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# **Negative Symptoms of Schizophrenia and Psychosocial Treatment: Thematic Analysis of Stakeholders' Perspectives**

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BSc (Honours) in Psychology

Submitted in partial fulfilment of the requirements for the degree of Doctorate in  
Clinical Psychology

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## CHAPTER 1: SYSTEMATIC REVIEW

### **A narrative synthesis of the effective components of psychosocial interventions for the treatment of *specific* negative symptoms of schizophrenia.**

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## **Abstract**

**Purpose.** Negative symptoms in schizophrenia have a significant impact on recovery. There has been increased reporting in the literature on the benefits of psychosocial interventions for these symptoms. However, thus far no attempt has been made to disentangle the effective components of these interventions and the *specific* negative symptoms they target. This review aimed to address this need by systematically reviewing the literature utilising narrative synthesis techniques.

**Methods.** A literature search of electronic databases, reference lists and forward citations, and a hand search of Clinical Psychology Review and Schizophrenia Research was completed with authors contacted for unpublished data and/or further related work. Thematic analysis techniques were employed to extricate common psychosocial components from interventions.

**Results.** Eleven articles met inclusion criteria with all reporting reduction rates in *specific* negative symptoms. Avolition was the most common target of interventions. There is marked variance in methodologies employed across the included papers with various theoretical frameworks guiding intervention. Descriptions of psychosocial interventions in papers are not sufficient to allow for clear understanding of the components of interventions that target *specific* symptoms. Common themes of treatment components were identified.

**Conclusions.** The review is the first of its kind in attempting to define and synthesise effective psychosocial intervention components and the *specific* negative symptoms they target. The reviewed interventions report positive effects on negative symptoms but there is marked variance in methodologies. The implications of this variance are discussed and future avenues of research identified.

## **Practitioner points**

- The psychosocial approach to treating negative symptoms is an emergent field of research indicating beneficial effects.
- There is a need to develop a unified approach to research in this field.
- Avolition is amenable to psychosocial intervention, consistent with research outcomes.
- Common intervention components are identified which may guide clinical intervention strategies.

## Introduction

People diagnosed with schizophrenia experience symptoms classified as *positive*, those that are abnormal by virtue of their presence, and *negative*, those which reflect a loss or diminution of a previously present capacity (Carpenter, Heinrichs, & Wagman, 1988). Negative symptoms in schizophrenia are characterised by a lack of motivation, reduced capacity for enjoyment and engagement in everyday activities. Up to 40% of individuals with chronic schizophrenia can experience negative symptoms (an der Heiden, Leber, & Hafner, 2016).

There remains a gap in knowledge about effective treatments for negative symptoms and there is significant variability in current approaches, highlighted recently in a systematic review by Elis, Caponigro and Kring (2013). It is important to understand how change is brought about through a given intervention, specifically what the mechanisms of change may be for negative symptoms (Kaiser, Lyne, Agartz, Clarke, Morch-Johnsen, & Faerden, 2016). Elis et al (2013) described a variety of psychosocial interventions and their influence on negative symptom outcomes. It is unclear what the effective mechanisms of psychosocial interventions are and what specific negative symptoms they target, factors which the Medical Research Council (MRC) indicate are important in intervention development (Craig, Dieppe, Macintyre, Michie, Nazareth, & Petticrew, 2008). This is also important for understanding the long-term effects of treatments and may aid in adapting interventions to meet individual need (Chien, Leung, Yeung, & Wong, 2013).

The evolution of negative symptom conceptualisation may be a contributing factor to the noted variance in psychosocial intervention/outcomes. Recent views suggest negative symptoms can be meaningfully subdivided into expressive and experiential deficits (Foussias & Remington, 2010; Foussias, Agid, Fervaha, & Remington, 2014). Kaiser et al (2016) highlight an issue in the ways in which these subdomains are defined across the literature (i.e. 'avolition' being used interchangeably as a 'symptom' or a blanket term for other symptoms). Conceptualising negative symptoms is further complicated by primary and secondary symptoms. Kirschner, Aleman, and Kaiser (2016) recently indicated the need for assessment and treatment of symptoms intrinsic to schizophrenia (primary) and those stemming from other influences (secondary). Secondary symptoms may emerge through the impact of positive symptoms, comorbid mental health disorders (e.g. depression), or through medication side effects. It is possible that the mechanisms underlying the development and/or maintenance of *specific* negative symptoms may vary (Kirschner et al, 2016) and this will have implications for identifying mechanisms of therapeutic effect. For example, social skills training (SST) may improve social skill deficits but not

cognitive impairment. Therefore, understanding specific intervention mechanisms may aid in matching treatment to symptoms.

Finally, Moritz, Berna, Jaeger, Westermann, & Nagel (2016) recently highlighted the variance in treatment outcome priorities between patients, carers, and professionals. This can make measurement of intervention '*success*' difficult. For example, Schooler et al's (2015) consensus statement provides clinical guidelines on what constitutes acceptable recovery indicators. Yet, this notion of recovery may be at odds with what people who experience schizophrenia find acceptable from interventions (Sterk, Winter van Rossum, Muis, & de Haan, 2013). Additionally, no systematic attempt has thus far been made to extricate treatment effects in relation to negative symptom subdomains (Galderisi, Farden, & Kaiser, 2016). It is therefore crucial to address this gap and to understand what negative symptom interventions are currently acceptable.

## **Objective**

To analyse psychological treatment studies and extract descriptions of effective psychosocial treatment techniques that target *specific* negative symptoms. The following questions guided the systematic review:

1. What psychosocial treatment techniques have proven effective in the treatment of *specific* negative symptoms and how are they described in the literature?
2. What *specific* negative symptoms do these techniques improve and how are improvements measured?
3. How acceptable are the interventions and the associated outcomes to patients?

## **Methods**

A systematic review of the literature was completed in accordance with the PRISMA statement (Moher, Liberatti, Tetzlaff, & Altman, 2009). The following inclusion and exclusion criteria were applied.

Inclusion criteria:

- Adult participants (aged 18-65) with a reported diagnosis of a Schizophrenia Spectrum Disorder (SSD).
- Provides descriptions of psychosocial interventions for the treatment of negative symptoms.
- Mixed methodologies, including meta-analyses and systematic reviews.

- Primary or secondary clinical outcomes for *specific* subdomains of negative symptoms.

Exclusion criteria:

- Non-psychosocial interventions (e.g. solely drug studies).
- Clinical guidelines, conference/presentations, editorials, theoretical papers, book chapters, and grey literature.
- Papers not written in English.

### *Search Strategy*

The literature search, carried out in August 2015, consisted of a mixture of both electronic and hand searching of resources. The following online databases were searched up to August 2015: EBSCO - CINAHL, MEDLINE PyschINFO, and Psychological and Behavioural Sciences Collection; Ovid – Journals@Ovidfulltext. NHS Scotland Journals, Ovid Medline, and Embase; and NCBI – PubMed.

For each of the databases two groups of terms were applied. Group one consisted of a broad set of terms related to psychosocial interventions (e.g. “psychosocial interventions”... “Psychosocial therapy”) and a narrow set of terms (e.g. “cognitive therapy”), which were then grouped together using the Boolean operator “OR”. Group two consisted of a broad set of terms related to schizophrenia and negative symptoms (e.g. “schizophrenia...psychosis”) and a narrow set of terms (e.g. “alogia, anhedonia, apathy”), which were then grouped together using the Boolean operator “OR”. These two groups were combined using the Boolean operator “AND” to perform the search. Three authors were contacted for original papers where items were electronically inaccessible, all responded.

To identify further relevant articles that the electronic search may have overlooked, forward citation of two key papers (Elis et al, 2013; Schooler et al, 2015) and a hand search of their reference list was carried out by one author (PS). An additional hand search of two journals (Clinical Psychology Review and Schizophrenia Research) was conducted. This stage of the search identified a combined total of 1,392 papers for initial screening.

### *Screening*

A small sample of titles and abstracts were independently screened by two authors (HM and PS) as part of eligibility screening to ensure the inclusion/exclusion criteria were sufficient and to minimise bias. A concordance rate of 80% was achieved with disagreements resolved by discussion as per predefined strategy in the review protocol. The eligibility criteria were applied to all titles and abstracts which led to 1,047 papers being excluded.

Full screening of 182 papers was completed, leading to 173 papers being rejected. Nine papers were identified for inclusion and a hand search of each reference list was completed. Furthermore, the authors of these nine included papers were contacted to enquire for further data (both published and unpublished). This led to an additional two papers identified for inclusion, providing a final total of 11 included papers (see Figure 1).

#### *Data extraction and synthesis*

The characteristics of participants, methodologies applied, and interventions used within the included studies varied. Popay et al (2006) provide guidance on conducting a narrative-synthesis approach to tackle this issue of heterogeneity when assessing the effects of interventions from research evidence. The synthesis can include the following phases:

- Developing a preliminary synthesis of findings of included studies.
- Exploring relationships in the data.
- Assessing the robustness of the synthesis.

This approach was adopted within this review and utilised further techniques described by Arai et al (2007). Thematic analysis was adapted from strategies reported elsewhere in the literature (see Bird, Boutillier, Leamy, Williams, Bradstreet & Slade, 2014). The extraction and synthesis of data was carried out in a number of stages, described below.

#### *Stage One – Data extraction, tabulation, and quality rating*

The sources of data were heterogeneous in nature (i.e. a mixture of both quantitative and qualitative studies with mixed methodologies). The first step included extracting information from each study for quality rating (see Table 1). This information was then transformed into a tabulated format providing descriptions of key factors relevant to the review objective (see Tables 2 and 3 below).

Following this, the psychosocial intervention, described in each paper, was analysed by one author (PS). These were diluted into single coded components to identify the specific technique being described.

#### *Stage Two – Exploring relationships between studies*

Intervention descriptions, outcome measurement, and negative symptom outcome were explored to identify relationships between studies in relation to the objectives of the study.

#### *Stage Three – Thematic analysis*

Thematic analysis (Braun & Clarke, 2006) was used as a framework and applied to the psychosocial components identified in *Stage One*. The coded psychosocial

components were cross referenced by one author (HM) for triangulation. For example, enhancing the ability to take the perspective of others was coded '*developing skills to understand and respond in social situations*' and coping with stressors was coded as '*developing skills to meet challenges*'. Further similar codes, within and across studies, were collated and formed the broad theme of '*developing generic problem solving skills that enable people to understand and respond to everyday challenges*'. Themes were then vote counted across all the studies. A decision was made a priori that themes would be included should they occur in at least five or more of the 11 included studies.

### **Quality Rating**

Papers were appraised for quality by one author (PS) and an independent rater using the Crowe Critical Appraisal Tool (CCAT; Crowe and Shepperd, 2011). This tool can be used across research designs and provides a comprehensive user guide which can aid inter-rater reliability (Crowe, Sheppard, & Campbell, 2012). The CCAT is comprised of 8 sub-categories and a total quality score. A threshold was set a priori indicating no more than a difference of 3 points on a 40 point scale for agreement in quality. Seven of the included studies reached this level of agreement and the range of discrepancy on the other papers ranged from 5 to 7. Discrepancies were resolved by discussion and a consensus score reached (see Table 1).

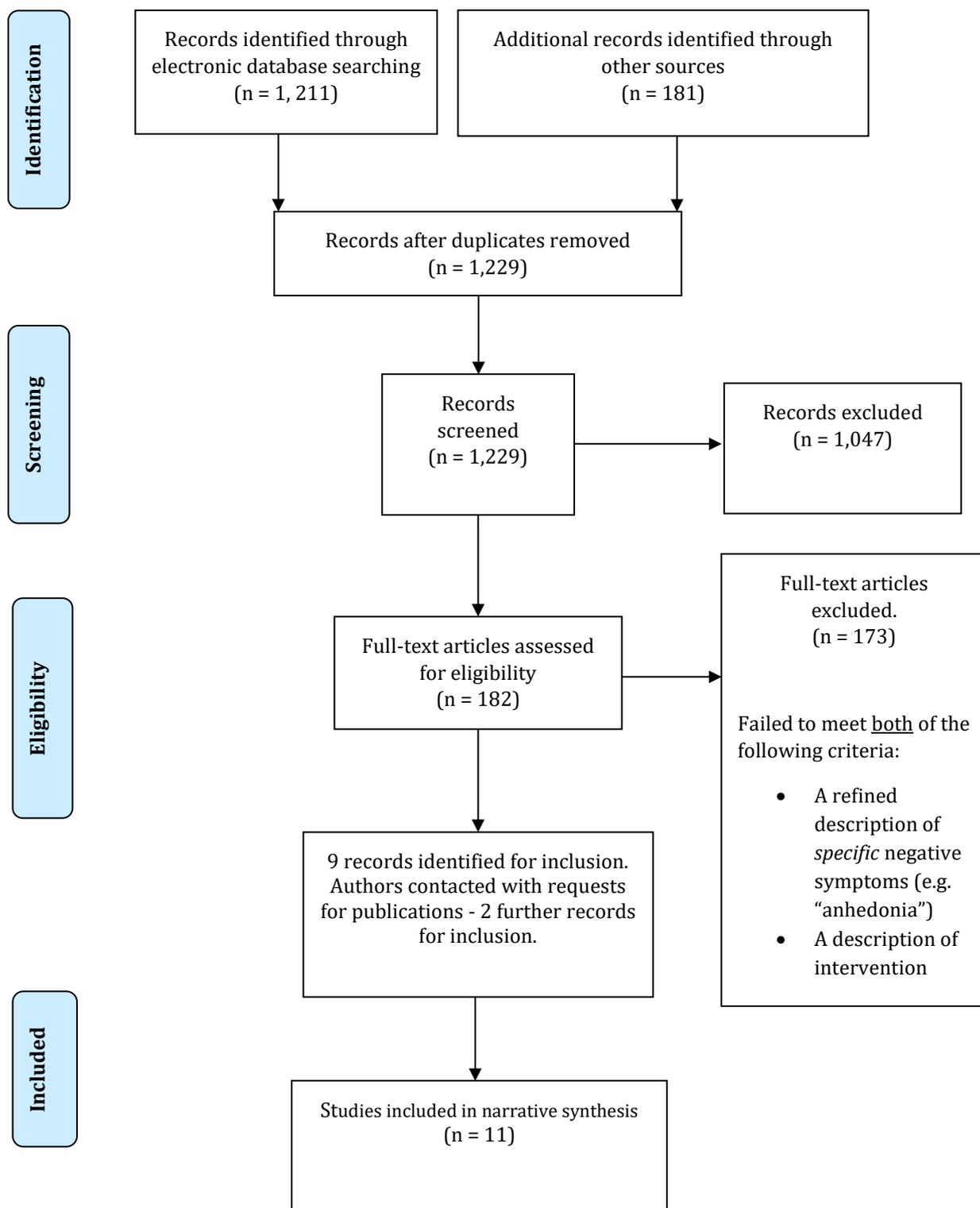
**Table 1 - CCAT Quality Appraisal Scores**

Study	Total (Max =40)	% Score	Preamble	Intro	Design	Sample	Data	Ethics	Results	Disc
Eack, Mesholam-Gately, Greenwald, Hogarty, & Keshavan (2013)	26	65	3	3	3	2	4	2	5	4
Favrod, Giuliani, Ernst & Bonsack (2010)	22	55	3	5	2	1	2	1	3	4
Favrod et al, (2015)	30	75	5	5	3	3	3	4	4	3
Granholm, Holden, Link & McQuaid (2014)	35	88	5	5	5	3	4	4	4	5
Grant, Huh, Perivoliotis, Stolar, & Beck (2012)	32	80	4	2	5	4	5	4	4	4
Johns, Sellwood, McGovern & Haddock's (2002)	22	55	4	3	2	2	3	2	4	2
Johnson, Penn, Fredrickson, & Meyer Kring & Brantley, (2009)	10	25	3	3	1	0	1	0	1	1
Johnson et al (2011)	24	60	2	5	3	2	2	4	4	2
Klingberg et al (2011)	37	93	5	5	5	5	4	5	4	4
Rohricht & Priebe, (2006)	34	85	5	3	4	4	4	5	5	4
Rohricht, Papadopoulos, Holden, Clarke, Priebe, (2011)	29	73	5	4	4	3	3	3	3	4

## Results

Figure 1 highlights the flow diagram for the process and selection of the final eleven included studies. See Appendix 1.2 for examples of excluded studies with reason for exclusion. Results are presented below in relation to the three review objectives.

**Figure 1: Flow Diagram of Study Selection**



*Objective 1:* What psychosocial treatment techniques have proven effective in the treatment of *specific* negative symptoms and how are they described in the literature?

