		Proud	<p>"it was a very proud moment for me actually, a proud moment for us all."</p>	<p>P3 492-3</p> <p>P1</p> <p>P8</p>

	Cause of emotion	Value of staff member determined by extent of service user's progress	<p>"I get quite proud of myself when I've actually achieved it"</p> <p>"it's good when you see somebody coming down all nicely dressed and their hair done"</p> <p>"I feel rubbish when I can't achieve it"</p> <p>"when I do achieve it I feel like yeah, I have achieved something today"</p> <p>"if you're not successful you can get disheartened"</p> <p>"if you can make a change that's good for your sense of worth"</p> <p>"get fed up and think you're not achieving something"</p> <p>"when I can't achieve it, because it makes you feel like you haven't done your job"</p> <p>"I haven't possibly done my best"</p>	<p>P1 298</p> <p>P1 299-300</p> <p>P1 420</p> <p>P1 421</p> <p>P2 377-8</p> <p>P2 448</p> <p>P2 504-5</p> <p>P5 349-50</p> <p>P1 420-21</p> <p>P1 423-24</p> <p>P6</p> <p>P8</p>
	Challenges	Compliance	"they'll do it, but they'll do it under protest"	<p>P1 253</p> <p>P5 212</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Engagement	<p>"part of the problem is engagement"</p> <p>"patients can be difficult to engage"</p>	<p>P2 309</p> <p>P2 560</p> <p>P3 190-1</p> <p>P5 213</p>
		Lack of resources	<p>"the evidence base for what works in negative symptoms, is a lot harder"</p> <p>"if there was an evidence based, very effective intervention that would address that, that would be very helpful"</p> <p>"availability of resources as well"</p> <p>"finances for that are increasingly limited"</p>	<p>P2 323-4</p> <p>P2 353</p> <p>P2 351-2</p> <p>P2 357</p> <p>P4 190-1</p> <p>P5 258-9</p> <p>P6</p> <p>P8</p>
		Autonomy	"you're always kind of worried that you're going to seem	P2 328-9

			<p>paternalistic about, you know, taking over someone's life"</p> <p>"some people might view it as paternalistic"</p> <p>"we are trying to stop being too dependent on us for doing things as well, so that's another dynamic"</p> <p>"they can choose unwisely to live in terrible circumstances and neglect themselves"</p> <p>"in what you think is their best interest you can come into problems"</p> <p>"Is it appropriate to do something?"</p> <p>"if you're quite happy losing weight, not eating very much, don't mind that your clothes are in tatters and you're living in squalor"</p>	<p>P2 346</p> <p>P2 508-9</p> <p>P3 165-7</p> <p>P2 570-1</p> <p>P5 285-6</p> <p>P2 331-2</p> <p>P2 528</p> <p>P2 566-8</p> <p>P6</p> <p>P8</p>
		Service user capacity	"issues around capacity"	<p>P2 568-9</p> <p>P3 311-3</p> <p>P3 323-4</p> <p>P5 242</p>
		Staff inconsistency	"different things or approach it differently it doesn't work"	<p>P1 206</p> <p>P3</p> <p>P7</p>
	Staff attitudes to self-neglect	Self-neglect presentation does not affect staff	<p>"I mean for staff if we've got to go out with somebody who doesn't want to attend to their personal care its not really an issue for us"</p> <p>"I don't think it really has an impact"</p>	<p>P178-80</p> <p>P1 436</p> <p>P7</p>
		Gender	<p>"harder with men than it is with the women."</p> <p>"that side of it"</p> <p>"women don't care if they take their clothes off in front of another woman but if a am was taking his clothes off in front of another male staff"</p> <p>"the females, we sort of get on with it"</p> <p>"maybe the male staff feel embarrassed about it"</p>	<p>P1 38</p> <p>P1 237</p> <p>P1 241</p> <p>P1 243</p> <p>P1 244-245</p> <p>P6</p> <p>P7</p> <p>P8</p>

	Staff priorities	Physical health prioritises self-neglect	<p>“her personal care is not really our main concern as such because of her physical health”</p> <p>“physical is more of a concern”</p> <p>“if physical needs take precedence on that it would come kind of lower down”</p> <p>“not going to be prompting her everyday when our main concern is just to get her to come down for medication”</p>	<p>P1 line 97</p> <p>P1 line 97-98</p> <p>P1 line 101</p> <p>P1 103-104</p> <p>P7</p>
		Safety of the service user	<p>“Everyone’s safe, everyone’s here.” So, self-neglect can be something that’s put to one side</p>	<p>P6</p> <p>P7</p> <p>P8</p>
Perceptions of origins and maintenance of self-neglect	Origins	Practicality	<p>“it could include the practical aspects of washing”</p> <p>“not able to attend to themselves going to the toilet”</p>	<p>P2 22-23</p> <p>P2 72-73</p> <p>P8</p>
		Medication side effects	<p>“side effects of medication which they may not attend to”</p>	<p>P2 62/3</p> <p>P4</p> <p>P6</p> <p>P8</p>
		Lack of awareness	<p>“aren’t either aware of it”</p> <p>“is this a conscious process?”</p> <p>“wouldn’t necessarily be thinking to do”</p> <p>“patients may not realise there are problems, issues that need addressing”</p> <p>“somebody who’s manic will always do things and forget to do the routine things”</p>	<p>P2 25</p> <p>P2 65</p> <p>P2 90-91</p> <p>P2 284</p> <p>P2 298-299</p> <p>P3 199-200</p> <p>P4</p> <p>P8</p>
		Consequence of impact of mental health difficulty	<p>“something due to depression?”</p> <p>“negative cognitions that come from depression”</p> <p>“these things are arising usually because of active symptoms”</p> <p>“the patient lacks motivation, they’re apathetic, they lack the drive to do things”</p> <p>“it may be due to positive symptoms”</p> <p>“the psychomotor retardation”</p> <p>“profoundly unwell and</p>	<p>P2 92</p> <p>P2 92-93</p> <p>P2 104</p> <p>P2 105</p> <p>P2 109</p> <p>P2 110</p> <p>P2 151</p> <p>P2 158</p> <p>P2 264-5</p> <p>P2 267-9</p>

