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PRiorItieS: A study exploring PReferences for treatment, Internalised Stigma & social defeat among individuals in receipt of care for psychosis from mental health services

And Clinical Research Portfolio

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Chapter One: Systematic Review

Ways of Eliciting & Measuring Preferences for the Treatment of Psychosis: A Systematic Review

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Abstract

Background: Incorporating patient preferences in treatment planning has become increasingly important. Despite the growing literature on preferences for the treatment of psychosis, there have been no systematic reviews on the ways that such preferences have been elicited.

Objectives: This review examined methods used to elicit treatment preferences for psychosis and to evaluate the strengths and the weaknesses of each method.

Method: PsycINFO, Psychology and Behavioural Sciences Collection, MEDLINE, EMBASE and CINAHL were searched for relevant articles. The electronic database of a key journal, 'Schizophrenia Research', was also searched. Finally, the methodological quality of included studies was assessed.

Results: There were variations across studies concerning the types of treatments subjected to preference assessment, the types of problems examined, and the methods used. A lack of information regarding preference elicitation made methodological comparisons difficult and limited the ability to derive any robust conclusions about the utility of each method. The use of non-standardised elicitation methods was common across studies.

Conclusion: Researchers should apply rigorous methods, which involve the provision of information to patients, to obtain valid preferences. Further research is required to build on the findings of this review and include other methods that may be of use.

Keywords: Psychosis, treatment preference, preference elicitation.

1. Introduction

Taking account of patient preferences in treatment planning is essential in providing patient-centred care (Green et al., 2014), and has been associated with improved outcomes, increased patient satisfaction and treatment adherence (Lindhiem, Bennett, Trentacosta, & McLear, 2014). Clinical practice guidelines & UK policy directives have also argued that patient involvement in their treatment is an indicator of high-quality mental health care and should be facilitated (Department of Health, 2012; National Institute for Health and Clinical Excellence, 2009). However, there is little evidence that patient preferences relating to their treatment are accommodated (Goss et al., 2008) as there are often significant differences in the priorities of patients and clinicians (Greenwood et al., 2010).

1.1. Operationalisation of Treatment Preferences

Despite its wide use, the term 'treatment preferences' lacks a clear and consistent definition. Most studies in the area of mental health have used the term to describe the '*relative desirability of a range of treatment options'* (Brennan & Strombom, 1998), treatment goals or outcomes (Byrne, Davies & Morrison, 2010). Other studies have attempted to elicit preferences by exploring patients' attitudes, satisfaction or experience with a treatment intervention (Klose et al., 2016). Klose et al. (2016) have proposed a new conceptual framework for patient preference in healthcare, in which preference is viewed as a choice over a treatment option. This choice involves an understanding of the treatment option presented (Corrigan & Salzer, 2003), as well as a perception of how beneficial this treatment is (Becker, Darius, & Schaumberg, 2007). Thus, they propose that preferences regarding treatment outcomes differ, as they focus on patients' preference over a health status (e.g. improved social functioning), whereas preferences over health experiences focus on treatment elements the person has found helpful.

1.2. Rationale for this review

Despite the importance of patient preference on treatment outcomes and adherence, only a few systematic reviews looked at the preferences for psychosis treatment (McHugh, Whitton, Peckham, Welge, & Otto, 2013; Eiring et al., 2015) and the effects of these on treatment outcomes and satisfaction (Lindhiem et al., 2014). Of these, Eiring et al. (2015) examined whether patients prefer pharmacological over psychological treatments, whilst McHugh et al. (2013) explored preferences for pharmacological associated treatment outcomes. To our knowledge, there have been no efforts to systematically review and synthesize information about the ways that preferences for the treatment of psychosis are assessed.

1.3. Systematic Review Questions

This review will answer the following questions:

- What are the various methods of assessing treatment preferences in research with people diagnosed with psychosis?
- What are the strengths and weakness of each method?

2. Materials & Methods

A review protocol was developed and registered on PROSPERO (registration number CRD42019129702; accessible at: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42019129702).

2.1. Search Strategy

Searches of the Cochrane database and PROSPERO were completed prior to conducting the review to ensure there were no existing reviews on the selected subject. PsycINFO, Psychology and Behavioural Sciences Collection, MEDLINE, EMBASE and CINAHL were searched in March 2019 for relevant articles. The electronic database of a key

journal ('Schizophrenia Research') was also searched to identify any studies missed by the electronic searches. Search terms were developed after searching the PubReMiner database and looking at previous systematic reviews on treatment preferences (Appendix 1.2). A subject librarian was also consulted due to the differences in the indexing of search terms across databases. The final search algorithm for title, keyword and abstract searches was:

1. Psychosis OR Psychoses OR Psychotic* OR schizo*

AND

2. (Treat* or Patient* or Client*) ADJ2 (Prefer* or Priorit*)

AND

3. Measur* OR assess* OR evaluat* OR explor* OR identif* OR investigat* OR elicit* OR scale* OR tool* OR survey* OR interview* OR questionnaire* OR focus group

2.2. Eligibility Criteria

Studies meeting the following criteria were included in review: studies with adults diagnosed with schizophrenia or schizophrenia spectrum disorder; studies published in English language; in peer reviewed journals; between the years 2000 to 2019; full text availability; and studies exploring self-reported stated preferences. No restrictions were applied to study design or methodology. Furthermore, the scope of this review was restricted to preferences for treatment options (Klose et al., 2006). Thus, studies of patient satisfaction, attitudes or experience were excluded. Similarly, studies on patient's quality of life, preferred outcomes, or studies exploring preferred elements or attributes of care in general that were not specific to psychosis were excluded. Studies on pathways to care and help seeking behaviour were also excluded as they involved review of observed data or non-clinical populations. Moreover, among Randomised Controlled Trials (RCTs) the assessment of preference must have occurred prior to the selection of (or randomization to) treatment.

Finally, studies involving individuals with various diagnoses, where those with psychosis consisted of less than 50% of the total sample were excluded.

2.3. Quality Appraisal Strategy

The methodological rigour of the studies was assessed using Version 1.4 of the Crowe Critical Appraisal Tool [CCAT] (Crowe & Sheppard, 2011; Crowe, 2013). The CCAT consists of 22 items, across eight categories (Appendix 1.3). Each category has multiple item descriptors, which are rated on a nominal scale as Present, Absent or Not Applicable. Each category is then rated on a 6-point scale from 0-5, with lower ratings reflecting lower quality. Following scoring of each category, a total score and a total percentage were given to each study. Walsh and Downe's (2006) qualitative descriptors were used to interpret the results of the appraisal. Thus, studies demonstrated 'good' quality if they received a total percentage of >75%, showed 'acceptable' quality if they scored >50%, and were of 'poor' quality if they scored <50%.

To improve the rigour of the methodological critique, an independent reviewer also assessed five of the included studies for risk of bias. There was an 87.5% agreement between the author and the independent rater and discrepancies were resolved through discussion.

2.4. Data Extraction & Synthesis

All data were extracted using a standardised data extraction form which was adapted from Eiring et al. (2015) to match the purpose of this review (Appendix 1.4). Due to the nature of this review (exploratory, mixed-methods review) and the heterogeneity of the study methodologies and designs, a narrative synthesis approach was undertaken to synthesise the data (Siddaway, Wood & Hedges, 2019).

3. Results

3.1. Study Selection

The search yielded a total of 2723 results, of which 757 duplicates were removed using EndNote X9. The author screened the titles and abstracts of 1966 articles for relevance and following this, the full-texts of 25 articles. Of these, the full-text of one article was retrieved via university inter-library loans and, following screening, it was excluded, as it did not report sample characteristics. The rest of the articles were excluded for reasons shown in Fig. 1. This resulted in 12 studies being included in the review.