The included papers, which dated from 2002 to 2015, present a variety of methodologies, interventions, therapeutic targets, and outcomes. Table 2 highlights the reported outcomes from each study. All studies reported positive effects on negative symptoms yet some studies did not report effects that were statistically significant. The included interventions can be generally grouped into two categories: cognitive-behavioural interventions and integrative therapies. A brief description of commonalities across each group is provided below before focusing on treatment techniques.

**Table 2: Treatment Targets and Outcomes**

Study	Treatment Target	Outcome Measure*	Negative Symptom Outcome
Eack et al. 2013	Social and non-social cognition.	WNSS / BPRS	CET group - Overall 2 year improvement in negative symptoms (significant and medium effect size). Analysis of differential effects of CET on negative symptom domains indicated improvements in social withdrawal ( $d = 1.08$ ), motor retardation ( $d = 0.63$ ), and affect flattening ( $d = 0.68$ ).
Favrod et al 2010	Anhedonia	Primary - TEPS/ TBM Secondary - CDSS.	All participants had significant clinical change in anticipatory pleasure. They showed an increase in the number of activities as well as in the complexity of these activities.
Favrod et al 2015	Anhedonia and apathy.	SANS/ CDSS/ SBI	Significant reduction of symptoms. Cohen's $d$ ES= 0.50 for Anhedonia-Asociality and 0.57 for the Avolition- Apathy. Moderate overall effect size.
Granhölm et al 2014	Amotivation/asociality and self-efficacy.	Primary measure: ILSS. Secondary measures: CMT/ MASC/ PSR/ PANSS/ SANS/ BDI-II/ DPAS	Significant improvement over time for functioning, negative symptoms, defeatist attitudes and skill knowledge related to CBSST. Positive effects for CBSST noted in the reduction in scores for diminished motivation and diminished expression.
Grant et al 2012	Global functioning and negative symptoms.	Primary – GAS Secondary - Subscales of SANS/ Total of SAPS	CT group showed significantly greater improvement in global functioning and significant reduction in Avolition-Apathy.
Johns et al 2002	Avolition/apathy: targeted both objective (levels of activity) and subjective (associated distress).	Primary: SANS/ SENS Secondary: CDSS/ LUNBERS	No significant difference in total scores for negative symptoms. However, there was a significant reduction in avolition scores for three of the four participants.
Johnson et al 2009	Three individual case studies each experiencing different negative symptoms	Not specified.	Two cases reported improvements in negative symptoms.
Johnson et al 2011	Anhedonia, avolition, and asociality,	mDES/ CAINS/ TEPS/Psychological recovery measured using specific subscales from SPWB/ THS/ SWLS	Substantial improvements in frequency and intensity of positive emotions at post-treatment and 3-month follow up. Large decrease in total negative symptoms and anhedonia (large effect size) as well as asociality (medium effect size) at post-treatment and 3-month follow-up. Analyses of consummatory pleasure yielded a large positive effect size at post-treatment. Environmental mastery, self-acceptance, and satisfaction with life all improved.
Klingberg et al 2011	Defeatist beliefs. Socio-cognitive skills (emotion detection/expression)	Primary –PANSS Secondary - Standard scale of PANSS/ SANS	No significant difference of negative symptoms between CBT group and CR group. However, CBT group reduced scores for each SANS subscale and for total score (non-significant).
Rohricht & Priebe, 2006.	Emotional withdrawal/affective blunting and motor retardation.	Primary - negative subscale of PANSS. Secondary - EPS/ SQOL/ MANSA/ CAT/ HAS	BPT group had significantly lower PANSS negative symptom scores than SC group after treatment. Also, BPT group experienced significant reductions in negative symptoms of blunted affect and motor retardation. No variation between groups in other measures of psychopathology.
Röhricht et al 2011	Emotional withdrawal/affective blunting and motor retardation.	Primary - Sub-scale "negative" on PANSS/ Subscale "anergia" on BPRS. Secondary – PANSS/ MANSA/ SFS	Significant reduction in PANNS negative scale scores. Significant reduction in negative symptoms of anergia and flat affect (BPRS).

\* BDI-II –Beck Depression Inventory, BPRS - Brief Psychiatric Rating Scale, BPT – Body-orientated Psychotherapy, CAINS - Clinical Assessment Interview for Negative Symptoms, CAT – Client's Assessment of Treatment, CBSST – Cognitive Behavioural Social Skills Training, CDSS –Calgary Depression Scale for Schizophrenia, CET – Cognitive Enhancement Therapy, CMT - Comprehensive Module Test, CR- Cognitive Remediation Therapy, CT –Cognitive Therapy,  $d$  – Cohen's  $d$ , DPAS - Defeatist Performance Attitude Scale, DES-IV – Differential Emotions Scale, EPS - Extrapyramidal Symptom Scale, GAS - Global Assessment Scale, HAS – Helping Alliance Scale, ILSS - Independent Living Skills Survey, LUNBERS – Liverpool University Neuroleptics Side Effects Ratings Scale, MANSA – Manchester Short Assessment of Quality of Life, MASC - Maryland Assessment of Social Competence, mDES - Modified Differential Emotions Scale, PANSS - Positive and Negative Syndrome Scale, PSR - Psychosocial Rehabilitation Toolkit, SANS - Scale for the Assessment of Negative Symptoms, SANS - Scale for the Assessment of Negative Symptoms, SAPS - Scale for the Assessment of Positive Symptoms, SBI - Savoring Belief Inventory, SC- Supportive Counselling, SENS, - Subjective Experience of Negative Symptoms Scale, SFS – Social Functioning Scale, SQOL – Subjective Quality of Life, SWLS – Satisfaction with Life Scale, SWPB – Scales of Psychological Well Being, TBM - Time Budget Measure, TEPS - Temporal Experience of Pleasure Scale, THS -Trait Hope Scale, WNSS - Wing Negative Symptom Scale

### *Cognitive-Behavioural Interventions*

Five studies utilised elements of cognitive behavioural therapy (CBT) with variance in their application across each study (Favrod et al, 2010; Favrod et al, 2015; Grant et al, 2012; Johns et al, 2002; Klingberg et al, 2011). Three studies also employed traditional concepts from CBT including individual case formulation, collaboration, and developing a therapeutic relationship (Grant et al, 2012; Johns et al, 2002; Klingberg, 2011).

### *Cognitive Components*

Two interventions (Favrod et al, 2010; Favrod et al, 2015) place substantial emphasis on different cognitive processes in targeting negative symptoms. The cognitive-sensory intervention for severe anhedonia described by Favrod et al (2010) focused on cognitive skills development (e.g. imagining images, emotional experiences, and memory recall). However, in the Positive Emotions Program for Schizophrenia (PEPS; Favrod et al, 2015), which also targets anhedonia and apathy, the focus is on cognitive control of positive emotions. PEPS aims to enhance this through challenging defeatist beliefs and also in developing skills in anticipating and maintaining positive emotions.

The salient role of defeatist beliefs in the maintenance of negative symptoms was a major concept in three studies (Favrod et al, 2015; Grant et al, 2012; Klingberg et al, 2011). These studies indicate that challenging defeatist beliefs is an important component in treatment. Johns et al (2002) also incorporate negative thought challenging within the study description but it is unclear which specific thoughts were targeted.

### *Behavioural (Skills) Components*

Grant et al's (2012) CBT intervention placed a significant emphasis on skills based activities during treatment in line with their goal focused outcomes. Several activities (e.g. role play and community trips) were utilised to develop skills that would help people increase their daily functioning skills. Klingberg et al (2011) had a similar substantial focus on skills development with modules targeting individual negative symptoms through techniques such as social activity and emotional participation and expression. The PEPS (Favrod et al, 2015) incorporates skills practice in each session which can include both cognitive elements (e.g. imagining exercises) or behavioural strategies (e.g. learning how to express positive emotions through behavioural expression).

Johns et al (2002) indicate that behavioural goals are an integral part of their treatment but no further specific information is provided. Favrod et al (2010) focus heavily on cognitive processes and state behavioural skills are practiced once the cognitive skills have developed (i.e. completing a daily living activity as homework).

### *Integrative Therapies*

Two studies rely on the amalgamation of different therapeutic interventions to target negative symptoms. Cognitive Enhancement Therapy (CET; Eack et al, 2013) incorporates a substantial repertoire of computer-based cognitive training that is then enhanced by peer group therapy. CET was not intended as a specific treatment for negative symptoms with post hoc analysis revealing positive effects.

Granholtm et al (2014) describe Cognitive Behavioural Social Skills Training (CBSST), a hybrid treatment, drawing on elements of CBT and SST both of which have been shown to be beneficial in reducing negative symptoms (Elis et al, 2013). A prominent issue that emerges in the synthesis of both studies (Eack et al, 2013; Granholtm et al, 2014) relates to the multiple treatment elements that will have complex and interacting effects on negative symptom outcomes.

Two treatments utilised different theoretical backgrounds to conceptualise interventions which differ from the more mainstream techniques described above. Loving Kindness Meditation (LKM; Johnson et al, 2009; Johnson et al, 2011) assumes that patients need to re-learn the ability to feel warmth, compassion, and connectedness. LKM draws upon third-wave CBT elements (e.g. relaxation and meditation) with an aim to develop these skills thus increasing feelings of warmth and compassion for self, and others. This is postulated to then impact on a person's life experiences and their emotional responses. This overall process is based on Fredrickson's (2001) broaden-and-build theory which stipulates that developing one's experience of positive emotions has a beneficial impact on psychological resources and overall well-being.

Röhricht and Priebe (2006) report on a novel intervention for negative symptoms focussing on physical movement. Body-orientated Psychotherapy (BPT) is based on an assumed link between physical movement and emotional experience and thus targets specific negative symptoms (flat affect and motor retardation). A more recent pre/post study of BPT (Röhricht et al, 2011) was delivered following the approach described by Röhricht and Priebe (2006) – yet there are discrepancies in the reported effectiveness of BPT across these two trials.

### **Commonalities across Studies**

#### *Design*

Four randomised controlled trials (RCT) were included in this review (Granholtm et al, 2014; Grant et al, 2012; Klingberg et al, 2011; Röhricht & Priebe, 2006). Eack et al (2013) utilised an exploratory post hoc analysis of a previous RCT study which identified significant intervention effects on negative symptoms. An issue is highlighted in the variance of comparator therapy in each of these studies and

the intervention dosage between the experimental/control groups within the same study may not be matched.

Röhrich et al (2011) utilised a pilot study to evaluate their intervention in open clinical settings and Johnson et al (2011) adopted a similar design for their pilot/feasibility study. Three studies (Favrod et al, 2010; Favrod et al, 2015; Johns et al, 2002) were also pilots of novel interventions and employed before-and-after designs. A case study design was used by Johnson et al (2009) to illustrate the impact of their intervention in people with different presentations of negative symptoms.

#### *Addressing Secondary Symptoms in Methodology*

Only five papers assessed secondary negative symptoms in their methodology. Favrod et al (2010) assessed depression at pre-test only whereas Klingberg et al (2011) included depression assessment as a secondary endpoint. Depression was also assessed at pre/post in the PEPS pilot and an analysis was completed to extricate negative symptoms from depression (Favrod et al, 2015); a similar approach was used by Johns et al (2002). The primary outcome measures in the BPT trial (Röhrich & Priebe, 2006) are explicitly stated to measure primary negative symptoms, with secondary negative symptoms (i.e. extrapyramidal symptoms) accounted for with a different measure.

#### *Sample Characteristics*

Participants in the included studies were all male or female adults (18-65) with a mix of diagnoses along the schizophrenia/psychosis spectrum. Sample size varied by study and ranged from 3-198.

Four studies included participants with an explicit diagnosis of schizophrenia (Favrod et al, 2010; Klingberg et al, 2011; Röhrich & Priebe, 2006; Röhrich et al, 2011). The LKM studies had added diagnosis inclusions of both psychotic disorder NOS and schizophreniform disorder. Eack et al (2013) included schizophrenia, schizoaffective, and schizophreniform disorder all in their early course (Eack et al, 2013). The remaining studies included participants with a diagnosis of either schizophrenia or schizoaffective disorder.

Six studies reported negative symptoms specifically as part of their inclusion criteria (Favrod et al, 2015; Grant et al, 2012; Johns et al, 2002; Klingberg et al, 2011; Röhrich & Priebe, 2006; Röhrich et al, 2011). Johnson et al (2011) indicated negative symptoms were measured for participants but this was not stated as an explicit inclusion criteria. Exclusion criteria varied by study and included factors such as organic disease that may impact on cognitive functioning (e.g. Grant et al, 2012) or prior exposure to the intervention being investigated (e.g. Granholm et al, 2014). Two studies did not stipulate exclusion criteria (Favrod et al 2015; Johnson et al, 2009) and one study did not explicitly state

either inclusion or exclusion criteria (Johnson et al, 2011). Only two studies provided sample size calculations (Klingberg et al, 2011; Röhricht & Priebe, 2006).

The reported mean duration of illness ranged from 3.19 to 21.3 years with four studies not stating this information explicitly (Favrod et al, 2010; Klingberg et al, 2011; Johnson et al 2009; Johnson et al 2011). A number of studies indicated participants were on standard medication. Two studies (Eack et al 2013; Röhricht & Priebe, 2006) explicitly stated changes in medication were permitted during the course of participation.

#### *Delivery Format*

Eight studies utilised group therapy format (Eack et al, 2013; Favrod et al, 2015; Granholm et al, 2014; Johns et al, 2002; Johnson et al, 2009; Johnson et al, 2011; Röhricht & Priebe, 2006; Röhricht et al, 2011) with the two CBT trials adopting a one-to-one format (Grant et al, 2012; Klingberg et al, 2011).

Favrod et al (2010) described two of their five participants receiving group therapy while the others received individual therapy. There is no rationale provided for this but the authors note that an attempt was made to meet individual needs of participants. There was a wide range of professional experience in therapists delivering interventions (see Table 3).

**Table 3: Treatment Resources**

Study	Number of Sessions	Duration of Sessions	Delivery format	Therapist Characteristics
Eack et al 2013	45 socio-cognitive + 60 computer based, delivered over 24 months.	60-90 mins.	Group.	Nurse specialists (MSc's).
Favrod et al 2010	Varied, mean hours of therapy 17.6 hrs	Unclear.	Individual /Group.	Not explicitly stated.
Favrod et al 2015	8.	60 mins.	Group.	Nurses, nursing assistants, & social workers trained (1 day) in the intervention.
Granholt et al 2014	36 over 9 months, 12 boosters monthly.	120 mins with break & a snack.	Group.	2 MSc or PhD therapists with min 2 year CBT experience.
Grant et al 2012	Up to 72 (scheduled weekly for 18 months).	50 mins.	Individual.	Doctoral level (PhD or MD).
Johns et al 2002	16.	1 to 2.5 hours with a break.	Group.	Clinical psychologists (PhD; 2 per group).
Johnson et al 2009	6, with one review 6 weeks post treatment.	60 mins.	Group.	Marriage & family therapist (MSc) with 25 years meditation experience.
Johnson et al 2011	6, with one review 6 weeks post treatment.	60 mins.	Group.	Marriage & family therapist (MSc) with 25 years meditation experience.
Klingberg et al 2011	20.	Mean 51.8 mins.	Individual.	5 clinical psychologists varied experience (MSc's/3 had additional 3 year CBT training).
Rohricht & Priebe, 2006.	20.	60-90 mins.	Group.	Part-time dance movement therapist.
Röhricht et al 2011	20.	60-90 mins.	Group.	Dance therapists.

### *Dose and Duration*

Three studies describe large dosage ranges with 36 to 72 sessions delivered over a number of months (see Table 3; Eack et al, 2013; Granholt et al, 2014; Grant et al, 2012; Klingberg et al, 2011). Additional therapeutic input is also highlighted in the CET study in the form of computer-based sessions (Eack et al, 2013) and Granholt et al (2014) indicated extra dosage through individual goal setting sessions prior to intervention, counter-balanced across treatment arms.

Four studies indicate a moderate dosage rate of 16 to 20 sessions (Johns et al, 2002; Klingberg et al, 2011; Röhricht & Priebe, 2006; Röhricht et al, 2011) with the remaining studies detailing low dosage (Favrod et al, 2010; Favrod et al, 2015; Johnson et al, 2009; Johnson et al, 2011).

The duration of sessions varied by study but were all within a range of 50-180 minutes. The longer sessions were accompanied by a break (i.e. Granholt et al, 2014; Johns et al, 2002).