			<p>neglecting themselves”</p> <p>“impact of psychosis or depression”</p> <p>“if you have someone who’s dependent on substances the substance becomes their focus”</p> <p>“if they’re maybe intoxicated all of the time they’re not focusing on other things like their diet, they’re not looking after themselves”</p> <p>“positive symptoms, if they’re distracting can have an impact on someone’s behaviour and therefore self-neglect”</p> <p>“psychosis – thought processes and disorganised person”</p> <p>one feature of a lot of my patients”</p> <p>“psychoses that we are dealing with and that links in with self-neglect”</p>	<p>P2 277-8</p> <p>P2 280</p> <p>P3</p> <p>P4 37</p> <p>P5</p> <p>P5 43</p> <p>P6</p> <p>P7</p> <p>P8</p>
		Abuse	<p>“a consequence of people being taken advantage of”</p>	<p>P2 139</p> <p>P3</p> <p>P8</p>
		Organic causes	<p>“their grey matter function is damaged”</p>	<p>P4 66 - 8</p> <p>P4 14</p> <p>P4 140</p> <p>P4 196-8</p> <p>P5 43-4</p> <p>289</p>
	Maintaining factors of self-neglect	Resignation	<p>“they’ll probably think “why bother?””</p>	<p>P1 131</p> <p>P4 70-1</p>
		Reacting to losing control	<p>“being put in hospital, being told what to do, on medication, takes that loss of control”</p> <p>“well this is the only part of me I have control over”</p> <p>“you might see somebody who’s really well groomed, but you don’t see that side very often, it always seems to be the neglect side of it”</p> <p>“give her some control over it now”</p> <p>“they’ll describe very early on when I speak to people about</p>	<p>P1 166-167</p> <p>P1 167</p> <p>P1 167-169</p> <p>P1 277-8</p> <p>P3 318</p> <p>P7</p>

			issues around loss of control, they'll always say "Well I've lost my freedom, I don't have choices at the moment because I'm under a section"	
		Avoidance	"they're going to stay in bed anyway because they don't have to come down and face anything" "they're afraid to go to the dentist so they don't brush their teeth very often"	P1 23-124 P2 16
	Origin and maintaining factors	Command hallucinations	"someone's hearing voices and they're telling them not to listen" "whatever the voices are saying is paramount for that person" "regardless of what it is, regardless of what they think they still do that"	P1 line 117 P1 line 118 P1 176 P3 201-3
		Negative symptoms	"lacking motivation"	P2 62-3 P2 224 P2 91-92 P6 P7 P8









## Appendix XIII. Interview Schedule

### Interview Schedule (Version 1.0 17<sup>th</sup> September 2017)

#### Interview Questions

Orientation: Thinking about your work in AOT / Rehab...

#### *Part 1: what is self-neglect?*

- What does self-neglect mean to you? [Prompts: How would you define self-neglect? What is your understanding of self-neglect?]
- When people self-neglect, what sorts of things do you see? [Prompt: what are the most noticeable signs? Is it just this aspect of their lives or does it affect others? What are the first signs you see that tell you someone might be neglecting themselves? How does it progress? Does it stay the same or get worse? In what ways?]
- What mental health difficulties have you encountered in people with self-neglect issues in AOT / rehab? [Prompt: psychosis, non-psychosis symptoms, like anxiety, low mood]
- Is there anything particular about the self-neglect you see in people with psychosis? If so, what?
- In what ways do you think people's mental health and self-neglect might be linked (if at all)? [Prompt: How does the psychosis affect the self-neglect and vice versa?]

#### *Part 2: what do you do about it?*

- How do you address self-neglect with service users?
- How do you manage the presentation of self-neglect? What would you like to do to help manage it (even if you cannot at the moment)? [Prompt: what are some of the challenges of working with self-neglect? What are some of the opportunities of working with people who self-neglect?]
- What interventions have you used / tried for self-neglect? (Prompt: psychological, social, medical?)
- How do you decide what to do? (Prompt: By who? How do arrive at a decision?)
- In your experience, what interventions seem to have been effective when working with people who are neglecting themselves?
- What interventions have not worked so well?
- How do you feel when working with people who neglect themselves?