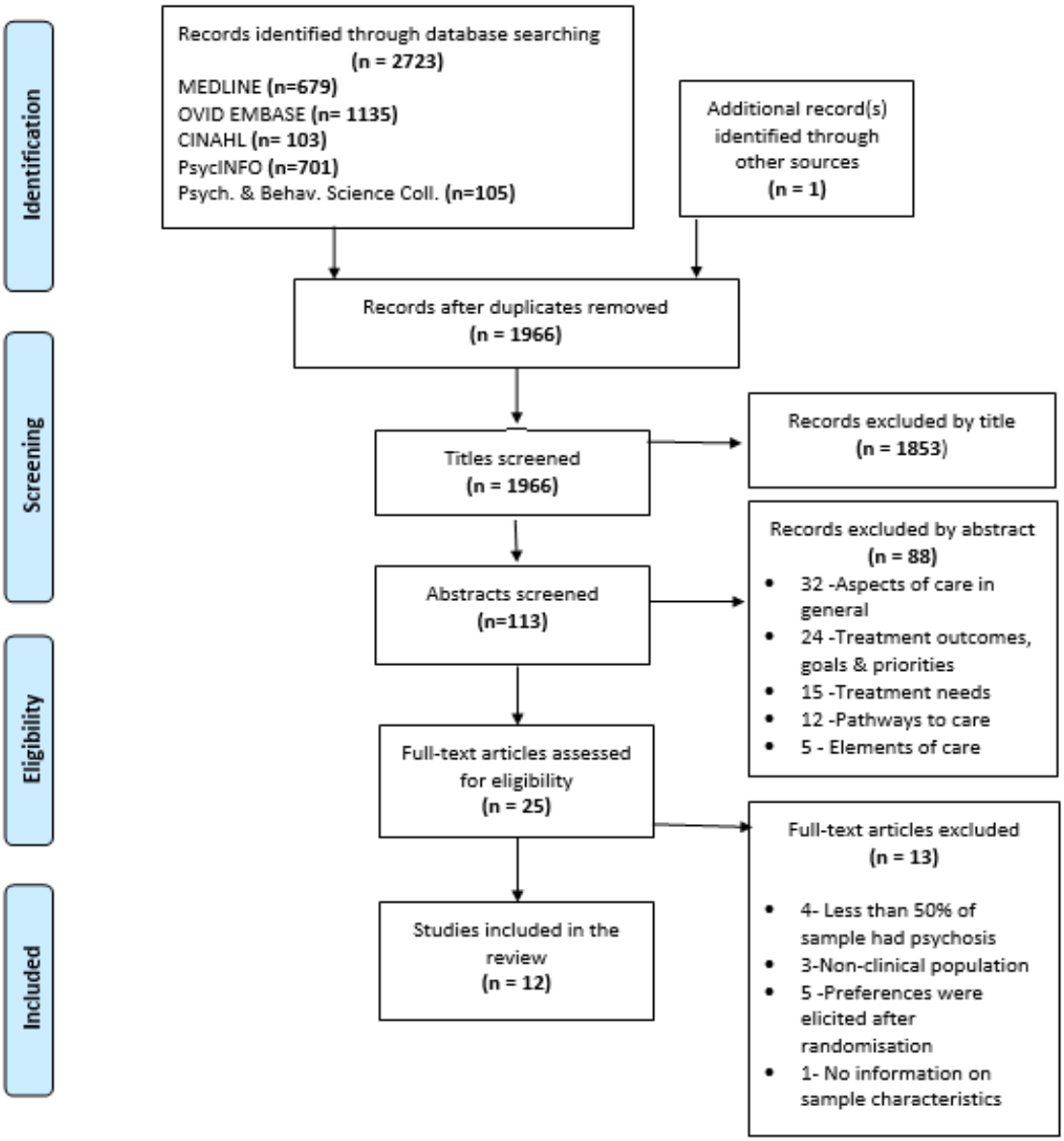

Fig 1. PRISMA flow diagram

3.2. Study Characteristics

The 12 studies included in the review spanned the years 2003-2018 and were conducted in the United Kingdom (6) United States of America (2), Germany (2), France (1) and Taiwan (1).

3.2.1. Study Design

All studies employed a cross-sectional design except Wilder, Elbogen, Moser, Swanson & Swartz (2010), who compared medication preferences to prescribed medications over 12 months as part of a larger RCT. One study, which was also a sub-study of an RCT, used thematic analysis to examine crisis plans, a form of advance statements (Farrelly et al., 2014). Two studies employed a sequential mixed-methods design to first elicit patient preferences and then explore the reasons of such preferences (Caroli et al., 2011; Sumner et al., 2014). Four were survey or questionnaire studies (Crawford, Gibbon, Ellis, & Waters, 2004; Huang, Shang, Shieh, Lin & Su, 2011; Moritz, Berna, Jaeger, Westermann, & Nagel, 2017; Patel, De Zoysa, Bernadt, & David, 2009) and used a single group design, except Khan and Pillay (2003), who conducted a comparative study. One study used a Patient Preference Trial (PPT) design (Haddock et al., 2018), one a Discrete Choice Experiment (DCE) design (Levitan et al., 2015), while Mendel et al. (2011) used an experimental, randomised, between-groups design.

3.2.2. Participant characteristics.

The number of participants in each study ranged from 55 to 271**.** Mean age was 39.38 years (reported in 10/12 papers). 56.95% of participants across the studies were male (range: 37.5- 75.6%), and all but two studies (Huang et al., 2011; Mendel et al., 2011) recruited outpatients. 62% of participants across the studies were White/Caucasian (based on 8/12 studies reporting ethnicity distribution). All studies recruited individuals with affective and/or

non-affective psychosis, whereas two studies also recruited participants with multiple sclerosis (Mendel et al., 2011), substance misuse, neurosis and personality disorder diagnoses (Crawford et al., 2004).

3.3. Aspects of Preference Elicitation

3.3.1. Methods of Preference Elicitation

All studies used self-report methods, with six studies using surveys or questionnaires with closed questions to elicit preferences (Caroli et al., 2011; Crawford et al., 2014; Khan & Pillay, 2003; Moritz et al., 2017; Patel et al., 2009; Sumner et al., 2014). In these studies, participants were presented with various treatment options and were asked to choose the one they preferred the most. Their responses were either discrete (e.g. prefer A vs prefer B) or graded (e.g. strongly prefer A vs prefer A vs indifferent etc.). Open-ended questions were also included in three of these studies (Caroli et al., 2011; Khan & Pillay, 2003; Sumner et al., 2014) and in Haddock's et al. (2018) study to explore the reasons for participant choices. In Haddock's et al. (2018) study a semi-structured interview which included closed, open-ended questions and a preference scale were used, whereas Mendel et al. (2011) used a hypothetical scenario to elicit preferences. Finally, Huang et al. (2011) designed a brief scale to assess treatment seeking behaviour and preferences ('The Preference for Treatment Scale'). This was a Likert Scale measuring relative preference between psychiatric and religious intervention. There was no information provided on the psychometric properties of this scale.

Most questionnaires were completed in face to face meetings with the researchers, apart from one study which posted a survey on the internet (Moritz et al., 2017). Levitan et al. (2015) also recruited participants though an online patient panel. In their study, participants completed an online survey and preferences were elicited via a series of choice

tasks drawn from DCE methodology, where participants were asked to indicate which of several hypothetical treatment alternatives they think is better for a hypothetical patient with schizophrenia.

Finally, two studies assessed treatment preferences though the review of advance statements, such as Joint Crisis Care Plans (JCPs) and Psychiatric Advance Directives (PADs) (Farrelly et al., 2014; Wilder et al., 2010). These were studies that explored treatment preferences in the event of a future relapse or mental health crisis. JCPs were completed jointly in a meeting with the patient, their clinician and an external facilitator. PADs were also completed during a structured interview with a facilitator.

3.3.2. Categories presented for preference elicitation

Four studies asked patients to choose from different types of antipsychotic medication or drug formulations, such as oral or injectable medication (Caroli et al., 2011; Levitan et al., 2015; Patel et al., 2009; Wilder et al., 2010). Two studies explored preference regarding the delivery, setting or intensity of treatment patients wished to receive (e.g. treated at home vs hospitalisation) (Crawford et al., 2004; Khan & Pillay, 2003). Two studies (Haddock et al., 2018; Sumner et al., 2014) offered choices between different modalities of psychological interventions and treatment as usual, compared to Huang et al. (2011) and Moritz et al. (2017), who asked participants to choose from a variety of interventions, including medical and non-medical treatments. Finally, two studies did not explicitly state the options presented (Farrelly et al., 2014; Wilder et al., 2010).

3.3.3. Psychoeducation about treatment options

Five out of 12 studies provided explanatory information regarding the treatment options presented to participants (Crawford et al., 2004; Haddock et al., 2018; Farrelly et al., 2014; Mendel et al., 2011; Sumner et al., 2014). All four of these reported providing brief

information sheets or verbal information, compared to Crawford et al. (2004) who only provided clarification of the term 'compulsory treatment'.

3.3.4. Sources used in option selection.

There was limited information about the sources used in the selection of treatment options. Only five studies reported consulting patients, carer organisations and/or experts, conducting literature reviews or using anecdotal evidence, in the construction and selection of treatment options (Caroli et al., 2011; Farrelly et al., 2014; Khan & Pillay, 2003; Levitan et al., 2015; Wilder et al., 2010).

3.4. Study Results

In studies of preferred treatment delivery, participants reported a preference for home treatment (Crawford et al., 2004; Farrelly et al., 2004; Khan & Pillay, 2003). Among studies exploring preference for drug formulation (e.g. oral vs injectable antipsychotic medication), the results were inconclusive, with injections to be preferred over oral medication (Caroli et al., 2011), and with preference associated with medication adherence (Levitan et al., 2015) and with current formulation among patients on anti-psychotics (Patel et al. 2009). The main study findings, characteristics, and aspects of preference elicitation are described in Table 1.

Table 1.

Summary of extracted data from the included studies.