### *Psychosocial Techniques Utilised*

The descriptions for interventions varies in the amount of detail each paper provides. In general, included information tends to be brief and lacks enough descriptive data to be able to gain a comprehensive understanding of the intervention.

However, the information that is available does provide a general idea of each intervention and the techniques used within. Some explanations provide coherent explanations of intervention rationale, techniques, and related outcomes (e.g. Favrod et al, 2015). Other papers provide contradictory evidence of the effectiveness of interventions following the same treatment manual, such as the different impact of BPT on motor retardation across both studies (Röhricht & Priebe, 2006; Röhricht et al, 2011).

Some interventions report beneficial outcomes on pre-specified targeted negative symptoms (e.g. Favrod et al, 2010; Röhricht & Priebe, 2006). However, Röhricht and Priebe's description of the BPT intervention indicates a large repertoire of biopsychosocial techniques (e.g. body movement, group exercise, reflection) making linkages between a technique and negative symptom domain difficult. This is a pattern across all of the included studies.

### *Thematic Analysis of Psychosocial Techniques*

Thematic analysis techniques were employed to aggregate and synthesise psychosocial techniques common across the included studies. The themes represent treatment components that may have beneficial impact on negative symptoms. Table 4 indicates the six most common themes.

**Table 4 – Psychosocial Technique Themes**

<b>Theme</b>	<b>Example(s)</b>
Providing education on psychological processes involved in negative symptoms and for the theory of the given intervention	<i>“The group content included: psychoeducation and understanding negative symptoms...” (Johns, et al (2002)).</i>
Developing generic problem solving skills that enable people to understand and respond to everyday challenges.	<i>“...The focus was on developing specific, feasible plans to solve real-world problems, including scheduling pleasant activities, improving living situations, handling finances, using public transportation, finding a volunteer or paid job, and enrolling in classes...” (Granholm et al, 2014).</i>
Developing skills to help people effectively communicate positive emotions to others through verbalisation and/or body language.	<i>“...Increasing behavioural expression of emotion involves using facial expressions or gestures to accompany that positive emotion...” (Favrod et al., 2015).</i>
Developing the ability to set realistic goals and supporting people to achieve this.	<i>“...Therapy aimed to stimulate patients’ interest and motivation to focus respectively on achievable long-term goals...intermediate-goals and short-term goals...” (Grant et al, 2012).</i>
Building motivation to practise the skills from therapy outside of the therapeutic context.	<i>“...collaboratively devised action plans for practice outside the session...” (Grant et al, 2012).</i>  <i>“...A simple homework task is assigned to be done between each session...” (Favrod et al (2015)).</i>
Developing skills focussed on challenging unhelpful beliefs associated with negative symptoms (i.e. challenging nihilistic beliefs).	<i>“...thought challenging skills were the exclusive focus.... (e.g. to address defeatist attitudes and other thoughts that could be obstacles to skill learning or goal achievement)...” (Granholm et al, 2014).</i>

*Objective 2 - What specific negative symptoms do these techniques improve and how are improvements measured?*

As can be seen from Table 2 above, common targets are symptoms in the diminished experiential subdomain, with avolition and anhedonia reported to be amenable to psychosocial intervention. There is considerable variability in the chosen primary outcomes and standardised measures across the included studies. The Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1984) is the most common, appearing in six of the study methodologies, with the Positive and Negative Syndrome Scale for Schizophrenia (PANSS; Kay, Fiszbein, and Opler, 1987) appearing in four.

The use of specific subscales of various psychometric outcome measurements to detect changes in negative symptoms presents a problem when attempting to analyse effects across studies. Further issues are indicated when considering discrepancies between therapist and participant ratings (e.g. Röhrich et al (2011) describe participants providing higher self-ratings in measures of affect) and the variance in targeted symptoms across each study.

*Objective 3* - How acceptable are the interventions and the associated outcomes to patients?

Three papers explicitly address participant satisfaction with intervention as primary outcomes in their methodologies, with one utilising a standardised measure to assess this (Röhricht & Priebe, 2006) and the others non-standardised methods (e.g. questionnaires; Johnson et al, 2011; Johns et al, 2002). All three studies indicate participants reported positive satisfaction with interventions. However, in the RCT of BPT this did not differ from the comparator group.

Granholtm et al (2014) do not measure satisfaction but focus on treatment fidelity and adherence, which can give an indication of satisfaction (i.e. higher adherence may indicate greater satisfaction). The LKM case studies (Johnson et al, 2009) provide anecdotal evidence of treatment satisfaction. The six remaining papers do not assess for participant satisfaction with intervention.

## **Discussion**

The aim of the review was to analyse effective psychosocial treatments for *specific* negative symptoms. Elis et al (2013) highlighted the need to describe effective components of interventions to develop current understanding of mechanisms of change, which could lead to more effective treatments (Kaiser et al, 2016). A total of 11 studies with treatment approaches from different theoretical perspectives and with various methodologies/outcomes were included. Narrative synthesis techniques were employed and opportunities to move this field of research further were identified.

### *Main Findings*

#### *Variability in Methodological and Conceptual Approaches*

Nine of the 11 studies reported clinically significant positive effects on negative symptoms. Similar to the review by Elis et al (2013), the present synthesis revealed heterogeneity across various important aspects of study methodologies, which complicated cross-study comparison (e.g. variation in measurement of negative symptoms). Some studies used pilot before-and-after designs employing a very small sample (e.g. Favrod et al, 2010; Johns et al, 2002), whilst others had a large sample, and high dosage RCT design (e.g. Granholtm et al, 2014). Certain interventions (Eack et al, 2013; Favrod et al, 2010) required substantial cognitive abilities from a population who experience known problems in neurocognitive functioning (Foussias et al, 2014). The RCT's all used a different comparator with various follow-up points and the intervention dosage between the experimental and control groups within the same study may not be matched (see Eack et al, 2013). A number of samples included mixed diagnoses

of schizophrenia and schizoaffective disorder which becomes problematic in relation to the debate around negative symptom severity (Foussias et al, 2014). For example, negative symptoms in schizophrenia may be more severe than schizoaffective disorder which may impact on outcomes. While early trials of a novel treatment (Röhrich & Priebe, 2006; Röhrich et al, 2011) indicated positive outcomes for negative symptoms, a more recent multisite RCT indicated this effect was not replicated (Priebe et al, 2016).

Additionally, the process of this review indicated a general problem with the current intervention literature in relation to studies not subdividing negative symptoms. For example, Staring, Huurne, and van der Gaag's (2013) pilot of CBT for negative symptoms was excluded from this review as it failed to provide outcomes related to *specific* negative symptom subdomains. In addition, a recent review (Aleman et al, 2016) also focused on *general* negative symptom reduction. Future research may need to employ validated outcome measurements that are specific to negative symptoms (e.g. see Strauss and Gold, 2016) which can then be used to reliably identify *specific* negative symptoms. This would allow for a better understanding of the pathway between an intervention component to an outcome in a *specific* negative symptom (e.g. amotivation or apathy). This may then indicate what particular mechanism of change is responsible for the outcome.

Overall, this highlights the ongoing need to develop a better understanding of *specific* negative symptoms and their treatment. The recent changes in our understanding of symptoms (e.g. expressive versus experiential deficits) has led to a number of different treatment approaches all targeting various aspects of negative symptoms. Research may need to begin separating these symptoms to aid the identification of mechanisms of change (e.g. Kaiser et al, 2016), ultimately leading to more effective and efficient interventions.

#### *Intervention Description*

CONSORT guidelines (Schulz, Altman, and Moher, 2010) indicate trials should provide sufficient detail for study replication. Broadly speaking, authors of the included studies are constricted to brief descriptions of interventions. While protocols may exist for some (e.g. Röhrich & Priebe, 2006) they are not always available in the published manuscripts and adaptations may have been made to existing protocols without explicit information as to the nature of these adaptations (i.e. Grant et al, 2012).

This indicates a problem with the ways in which interventions are reported in the literature in general. The lack of full intervention description leaves readers with a poor understanding of the psychosocial components involved. It would be prudent for intervention studies to include a detailed step-by-step description of the intervention and/or full protocol. This would help to focus treatment on

clearly defined negative symptom targets and elucidate links between reported outcomes and mechanisms of change. This issue also indicates a need for a taxonomy of behaviour change techniques that can be mapped onto interventions (see Michie, van Stralen, and West, 2011).

### **Strengths and Limitations**

This review is the first of its kind to attempt to disentangle and analyse effective psychosocial intervention components that explicitly target *specific* negative symptoms. The synthesis provides salient information that may be beneficial in developing further research into psychosocial interventions for negative symptoms.

Due to the heterogeneity of studies included in this review a meta-analysis could not be completed. This confounded the possibility of comparing any effect sizes of reported outcomes in trials. Despite this, the qualitative synthesis allowed for a variety of studies to be reviewed. The authors of this review have made every attempt to be transparent through the description of methods and synthesis of results.

Thematic analysis identified treatment components common across included studies. Negative symptoms in the diminished experiential subdomain were identified as amenable to psychosocial intervention. Taken together, this information might be used as a starting point for future research into treatments for negative symptoms.

Overall, the review highlights numerous approaches to psychosocial treatment of negative symptoms. Perhaps as the scientific evidence matures more robust techniques (i.e. meta-analysis) can be applied in future reviews. Currently there are multiple intervention techniques being utilised, often packaged in idiosyncratic ways, and assessed with a variety of outcome measures. This indicates a need for developing new research with *specific* negative symptoms as a primary outcome measure.

### **Recommendations for Future Research**

Future studies could use Michie et al's (2011) behaviour change taxonomy as a focus for conceptualising interventions for negative symptoms. Research focused on intervention development could utilise the current findings to promote an approach to targeting single negative symptoms. A transdiagnostic approach may help to eliminate the confounding factors of symptom severity across diagnoses.

Many participants were on long-term medication which adds the confounding variable of negative symptoms related to extrapyramidal side-effects (e.g. see Foussias et al, 2014). There is also a lack of focus on disentangling primary and

negative symptoms across some methodologies. More robust study methodologies may be able to address these issues, perhaps through the process of randomisation, which a number of included studies did not utilise.

The majority of studies did not assess the acceptability of interventions for participants; future studies will need to address this. Some studies utilise substantial resources (e.g. 72 sessions of CBT). This is important when considering the long-term goal of application to clinical practice. MRC guidance (Craig et al, 2008) indicates products need to match the expectations of their consumers – understanding acceptability is a key factor in this.

## **Conclusions**

Recent studies indicate discrepancies in patient versus therapist views on treatment goals for schizophrenia (Moritz et al, 2016; Sterk et al, 2013). In general this emergent literature indicates that patients and their families/carers desire help with negative symptoms and indicate specific subdomains that could be targeted (e.g. avolition). The present review indicates psychosocial treatments are emerging yet this field of research needs further development. The analysis indicated that avolition may be responsive to psychosocial intervention and the themes identified provide examples of techniques that may impact on this subdomain. However, there remains a need to explore what the key negative symptom subdomain targets are for psychosocial intervention based on the opinions of those with the most experience – people who experience negative symptoms, their carers, and professional carers.

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## **CHAPTER TWO: MAJOR RESEARCH PROJECT**

### **Negative Symptoms of Schizophrenia and Psychosocial Treatment: Thematic Analysis of Stakeholders' Perspectives**

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## Plain English Summary

### **Introduction:**

People with schizophrenia experience symptoms classified as positive (i.e. a change in behaviour of thinking) and negative (i.e. a change in emotions). Negative symptoms in schizophrenia are characterised by a lack of motivation, enjoyment and engagement in everyday activities. Up to 30% of individuals with chronic schizophrenia have negative symptoms.

However, there remains a gap in knowledge about effective psychosocial (i.e. non-medicated) treatments due to the variability in current approaches (Elis, Caponigro and Kring, 2013). There have been recent attempts by clinicians and researchers to clarify what specific negative symptoms should be targeted and how therapeutic change should be measured. Major stakeholders' views (e.g. service users and carers) would provide further knowledge on the experience of negative symptoms and in the development of effective treatments (Schooler et al, 2015). Additionally, this information may provide valuable insight into ways in which new interventions can be incorporated into everyday clinical practice.

### **Methods:**

A review of the relevant literature associated with psychosocial treatment of negative symptoms was conducted. Data was analysed and important treatment factors, such as treatment preference and improvements in specific symptoms, were identified. This information was used to develop an interview script with questions based on these factors and service users, carers, and healthcare professionals were invited to participate in interviews. Interviews were recorded and transcribed. Data was then analysed using thematic analysis (a technique used to find important themes in written data). The study was conducted at two NHS mental health sites (one inpatient and one community) to try and capture a broad view of different perspectives. The study was given ethical approval and individuals provided written consent to participate.

### **Results:**

A common theme across all groups is the need for treatments to be tailored to individual preferences. Other themes indicate the need for a well-informed, graded approach to therapy which is supported by organisational resources with staff training needs addressed. There was disagreement in treatment preferences across groups in relation to treatment of specific negative symptoms.

## **Discussion**

The need for treatments to be tailored to individuals is consistent with the current recovery movement which places importance on outcome factors such as empowerment and meaning in life. The findings indicate further work is needed to understand treatment preferences across different groups which has been identified as a need for schizophrenia treatment in general. There are barriers to interventions being successfully implemented and findings suggest solutions to these problems, for example through staff training.

## **Conclusions**

An individualised approach to psychosocial treatment of negative symptoms is needed. There is disagreement in treatment preferences for negative symptoms across major stakeholders. Further research focusing on patient treatment preferences is needed.

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## **Abstract**

**Objectives.** Recent literature indicates variance in psychosocial treatment preferences for negative symptoms of schizophrenia. Attempts at defining therapeutic aims and outcomes for negative symptoms to date have not included major stakeholder groups. The aim of the present study was to address this gap through qualitative methods.

**Design.** Thematic Analysis was applied to qualitative semi-structured interview data to gather the opinions of people who experience negative symptoms, carers, and healthcare professionals. Participants were recruited from two mental health sites (inpatient/community) to increase generalisability of results. Ten people participated in the research.

**Methods.** Semi-structured interview scripts were designed utilising evidence from the review in Chapter 1 of effective psychosocial intervention components for specific negative symptoms. Interviews were audio recorded and transcribed verbatim. Thematic analysis was employed to analyse data.

**Results.** A common theme across groups was the need for a personalised approach to intervention for negative symptoms. Other themes indicated different opinions in relation to treatment targets and the need for a sensitive and graded approach to all aspects of therapy. This approach needs to be supported across systemic levels of organisation with specific training needs for staff addressed.

**Conclusions.** There is disparity in treatment preferences for negative symptoms across major stakeholders. The findings suggest an individualised approach to intervention of negative symptoms that is consistent with recovery. Implementation barriers and facilitators were identified and discussed. There remains a need to develop a better understanding of treatment preferences for patients.

## **Practitioner points**

- Interventions need to be developed in line with major stakeholder preferences and consistent with recovery.
- Healthcare professionals may require specific training for working with this population.
- Organisations need to commit to supporting intervention development and implementation in order to produce positive gains for this population that can be maintained over time.

## **Introduction**

### *Negative Symptoms*

Recent years have seen a focused approach to the scientific understanding and clinical treatment of negative symptoms in schizophrenia. This is an important area for research when considering these symptoms are core features of the illness (Bleuler, 1950) and issues such as debate related to the content of professional guidelines for schizophrenia treatments (e.g. NICE versus SIGN; see Kendall et al, 2016). It is reported that 20-40% of individuals with long-term illness experience negative symptoms (an der Heiden, Leber, & Hafner, 2016).

Negative symptoms of schizophrenia are part of a discrete domain separate from other common features of the illness (Foussias and Remington, 2010). Difficulties exist in differentiating primary negative symptoms (i.e. illness related) from secondary symptoms (related to various factors, such as the experience of psychosis itself). Complications like these can have an impact on factors such as obtaining accurate prevalence rates or on methodologies employed in treatment trials (see Mucci, Merlotti, Uçok, Aleman, & Galderisi, 2016).

Furthermore, Galderisi, Farden, and Kaiser (2016) draw attention to the variance amongst researchers in relation to the methods of assessment of negative symptoms and models for understanding their underlying mechanisms. The severity of these symptoms can impact on therapeutic outcomes for patients experiencing schizophrenia (Foussias, Agid, Fervaha, & Remington, 2014), yet there is a current need to develop comprehensive psychosocial interventions in tackling these symptoms (Aleman et al, 2016).