Study	Population	N Mean age Gender Ethnicity	Design	Preferences as main objective (Y/N) Objective/s	Categories presented for preference elicitation	Preference elicitation method	Main findings related to treatment preferences
Sumner et al., 2014 UK	Outpatients with non-affective psychosis (ICD-10).	N=90 Mean age=37.22 (19-63) Male (n=68) White (n=77)	Mixed Methods-Sequential	Yes Preferences over treatment interventions	Treatment interventions: Treatment as usual (TAU), Self-Help manual with Telephone CBT and peer support, (SHT) & SHT plus Group support (SHG).	Questionnaire involving closed and open-ended questions about patient preferences and the reasons for these.	SHT was the most preferred option (43%), followed by preferred SHG (33%) and TAU (22%)
Crawford et al., 2004 UK	Patients discharged from two mental health units.	N=109 (74 of those had a diagnosis of a psychotic disorder) Mean age=41.2 (SD= 15.4) Male (n=64) White (n=54) Black (n=25) Other (n=17)	Exploratory - Cross-sectional Survey	Yes Preferences over the delivery of treatment	Treatment setting/delivery: Home vs hospital vs community centre	Short questionnaire, consisting of open and closed questions about compulsory treatment in different settings.	48% preferred to be treated at home, 40% preferred hospital treatment and 13% preferred treatment in a community centre

Moritz et a.l, 2017 Germany	Outpatients diagnosed with Schizophrenia.	N=80 Mean age=40.4 (SD= 9.43) Male (n=30) Ethnicity not reported	Exploratory. Cross-sectional Survey	Yes Preferences over treatment interventions	Treatment interventions including psychological, medical, occupational, social etc. interventions.	Online Survey including questions regarding patient experience with various interventions and a 4-point Likert scale.	Talking Therapy (M=3.18, SD= 0.88) Psychoanalytic Therapy, (M=3.08, SD=1), Art Therapy (M=2.92, SD=1.04) & Metacognitive Training (MCT), (M=2.91, SD= 0.95) were appraised as the most helpful treatments.
Farrelly et al., 2014 UK	Outpatients with affective and non-affective psychosis.	N= 221 Mean age=40.4 (SD= 1.44) Male=51% White (n=63.5%) Black (n= 23.5%) Other (n=13%)	Qualitative. Thematic Analysis of JCPs (Part of an RCT)	Yes Preferences over treatment interventions during a crisis or relapse	Patients were presented with categories from a care plan 'menu' to select from. No further information was provided.	JCPs, including items on preferred treatment interventions in a crisis or relapse.	Most preferred option was home treatment team support (35% of the sample), followed by hospitalisation (19%) and medication changes (14%).
Haddock et al., 2018 UK	Outpatients diagnosed with a Schizophrenia spectrum disorder (ICD-10)	N=89 (N=3 of which chose to be randomised) Mean age=36 (SD=10.9) Male (n=60) White (n=76) BME (n=13) Mixed race (n=4) Not reported (n=2)	Experimental. PPT Trial	Yes Preferences and outcomes of different methods of delivering CBT for psychosis.	Preference to be randomised to a treatment intervention or not. Treatment Interventions included Treatment As Usual (TAU), TAU plus Telephone CBT & self-help manual (TS), High Support CBT (HS).	Semi-structured Interview, including questions over which intervention they prefer, the strength of their preference (as measured by a Likert scale) and the reasons for their choice.	TS was the most preferred option (33%), followed by TAU (31%), HS (22%), Not allocation (6%), and preference to be randomised (3%).

Mendel et al., 2011 Germany	Inpatients diagnosed with Schizophrenia (ICD-10) & Multiple Sclerosis (MS).	Schizophrenia (N=102) & MS (N= 101). M=36.5 (SD: 11.42) Male (n= 56) Ethnicity not reported	Experimental. Randomised, Between groups design	Yes Influence of physician's advice and confidence (experimental condition) in patient's advice taking and treatment preferences	Hypothetical drugs (Drug A vs Drug B) that only differ in side-effects.	Questionnaire describing a hypothetical decision scenario. Preferences were assessed pre and post clinician's recommendation.	Initial choice of patients with schizophrenia was Drug A (67%). But 48% of them later followed the advice of their doctor and chose the treatment option that was against their initial choice (e.g. Drug B)
Huang et al., 2011 Taiwan	Inpatients diagnosed with Schizophrenia (DSM-IV)	N=55 Mean age= 37.2 (SD= 10.5) Male (n=22) Ethnicity not reported	Cross-sectional, questionnaire study	No Relationships between religion, psychopathology with religious content, treatment preference and outcome	Treatment Interventions: Psychiatric treatment vs religious intervention	Semi-structured questionnaire, which included a '*Preference for Treatment Scale'*.	Patients with religious affiliation showed less preference toward psychiatric treatment (M=3.4, SD=0.8) than those without a religious affiliation (M=4.6, SD=0.8). More preference toward psychiatric treatment was predicted by lower religiosity score, higher satisfaction with psychiatric treatment and lower years of education (β=-0.077, P<0.001, F value = 11.562, Variance = 37%)

Levitan et al., 2015 US	Outpatients with a self-reported physician diagnosis of Schizophrenia.	N=271 M= 38.4 (SD= 11.9) Male = 60% White = 73%	Experimental, DCE methodology	Yes Judgements on important attributes of antipsychotic medication & preferences related to their risks & benefits.	Hypothetical Drugs (Medication A vs Medication B) Preferences on the mode of administration & preferences related to risk & benefits of medication were inferred through the choices of drugs.	Online Survey containing choice tasks, which involved selecting the 'best' hypothetical treatment for a hypothetical patient.	Patients judged oral formulations to be better for adherent patients but judged a monthly injection to be better for non-adherent. Improvement in positive symptoms was the most important outcome (M=10) and hyperglycaemia was judged as the most important side effect (M=3.6)
Wilder et al., 2010 US	Outpatients diagnosed with affective and non-affective psychosis, and psychotic depression.	N= 123 (15 of which had psychotic depression) Mean age= 44.5 (SD=9.9) Male (n=50) Caucasian (n=58) African American: (n=65)	Longitudinal (Part of an RCT)	Yes Medication preferences and associations with future prescription and adherence	Patients were asked to identify medications they would request/or would refuse to take if they were in a crisis. There was no further information on the options presented.	PADs. These included items on medication preferences and questions on preferred facilities & crisis interventions .	Medications requested/ preferred: Valproate (25%), followed by risperidone (20%) and olanzapine (17%) Medications refused: Haloperidol (24%), followed by Lithium (23%). Medications prescribed: Risperidone (26%) followed by valproate (25%) Being prescribed a medication requested in the PAD predicted higher medication adherence.

Caroli et al., 2011 France	Outpatients diagnosed with schizophrenia	N=206 48% fell within the '35-49' age category Male= 65% Ethnicity not reported.	Mixed Methods, survey study	Yes Preferences (defined as opinions) regarding injectable medication	Forms of medication: a) injections b) oral tablets c) drinkable solutions d) orally disintegrating tablets e) no preference	Survey including medication options & open-ended questions to explore reasons for preferences.	Injections were the most favoured dosage form (47%), followed by oral tablets (35%), drinkable solutions (7%) and orally disintegrating tablets (1%). 10% did not express a preference. Main reason: dosages were spread out over time (41%)
Patel et al., 2009 UK	Outpatients with a diagnosis of schizophrenia or schizoaffective disorder (ICD-10)	N=222 39.1 % fell within the '45+' age category Male (n= 143) White (n=110) Other (n=77) Not reported (n=35)	Cross-sectional, questionnaire study	Yes Attitudes towards antipsychotic medication, side effects, insight, and formulation preferences.	Antipsychotic drug formulation: Oral vs depot vs no preference	Questionnaire involving direct questions on formulation preference.	Patients on orals expressed a preference for their current formulation (91.8%) whereas those on depot were generally indifferent (43.4% preferred depot, and 30.3% preferred tablets).
Khan & Pillay, 2003 UK	Outpatients diagnosed with Schizophrenia (ICD-10).	N= 61 Age Range: 16-65 (Mean age not provided) Male (n=41) White Residents of the British Isles (n=26) South Asian (n= 35)	Cross-sectional, comparative study	Yes Preferences (defined as attitudes) towards home and hospital treatment in a crisis or emergency.	Treatment Setting: Home vs Hospital Treatment	Structured questionnaire, including questions about preferences and reasons for these, measured on a 5-point Likert scale.	Both groups expressed preference for home treatment. Reasons for their preferences differed; for Asian respondents the main reasons were: stigma associated with hospitalisation (82.8%) & religious need (74.3%).

Note. Descriptive & inferential statistics are provided where reported in studies. SD=Standard Deviation, M=Mean.

3.5. Study Quality

Total scores and percentages as well as category scores per paper are presented in Appendix 1.5. Using Walsh and Downe's (2006) criteria, the methodological quality of most studies was considered 'good', with only three studies (Khan & Pillay, 2003; Mendel et al., 2011; Patel et al., 2009) being appraised as 'acceptable'.