It may be that disparity amongst clinicians and researchers in relation to the notion of recovery (e.g. Slade, 2012) adds to the challenge in developing effective treatments. Recent years have seen the evolution of the recovery movement in mental illness. The CHIME conceptual framework (Leamy, Bird, Le Boutillier, Williams, and Slade, 2011) highlights a greater emphasis on idiosyncratic outcomes (i.e. personal meaning) as opposed to typical nomothetic outcomes reported in studies focussing on 'clinical recovery'. For instance, a recent review indicates the literature on recovery in negative symptoms tends to focus on symptomatic reduction and/or functional outcomes (see Valencia, Caraveo, Colin, Verduzo, & Coronoa, 2014). Additionally, there is noted variance in patient versus clinician preferences for treatment outcomes in schizophrenia (Moritz, Berna, Jaeger, Westermann, & Nagel, 2016; Sterk, Winter, Muis, & de Haan, 2013). This disparity indicates a need for research to explore treatment targets and outcomes most relevant to key stakeholders in relation to negative symptoms.

A recent clinician-researcher panel (Schooler et al, 2015) partially addressed this need by providing a consensus statement detailing a set of criteria upon which therapeutic impact on negative symptoms can be measured. There is a specific focus on symptom remission (or decrease in intensity) and functional outcomes. However, this does not seem to fit the framework and ideas fuelling the current recovery movement. Additionally, as the authors note, key stakeholders (e.g. patients, professional/family carers, and policy makers) were not included in the panel. This needs addressed to gain a better understanding of negative symptoms and their treatment. Furthermore, this lack of a universally agreed definition draws attention to the gap in current knowledge on negative symptom treatment.

### *Psychosocial Intervention*

Intervention is complicated when considering people with schizophrenia are thought to experience poor insight into their illness (Lysaker et al, 2011a) and may struggle with metacognition in general (Lysaker et al, 2011b). Specifically, they may struggle to understand themselves and the people around them, making psychotherapy a difficult process to engage in. People with negative symptoms can also experience comorbidity of other psychiatric illnesses (e.g. depression; see Buckley, Miller, Lehrer & Castle, 2009).

A recent comprehensive review of psychosocial treatments for negative symptoms indicates positive outcomes (Elis, Caponigro, & Kring, 2013). Elis et al focus on three types of intervention – cognitive behavioural therapy (CBT), social skills training (SST) and combined treatment interventions. The review specifies that psychosocial treatments have the potential to alleviate negative symptoms. Yet, outcomes are reported in relation to impact on negative symptoms in *general* (i.e. reduction of total scores on measures) and the variance in outcomes (e.g. maintenance factors at follow up) makes cross treatment comparisons difficult. Furthermore, Aleman et al's (2016) more recent review also highlights the lack of interventions focussed on treating *specific* negative symptoms. This is a key area for research in order to develop a treatment acceptable to stakeholders that is targeted at specific domains of negative symptoms and can be implemented in clinical practice.

### *Implementation*

Wykes (2016) indicates an urgent need for research related to patient preference and informed treatment in schizophrenia in order for this to be disseminated for implementation in clinical practice. The Medical Research Council's (MRC) framework for complex interventions (Craig, Dieppe, Macintyre, Michie, Nazareth, & Petticrew, 2008) details a phased approach to the development and implementation of interventions. A key message from the MRC relates to the importance of investment at the development stage of research, prior to large

scale evaluations. This approach may tackle noted problems related to empirically formulated interventions not achieving successful implementation in everyday clinical settings (Durlak & Dupree, 2008). To tackle implementation issues there is a need to understand stakeholders' perspectives in relation to treatment preferences. Obtaining the opinions of these groups will provide evidence that will improve treatment targeting for negative symptoms and also provide knowledge related to implementation issues. The development of future interventions for negative symptoms will benefit from this knowledge.

### *Exploration of Stakeholder Opinions*

Qualitative research in the field of schizophrenia has added to scientific understanding of the experiential nature of the illness (McCarthy-Jones, Marriott, Knowles, Rowse, & Thompson, 2013). Furthermore, qualitative methodology can provide a robust framework for exploration and discovery when consideration is given to sampling procedures (e.g. utilising specific inclusion/exclusion criteria with generalisability in mind; Lewis & Ritchie, 2003).

Waller et al (2013) utilised thematic analysis to explore key stakeholder views on their experiences of participating in a pilot of a novel low intensity CBT intervention for psychosis. Waller et al conducted semi-structured interviews with both staff and service users to investigate the positive/negative factors associated with the intervention. An additional factor they explored with the staff group related to the feasibility of long-term implementation of the intervention. This process provided a wealth of data which would not be captured using quantitative methodologies. Therefore, explorative methodologies may be an efficient approach to engage with stakeholders in relation to negative symptoms.

The present study will utilise qualitative methods to provide further clarity in relation to the consensus statement provided by Schooler et al (2015). The study aims to address the gap in current knowledge by gaining an understanding of negative symptoms and their treatment from the experience of major stakeholders.

Specifically, the study will draw upon the methodology used by Waller et al (2013) with a focus on consulting patients and family/professional carers to explore their views on negative symptoms and their treatment. The exploration will be guided by the findings from the systematic review in Chapter 1.

The study aims to explore key areas, including: treatment need for negative symptoms; the specific negative symptoms that could be targeted; the preferred method of intervention; the philosophy underpinning recovery; and challenges related to implementation.

## **Methods**

### *Design*

Thematic Analysis (Braun & Clarke, 2006) was applied to qualitative semi-structured interviews consisting of prompt questions. Interview scripts were derived from the systematic review of the literature and two versions were produced. One script targeted patients (see Appendix 2.1) and the other carers/healthcare professionals (see Appendix 2.2). The scripts were used primarily as a guide for the researcher during interviews as it was recognised the language used in scripts would need to be adjusted to individual needs. As part of this research participants were invited to be consultants at future information events related to the study topic (see Appendix 2.3).

### *Participants*

The qualitative design of the study allowed for a small sample to be recruited which enabled a deeper exploration of individual experience during interview. Participants were recruited between April 2016 and June 2016 from two NHS sites in Scotland (inpatient/community). An attempt was made to recruit even numbers from each group through opportunity sampling across both the community and inpatient settings in order to provide a representative sample. Three groups were recruited – patients, carers, and healthcare professionals – using information sheets tailored by group and location (for examples of these see Appendices 2.4, 2.5, & 2.6 respectively). Mental health teams at both sites were approached to participate in the study and to aid with recruitment. Carers were identified by the teams and invited to participate by letter (see Appendix 2.7). Recruitment of inpatients proved to be difficult with a number of people stating an interest but refusing to participate on the day. The principal researcher tried to visit the inpatient site at various times during the day to be available to speak to people. However, despite this, recruitment of patients at the inpatient site was unsuccessful.

Separate inclusion/exclusion criteria were applied to ensure homogeneity within groups – a salient factor in exploration of subjective experiences. Inclusion criteria for patients were: a) adults with a diagnosis of schizophrenia or related psychoses with experience of negative symptoms, and b) aged 18-65 to fit with referral criteria for Adult Mental Health services. Exclusion criteria: present experience of substance abuse, low cognitive functioning, or capacity and consent issues. Teams identified carers with extensive of experience in caring for someone with negative symptoms. Inclusion criteria for healthcare professionals was experience of working in face-to-face therapeutic setting with people who experience negative symptom. Exclusion criteria were: a) no experience of working with people who experience negative symptoms, b) those who do not engage in psychosocial therapeutic work with people who experience negative

symptoms. A total of 10 participants consented to the research (two patients, four carers, and four healthcare professionals). See Tables 1 and 2 for participant demographics.

**Table 1 – Patient Demographics**

<b>ID</b>	<b>Gender</b>	<b>Age</b>	<b>Diagnosis</b>	<b>Duration of Illness (years)</b>
P1	M	44	Treatment Resistant Schizophrenia	>25
P2	M	47	Schizophrenia	>20

\* > - over, M - male.

**Table 2 – Carer and Healthcare Professional Demographics**

<b>ID</b>	<b>Gender</b>	<b>Age</b>	<b>Role</b>	<b>Years of experience</b>
C1	M	81	C	>25
C2	F	70	C	>25
C3	F	60	C	>30
C4	F	72	C	>25
HP1	F	49	CPN	31
HP2	F	59	CPN	18
HP3	F	35	SOT	6
HP4	M	49	CN	20

\* > - over, M - Male, F - Female, - carer, CPN - Community Psychiatric Nurse, SOT - Specialist Occupational Therapist, CN - Charge Nurse

### *Procedure*

Participants were invited to take part in interviews lasting approximately 30 minutes with the principal researcher at each NHS site. Prior to interview participants provided written consent. Interviews were audio recorded and transcribed verbatim. Personal identifiers were removed to ensure anonymity. A debrief post-interview allowed for general discussion and the chance for participants to ask questions regarding the research.

### *Data Analysis*

Analysis of data was conducted following thematic analysis guidance (Braun & Clarke, 2006). Thematic analysis was chosen as it is free from being rooted in any pre-existing theoretical frameworks and is flexible in its application across various epistemologies (Braun & Clarke, 2012). For instance, thematic analysis can be applied across a variety of theoretical frameworks and within these allows researchers to provide a transparent position of theoretical stance in relation to the analysis of data (Braun and Clarke, 2012). The analysis process included the

production of an initial coding framework developed through the independent coding of a full interview transcript by two authors (PS and HM). The progression of analysis included using the coding framework while reading and re-reading all transcripts. This process led to a re-iteration of the coding framework and manuscripts were re-analysed. Some themes were anticipated through the semi-structured interview questions, yet other unexpected themes and associated sub-themes emerged through this process.

### *Reflexivity*

The principal researcher adopted an inductive, semantic and realistic approach to thematic analysis in line with the research aims of obtaining the subjective perspectives of participants. This approach allowed for exploration of individual experience and the meaning people attach to these. The principal researcher's competency for the process of interpretation, and understanding, of explicit meanings was deemed adequate through his training in clinical psychology and previous research experience utilising thematic analysis. Furthermore, the principal researcher has direct clinical experience in working with the present population. Investigator triangulation was completed by the principal researcher and one author (HM) in recognition of potential bias in interpretation of the data.

### *Ethical Issues*

An application was submitted to the West of Scotland Research Ethics Service and approval was gained (see Appendix 2.8). Further approval was gained from each NHS Research and Development departments for the local sites participating (see Appendix 2.9 & 2.10). The principles of the Declaration of Helsinki (World Medical Association, 1964) were followed throughout this research.

## Results

Tables 3 and 4 highlight themes and sub-themes identified through the analysis process. These are described below with quotes highlighted to demonstrate salient points.

**Table 3 – Patient Themes and Sub-themes**

<b>Group</b>	<b>Themes</b>	<b>Sub-themes</b>
Patients	Pre-intervention Considerations	<i>Overcoming Inertia</i> <i>Medical Model Focus</i>
	Individual Needs Approach	<i>Empowerment of Individuals</i> <i>Personalised Treatment</i>

**Table 4 – Carer and Healthcare Professional Themes and Sub-themes**

<b>Group</b>	<b>Themes</b>	<b>Sub-themes</b>
Carers and Healthcare Professionals	Individual Needs Approach	<i>Choice and Values</i> <i>Attunement and Personalised Treatment</i>
	Informed Intervention	<i>Treatment Targets</i> <i>Graded and Flexible Approach</i> <i>Well-timed/Safe Intervention</i>
	Whole Systems Approach	<i>Education and Awareness</i> <i>Staff Training</i> <i>Barriers to Treatment</i>
	Complexity	<i>Interplay of Positive and Negative Symptoms</i> <i>Sensitivity to Psychological Processes</i>

## **Patient Interviews**

### **Pre-intervention Considerations**

*Overcoming Inertia.* Both participants referred to amotivation in relation to engagement in a psychosocial therapy:

*"...I couldn't be bothered, d'you know what I mean mate, I see X [CPN] at home know what I mean?" (P1, page (pp.) 6, line (l.) 192).*

*"...I don't want to talk to people...and they think it, they think that it's them, that I'm not talking to them because maybe they think that I've maybe fell out with them or something like that but ehm, and usually it's not it's me, just can't be bothered doin anything". (P2, pp. 1, l. 10-16).*

*Medical Model Focus.* Both participants commented on medication being helpful and one participant repeatedly referred back to medication as being a solution to problems, indicating perhaps a lack of understanding about psychosocial intervention:

*"...Well if it wasn't for my olanzapine I don't know where I would be the now, y'know that helps a great deal. The medication." (P2, pp. 10, l. 324-325).*

*"... [Response to communication skills question] Oh, well, exact same, take your tablets, to help people, take your tablets and that, to help people." (P1, pp. 3, l. 86).*

*"... [Response to goal setting question] Just eh, just, just take your tablets and that know what I mean, I don't know much about that" (P1, pp. 4, l. 104).*

### **Individual Needs Approach**

*Empowerment of Individuals.* Both participants noted that learning skills would be beneficial for individuals who experience negative symptoms in developing a sense of autonomy and independence:

*"...Oh just to, to help them and that, to help themselves and that...know what I mean to help yourself." (P1, pp. 5, l. 135).*

*"...It makes people independent for themselves." (P2, pp.3, l.76).*

*Personalised Treatment.* It was apparent from comments across both interviews that each individual had their own different preference for the type of therapy they would consider participating in. Questions regarding group therapy highlight this point:

*"... [Group therapy] had it before...[not helpful]...it's just, just, it's the way I am d'you know what I mean, it's the way I am...[felt] uncomfortable..." (P1, pp. 6, l. 165-173).*

*"...Cause it's good to all get together... meet other people that's got the same problems." (P2, pp. 2, l. 45-47).*

### ***Carer and Healthcare Professional Interviews***

The process of analysis led to a number of core themes being identified across both carer and healthcare professional interviews. There were commonalities across both groups which led to further analysis and the identification of a final set of four main themes with related specific sub-themes.

### ***Individual Needs Approach***

*Choice and Values.* The majority of carers commented on the need for careful consideration of individual *choice* within an intervention framework. Two carers commented on a collaborative approach to decision making with regards to participation in weekly sessions and in reviewing progress:

*"... [if] they were showing anything [progress] then you could say 'how would you like to come two days a week?' or something like that..." (C1, pp. 9, l. 314-316).*

*"...just really say this might be ongoing as long as everybody wants to do this, how'd you feel about it? Do we want to have this group every week? Talk about that, what you're getting through it?" (C3, pp. 8, l. 293-295).*

One carer discussed her son's participation in an art therapy class and reflected on the need for interventions to tap into individual interests and *values*, an aspect which may be missing from current treatments:

*"...I suddenly realised that one of the keys for [person with schizophrenia; PwS] has been the huge danger that there is of ignoring the sort of slight more emotional spiritual creative person in all of that, that's unhelpful not to tap into one of the most productive channels he's got for rebuilding his inner self..." (C3, pp. 8, l. 292-295).*

The notion of *values* was echoed across healthcare professional interviews with a focus on engagement or 'buy in' to an intervention:

*"...it's almost like getting them to want to do it or they, they value it..." (HP3, pp. 3, l. 83-84).*

*"...the cost/benefit analysis its needs to be much more worthwhile for somebody to actually invest in it..." (HP4, pp. 2, l. 44-45).*

*Attunement and Personalised Treatment.* Carers indicated the need for professionals to be *attuned* to the individual they are working with. This related to various factors, such as noticing an individual's mood fluctuations or in learning how to read non-verbal language over time:

*"...d'you know ways round about it, you know how to eh, bring them on, you know how eh, their bad moods you know their bad days you know their characteristics..."* (C2, pp. 9, l. 324-325).

*"...but I learnt that very quickly how to deal with [PwS] through his body language rather, because sometimes [PwS] would not speak for days because the negatives were showing their ugly head..."* (C3, pp. 3, l. 113-116).

The need to be attuned to individuals was reflected in various healthcare professional comments related to *personalised treatment*. For example, two professionals commented on the need to be attuned to individuals in relation to psychoeducation and to intervention delivery format:

*"...I think it [approach to education] might be something individual, it would need to be something simple..."* (HP2, pp. 3, l. 29-30).

*"...[group delivery format] there are people that might not, again it might just suit to work on a one-to-one basis... there could be something, something specific somebody really doesn't want to discuss and the group thing they might find quite embarrassing not got the confidence to discuss..."* (HP4, pp. 7, l. 276-279).

### ***Informed Intervention***

*Treatment Targets.* There was variation in agreement between carers and health professionals in relation to treatment targets. Learning how to communicate positive emotions was regarded by all professionals to be an important area of intervention, with possible benefits for both the individual and for the professional, specifically in relation to obtaining patient feedback:

*"...Yep, absolutely, yep, because I think that's something as well that you feel then that you're doing something right, the treatment that they are receiving is obviously helping, y'know, so they're feeding back to you..."* (C1, pp. 4, l. 126-128).

However, this was not fully representative of carer views with two specifically stating individuals retain this particular ability, for example:

*"...I mean let's say she went to the seaside and enjoyed herself I think she could, I mean she could, I think she could express herself there, y'know, I had a good day at the beach', y'know."* (C1, pp. 5, l. 181-182).

*"...Oh sometimes he'll wake up in the morning and he'll say to me, mum d'you know I've got a great day the day..."* (C2, pp.3, l. 116-117).

Three carers commented that changing beliefs associated with negative symptoms would be a difficult process that may take significant effort over a long period of time and could also require opportunistic timing for intervention:

*"...it would be really, d'you know, it would be really, really hard... it's very, very hard to change their thoughts. See the thought process it's very, I've lived with it all those years, it's very very hard to change a thought, you've got to really work at it..."* (C2, pp. 6, L. 214-217).

*"...just sometimes he's in states where it's very difficult to approach that with him. You need to look for windows of opportunity..."* (C4, pp. 10, l. 384-386).

Professional perspectives differed from carers with positive comments on challenging thoughts related to negative symptoms and ideas for other areas to target:

*"...if you're teaching them to kinda like, almost like CBT approach re-think what they're thinking then brilliant..."* (HP3, pp. 5, l. 170-171).

*"...y'know kind of exploring the more, the, the mood type of things and ehm self-beliefs and self-esteem, self-worth..."* (HP2, pp. 6, l. 216-218).

*Graded and Flexible Approach.* The majority of both groups indicated the need for a graded and flexible approach across all aspects of treatment. For example, it was important to both groups that goals were: set in line with the individual; sensitive to the impact of negative symptoms; realistic and safe:

*"...I think even if you can get them be able to think about what their goals are when they've got negative symptoms is quite a massive achievement..."* (HP3, pp. 4, l. 123-124).

*"...providing that you keep it [goal setting] reasonable...most setting a target is a wee bit out, out with, y'know tryin to, be clever, y'know, and sometimes it upsets the whole apple cart."* (C1, pp. 6, l. 203-207).

Other ideas of grading covered aspects including engagement and skills development, safe approaches to thought challenging, and interventions characteristics (e.g. format):

*"...generally just try and build that rapport then try and get them do something that they enjoy and just build it up and up..."* (HP3, pp. 4, l. 134-135).

*"...it's a risk to take and it could either push it to, to the limit, or you could take a step back and continue to observe, and the belief could continue and where do you, where do you intervene?"* (C3, pp. 6, l. 220-222).

*"...I think combination's [individual and group therapy] probably the best approach, ehm, think yeah, I think one-to-one's probably the key to starting off..."* (HP3, pp. 6, l. 220-222).

While grading of interventions was important it was also clear from both groups that a flexible approach must be adopted to meet individual needs:

*"...[engaging in one-to-one therapy] that again's down to observation, how that person is on that particular day...this will work today or no it won't work today, and say oh we'll try it again tomorrow or we'll try it next week when you're feeling a wee bit better..."* (C3, pp. 7, l. 262-267).

*Well-Timed/Safe Intervention.* Two carers stressed the importance of well-timed intervention in relation to stage of illness with one commenting specifically on the present model of crisis intervention and the subsequent lost opportunities for people to engage in therapy:

*"...[discussing skills development through intervention]... I think initially of course the patient is perhaps in a chronic state that's not ehm, that might not be necessary at that particular point in time....the timing of it is crucial...timing is, is, if I was to say, perhaps of the essence in recovery."* (C3, pp. 2, l. 48-58).

*"...[open discussion] ...he gets all the treatment and all the interaction with professionals and experts when he is ill rather than well...but even with very ill people like [PwS] there are periods of, eh plateaus, eh, or remission...where there's a much greater policy-, possibilities, you know, for logical communication and insight for reflection from the patient...yet for some reason contact is almost entirely limited to illness and rather than what insight they can get and what communication the patient can give them about how these things affect them and what would help them and, to me, that loss is huge..."* (C4, pp. 16, 611-620).

The majority of both carers and professionals stressed the need for intervention to feel safe for individuals. This related to making change in general, familiarity, and the therapeutic environment:

*"...to do something, to make a change or try to work with something to address certain issues they've got, they've got to feel safe..."* (HP4, pp. 5, 166-168).

*"... [discussing one-to-one therapy] You'd need somebody familiar with them, see likes of X [nurse] somebody from their, they like familiarity..."* (C2, pp. 6, l. 234-235).

*"... [setting] well it has to be relaxed...has to be relaxed, has to be familiar and it has to be welcoming, not formal, friendly."* (HP1, pp. 9, 293-294).

### **Whole Systems Approach**

*Education and Awareness.* Two healthcare professionals indicated the need to educate individuals about their illness and how a treatment works, with one stipulating a need to provide specific information on both positive and negative symptoms:

*"...I think encompass the fact that, you know, you can have symptoms like hallucinations delusions but what can happen due to this, as well, is the fact that you can become a bit depressed, you can become a bit lethargic, lacking motivation, volition, you know all these kinda things..."* (HCP1, pp. 1, l. 7-9).

Three carers described a need for education and awareness raising across multiple systemic levels. For example, a need was identified for carers/families to be well-informed of the illness/treatment and one carer commented on personal fears related to the stigma that still surrounds schizophrenia:

*"... [informed of treatment] that would be helpful. I think it would be, yeah a brief description or some, some literature that maybe handed out too... to parents or carers with regards to ehm the topic he's sitting down and discussing with X [therapist]...carers can be left in the dark..."* (C3, pp. 1, l. 34-36).

*"... [discussing the impact of providing care] It's worth the hard work, it's really worth it because people don't, either put labels on people, schizophrenic, 'oh god'. See although my family know there's something obviously wrong with [PwS] ...how does [PwS] not go out on his own or how, y'know, but I couldn't say he's schizophrenic..."* (C2, pp. 6, l. 221-225).

Systemic education was also a need reflected by three professionals focused at the levels of individuals, health professionals, and the organisation in general:

*"...[individually tailored psychoeducation] I think it's having a variety of ways cause individuals will suit different ways...I think it really depends on you-, your target group, or your individual ..."* (HP3, pp. 2, l. 14).

*"...if staff can have a, a kind consistent approach and more empathy...and understanding that even might be just more beneficial..."* (HP3, pp. 10, l. 337-338).

*"...there's extreme lack of knowledge about negative symptoms and there's an extremely unhelpful [organisational] culture surrounding people's ability, or perceived ability, to help people with negative symptoms, there's a very negative and pessimistic attitude towards helping people with negative symptoms...these attitudes pervades, 'there's not a lot we can do about negative symptoms', ehm,*

*'medication doesn't work for them there's not much we can do' ehm, and there's still a culture that I perceive it's not disappeared...'* (HP4, pp. 1, l. 8-25).

*Staff Training.* Three healthcare professionals commented on the need for well-trained staff for working with negative symptoms. Two professionals identified specific training needs - to overcome gaps in skills and re-build confidence in therapeutic abilities:

*"...I've not really, been able to teach somebody how to, with negative symptoms, how to be able to, you know, communicate... I wouldn't say we've been taught the skills for that I don't think..."* (HP2, pp. 4, l. 130-135).

*"...people [professionals] don't feel particularly empowered or skilled, ehm in addressing these issues, so for me it's a fundamental ehm and essential part of informing treatment, interventions for patients and training for staff...to make them much more skilled and much more confident in going about it, and not to be frightened, or feel helpless when working with people with kinda severe negative symptoms..."* (HP4, pp. 4, 11-17).

*Barriers to Treatment.* Various barriers were highlighted in the healthcare professional group. Engagement was a concern for all professionals:

*"...Eh, they tend to non-engage [in group therapy] ...probably mostly non-engagement I would say would be the main thing for when...we did group therapy..."* (HP2, pp. 8, l. 255-257).

*"...somebody's got negative symptoms they're much more difficult to engage in those kinds of approaches..."* (HP3, pp. 1, 13-15).

Organisational resources were identified by three professionals as having implications for implementing treatments for negative symptoms, with one stressing the need for extra support services:

*"...you've got resource, trying to find a suitable locations, staff giving up staff time for the training and delivery, ehm the commitment yeah, so organisations always an issue."* (HP3, pp. 9, l. 324-325).

*"...resources, eh, are really important, having the correct amount of resources the correct amount of skill mix to deliver, eh, is vitally important there's no point in starting something I don't think unless you've got that eh support from management and recognising it needs to be ring-fenced and fully resourced, whether that be staffing or financed ehm, they need to buy into it as an idea you can't go off half cold doing this stuff, there needs to be a commitment that it's something good to do..."* (HP4, pp. 10, 385-390).

*"...and you can't always depend on carers [to provide motivation] because carers have got a life as well, they've got, y'know they can't be there all the time because it's very, very stressful... [there is a need for]...Support. Other support. Extra support... Ehm, a service there that's what they actually do, that's what they focus on..."* (HP1, pp. 6, l. 181-192).

Carers commented on individual's lack of insight into their illness, which has the potential to act as a barrier to engagement in therapy:

*"...patients may not refer to their illness as they don't actually see themselves as being ill. That is something that's so important. [PwS] did not or does not see himself as a schizophrenic person..."* (C3, pp. 3, l. 82-84).

*"...[weekly therapy sessions] No I don't think so. Because d'you know something they'll feel as though it's a chore. They're making me go here, they're making me go here... I've got to go there, I've got to go there, you know what I mean, as if, what's the matter that I've got to go there and nobody else has got to go there, y'know?..."* (C2, pp. 255-261).

### **Complexity**

*Interplay of Positive and Negative Symptoms.* The majority of carers and professionals commented on the complex interaction of positive and negative symptoms and how these may impact on interpreting social situations or in relation to challenging beliefs associated with positive symptoms:

*"...I notice on the train he would become upset he would become anxious ehm, I don't know particularly what he was thinking, maybe he thought people were looking at him, maybe he felt ehm under pressure, and maybe he was becoming delusional because of this..."* (C3, pp. 2, l. 70-74).

*"...[discussing social situations] especially people with psychosis because they can misinterpret situations really rapidly..."* (HP4, pp.4, l. 130).

*"...somebody with a, a concrete belief [related to positive symptoms] might, might not be receptive to have that challenged..."* (HP3, pp.5, l. 174).

*Sensitivity to Psychological Processes.* All carers and professionals commented on various psychological factors adding to complexity in the treatment of negative symptoms. These included:

Sensitivity to individual cognitive ability:

*"...part of [PwS] trouble, another part of it, is eh, her forgetfulness, she's very very very, very forgetful, bad memory..."* (C1, pp. 10, l. 367-368).

*“...people who’ve got a severe psychosis ehm, who may have cognitive deficits, who may have difficulty processing information, comprehending information...”* (HP4, pp. 4, l. 114-116).

Awareness of comorbidity:

*“...very serious ehm psychotic illness, ehm diagnosed with schizophrenia, ehm, and he has autism as well...”* (HP1 pp.5, 156-157).

Consideration of other possible important psychological constructs to target through intervention:

*“...y’know, he lost a lot of his confidence...”* (C2, pp. 2, l.52).

*“...y’know assertiveness and all that kinda stuff...that’s something as well where I think patients with schizophrenia that’s not really focussed on... things like their...confidence in their own abilities...”* (HP1, pp. 4, 143-146).

## **Discussion**

The aim of this study was to improve understanding of psychosocial treatment needs for negative symptoms by obtaining the perspectives of major stakeholders – patients, carers, and healthcare professionals. The qualitative analysis and emergent themes provide important information related to treatment need, intervention planning, and implementation factors.

### *Treatment Need*

A substantial finding from the present study is the need for future psychosocial interventions to be developed in line with recovery principles (Leamy et al, 2011). The present subthemes of choice, values, and empowerment are consistent with Wallace et al’s (2016) findings from a recent exploration of patient experiences of a recovery-oriented complex intervention. Collaboration and respect are crucial in creating the right therapeutic environment across all stages of intervention and are important elements in an individual’s journey towards recovery. Future intervention development may need to consider methods to meet these needs.

Hamman et al’s (2015) survey of psychiatrist’s opinions in relation to shared decision making with patients may provide a starting point for understanding how to meet this challenge. The survey indicated psychosocial aspects of treatment may be a key area for shared decision making. Patients in general value shared decision making (see Lester, Tritter, & England, 2003) and people who experience negative symptoms have specific treatment preferences (Moritz et al, 2016). Shared decision making can tackle preference, collaboration and respect

in line with recovery. The importance of this is indicated in relation to the different patient preferences for treatment format in the current study.

All carers and professionals commented on the need for a graded approach across all aspects of treatment. For example, grading of goal setting, review of progress, and in deciding end point of treatment. This finding suggests a flexible and graded approach to measuring therapy 'success' which is at odds with the specific clinical/functional criteria recently suggested by Schooler et al (2015). This highlights the disparity in user-defined versus clinician-defined outcomes and understanding of recovery.

### *Specific Intervention Targets*

The present findings support previous studies (e.g. Lasalvia et al, 2012) which suggest a lack of consensus amongst patients, carers, and healthcare professionals in relation to treatment priorities. Moritz et al's (2016) study highlights that patients rate amotivation as a high priority target of intervention, which is consistent with patient's comments in the present study. Furthermore, patient's comments on medication being helpful may reflect a similar finding by Sterk et al (2013) in relation to patient satisfaction with medical treatment.

However, patients may be so highly conditioned to the medical model of treatment that it is difficult for them to be able to conceive of 'treatment' as anything other than a pill to take. One patient consistently referred to medication compliance which may be indicative of the way the medical model fosters an external locus of control in individuals which may subsequently impact on their illness beliefs and self-efficacy. It could also convey a message about the systemic attitude to negative symptoms in general. As noted by one healthcare professional, unhelpful attitudes towards negative symptoms exist across organisational systems, with staff at times mirroring negative symptoms (e.g. a sense of apathy in their approach to intervention). However, Elis et al (2013) highlight the role of medication in many of the reported helpful psychosocial treatments for negative symptoms, indicating a need to find a balance between medicine and psychosocial input in order to meet individual's needs.

There were different opinions amongst carers and professionals in relation to treatment offering development of skills to challenge thoughts and in developing positive communication techniques. These are key intervention ingredients for a number of psychosocial treatments for negative symptoms, such as Cognitive Behavioural Social Skills Training (CBSST; Granholm, Holden, Link & McQuaid, 2014). This may indicate a need to further our understanding of treatment priority.

There was general agreement across both carers and professionals in relation to the complexity of treatment of negative symptoms. The theme of 'complexity' may be a reflection of the difficulties staff face (e.g. therapeutic pessimism) when dealing with negative symptoms. This may be a reason negative symptoms can be ignored or avoided as a treatment need. It is clear individuals can present with comorbid factors such as cognitive impairment or other mental health disorders. Healthcare professionals in the study identified the need for training in order for them to feel empowered and able to address complexity.

It is also apparent that negative symptoms are transdiagnostic – that is they are common features of other mental disorders, such as depression (see Buckley et al, 2009). Carers and professionals in the present study commented on psychological targets that are not addressed in the treatment of schizophrenia (e.g. confidence). Moritz et al (2016) indicate that patients rated low self-esteem as the most urgently needed area for psychosocial intervention. This highlights two possible avenues of research. Firstly, research could begin to focus on single negative symptom using comprehensive assessment tools, such as the Zurich Negative Symptom Scale (Kaiser, 2016), to filter out specific symptoms at recruitment stages. Alternatively, a solution may be to develop a transdiagnostic approach to negative symptoms that can be applied across mental health disorders.

### *Implementation*

Carers and professionals noted that patient lack of insight into their illness may act as a potential barrier to engagement. Patients also commented on their experience of low motivation to engagement, which may be a by-product of poor insight. Lysaker et al (2011a) indicate the role of metacognition in insight and more recently Buck et al (2014) suggest that individuals with poor metacognitive ability may be a barrier to overcoming negative symptoms. The current findings support the notion of developing patient metacognition as a first step to treatment.

Both carers and healthcare professionals indicated a need for a systemic approach to raising awareness and understanding of negative symptoms, with one participant specifically noting unhelpful organisational attitudes. As noted in a recent review (Morera, Pratt, & Bucci, 2016) the medical model remains prominent in staff perspectives and can have a negative impact on their attitudes towards recovery. Le Boutillier et al (2015) draw attention to the disparity between clinical recovery, personal recovery, and service-defined recovery, the latter being driven by organisational factors. Patients consider professional attitudes important in the therapeutic process (Sterk et al, 2013) and this may be an area for organisational improvement. Staff may need to be trained to develop a better understanding of recovery.