All studies received four or five out of five for the Introduction and Discussion categories, and all but two studies (Caroli et al., 2011; Khan & Pillay, 2003) received four out of five for the Results category. Moreover, all but Khan and Pillay (2003) received four or five out of five for the Preliminaries category (defined as abstract, title, aims and style), whereas three studies scored less than four or five out of five in the Design category (Crawford et al., 2004; Khan & Pillay, 2003; Mendel et al., 2011). This indicates that most studies gave adequate summaries of current knowledge, had clear aims, used appropriate designs and interpreted clearly their results.

Most studies received the lowest scores in the Sampling, Data Collection & Ethical Matters categories. In the Data Collection category, Patel et al., 2009 scored two out of five as there was limited information on the data collection methods used. Moreover, three studies scored two out of five in the Sampling category as they did not report their sampling methods (Crawford et al., 2004; Mendel et al., 2011; Sumner et al., 2014). Finally, three studies scored one or two out of five in the Ethical Matters category for not reporting their ethical approval or other ethical procedures (Huang et al., 2011; Khan & Pillay, 2003; Moritz et al., 2017).

3.6. Weaknesses and Strengths of Preference Elicitation Methods

Appendix 1.6 shows the strengths and weaknesses of the preference elicitation methods across studies. For the purposes of the synthesis, strengths and weaknesses were thematically organised into the following categories; a) quantitative, which included choice-

based techniques (e.g. questionnaires with closed questions and discrete choice tasks) and rating techniques (e.g. Likert scales), and b) qualitative, which included the use of open-ended questions and structured tools (i.e. advance statements) to elicit preferences in a meeting or interview with the researcher.

Although most studies stated the limitations and strengths of their study design, justification for choosing the specific preference elicitation method was limited. When Likert scales were used, information on the psychometric properties of the scale was not provided. Moreover, although single questions were chosen as they provided a structured way to elicit and analyse preferences, they may have failed to identify wider elements of patient preference such as the individual's perception about the treatment option and its attributes (Bowling & Rowe, 2005). This could lead to biased inferences about patient preferences and threat the validity of their choices.

To address this, some studies used qualitative-based techniques; these were chosen as they allow the exploration of factors involved in patient's choice and to ensure participants' understanding of the treatments presented (Sumner et al., 2014). However, such techniques can make comparisons across participants difficult and they involve more time and resources as indicated by the JCP meetings, which required several key stakeholders to be present.

Levitan et al. (2015) chose the DCE methodology to address such problems, as it can provide both information on the actual preference, as well as information on patients' consideration of the treatment options' attributes (Bridges et al., 2011a). However, as with most techniques involving evaluation of cognitive tasks, the authors reported that there could be difficulties when using these methods with individuals with psychosis due to high cognitive load which may affect task completion.

4. Discussion

4.1 Results in context

The primary aim of this review was to explore the way that patient preferences for the treatment of psychosis have been elicited in the literature. Consistent with previous reviews (McHugh et al., 2013; Ryan et al., 2001) our findings suggest that there is variation across studies in the methods used to assess preferences. This could be explained by the different objectives and questions posed across studies.

Moreover, this study found that there was variation with regards to the types of treatments that were subjected to preference assessment, with most studies exploring preference for 'formal' treatment interventions (e.g. medical or psychological interventions). Similar to Lindhiem et al. (2014), our findings suggest that preferences were measured without providing information on treatment components, risks or benefits. Where information was provided, the content and format for disseminating this were not described. Such findings raise questions about the validity of participants' choices and as to whether informed choices would differ, as provision of information could affect patient choices (Koedoot et al., 2003).

The second aim of the review was to explore the strengths and weaknesses of the preference elicitation methods. Our findings indicate that among studies using quantitative methods, the measures used were easy to administer but were either non-validated or too simplistic. Qualitative methods provided richer information on patient choices but were more resource heavy. DCE methodology was the only method involving both information on the preferred choice and on the trade-offs but required greater cognitive effort and active participation. However, it could be argued that active participation is a pre-requisite for all research involving individuals with psychosis and is, in fact, highlighted as a potential limitation in other studies (e.g. Farrelly et al., 2014; Wilder et al., 2010). Moreover, there is

evidence that patients with schizophrenia can meaningfully engage in discrete choice tasks and weight risks and benefits when making treatment choices (Bridges et al., 2011b).

Furthermore, there are additional methodological limitations across the studies that could affect preference elicitation and thus, the validity of the choices made. These relate to the data collection (e.g. whether tasks were completed during face-to-face meetings with the researchers or online) and associated biases, such as the interviewer effect or the use of more educated and less representative sample. Furthermore, the use of hypothetical treatment alternatives across most of the studies could lead to biased results, as hypothetical preferences may differ from actual preferences.

Overall, our findings suggest that there is variation across studies in relation to the methods used to elicit preferences and that there are strengths and weaknesses for each method. This could be explained by the different objectives and questions posed across studies. In particular, where the objective of the study was to explore differences among participants in terms of a particular preference, researchers used quantitative methods, mainly questionnaires or surveys with closed questions. Conversely, when the focus was on the experiences of service users with a variety of treatments and on the reasons behind treatment preferences, studies used qualitative methods, such as semi-structured interviews, and open-ended questions. This has clinical implications for future research, as variation should be seen as a function of the study's purpose and as the difference in methodology could not necessarily reflect poorer study quality, but different objectives. Therefore, future studies should not only consider the advantages and disadvantages of each preference method, but also ensure that the method of their choice is in line with their objectives and the questions to be answered.

4.2. Limitations & strengths of the review

This is the first review which has attempted to systematically describe and evaluate the strengths and weaknesses of the methodologies employed to elicit preferences for the treatment of psychosis. Specifically, this review included studies conducted in various mental health systems and cultures and studies using various methodologies. However, the heterogeneity of methods, samples, and treatment interventions being assessed may limit the robustness of the conclusions that can be drawn.

Moreover, although we aimed to only include studies with the highest methodological rigour (i.e. peer reviewed studies) the exclusion of unpublished studies might have limited the validity of our findings. Furthermore, due to the poor indexing of treatment preferences, a highly sensitive and specific retrieval was not feasible. However, we aimed to address this by consulting a librarian, by drawing on treatment preference literature and by conducting searches of a key journal in psychosis research.

Finally, this review used an established tool and an independent rater to assess the quality of included studies at the full-text screening stage. However, due to time restraints additional ratings at different stages of the screening process were not conducted. Thus, this could have affected our review's methodological rigour.

4.3. Implications

It has been proposed that systematic reviews on patient preferences should be considered when developing clinical guidelines (Lenert & Kaplan, 2000). The results of this review could be useful to authors of guidelines and policy makers, as they highlight the limitations and validity threats associated with non-standardized methods used to elicit preferences. Our findings also suggest that patient preferences may not be well-informed and may not accurately portray patient choice. This has implications both for clinicians and

researchers, who should ensure that detailed information on treatment components, risks and benefits is provided prior to treatment selection to allow informed choices to be made (Dwight-Johnson, Unutzer, Sherbourne, Tang, & Wells, 2001). Moreover, researchers and clinicians should ensure that they not only provide full information prior to treatment selection, but also give service users the opportunity to share their experience with the researchers and determine their own preferences. This may be particularly important for fostering choice and autonomy, considering the lack of involvement in decision-making among individuals with psychosis (Schizophrenia Commission, 2012).

This review concluded that there are various methodologies used to elicit preferences, with no one best method being identified. Specifically, our study highlighted the need for considering the aims and purpose of the study when deciding on which elicitation method to choose. For instance, studies aiming to explore service user choice of treatment as an outcome of their experiences with that particular treatment, or studies focusing on the reasons behind treatment preferences should use qualitative methods, whereas quantitative methods could be used when exploring differences in preferences.

Furthermore, several of the included studies scored low in relation to their data collection procedures and lacked information on the specific techniques used. Researchers should pay attention to not just choosing the most appropriate method to answer their question, but to also rigorously conduct it.

Finally, this review found differences in the way that studies operationalise treatment preferences, which could explain inconsistencies in their measurement. Despite this review's preliminary recommendations, clearer guidance on how to conduct research on patient preferences for the treatment of psychosis is needed to allow for meaningful comparison of findings.

5. Conclusion

Our findings suggest that from the variety of methods used to elicit treatment preferences, there is no single best method. Researchers should be encouraged to apply rigorous methods to elicit treatment preferences and clinical practice should be guided by a careful consideration of what constitutes a valid preference. Further research is required to include studies on different operationalisations of treatment preferences and to explore other methods used.