Healthcare professionals in the present study also identified the need for specific training for working with negative symptoms, and for a shared vision across all levels of organisation in achieving this. This reflects findings of a review from Ince, Haddock, and Tai (2015) who highlighted the need for well-planned training for staff and commitment across organisational levels. Both carers and professionals in the present study commented that patients have a need for well-timed interventions. The importance of this is indicated by one carer's comment referring to missed opportunities of current interventions through their reactive approach to schizophrenia in general. It may be that a stepped-care model can address this issue through a proactive approach to treatment. For example, through stepping-up community input to deter crisis and subsequent hospital admissions.

The identification of organisational resources as a barrier to treatment is consistent with the literature (Williams, Prillo, & Brown, 2015). Interventions do not happen in isolation and extra support outwith a treatment in the form of supportive scaffolding or social groups may be beneficial to maintain gains. Elis et al (2013) highlight the self-defeating approach of giving people the skills to adapt to social situations while in therapy, yet they may not have the opportunity to apply these in real life. Providing opportunity is a key aspect of behaviour change (see Michie, van Stralen, and West, 2011) which organisations may need to consider. However, this would require substantial resource and planning across organisations which should be informed by an ecological approach to implementation (Raghavan, Bright, & Shadoin, 2008) – specifically, integrated policymaking across political, organisation, regulatory and social levels that aims for successful and sustainable implementation of interventions.

### *Strengths and Limitations*

To our knowledge this is the first study to utilise qualitative methods to understand the treatment preferences of major stakeholders in relation to negative symptoms. The qualitative methodology allowed an in-depth exploration of these key stakeholder perspectives. An interesting outcome of this research is related to the process of study recruitment. Inpatients initially agreed to participate yet pulled out on the day. They may have felt overwhelmed by the interview process. Or this may reflect other deficits related to effort-based decision making (Treadway, Bossaller, Shelton, & Zald, 2012) or being able to foresee any benefits in taking part in the research (Treadway & Zald, 2013). Consideration should be given to these factors if this group are to be given a platform for their opinions to be heard. A more active approach to research recruitment should be employed in obtaining the perspectives of this particular group.

Additionally, research could build upon the present findings by utilising quantitative methodologies (e.g. online survey) to capture the views of larger

representative numbers from each stakeholder group. It is acknowledged that the findings of the present study may not be representative of other people's own personal experiences and views on negative symptoms and their treatment.

## **Conclusions**

The study aimed to explore the views of key stakeholders in relation to negative symptoms and their treatment. The findings address gaps in the literature on psychosocial treatment of negative symptoms (e.g. Schooler et al, 2015) and also in attempting to generate knowledge about what patients value (Wykes, 2016).

Themes suggest an individualised treatment consistent with recovery, set within a whole systems approach. This approach may best be framed in a stepped-care model of delivery. A number of implementation barriers were identified with solutions suggested. There may be scope in the development of a transdiagnostic approach to the treatment of negative symptoms to address the identified theme of complexity.

Overall, no study to date has explored the opinions of major stakeholders in relation to treatment preferences. We have identified that patients may find engaging in research a challenging process and may experience difficulties in communication during research. There remains a need for research to target this population to develop our understanding of their treatment preferences in working towards developing an evidence-based psychosocial intervention for negative symptoms.

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## **Appendix 1.1: Authors Instructions for Journals**

### **Journal for both Systematic Review and MRP:**

#### **Psychology and Psychotherapy: Theory, Research and Practice.**

Impact Factor: 1.661, ISI Journal Citation Reports © Ranking: 2015: 47/76 (Psychology); 62/121 (Psychology Clinical); 71/136 (Psychiatry (Social Science)); 93/140 (Psychiatry), Online ISSN: 2044-8341

#### **Author Guidelines**

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

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

#### **1. Circulation**

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

#### **2. Length**

All articles submitted to PAPT must adhere to the stated word limit for the particular article type. The journal operates a policy of returning any papers that are over this word limit to the authors. The word limit does not include the abstract, reference list, figures and tables. Appendices however are included in the word limit. The Editors retain discretion to publish papers beyond this length in cases where the clear and

concise expression of the scientific content requires greater length (e.g., a new theory or a new method). The authors should contact the Editors first in such a case.

Word limits for specific article types are as follows:

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

### 3. Brief reports

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

### 4. Submission and reviewing

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

### 5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded [here](#).
- The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and refer to any previous work in the third person.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results,

Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.

- All Articles must include Practitioner Points – these are 2-4 bullet points, in addition to the abstract, with the heading ‘Practitioner Points’. These should briefly and clearly outline the relevance of your research to professional practice.
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide DOI numbers where possible for journal articles.
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- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
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Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper. A copy of the Colour Work Agreement form can be downloaded [here](#).

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## 14. Early View

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

## Appendix 1.2: Details of Excluded Studies

Table 1 provides examples of prominent systematic reviews and treatment studies that were considered for final inclusion but failed to meet specific inclusion criteria.

**Table 1: Examples of Excluded Studies**

Reference	Reason for Exclusion
Dickerson, F. B., & Lehman, A. F. (2006). Evidence-based psychotherapy for schizophrenia. <i>The Journal of nervous and mental disease</i> , 194(1), 3-9.	<ul style="list-style-type: none"> <li>• Explicit reference to sub-domains of negative symptoms was not included in results analysis.</li> <li>•</li> </ul>
Gold, C., Solli, H. P., Krüger, V., & Lie, S. A. (2009). Dose-response relationship in music therapy for people with serious mental disorders: Systematic review and meta-analysis. <i>Clinical psychology review</i> , 29(3), 193-207.	<ul style="list-style-type: none"> <li>• Explicit description of music therapy not included.</li> <li>• Explicit reference to sub-domains of negative symptoms was not included in results analysis.</li> </ul>
Mairs, Hilary, Karina Lovell, and Philip Keeley. "Carer and mental health professional views of a psychosocial treatment for negative symptoms in psychosis: A qualitative study." <i>International journal of nursing studies</i> 49.10 (2012): 1191-1199.	<ul style="list-style-type: none"> <li>• Explicit reference to sub-domains of negative symptoms was not included in results analysis.</li> </ul>
Mairs, H., Lovell, K., Campbell, M., & Keeley, P. (2011). Development and pilot investigation of behavioral activation for negative symptoms. <i>Behavior modification</i> , 35(5), 486-506.	<ul style="list-style-type: none"> <li>• Explicit reference to sub-domains of negative symptoms was not included in results analysis.</li> </ul>
Perivoliotis, D., & Cather, C. (2009). Cognitive behavioral therapy of negative symptoms. <i>Journal of clinical psychology</i> , 65(8), 815-830.	<ul style="list-style-type: none"> <li>• The description of neurocognitive assessment of case study indicated historical attentional problems. Early years assessments did not confirm ADHD. However, it was unclear if case study neuropsychological impairments were closely linked with schizophrenia or a long standing separate neurological deficit. Therefore a decision was made to exclude due to generalisability issues.</li> </ul>
Staring, A. B., ter Huurne, M. A. B., & van der Gaag, M. (2013). Cognitive behavioral therapy for negative symptoms (CBT-n) in psychotic disorders: a pilot study. <i>Journal of behavior therapy and experimental psychiatry</i> , 44(3), 300-306.	<ul style="list-style-type: none"> <li>• Explicit reference to sub-domains of negative symptoms was not included in results analysis.</li> </ul>

## **Appendix 2.1: Patient Interview Script and Questions**

There are many treatments that have been shown to be effective for common problems of schizophrenia. These treatments tend to focus on hallucinations and delusional thinking, known as positive symptoms. However, there is little known about effective psychological treatments for the negative symptoms of schizophrenia.

These symptoms, known as negative symptoms, can include experiencing a lack of motivation, not looking forward to things, feeling emotionally flat, or feeling disinterested in having social interactions with other people. These problems can be a barrier to recovery and can stop people living the life they would like to.

This interview will ask questions about specific factors related to the psychological treatment of these negative symptoms. We are interested in your opinion of these psychological treatments.

### **Effective psychosocial components**

There are common factors in the treatments that have been shown to be helpful for these symptoms.

**Q1.** Based on your own experience, how important would it be for you for a treatment to provide information specific to schizophrenia and negative symptoms? (*prompt* use the above problems to describe negative symptoms if needed)

*Follow-up...* How important would it be for you for a psychological treatment to provide information about how the treatment works?

**Q2.** Based on your own experience, how important would it be for you to receive training in problem solving skills for:

1. Everyday problems? (*prompt* such as planning a shopping trip, handling money and bills, looking for a job, using public transport)?
2. Understanding social situations? (*prompt* For instance, to help in understanding what yourself and others are thinking and feeling).

**Q3.** Based on your own experience, how important would it be to you for a treatment to help develop your ability to communicate to others when you feel positive emotions?

**Q4.** Based on your own experience, how important would it be to you for a treatment to help you develop skills in setting realistic goals and supporting you to achieve these goals?

**Q5.** Based on your own experience, how important would it be to you to be encouraged to practice the skills learned in therapy?

**Q6.** Based on your own experience, how important would it be to you for a treatment to develop skills that would help you to challenge the beliefs that may be holding you back from things you want to do?

### **Delivery**

The treatments that have been shown to be helpful tend to be delivered in different ways and in different settings.

### *Format*

**Q7.** For you, based on your own experience, can you comment on the idea of being part of a group receiving a treatment for negative symptoms?

- *Follow-up...* Would the number of people in a treatment group be important to you?
- *Follow-up...* Other treatments are delivered in a 1-2-1 format with the therapist and client, can you comment on this idea?

#### *Sessions*

**Q8.** The treatments that have been shown to be helpful tend to last between 1-2 hours....How important is the duration of treatment sessions for you?

- *Follow-up...* Therapy sessions tend to be delivered weekly...from your own experience, how important is this for you?
- *Follow-up...* Based on your own experience, what would be the suitable number of sessions a treatment should aim to finish in?

The treatments that have been shown to be helpful tend to be delivered in different settings and these can include clinical settings, community settings such as local GP clinics, the client's home, or as part of routine care for people in hospital settings.

**Q9.** From your own experience, how important is the setting in which a treatment takes place?

#### **Therapists**

The treatments that have been shown to be helpful tend to be delivered by different professionals. Some are delivered by people such as psychologists and psychiatrists. Others treatments are delivered by nurses, family therapists, or social workers.

**Q10.** Based on your own experience, how important to you is it that treatments are delivered by a particular professional?

#### **Implementation**

**Q11.** Based on your own experience, do you have any ideas of what might get in the way of treating negative symptoms?

#### **Open ended section**

**Q12.** Based on your own personal experience, is there anything else about treating negative symptoms you would like to comment on?

#### **Prompt –**

- Please remember, the focus of this interview is to get your opinion on treatment factors for problems like feeling emotionally flat, having low motivation, or feeling disinterested in communicating with others. These are known as negative symptoms.

## Appendix 2.2: Interview Script and Questions (Carer and Professional Carer Version)

There are many treatments that have been shown to be effective for common problems of schizophrenia. These treatments tend to focus on hallucinations and delusional thinking, known as positive symptoms. However, there is little known about effective psychological treatments for the negative symptoms of schizophrenia.

These symptoms, known as negative symptoms, can include experiencing a lack of motivation, not looking forward to things, feeling emotionally flat, or feeling disinterested in having social interactions with other people. These problems can be a barrier to recovery and can stop people living the life they would like to.

This interview will ask questions about specific factors related to the psychological treatment of these negative symptoms. From your experience of caring for someone who experiences negative symptoms, we are interested in your opinion of these psychological treatments.

### **Effective psychosocial components**

There are common factors in the treatments that have been shown to be helpful for these symptoms.

**Q1.** Based on your own experience, how important would it be for you for a treatment to provide education specific to schizophrenia and negative symptoms? (*prompt* use the above problems to describe negative symptoms if needed)

*Follow-up...* How important would it be for you for a psychological treatment to provide education about how the treatment works?

**Q2.** Based on your own experience, how important would it be for you for a treatment to include training in problem solving skills for:

3. Everyday problems? (*prompt* such as planning a shopping trip, handling money and bills, looking for a job, using public transport)?
4. Understanding social situations? (*prompt* For instance, to help the person understand what they and others are thinking and feeling).

**Q3.** Based on your own experience, how important would it be to you for a treatment to develop skills in helping people to communicate to others when they feel positive emotions?

**Q4.** Based on your own experience, how important would it be to you for a treatment to develop skills in setting realistic goals and in being supported to achieve these goals?

**Q5.** Based on your own experience, how important would it be for a treatment to encourage people to practice the skills learned in therapy?

**Q6.** Based on your own experience, how important would it be to you for a treatment to develop skills that would help people to challenge the beliefs that may be holding them back from things they want to do?

### **Delivery**

The treatments that have been shown to be helpful tend to be delivered in different ways and in different settings.

*Format*

**Q7.** Based on your own experience, can you comment on the idea of group therapy for people receiving a treatment for negative symptoms?

- *Follow-up...* Would the number of people in a treatment group be important?
- *Follow-up...* Other treatments are delivered in a 1-2-1 format with the therapist and client, can you comment on this idea?

#### *Sessions*

**Q8.** The treatments that have been shown to be helpful tend to last between 1-2 hours....How important is the duration of treatment sessions?

- *Follow-up...* Therapy sessions tend to be delivered weekly...from your own experience, how important is this?
- *Follow-up...* What would be the suitable number of sessions a treatment should aim to finish in?

The treatments that have been shown to be helpful tend to be delivered in different settings and these can include clinical settings, community settings such as local GP clinics, the client's home, or as part of routine care for people in hospital settings.

**Q9.** From your own experience, how important is the setting in which a treatment takes place?

#### **Therapists**

The treatments that have been shown to be helpful tend to be delivered by different professionals. Some are delivered by people such as psychologists or psychiatrists. Others treatments are delivered by nurses, family therapists, or social workers.

**Q10.** Based on your own experience, how important to you is it that treatments are delivered by a particular professional?

#### **Implementation**

**Q11.** Based on your own experience, do you have any ideas of what might get in the way of treating negative symptoms?

#### **Open ended section**

**Q12.** Based on your own personal experience, is there anything else about treating negative symptoms you would like to comment on?

**Prompt** – Please remember, the focus of this interview is to get your opinion on treatment factors for problems like feeling emotionally flat, having low motivation, or feeling disinterested in communicating with others. These are known as negative symptoms.

## Appendix 2.3: Information and Consent for Future Information Events

Centre Number:  
Project Number:  
Subject Identification Number for this trial:

### INFORMATION AND CONSENT FORM

People who have taken part in this study are being asked if they would like to act as consultants on future research that effects people with severe and enduring mental illness. Specifically you are asked if you would consent to:

1. Being informed of upcoming events related to psychosocial treatments.
2. Being invited to attend these events to provide input based on your own personal experience.

If you are interested in this please provide your name and contact details below and enclose in the envelope provided. This will be kept with the clinical care team who will contact you with information related to upcoming events. This will be stored in accordance with NHS policy.

Name:.....

Contact details (email or phone):

.....

.....

**initial box** **Please**

I confirm that I have read and understand the above information sheet  
have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at  
any time, without giving any reason, without my legal rights being affected.

I agree to being informed, and invited to, these upcoming events.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(1 copy for participant)

## **Appendix 2.4: Participant - Information Sheet**

### **Study Title:**

Treatment of negative symptoms in schizophrenia: An exploration of key stakeholders views on treatment gap, intervention, and recovery.

### **Brief Summary:**

Symptoms of schizophrenia can include difficulties with motivation, reduced emotional expressiveness, and low interest in activities. These symptoms can be particularly burdensome but there is a lack of understanding about the best approach to treatment. In order to develop better treatments, this study invites people to participate in a one-to-one interview with a researcher to discuss their views about these symptoms of schizophrenia and their treatment.

### **Who is conducting the research?**

This study is being carried out by Phil Smith and is supervised by Dr Hamish McLeod (University of Glasgow) and Dr. Polash Shajahan (NHS Lanarkshire).

### **Invitation**

You are being invited to take part in a research study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. It is important that you take the time you need to decide whether or not you wish to take part.

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

Symptoms such as difficulties with motivation, reduced emotional expression, and a low interest in activities (known as negative symptoms) can be burdensome for people who experience schizophrenia. This study seeks to improve our understanding of treating these symptoms. We are consulting people with experience in order to gather vital information that can be used to improve the treatments we offer in health service settings.

The current study aims to explore this by inviting people who have experience of negative symptoms to participate in an interview to provide their views on these symptoms and their treatment. Your involvement in the study will last for the duration of the interview (approx 30 minutes). The study will be submitted as part of Phil Smith's Doctorate in Clinical Psychology research portfolio.

We would also like to seek consent from people to be invited as consultants on future research that affects people with severe and enduring mental health issues. This would involve you providing consent to being told about upcoming events related to psychosocial treatments which you would be invited to attend to provide input from your own personal experience. This will be discussed further at the interview debrief, where questions can be asked and consent forms provided if interested.

### **Why have I been chosen?**

You may currently experience/ have past experience of negative symptoms of schizophrenia.

### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you opt in, you will be asked to sign a consent form. You are free to withdraw at any time and without giving a reason. Regardless of whether you decided to participate or not, it will not affect the treatment that you receive.

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

You will be invited to attend a single interview with the researcher which will last approximately 30 minutes. This will take place in a private room within the ward. You will be asked your opinions about the negative symptoms of schizophrenia and their treatment. The interviews will be audio recorded so that they can be transcribed for analysis. Any direct quotes used in the final written version of the study will be anonymized. You will have an opportunity to ask questions about the study.

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

Some people may find that the interviews address sensitive issues. But, there is no plan to intentionally ask distressing or upsetting questions.

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

You will receive no direct incentives or rewards from taking part in this study. The information you provide will give us a better understanding of negative symptoms and their treatment. This will help to inform the development of new interventions for negative symptoms.

### **Will my taking part in this study be kept confidential?**

All information collected about you and the things you say during the research will be kept strictly confidential. Your study records will be identified only by an ID number and any personal identifying information (e.g. name, address) will be concealed. Confidentiality will be strictly maintained unless we detect that there is evidence of serious harm or risk of serious harm to any person. In such cases we may have an obligation to contact relevant statutory bodies/agencies. Where possible we will discuss this action with you ahead of time. As part of routine regulation qualified NHS regulators may audit research projects to ensure quality is being maintained.

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

The results of the study will be written into a thesis and submitted to the University of Glasgow as part of the main researcher's (Phil Smith) requirements for the Doctorate in Clinical Psychology. A summary of this report will be sent to Dr. Polash Shajahan for distribution to participants. This report is expected to be completed by August 2016. The overall results of the research may also be submitted for publication in a scientific journal. No individual will be identifiable from any published work.

### **Who is organizing and funding this research?**

The research is organised by the University of Glasgow and supported by NHS Lanarkshire. There is no funding associated with this research.

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

All research in the NHS is scrutinized by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed by the West of Scotland Ethics Committee Service (WoSRES) and favorable opinion has been given.

### **If you have any further questions**

If you would like more information about the study and wish to speak with someone who is independent of the research team, please contact **Dr Sue Turnbull, Research Tutor, University of Glasgow, email: [s.turnbull@glasgow.ac.uk](mailto:s.turnbull@glasgow.ac.uk), Tel no: 0141 2113937**

### **If you have a complaint about any aspect of the study**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint procedure is also available for you. The contact person for making a complaint in NHS Lanarkshire is: **Laura Jack, NHS Lanarkshire Headquarters, Kirklands Hospital, Fallside Road, Bothwell, G71 8BB, Tel: 01698 858321, Email: [laura.bryan@lanarkshire.scot.nhs.uk](mailto:laura.bryan@lanarkshire.scot.nhs.uk)**

### **Contact details - If you would like further information, you can contact:**

#### **Main Researcher (Trainee Clinical Psychologist):**

Phil Smith

University of Glasgow

Institute of Health and Wellbeing 055 Great Western Road

Glasgow, G12 0XH

[p.smith.4@research.gla.ac.uk](mailto:p.smith.4@research.gla.ac.uk)

## **Appendix 2.5: Carer - Participant Information Sheet**

### **Study Title:**

Treatment of negative symptoms in schizophrenia: An exploration of key stakeholders views on treatment gap, intervention, and recovery.

### **Brief Summary:**

Symptoms of schizophrenia can include difficulties with motivation, reduced emotional expressiveness, and low interest in activities. These symptoms can be particularly burdensome but there is a lack of understanding about the best approach to treatment. In order to develop better treatments, this study invites people to participate in a one-to-one interview with a researcher to discuss their views about these symptoms of schizophrenia and their treatment.

### **Who is conducting the research?**

This study is being carried out by Phil Smith and is supervised by Dr Hamish McLeod (University of Glasgow) and Dr. Ian-Mark Kevan (NHS GG&C).

### **Invitation**

You are being invited to take part in a research study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. It is important that you take the time you need to decide whether or not you wish to take part.

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

Symptoms such as difficulties with motivation, reduced emotional expression, and a low interest in activities (known as negative symptoms) can be burdensome for people who experience schizophrenia. This study seeks to improve our understanding of treating these symptoms. We are consulting people with experience in order to gather vital information that can be used to improve the treatments we offer in health service settings.

We are inviting carers and/or family members of someone with experience of the above symptoms to participate in an interview. During the interview people can share their experience and provide their views on treatment for these symptoms. Your involvement in the study will last for the duration of the interview (approximately 30 minutes).

The study will be submitted as part of Phil Smith's Doctorate in Clinical Psychology research portfolio.

### **Why have I been chosen?**

We asked health service staff to approach people who have experience of caring for someone who currently, or previously, has experienced negative symptoms of schizophrenia.

### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you opt in, you will be asked to sign a consent form. You are free to withdraw at any time and without giving a reason. Regardless of whether you decided to participate or not, it will not affect the treatment that your loved one or family member receives now or in the future.

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

You will be invited to attend a single interview with the researcher which will last approximately 30 minutes. This will take place in a private room within the ward. You will be asked your opinions about the negative symptoms of schizophrenia and their treatment. The interviews will be audio recorded so that

they can be transcribed for analysis. Any direct quotes used in the final written version of the study will be anonymized. You will have an opportunity to ask questions about the study.

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

Some people may find that the interviews address sensitive issues. But, there is no plan to intentionally ask distressing or upsetting questions.

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

You will receive no direct incentives or rewards from taking part in this study. The information you provide will give us a better understanding of negative symptoms and their treatment. This will help to inform the development of new interventions for negative symptoms.

### **Will my taking part in this study be kept confidential?**

All information collected about you and the things you say during the research will be kept strictly confidential. Your study records will be identified only by an ID number and any personal identifying information (e.g. name, address) will be concealed. Confidentiality will be strictly maintained unless we detect that there is evidence of serious harm or risk of serious harm to any person. In such cases we may have an obligation to contact relevant statutory bodies/agencies. Where possible we will discuss this action with you ahead of time. As part of routine regulation qualified NHS regulators may audit research projects to ensure quality is being maintained.

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

The results of the study will be written into a thesis and submitted to the University of Glasgow as part of the main researcher's (Phil Smith) requirements for the Doctorate in Clinical Psychology. A summary of this report will be sent to Dr. Ian-Mark Kevan for distribution to participants. This report is expected to be completed by August 2016. The overall results of the research may also be submitted for publication in a scientific journal. No individual will be identifiable from any published work.

### **Who is organizing and funding this research?**

The research is organised by the University of Glasgow and supported by NHS GG&C. There is no direct funding of this research.

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

All research in the NHS is scrutinized by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed by the West of Scotland Ethics Committee Service (WoSRES) and favorable opinion has been given.

### **If you have any further questions**

If you would like more information about the study and wish to speak with someone who is independent of the research team, please contact Dr Sue Turnbull, Research Tutor, University of Glasgow, email: [s.turnbull@glasgow.ac.uk](mailto:s.turnbull@glasgow.ac.uk), Tel no: 0141 2113937

### **If you have a complaint about any aspect of the study**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint procedure is also available for you from the following internet address:

<http://www.nhsggc.org.uk/get-in-touch-get-involved/complaints/>

## Contact details

If you would like further information, you can contact:

Main Researcher (Trainee Clinical Psychologist):

Phil Smith

University of Glasgow

Institute of Health and Wellbeing

Admin Building

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow, G12 0XH

p.smith.4@research.gla.ac.uk

Research Supervisors:

Dr Hamish McLeod

University of Glasgow

Institute of Health and Wellbeing

Admin Building

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow, G12 0XH

hamish.mcLeod@glasgow.ac.uk

Field Supervisor: Dr. Ian-Mark Kevan

Consultant Clinical Psychologist, NHS Greater Glasgow & Clyde

Gartnavel Royal Hospital

1055 Great Western Rd, Glasgow G12 0XH

IanMark.Kevan@ggc.scot.nhs.uk

Thank you for taking the time to read this information sheet.

## **Appendix 2.6: Healthcare Professional - Participant Information Sheet**

### **Study Title:**

Treatment of negative symptoms in schizophrenia: An exploration of key stakeholders views on treatment gap, intervention, and recovery.

### **Brief Summary:**

Symptoms of schizophrenia can include difficulties with motivation, reduced emotional expressiveness, and low interest in activities. These symptoms can be particularly burdensome but there is a lack of understanding about the best approach to treatment. In order to develop better treatments, this study invites people to participate in a one-to-one interview with a researcher to discuss their views about these symptoms of schizophrenia and their treatment.

### **Who is conducting the research?**

This study is being carried out by Phil Smith and is supervised by Dr Hamish McLeod (University of Glasgow) and Dr. Polash Shajahan (NHS Lanarkshire).

### **Invitation**

You are being invited to take part in a research study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. It is important that you take the time you need to decide whether or not you wish to take part.

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

Symptoms such as difficulties with motivation, reduced emotional expression, and a low interest in activities (known as negative symptoms) can be burdensome for people who experience schizophrenia. This study seeks to improve our understanding of treating these symptoms. We are consulting people with experience in order to gather vital information that can be used to improve the treatments we offer in health service settings.

We are inviting healthcare professionals with experience of caring for someone who experiences negative symptoms to participate in an interview where they can provide their views on symptoms and treatment. Your involvement in the study will last for the duration of the interview (approximately 30 minutes). The study will be submitted as part of Phil Smiths Doctorate in Clinical Psychology research portfolio.

The study will be submitted as part of Phil Smiths Doctorate in Clinical Psychology research portfolio.

### **Why have I been chosen?**

You may be a healthcare professional with experience of caring for someone who currently experiences/ has past experience of negative symptoms of schizophrenia.

### **Do I have to take part?**

It is entirely up to you to decide whether or not to take part. If you opt in, you will be asked to sign a consent form. You are free to withdraw at any time and without giving a reason.

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

You will be invited to attend a single interview with the researcher which will last approximately 30 minutes. This will take place in a private room within the ward. You will be asked your opinions about the negative symptoms of schizophrenia and their treatment. The interviews will be audio recorded so that they can be

transcribed for analysis. Any direct quotes used in the final written version of the study will be anonymized. You will have an opportunity to ask questions about the study.

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

Some people may find that the interviews address sensitive issues. But, there is no plan to intentionally ask distressing or upsetting questions.

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

You will receive no direct incentives or rewards from taking part in this study. The information you provide will give us a better understanding of negative symptoms and their treatment. This will help to inform the development of new interventions for negative symptoms.

#### **Will my taking part in this study be kept confidential?**

All information collected about you and the things you say during the research will be kept strictly confidential. Your study records will be identified only by an ID number and any personal identifying information (e.g. name, address) will be concealed. Confidentiality will be strictly maintained unless we detect that there is evidence of serious harm or risk of serious harm to any person. In such cases we may have an obligation to contact relevant statutory bodies/agencies. Where possible we will discuss this action with you ahead of time. As part of routine regulation qualified NHS regulators may audit research projects to ensure quality is being maintained.

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

The results of the study will be written into a thesis and submitted to the University of Glasgow as part of the main researcher's (Phil Smith) requirements for the Doctorate in Clinical Psychology. A summary of this report will be sent to Dr. Polash Shajahan for distribution to participants. This report is expected to be completed by August 2016. The overall results of the research may also be submitted for publication in a scientific journal. No individual will be identifiable from any published work.

#### **Who is organizing and funding this research?**

The research is organised by the University of Glasgow and supported by NHS Lanarkshire. There is no funding associated with this research.

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

All research in the NHS is scrutinized by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed by the West of Scotland Ethics Committee Service (WoSRES) and favorable opinion has been given.

#### **If you have any further questions**

If you would like more information about the study and wish to speak with someone who is independent of the research team, please contact **Dr Sue Turnbull, Research Tutor, University of Glasgow, email: [s.turnbull@glasgow.ac.uk](mailto:s.turnbull@glasgow.ac.uk), Tel no: 0141 2113937**

#### **If you have a complaint about any aspect of the study**

If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance but the normal NHS complaint procedure is also available for you. The contact person for making a complaint in NHS Lanarkshire is: **Laura Jack, NHS Lanarkshire Headquarters, Kirklands Hospital, Fallside Road, Bothwell, G71 8BB, Tel: 01698 858321, Email: [laura.bryan@lanarkshire.scot.nhs.uk](mailto:laura.bryan@lanarkshire.scot.nhs.uk)**

**Contact details**

If you would like further information, you can contact:

**Main Researcher (Trainee Clinical Psychologist):**

Phil Smith

University of Glasgow

Institute of Health and Wellbeing

1055 Great Western Road

Glasgow, G12 0XH

[p.smith.4@research.gla.ac.uk](mailto:p.smith.4@research.gla.ac.uk)

**Research Supervisor:**

Dr Hamish McLeod

University of Glasgow

Institute of Health and Wellbeing

1055 Great Western Road

Glasgow, G12 0XH

[Hamish.McLeod@Glasgow.ac.uk](mailto:Hamish.McLeod@Glasgow.ac.uk)

**Field Supervisor:**

Dr. Polash Shajahan

Consultant Psychiatrist, NHS Lanarkshire Bellshill Community Health Clinic

Greenmoss Place

Bellshill, ML4 1PS

### **Appendix 2.7: Study Information Letter**

Dear Sir/Madam,

We are contacting you to inform you of a current research study you may be interested in. We are recruiting participants for our study entitled: **Treatment of negative symptoms in schizophrenia: An exploration of key stakeholders views on treatment gap, intervention, and recovery**. This study is being carried out at Bellshill Community Health Centre and Kelvin House, Gartnavel Royal Hospital.

Negative symptoms of schizophrenia include difficulties with motivation, reduced emotional expressiveness, and low interest in activities. The negative symptoms of the illness can be particularly burdensome for people who experience schizophrenia and those who care for them. However, there is a lack of understanding about the best approach to treatment. In order to develop better treatments, this study invites people to participate in a one-to-one interview with a researcher to discuss their views about the negative symptoms of schizophrenia.

An information sheet has been enclosed with further details of the study and contact details for the researcher.

Thank you for taking the time to read this information. I look forward to hearing from you.

Yours sincerely,

Phil Smith  
Trainee Clinical Psychologist  
College of Medical, Veterinary and Life  
Sciences  
University of Glasgow

Research Supervisor: Dr Hamish McLeod  
University of Glasgow  
Institute of Health and Wellbeing  
1055 Great Western Road, Glasgow, G12  
OXH

Email: [p.smith.4@research.gla.ac.uk](mailto:p.smith.4@research.gla.ac.uk)

[Hamish.McLeod@Glasgow.ac.uk](mailto:Hamish.McLeod@Glasgow.ac.uk)

## Appendix 2.8: West of Scotland Research Ethics Service Letter

**WoSRES**  
West of Scotland Research Ethics Service



Mr Phillip Smith  
Doctorate in Clinical Psychology Programme  
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**West of Scotland REC 5**  
West of Scotland Research Ethics Service  
West Glasgow Ambulatory Care Hospital  
Dainair Street  
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Date 02 March 2016

Direct line 0141 232 1809

E-mail [WoSRECS@ggc.scot.nhs.uk](mailto:WoSRECS@ggc.scot.nhs.uk)

Dear Mr Smith

**Study title:** Treatment of negative symptoms in people diagnosed with schizophrenia: An exploration of key stakeholders' views on treatment gap, acceptable interventions, and recovery.  
**REC reference:** 16/WS/0043  
**Protocol number:** L15062  
**IRAS project ID:** 179885

Thank you for your letter received on 26 February 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Sharon Macgregor, [WoSRECS@ggc.scot.nhs.uk](mailto:WoSRECS@ggc.scot.nhs.uk).