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Chapter two: Major Research Project

PRiorItieS: A study exploring PReferences for treatment, Internalised Stigma & Social Defeat among individuals in Receipt of care for Psychosis from Mental Health Services

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Prepared in accordance with '*Schizophrenia Research'* (see Appendix 1.1)
Word count including references: 6,818

Plain English Summary

Title: PRiorItieS: A study exploring PReferences for treatment, Internalised Stigma & Social Defeat among individuals in Receipt of care for Psychosis from Mental Health Services

Background: Research suggests that individuals with psychosis have reduced access to evidence-based treatment. Moreover, migrants experience greater delays and inequalities in accessing care, which could explain the higher prevalence of psychosis in this group. Factors such as experiences of stigma, social defeat or preference for non-medical treatments could delay help seeking and increase the risk of developing psychosis, as symptoms remain untreated for longer. Understanding these factors is essential to improving prevention and early intervention strategies and increasing access to treatment. Developing a reliable measure of treatment preferences may help in this respect.

Aims: The main aim of this study was to test the feasibility of recruiting individuals with psychosis to test out the validity and reliability of a new measure of treatment preferences – the Glasgow Mental Health Preferences Tool (GlasMPT). We also aimed to explore whether it is feasible to recruit migrants and non-migrants with experiences of psychosis to investigate differences on experiences of stigma, social defeat (the stress linked with the feeling of being an outsider), and treatment preferences between these groups.

Methods

1. Participants

Participants were individuals with lived experience of psychosis, aged 18 and older, fluent in English and were receiving care from acute and rehabilitation services across NHS Greater Glasgow & Clyde (GG&C). Migrants needed to be staying legally in the UK for the past six months or have applied for asylum.

2. Recruitment

Phase 1. A panel including clinicians working with individuals with experiences of psychosis and service users involved in research commented on the suitability and clinical utility of the tool, prior to testing it out in clinical settings.

Phase 2. Staff identified eligible participants and informed them about the study. Those interested in participating met with the researcher who provided further information and obtained consent. Participants then completed the measures on social defeat, stigma and the GlasMPT.

3. Design of study

This was a feasibility study, and therefore the analysis used was exploratory in nature.

4. Data collection

Participants attended up to two sessions with the researcher to complete some brief questionnaires, the GlasMPT, which was administered via a card-sorting task, and a demographic form. All sessions took place in psychiatric wards.

Main Findings: The study recruited 27 participants; only one migrant was recruited thus group comparisons were not conducted. The study showed that there are difficulties with recruiting migrants with psychosis. Verbal feedback from participants showed that the GlasMPT was useful and suggestions for improvement should be considered in future studies. Our study also found that participants preferred psychosocial interventions compared to medical or alternative types of treatment. We also found that those experiencing greater stigma also experienced greater social defeat. Future studies should build on these findings and test the tool with a bigger sample, comprising both of migrants and non-migrants, as our findings relating to the tool's validity were mixed, and could have been affected by our small sample size.

Key Reference:

Cantor-Graae, E., & Selten, J. P. (2005). Schizophrenia and Migration: A Meta-Analysis and Review. American Journal of Psychiatry, 162 (1), 12-24.

Abstract

Background: Research suggests that migrants have reduced access to treatment for psychosis, and more prolonged pathways to care, which could increase their risk for developing psychosis. Factors such as internalised stigma, experiences of social defeat and preference for non-medical treatment could delay help seeking, thereby leading to the development of psychosis.

Aims: Our primary aim was to pilot the feasibility of recruiting migrants and non-migrants with psychosis to test a new measure of treatment preferences. We also aimed to explore group differences on experiences of stigma, social defeat and treatment preferences.

Methods: Twenty seven individuals in receipt of care for psychosis completed measures of social defeat, internalised stigma and the GlasMPT.

Results: Difficulties with recruiting migrants are discussed. Results were also mixed with regards to the tool's psychometric properties, indicating the need for further refinements and testing. Exploratory analysis suggested that most participants preferred psychosocial interventions for their problems, and greater stigma was associated with greater social defeat.

Conclusion: Given the relationship between delays in help-seeking and development of psychosis, there is a need to understand barriers to help-seeking, particularly for those at risk, such as migrants. Future studies should draw on our findings to improve migrant recruitment and develop culturally sensitive measures of treatment preferences.

Keywords: treatment preferences, psychosis, psychometrics, feasibility

1. Introduction

There is a need to improve understanding of the factors that impede help-seeking for people with psychosis, given that there is reduced access to evidence-based treatments despite recommendations from clinical guidelines (Schizophrenia Commission, 2012; National Institute for Health and Care Excellence; NICE, 2014). Moreover, there is evidence of higher prevalence of psychosis in first and second-generation immigrants (Cantor-Graae & Selten, 2005), although the relationship between foreign migration and higher risk for developing psychosis remains ambiguous.

Several hypotheses have attempted to explain this relationship, including the selective migration of predisposed individuals, the tendency of clinicians to misdiagnose schizophrenia in individuals of non-dominant ethnicity, or that pre- or peri-migratory exposure to trauma could account for the high incidence of psychosis in refugees (Leao et al., 2006; Ödegaard, 1932; Sashidharan, 1993).

More recently, research on pathways into care has demonstrated that some ethnic groups may experience significantly longer delays for accessing treatment (Thomson, Chaze, George & Guruge, 2015). Longer duration of untreated psychosis has been associated with poorer prognosis and treatment outcomes (Birchwood, Todd, & Jackson, 1998). While some delays occur because of failure of services in detecting psychotic prodromes (Etheridge, Yarrow & Peet, 2004), there is also a delay in seeking treatment in those who are already in contact with services when they develop psychotic symptoms (Norman, Malla, Verdi, Hassall & Fazekas, 2004).

It is possible that a range of risk factors are potentiated within the period between migration and the onset of recognised psychotic symptoms requiring care, which increases the risk for developing psychosis (Cantor-Graae, Pedersen, McNeil, 2003). Factors such as internalised stigma (i.e. when a person considers publicly held stereotypes to be self-

relevant), experiences of social defeat post-migration (i.e. the stress produced after prolonged exposure to social adversity) and preference for non-medical treatments can contribute to delays in help-seeking, and thereby increase the risk for psychosis (Thomson et al., 2015).

In particular, 'feeling different' can often lead individuals to expect that others will judge them, which may result in hiding their difficulties and to delays in help-seeking (Gronholm, Thornicroft, Laurens & Evans-Lacko, 2017). Moreover, Cantor-Graae and Selten (2005) argue that prolonged exposure to social defeat experiences can lead to biased information processing. Furthermore, stigma and discrimination have been linked with the development of a paranoid attributional style (Garety, Kuipers, Fowler, Freeman & Bebbington, 2001), which could subsequently generalise into psychotic symptoms. Experiences of discrimination are higher among migrants (Veling et al., 2007) and can also provoke feelings of inferiority and social exclusion, contributing in this way to a delay in help-seeking. Finally, migrants are more likely to approach religious leaders, faith healers or family members before seeking psychiatric help (Rathod, Kingdon, Phiri & Gobbi, 2010). This can extend the duration their symptoms remain untreated, and thus, increase the risk for psychosis.

Despite the impact of the above factors on help-seeking for psychosis, there are no studies that have investigated treatment preferences among migrants in receipt of care for psychosis in the UK. It is possible that a lack of appropriate measures could account for this. This study aims to develop a culturally sensitive and reliable measure that assesses treatment preferences in a more engaging way (i.e. via a card-sorting task).

1.1. Primary Objective

1. To conduct a preliminary examination of the psychometric properties of a new measure of treatment preferences for individuals with experiences of psychosis – the Glasgow Mental Health Preferences Tool (GlasMPT)

1.2. Secondary Objectives

1. To explore the feasibility of recruitment of migrants and non-migrants with experiences of psychosis to investigate differences in treatment preferences, internalised stigma, and experiences of social defeat.
2. To examine the relationships between treatment preferences, internalised stigma and social defeat within each sub-group

2. Methods

2.1. Design

This was a cross-sectional, feasibility study comprised of two phases:

Phase 1 involved the development of a measure of treatment preference, during which an expert panel provided feedback on the suitability and clinical utility of the tool.

Phase 2 involved testing the tool in clinical settings and exploring the feasibility of recruiting migrants and non-migrants to explore differences in social defeat, stigma and treatment preferences.

2.2. Participants

Individuals were eligible if they had lived experience of psychosis and were receiving care from acute or long-term rehabilitation services in Greater Glasgow & Clyde (GG&C) health board area. Experience of psychosis involved participants with a diagnosis of schizophrenia spectrum disorder as defined by the ICD-10 (International Classification of Diseases of the World Health Organization; WHO, Tenth Edition), (WHO, 1992), as well as

participants who had not yet received a diagnosis but whose symptoms deemed severe enough to require treatment. Participants also needed to be over the age of 18 with conversational English language ability. Participants were excluded if they were not eligible for consent (e.g. if substance misuse, head injury or an organic disorder was the primary cause of psychotic symptoms). Participants who were acutely unwell or had a learning disability to the extent that it could affect their meaningful participation were also excluded.

For the non-migrant group, participants needed to be born in the UK and have British nationality, whilst for the migrant group participants needed to be first generation migrants, coming from Low And Middle Income Countries (LMIC) as per the World Bank's 2019 country classifications (Appendix 2.1), and staying in the UK legally or having applied for asylum.

2.3. Measures

The Glasgow Mental Health Preferences Tool (GlasMPT).

The GlasMPT was developed to assess treatment preferences for psychosis. The measure consists of two packs of cards. One of the packs contains descriptions of different types of problems drawn from research on relapse prevention for psychosis (Birchwood, Spencer & McGovern, 2000) and is divided into three categories: problems with thinking, problems with feelings and problems with behaviour.

The other pack describes different types of treatment and sources of help across a range of domains (e.g. medical, psychological, social and alternative treatments and sources of support). Blank problem and treatment cards were also included to allow participants to suggest other problems or treatment options not described in the tool. Appendix 2.2 provides a list of all the items included in the tool. Participants' answers and any comments related to the completion and acceptability of the tool were recorded in a card sort form (Appendix 2.3).

Participants were asked to select up to 15 cards describing the problems they would like most help with. They were then presented with the treatment cards and asked to choose the type of treatment(s) they would prefer to receive for each of the problem category they selected. Initial administration also involved ranking of the problem and treatment categories in terms of importance and preference, however this was later abandoned as pilot testing of the tool showed that it substantially increased the duration of the session (Appendix 2.4).

The Internalised Stigma of Mental Illness Scale (ISMI; Ritsher, Otilingam, & Grajales, 2003).

This 29-item scale was used to measure internalised stigma. The measure has strong internal consistency ($\alpha = 0.90$) and test–retest reliability ($r = 0.92$) (Ritsher & Phelan, 2004), and has been widely used in research (Boyd, Adler, Otilingam & Peters, 2014).

The Social Entrapment and Defeat Scales (Gilbert & Allan, 1998).

These two brief self-report questionnaires were used to measure experiences of social defeat. Both scales were administered as they are considered to assess the same construct and have demonstrated good psychometric properties (Taylor, Wood, Gooding, Johnson, & Tarrier, 2009).

The General Help Seeking Questionnaire (GHSQ; (Wilson, Deane, Ciarrochi & Rickwood, 2005).

The GHSQ was used to assess the construct validity of the GlasMPT. The GHSQ was chosen as it is a flexible measure of intentions to seek help from different sources and for different problems, and treatment preferences, among others, reflect an individuals' intention to seek help. The GHSQ has satisfactory reliability and validity (Wilson et al, 2005).

2.4. Procedure

2.4.1. Phase 1: *Development of the GlasMPT*

The GlasMPT items were generated through a multi-step process: 1) review of relevant measures and related papers; 2) use of the QUAID tool (Question-Understanding Aid; Graesser, Wiemer-Hastings, Wiemer-Hastings, & Kreuz, 2000b) to check the clarity and wording of provisional items; 3) online survey that gathered feedback from clinicians and experts by experience to ascertain the items' clarity and relevance.

Step 1 involved searching the literature for relevant papers that explored treatment preferences for psychosis (see Chapter 1 of the thesis). Initial steps also involved contacting authors of relevant studies to gather information on the development of their questionnaires. As this study aimed to target individuals from different ethnic backgrounds, we did not restrict the treatment items to 'formal' types of treatment (e.g. medical or psychological treatments) but decided to also include 'informal' sources of support such as religious healers or family and friends. The selection of these 'informal' types of help was based on studies on pathways to care for migrants with psychosis (Rathod et al., 2010).

Following this, a pilot questionnaire was initially constructed to assess treatment preferences. The questionnaire listed different types of treatment and asked participants to rate on a Likert scale their experience with each treatment and how beneficial they perceived this treatment to be. However, due to difficulties with engaging this population in research (Cook, Chambers, Coleman & Hart, 2005), it was decided that a more engaging way to administer the measure was required. Thus, we drew on our clinical experience with individuals with psychosis, and in particular, on the development of relapse prevention plans, where a card-sort task can be used to allow individuals to actively participate in the identification of their 'early warning signs' of psychosis (Birchwood et al, 2000). These signs are conceptualised as 'subtle changes in thought, affect and behaviour' that precede a

psychotic episode and can be easily identified by patients (Birchwood et al, 2000). Based on this, the content and the format of the GlasMPT was adapted to match that of the card-sort. Questions on experience were dropped to keep the measure brief and to simplify administration, and the final format consisted of a) problem cards (which were basically adaptations of the 'early warning signs' cards) and of b) treatment cards (which included items from pathways to care and conventional, 'formal' treatments).

Step 2 involved testing the wording of items for clarity using the QUAID tool, a web-based tool that assists in identifying potential problems in lay people comprehending the meaning of questions on questionnaires. The QUAID tool assessed the wording of the GlasMPT items across the following areas a) vague or imprecise or ambiguous terms b) complex syntax c) working memory overload (e.g. use of long sentences). Feedback from the QUAID suggested that the items were of adequate clarity and easy to comprehend by lay people.

During Step 3 an expert panel, which included clinicians and experts by experience, completed an online survey to provide their views on the draft tool. Clinicians were qualified mental health professionals working in the recruitment sites who agreed to act as local collaborators. Experts by experience were members of the University of Glasgow's Psychosis Research Group and had also agreed to act as advisors for this study. The panel was presented with provisional items of the GlasMPT and asked to rate the clarity and relevance of each item on a 9-point Likert-scale.

2.4.2. Phase 2: Validation of the GlasMPT & completion of questionnaires

The researcher met with clinicians to provide information about the study (Appendix 2.5) and answer any questions. Clinicians were asked to identify potential participants who met the eligibility criteria from their caseload and provide them with a study flyer (Appendix

2.6). Those who expressed an interest in the study were approached by the researcher to discuss the study and arrange a data collection session. Prior to data collection, participants were provided with participant information sheets (Appendix 2.7) and were asked to sign a consent form (Appendix 2.8) and complete a demographic form (Appendix 2.9).

2.5. Sample size

As this was a feasibility study we aimed to provide information that can be used by future studies for power and sample size estimations (Lancaster, Dodd & Williamson, 2004) and therefore we performed no formal calculations. However, we aimed to recruit at least 12 participants per group, as per Julious's (2005) recommendation for feasibility studies or a total sample size of 30 (Billingham, Whitehead & Julious, 2013).

2.6. Ethical approval

This study was approved by NHS West of Scotland Research Ethics Committee (Appendix 2.10) and the NHS GG&C Research and Development Department (Appendix 2.11). Responsible Medical Officers (RMOs) were also notified (Appendix 2.12).

3. Results

3.1. Recruitment

Of the 73 participants initially identified as eligible, 27 participants were included in the study. Fig. 1 illustrates the flow of participants. Feasibility data suggest that recruitment of individuals with psychosis was difficult, with only 55% of participants proceeding to the stages of written informed consent and data completion of all measures. As we only managed to recruit one migrant, comparisons on treatment preferences, stigma and social defeat between migrants and non-migrants were not conducted.