### Confirmation of ethical opinion

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

### Conditions of the favourable opinion

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

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

## Appendix 2.9: NHS Lanarkshire R&D Approval Letter



Philip Smith  
Trainee Clinical Psychologist  
NHS Lanarkshire  
Glendoe Building  
Coathill Hospital  
COATBRIDGE  
ML5 4DN

R&D Department  
Corporate Services Building  
Monklands Hospital  
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Date 18 March 2016  
Enquires to Elizabeth McGonigal,  
R&D Facilitator  
Direct Line 01236 712459  
Email elizabeth.mcgonigal@lanarkshire.scot.nhs.uk

Dear Phil

Project title: Treatment of negative symptoms in schizophrenia: An exploration of key stakeholders views on treatment gap, intervention and recovery

R&D ID: L15062

NRS ID NUMBER: NRS16/179885

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Dr Poolesh Shajahan	Consultant Psychiatrist	Local Collaborator	NHS Lanarkshire

As you are aware, NHS Lanarkshire has agreed to be the Sponsor for your study. On its behalf, the R&D Department has a number of responsibilities; these include ensuring that you understand your own role as Chief Investigator of this study. To help with this we have outlined the responsibilities of the Chief Investigator in the attached document for you information.

All research projects within NHS Lanarkshire will be subject to annual audit via a questionnaire that we will ask you to complete. In addition, we are required to carry out formal monitoring of a proportion of projects, in particular those projects that are Sponsored by NHS Lanarkshire. In either case, you will find it helpful to maintain a well organized Site File. You may find it helpful to use the folder that we have included for that purpose.

For the study to be carried out you are subject to the following conditions:

## Appendix 2.10: NHS GG&C R&D Approval Letter



Coordinator/Administrator: Ms Joanne McGarry  
Telephone Number: 0141 232 1828  
E-Mail: [Kayleigh.pender@ggc.scot.nhs.uk](mailto:Kayleigh.pender@ggc.scot.nhs.uk)  
Website: [www.nhs.gov.uk/r&d](http://www.nhs.gov.uk/r&d)

Research & Development  
West Glasgow ACH  
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09 March 2016

Mr Philip Smith  
Glendoe Building  
Coathill Hosptl  
Coatbridge  
M15 4DN  
NHS Lanarkshire

Dear Mr Smith,

### **NHS to NHS - Letter of Access for Research**

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through NHS Greater Glasgow and Clyde for the purpose and on the terms and conditions set out below. This right of access commences on 08/03/16 and ends on 30/09/18 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to NHS Greater Glasgow and Clyde premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through NHS Greater Glasgow and Clyde you will remain accountable to your employer NHS Lanarkshire but you are required to follow the reasonable instructions of your nominated manager Dr Iain Mark Kevan in this NHS organisation or those given on his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with NHS Greater Glasgow and Clyde policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with NHS Greater Glasgow and Clyde in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for

**Appendix 2.11: Major Research Proposal**

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**MRP –Proposal**

**Philip Smith**

**2109094S**

**University Supervisor: Dr. Hamish McLeod**

**Field Supervisor: Dr. Polash Shajahan**

**Submission Date: 16.03.2015**

**Version 2**

**Word Count: 3,305**

**Title:** Treatment of negative symptoms in schizophrenia: An exploration of key stakeholders views on treatment gap, intervention, and recovery.

**Abstract:**

*Background:* Negative symptoms can impact on therapeutic outcomes for patients experiencing schizophrenia. Up to 30% of people with a diagnosis of chronic schizophrenia exhibit negative symptoms yet there remains a gap in knowledge of effective negative symptom treatment. Psychosocial interventions show positive gains for patients yet the variance in outcomes across studies may indicate a lack of coherence in intervention formulation. Implementation science provides insight into the intricate nature of intervention development and successful integration to everyday practice. Canvassing the views of any recipients of an intervention can have a beneficial impact on its development and implementation. Utilising this approach may provide insight into negative symptom treatment.

*Aims:* To explore key stakeholder perceptions of negative symptoms and their treatment and the barriers/facilitators to the implementation of a new treatment intervention in a mental health setting.

*Methods:* A qualitative design incorporating semi-structured interviews will be employed. Data will be analysed utilising thematic analysis.

*Applications:* The data will form the basis for an initial first round Delphi process where a group of experts will be tasked with obtaining consensus views on a psychological treatment for negative symptoms.

**Introduction**

*Negative Symptoms*

Negative symptoms in schizophrenia are part of a discrete domain separate from other common features of the illness (Foussias and Remington, 2010). Difficulties exist in differentiating primary negative symptoms (i.e. illness related) from secondary symptoms (related to treatment factors or the experience of psychosis itself). Primary negative symptoms are further divisible into two separate sub-domains, that of diminished experience and amotivation/restricted expression (Favrod et al, 2014). These sub-domains consist of affective flattening, alogia, avolition, asociality and anhedonia (Foussias et al, 2014). Foussias and Remington (2010) state the estimated prevalence rates of negative symptoms are 25-30% in chronic schizophrenia. The severity of these symptoms can impact on therapeutic outcomes for patients experiencing schizophrenia (Foussias et al, 2014), yet White et al (2013) highlight a lack of activity in developing effective treatments to tackle these symptoms.

It may be that disparity amongst clinicians and researchers in relation to the notion of recovery (e.g. Slade, 2012) adds to the lack of activity in developing effective treatments. Recent years have seen the evolution of the recovery movement in mental illness. The CHIME conceptual framework (Leamy et al 2011) highlights a greater emphasis on idiosyncratic outcomes (i.e. personal meaning) as opposed to typical nomothetic outcomes reported in studies focussing on 'clinical recovery'. For instance, a recent systematic review indicates the literature on recovery in negative symptoms tends to focus on symptomatic reduction and/or functional outcomes (see Valencia et al, 2014). This disparity indicates a need for research to explore treatment targets and outcomes most relevant to patients.

In addition to this, Schooler et al (in press) draw attention to the lack of clarity "in the assessment of and meaningful improvement in negative symptoms..." This lack of clarity is related to the numerous factors involved in ascertaining what constitutes clinical relevance. For instance, carer burden is a well documented area related to schizophrenia but carers may have a different view on relevance than both clinicians and patients. Therefore, this current lack of clarity may impact on the development of effective interventions.

Utilising a clinician-researcher consensus panel, Schooler et al (in press) provide a set of criteria upon which therapeutic impact on negative symptoms can be measured. There is a specific focus on symptom remission (or decrease in intensity) and functional outcomes. However, this does not seem to fit the framework and ideas fuelling the current recovery movement. Additionally, as the authors note, key stakeholders (e.g. patients, professional/ family carers, and policy makers) were not included in the panel. Future research needs to address this if a robust definition of negative symptoms and related treatment outcome is to be obtained. Furthermore, this lack of a universally agreed definition draws attention to the gap in current knowledge on negative symptom treatment.

### *Intervention*

Elis et al (2013) provide a comprehensive review of psychosocial treatments for negative symptoms. Elis et al focus on three types of intervention – cognitive behavioural therapy (CBT), social skills training (SST) and combined treatment interventions. The review specifies that psychosocial treatments have the potential to alleviate negative symptoms. Yet, the variance in outcomes (e.g. maintenance factors at follow up) across each treatment may indicate the lack of a clear formulation on how best to intervene. Furthermore, there is clear evidence that outcomes are impacted by the type of intervention (e.g. individual versus group therapy, length of treatment, and the particular therapeutic focus).

This is further complicated when considering people with schizophrenia are thought to experience poor insight into their illness (Lysaker et al, 2011a) and may struggle with metacognition in general (Lysaker et al, 2011b). Specifically, they may struggle to understand themselves and the people around them, making psychotherapy a difficult process to engage in.

Additionally, variability of psychosocial intervention efficacy may be related to the co-morbidity of other psychiatric illnesses (e.g. major depressive disorder) in people experiencing negative symptoms (Buckley et al, 2009). Foussias et al (2014) also suggest that while negative symptoms may be present in other disorders, people with schizophrenia may experience more enduring negative symptoms in the course of their illness. This indicates that new conceptualisations of negative symptom treatment need to consider transdiagnostic processes and co-morbidity.

Lysaker et al, (2010) detailed two specific inter-related areas (i.e. self experience personal narrative and metacognition) future psychotherapy could address. Additionally, one line of future research stated is the “need for...the development of manualised treatments which could be tested for feasibility and effectiveness in randomised control trials” (Lysaker et al, 2010). However, the literature indicates that a number of empirically formulated interventions are not implemented successfully in everyday clinical settings (Durlak & Dupree, 2008).

### *Intervention, Implementation and Patient and Public Involvement (PPI)*

Implementation science is an emerging science focussing on how and why a new practice is successfully adopted by organisations. A generally accepted notion in this field of science indicates that despite the development of effective interventions many are not successfully implemented into routine practice. This issue has become a focus of scientific enquiry and in recent years guidelines have been developed to aid in the formulation, development and delivery of complex interventions.

The Medical Research Council’s (MRC) framework for complex interventions (Craig et al, 2008) details a phased approach to implementation. A key message from the MRC relates to the importance of investment at the development stage of research, prior to large scale evaluations. To achieve this, existing theory can be supplemented by involving key stakeholders in the research process (e.g. the individual/groups targeted by intervention). Their involvement in this process can create relevance – factors that are grounded in the day-to-day reality of stakeholders’ experiences. Therefore, patient and public involvement (PPI) should be considered by researchers in the formulation of complex interventions.

The developing science of PPI is relatively new to clinical psychology. In a recent article Rose (2014) discusses the ethical values driving PPI. These values are directly in line with the British Psychological Society’s core philosophy (BPS, 2001; e.g. equality,

respect, transparency and collaboration). Therefore, PPI involvement in psychotherapy intervention research may lead to new insights in treatment formulation and successful implementation.

The literature on PPI suggests involvement in research relates to three stages: consultation, collaboration and consumer-led research (e.g. Hewlett et al, 2006). A recent systematic review indicates the positive impact of PPI involvement at the early stages of research development (Brett et al, 2012). Studies in this review detail the ways in which PPI is useful, for example, in developing health research priorities and information materials for patients. A relevant message is that PPI at the consultation stage can have beneficial outcomes. Thus, the role of stakeholders may be crucial in successful implementation of complex interventions, yet this has often been overlooked in research (Staniszewska, 2013).

### *Exploration and Consultation*

Qualitative research in the field of schizophrenia has added to scientific understanding of the experiential nature of the illness (McCarthy-Jones et al 2013). Furthermore, qualitative methodology can provide a robust framework for exploration and discovery.

For instance, Waller et al (2013) utilised thematic analysis to explore key stakeholder views on their experiences of participating in a pilot of a novel low intensity CBT intervention for psychosis. Waller et al conducted semi-structured interviews with both staff and service users to investigate the positive/negative factors associated with the intervention. An additional factor they explored with the staff group related to the feasibility of long-term implementation of the intervention. The emergent themes provide constructive insights into the effectiveness of the new intervention and highlighted potential barriers for future implementation. Thus, explorative methodologies may be an efficient approach to engage with stakeholders in the consultation stage of research.

Furthermore, PPI provides a pragmatic foundation for qualitative research to address the identified gap in negative symptom clarity (i.e. lack of key stakeholder opinion) in Schooler et al's study (in press). Therefore, the present study will draw upon the methodology used by Waller et al (2013) with a focus on consulting patients and family/professional carers to explore their views on negative symptoms and treatment.

Specifically, the study aims to explore key areas, including: treatment need for negative symptoms; the specific negative symptoms that could be targeted; the preferred method of intervention; the philosophy underpinning recovery (i.e. CHIME); specific implementation issues; and how change will be measured over time.

## **Aims**

To explore client and family/professional carer views on the treatment of negative symptoms. Furthermore, an aim would be to explore perceived barriers/facilitators to the implementation of a new treatment for negative symptoms.

## **Plan of Investigation**

### **Participants**

Participants will be recruited utilising three separate procedures across the two participating sites.

### **Inclusion/ Exclusion Criteria**

Inclusion:

- Adults with a diagnosis of schizophrenia or related psychoses who are exhibiting negative symptoms
- Professional and family/guardianship carers who care for someone who experiences negative symptoms
- Aged 18-65 to fit with referral criteria for Adult Mental Health services.

Exclusion:

- Those who may struggle to meaningfully participate due to factors such as substance abuse, low cognitive functioning, or capacity and consent issues.

## **Recruitment Procedures**

### **In-patients / Out-patients**

Due to the nature of negative symptoms, an active recruitment procedure which reaches out to patients will be followed. Study information will be distributed to members of the MDT at both in-patient and out-patient research sites and MDT members will be asked to provide details of the study to eligible patients on their caseload. The study recruitment information will focus on offering eligible patients the chance to find out more about the study from the researcher. The researcher will be available at specific times at both of the sites for people to approach to gain further information. Individuals will be given 24 hours to consider their decision to participate. If people show an interest they will be invited to take part in the interview process in a room at each of the participating sites. Written consent documentation will be collected prior to participation.

### **Family Carers**

Requests will be made to members of clinical teams to identify people who act as a carer for individuals who meet the above 'patient' inclusion criteria. Invitation letters to the study will be distributed to carers identified by clinical staff. Clinical staff will be asked

to obtain consent from carers in order for the researcher to contact them. Additionally, the researcher's contact details will be provided for carers to respond to the invitation. If people show an interest they will be invited to attend a local health clinic to participate in the interview process. Written consent will be collected prior to participation.

### **Professional Carers**

Members of the MDT's at each site will be approached to take part in the interview process following the criteria below. This criterion has been set to ensure professional carers are working at a level in which they would likely see the impact of negative symptoms on therapeutic progress:

Inclusion:

- Experience of working in face-to-face therapeutic setting with people who experience negative symptoms.
- Specifically these would include Clinical Psychologists, Nurses, and Allied Health Professionals.

Exclusion:

- No experience of working with people who experience negative symptoms.
- Those who do not engage in psychosocial therapeutic work with people who experience negative symptoms.

### **Design**

The study will draw upon the methodology previously employed by Waller et al (2013) to explore patient and staff perspectives. Specifically, a qualitative design employing a semi-structured interview schedule will be used.

#### *Item Generation for Semi Structured Interviews*

A systematic review of psychosocial treatment of negative symptoms will be analysed and the key characteristics will be extracted along the following dimensions: delivery format, therapist characteristics, duration, intensity, target processes and symptoms, key outcomes, specific implementation issues, methods of monitoring and evaluation, and underlying philosophy (e.g. disease/deficit model, the CHIME recovery focus, etc). The interview questions and probes will be based on these characteristics. In addition, each section of the interview will also include a free-response component.

### **Research Procedures**

Semi-structured interviews will be conducted at both sites with patients, carers and staff. These will be audio recorded and transcribed verbatim.

### **Data Analysis**

The transcribed interviews will be analysed utilising thematic analysis (Braun & Clarke, 2006; Boyatzis, 1998). Information from the transcribed data will be coded and used to construct themes. Following an inductive (bottom-up) method of reasoning will ensure analysis is mainly data-driven (free from researcher biases). Procedures set out by Braun and Clarke (2006) will be followed to ensure verification (internal validity) of data.

### **Justification of Sample Size**

A small sample will be utilised for the semi-structured interviews based on thematic analysis guidelines. Thematic analysis can produce a wealth of data but takes considerable time to transcribe and analyse. This will be considered in selecting an appropriate sample size along with examples from the relevant qualitative literature. For instance, Waller et al (2013) interviewed seven staff members and 17 service users.

### **Settings and Equipment**

An audio recorder will be required for the interviews and an encrypted laptop with specific software to allow for transcription. (See Appendix 1).

### **Health and Safety Issues**

(See Appendix 2).

### **Ethical Issues**

An application will be submitted to the West of Scotland REC. Information sheets will detail the study, confidentiality and anonymity. Written consent will be obtained from participants with an opt-out option available at no repercussions. Data will be handled in line with relevant guidance (e.g. Data Protection Act (1998), Freedom of information Act (2000), NHS Confidentiality Code of Practise Guidelines (2003). Digital data (interview recordings) will be stored on NHS encrypted media devices and destroyed when the study is finished.

### **Financial Issues**

Travel expenses to each site for interviews will be required (this will be through an application to the primary researchers' employing board).

### **Timetable**

TBC.

### **Practical Applications**

The study will pave the way for future research focussing on a new treatment protocol for negative symptoms of schizophrenia. Specifically, the data will form the basis for an initial first round Delphi process where a group of experts will be tasked with obtaining consensus views on a psychological treatment for negative symptoms. PPI in this study allows individuals a chance to provide their own expert knowledge in an area that impacts on their daily life. The data will provide key insights into a long term feasibility plan for the implementation and scaling up of a new treatment protocol.

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