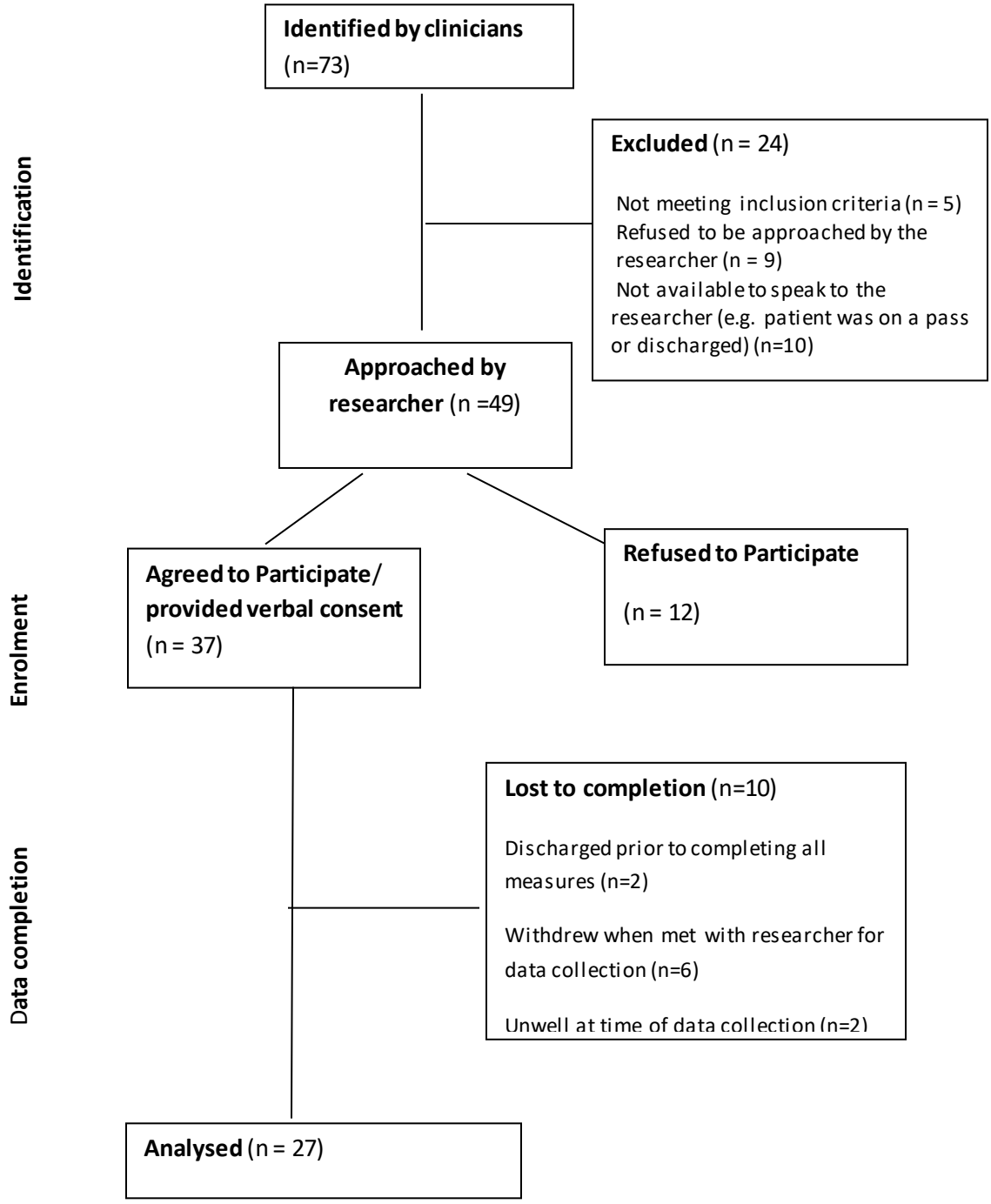

Fig. 1. Participant Flow

3.2. Sample Characteristics

The average age of participants was 38.96 years. 66.7% of the total sample were male and 74.1% identified as White British. Most common diagnosis was Paranoid Schizophrenia

(44.4%), and most participants were recruited from acute wards (88.9%). Table 1 illustrates participant characteristics for the total sample, including those who completed a sample of the measures. Comparisons on the demographic characteristics between those who completed all questionnaires (n=25) and those who completed a sample (n=2) were not made, as the subsample were very small and non-completion was due to the patients being discharged before their second meeting with the researcher.

Table 1.

Sample Demographics

Gender (N, %)	
Male	18 (66.7 %)
Female	9 (33.3 %)
Age (Mean, SD)	(M=38.96, 12.12)
Ethnicity (N, %)	
White British	20 (74.1 %)
White Irish	2 (7.4 %)
White Other (Irish)	1 (3.7 %)
Asian Chinese	1 (3.7 %)
Asian Pakistani	2 (7.4 %)
Asian Other (Indian)	1 (3.7 %)
Education (N, %)	
No degree	23 (85.2 %)
Degree	4 (14.8 %)
Religion/Belief (N, %)	
No Religion	11 (40.7 %)
Christianity	7 (25.9 %)
Islam	2 (7.4 %)
Buddhism	1 (3.7 %)
Jehovah's witness	1 (3.7 %)
Other (e.g. multireligious, humanist, nature)	4 (14.8 %)
Not reported	1 (3.7 %)
Marital Status (N, %)	
Married/civil partnership/cohabiting	2 (7.4 %)
Single	23 (85.2 %)
Divorced/separated	2 (7.4%)
Diagnosis (N, %)	
Paranoid Schizophrenia	12 (44.4 %)
Schizoaffective Disorder	4 (14.8 %)
Brief/Acute Psychotic Episode	4 (14.8 %)
Psychosis NOS	1 (3.7 %)
No diagnosis/psychotic symptoms	6 (22.2 %)
Level of Care/Setting (N, %)	
Acute ward	24 (88.9 %)
Rehabilitation ward	3 (11.1 %)
Mental Health Status (N, %)	
Informal	13 (51.9 %)
Detained under MHA	14 (48.1 %)

Note. *M* = Mean/Median, *SD* = Standard Deviation. *N* = 27

3.3. Data Analysis Strategy

Second generation migrants (n=3) were not excluded from the analysis due to having British nationality. Their data, along with data from the one participant in the migrant group were pooled with those of the non-migrant group and included in the analyses. One item from the GHSQ, (item 10: *'how likely is that you would seek help from anyone not listed above?'*) was excluded, as most participants reported that it was not applicable and thus did not complete it. Single missing items were limited (n<3) and were imputed using individual participant mean item scores on relevant questionnaires, following consultation with a statistician. Data were not included in the analysis when participants did not complete certain sections of the measures (i.e. when they did not identify any thinking problems). Finally, the assumptions of linearity and normal distribution of data were examined for all variables, and when violations were observed, non-parametric tests were used.

3.4. Psychometric Properties of the GlasMPT

3.4.1. Face Validity

Two clinical psychologists with 0-5 and >20 years of experience, and an expert by experience took part in the online survey between 2nd November and 14th December 2018. Four items (17.39%) in the 'problem' category and two (10%) in the 'treatment' category received an average rating between 5.6 and 7 (measured on a 9-point Likert scale). Although this suggests that the average clarity and relevance of the items were satisfactory, some of these items were eventually amended or excluded from the final version of the GlasMPT. An additional item, '*Looking after myself, by doing something relaxing, such as listening to music or having a massage'*, was also included to reflect the option of self-care.

3.4.2. Internal Consistency

Appendix 2.13 provides a summary of the internal consistency values for the Social Defeat, Entrapment, ISMI, GHSQ and GlasMPT measures. Hinton, Brownlow, McMurray, & Cozens's (2004) classification was used to interpret the alpha values.

Cronbach's alpha values for Social Defeat, Entrapment, ISMI & GHSQ ranged between .70 and .90 indicating that the scales and subscales of these measures showed 'high to excellent' reliability. For the GlasMPT problem cards, alpha values were calculated both overall and for each problem category (i.e. for emotional, thinking and behavioural problems), and ranged between .53 and .68, suggesting 'moderate' reliability. For the GlasMPT treatment cards, there were three alpha values calculated overall, each corresponding to treatments selected per problem category (i.e. all treatments selected for emotional problems, all treatments selected for thinking problems and all treatments selected for behavioural problems), as participants could select the same treatment cards for each problem category. These alpha values ranged between .61 and .77, indicating 'moderate to high' reliability.

Finally, alpha values for the GlasMPT treatment cards subcategories (i.e. the subcategory referring to the type of treatment selected for one problem category [e.g. 'Medical treatments selected for thinking problems']) ranged between -.14 and .69, indicating 'low to 'moderate' reliability.

3.4.3. Construct Validity

The two subscales of the GHSQ, the 'Emotional Problems' subscale and the 'Suicidal Thoughts' subscale, were used to assess whether participant's intention to seek help for emotional and thinking problems would be correlated with their intention to seek help, as

expressed by their answers on the 'Treatment for Feeling Problems' and 'Treatment for Thinking Problems' categories of the GlasMPT. Participants' answers on the GlasMPT were considered not only to reflect preference but also intention to seek treatment, as they were asked to choose the type of treatment they would like to receive for the problem they identified. The study found no significant association between the 'Emotional Problem' subscale of the GHSQ and the 'Treatment for Feeling Problems' category of the GlasMPT: $\tau(24) = .21$, 95%BCA CI [-.16, .54], $p>.05$. Moreover, no significant association was found between the 'Suicidal Thoughts' subscale of the GHSQ with the 'Treatment for Thinking Problems' Subscale of the GlasMPT: $\tau(22) = -.10$, 95%BCA CI [-.45, .26], $p> .05$.

3.5. Main Findings

3.5.1. Problems & Treatment Preferences

The most frequent type of problem that participants selected were emotional (M=56.89%, SD= 22.75), followed by problems with their thinking (M=46.86%, SD= 25.59), and behavioural problems (M=39.4%, SD=25.18). Most participants selected psychosocial types of support and treatment (Table 2) for the problems they identified, with social support being their first choice (M=59.97%, SD= 8.37), followed by psychological interventions (M=51.17%, SD= 9.40).

Table 2.

Percentages of treatment cards selected (out of all treatment types available) for each combination of problem category and type of treatment

	Type of Treatment											
	Medical			Psychological			Alternative			Social		
	%	SD	CI	%	SD	CI	%	SD	CI	%	SD	CI
Type of problem												
-Thinking N=24	44.79	32.95	30.88-58.71	50	35.44	35.03-64.97	34.03	18.86	26.06-41.99	52.08	40.32	35.06-69.11
- Feeling N=24	42.71	30.82	29.69-55.72	61.11	32.10	47.56- 74.67	36.59	20.06	27.92-45.27	68.75	32.35	55.09-82.41
-Behaviour N=22	37.5	29.63	24.36-50.64	42.42	32.82	27.87-56.98	34.85	23.37	24.48-45.21	59.09	39.75	41.47-76.72
Mean percentage	41.66	3.75	32. 33-50.99	51.17	9.40	27.82 -74.52	35.15	1.30	31.90 -38.40	59.97	8.37	39.18-80.76

**Note*. Type of treatment = medical, psychological, alternative, social. Medical treatment includes items such as seeing a doctor or taking a tablet, psychological includes seeing a psychologist, relaxation etc., social refers to support from family or friends and alternative includes spiritual help, self-help or alternative therapies. Type of problem = thinking, feeling and behaviour, SD= standard deviation, CI= confidence intervals 95%, N= sample size used in analysis.

3.5.2. Within group associations

Multiple bivariate correlations were used to examine the relationships between the key variables (treatment preference, internalised stigma and social defeat) within participants (Table 3). Non-formal treatments (i.e. alternative and social) were used in the analysis, given their potential to delay help-seeking (Thomson et al., 2015). There were significant associations between participant's scores on ISMI and social defeat scale, between entrapment and social defeat scores and between entrapment and ISMI. The results suggested that higher internalised stigma was associated with greater experience of social defeat and entrapment. Entrapment scores were also positively correlated with preferences for social support and treatment when participants identified emotional problems: the greater their feelings of entrapment, the more participants preferred to receive social support for their emotional problems. Moreover, participants' preferences to receive social support when they identified problems with their thinking correlated positively with their preferences to seek alternative sources of support for their thinking problem. Finally, preference to receive alternative treatments when participants identified problems with their behaviour was positively correlated with their preference to get social support for the same problem.

Table 3.

Sample sizes and correlations (Kendall's τ or Pearson's r) between Social Defeat & Entrapment Scales, ISMI and Non-Formal Treatments (Alternative & Social) selected per problem category in the GlasMPT.

				Non-Formal Treatments (GlasMPT)	
				Alternative	Social
	Entrapment	Defeat	ISMI	Thinking Feeling Behaviour	Thinking Feeling Behaviour
	Coef., BCa CI, N	Coef., BCa CI., N	Coef., BCa CI, N	Coef., BCa CI, N	Coef., BCa CI, N
Entrapment	1	.73** [.49, .86] 27	.30* [.10, .66] 26	.04 [-.39, .44] 22	.06 [-.24, .38] 24
				.34 [.01, .61] 23	.37* [-.02, .69] 24
				.04 [-.32, .39] 22	.21 [-.12, .50] 22
Defeat		1	.56** [.28, .76] 26	.06 [-.30, .39] 24	-.22 [-.49, .06] 24
				.005 [-.32, .35] 23	-.06 [-.43, .28] 24
				-.28 [-.59, .01] 22	-.21 [-.52, .12] 22
ISMI			1	.29 [-.05,.62] 24	-.02 [-.33, .30] 24
				.01 [-.33, .35] 23	-.19 [-.54, .16] 24
				-.06 [-.36, .29] 22	-.02 [-.34, .28] 22
Non-Formal Treatment (GlasMPT)					
Alternative					
- Thinking				1	.42* [0.10, .72] 24
- Feeling				1	.23 [-17, .52] 23
- Behaviour				1	.52** [.13, .82] 22
Social					
-Thinking					1
- Feeling					1
- Behaviour					1

*BCa bootstrap 95% Cls reported in brackets. N= sample size. *Correlation is significant at the .05 level (two tailed). ** Correlation is significant at the .01 level (two tailed)*

4. Discussion

4.1. Recruitment & Retention

This study aimed to examine the feasibility of recruiting migrants and non-migrants with psychosis to test a new measure of treatment preferences and explore differences on preferences, social defeat and stigma. Similar to existing research (Yancey, Ortega & Kumanyika, 2006) this study failed to recruit an adequate number of migrants to allow for group comparisons. Failure to recruit migrants was predominantly associated with lack of eligible participants in the recruitment sites. Specifically, only four people met criteria for the migrant group (i.e. first-generation migrants from LMICs). Of these, one migrant was transferred to another ward, one agreed to take part and two refused to participate, suggesting that acute admission units were not the best place to recruit migrants and that recruitment could be possible if access to migrants was facilitated.

This is an important implication for future studies, which suggests researchers should liaise with clinicians to identify through preliminary discussions or clinical audits, the services that are most likely to be used by migrants. As pathways to care may be different for migrants (Thomson et al., 2015) future studies should consider involving participants from a variety of services (e.g. primary, secondary or inpatient services), and with non-traditional pathways (e.g. through criminal justice system, religious organisations or voluntary sector). Consideration should be also given to recruiting migrants from specialist trauma services, as trauma has been associated with elevated risk of psychosis (Bendall, Jackson, Hulbert & McGorry, 2008) and as migrants are likely to experience greater trauma (Leao et al., 2006). Moreover, the inclusion of second-generation migrants may also provide valuable information about their treatment preferences compared to those of non-migrants, as research suggests a higher prevalence of psychosis among second-generation migrants (Cantor-Graae & Selten, 2005) and less traditional pathways to care (Thomson et al., 2015).

Although this study gained managerial approval to recruit from two psychiatric hospitals, patients allocated to Early Intervention Services in Psychosis (ESTEEM) within acute wards could not be approached, as additional approval from ESTEEM was not obtained. This could have affected recruitment, as feedback from clinicians confirmed that there was a high prevalence of migrant population within ESTEEM who met the eligibility criteria. It may be that the challenges already faced by services to engage migrants in treatment (Ouellet-Plamondon, Rousseau, Nicole & Abdel-Baki, 2015) can lead services to take a protective approach towards migrants, where any risk of unsettling them (including participation to research) is avoided. Future research should address this by liaising closely with services to provide information and reassurance, and by involving them in recruitment procedures so that the most efficient and least disruptive recruitment methods are identified.

Feasibility data highlighted that recruitment was also difficult for the non-migrant group. Several reasons, including the duration of the data completion, which lasted between 25 and 75 minutes, time restraints, and participants' mental state at point of approach by the researcher may have accounted for this. It is also likely that the nature of recruiting from acute wards, which involves a quick patient turnover, affected recruitment and participant retention. Future studies may benefit from a briefer assessment, more resources to facilitate frequent visits to the wards, and from following up participants in the community.

The higher recruitment rates in acute wards are probably related to participants being recruited from only one rehabilitation ward, with slower patient turnover, and patients with more chronic difficulties. Finally, lower recruitment rates were observed at start of recruitment. It is likely that this was related to recruitment being delayed due to difficulties in contacting ward managers to discuss recruitment, which resulted in having access to only two wards (one acute, and one rehab) for the first month of data collection. Subsequently a more assertive approach was undertaken which improved recruitment rates. Future studies should

factor in systemic factors, such as staffing issues or sickness, and use alternative approaches to liaise with services to improve communication and recruitment.

4.2. Main Findings

Our findings suggest that although the expert panel felt that the GlasMPT included relevant items, the data showed poor construct validity, raising questions about whether the operational definition that was chosen (i.e. intention to seek help) was reflecting the true theoretical meaning of treatment preferences. It is possible that a tool with a different operationalisation of treatment preferences could provide different results. It is also likely that the small sample size and the existence of outliers which were included in the analysis, affected our results.

Despite this, Cronbach alpha coefficients suggest 'moderate to high' internal consistency for the problem cards and the treatment cards when alpha values were calculated as an overall (i.e. when all sub-categories and sub-types of treatments and problems were included in the analysis). However, when analysis was conducted for each subcategory of treatments, alpha values reduced, with one value being negative, suggesting that removal of certain items was required. However, this could be explained by fewer observations being included in subcategory analysis and thus internal reliability being distorted by extreme values. Future studies should consider refining the tool by making the necessary amendments highlighted by the analysis.

Preliminary analysis of treatment preferences suggested that psychosocial types of treatment were the most preferred treatment options. This is consistent with previous research on treatment preferences for psychosis which indicated that patients preferred psychosocial types of treatment over medical treatments (Moritz, Berna, Jaeger, Westermann & Nage, 2017).

Moreover, our study found that within participants, those who experienced greater stigma also experienced greater experiences of entrapment and social defeat. This is not surprising, as experiences of stigma and discrimination could lead to a sense of social defeat, making individuals feel inferior and less worthy. Our findings also suggest that the greater their feelings of entrapment, the more participants preferred to receive social support for their emotional problems and that the more social support sources they selected for their thinking problems the more alternative types of treatment they also wished to receive. Finally, participants' preferences to receive alternative treatments when they identified problems with their behaviour was positively correlated with their preferences to get social support for the same problem. Although this study did not explore reasons for preferences, it is likely that non-formal treatments are perceived as more beneficial than medical treatments due to the risks associated with these (e.g. poor efficacy and side effects of medication; Farrelly et al., 2014), or due to previous negative experiences with mental health services, which could lead to a lack of confidence in services to treat patients effectively (Rathod et al., 2010).

An additional limitation was that the sample was too small to perform meaningful subgroup analysis on demographic variables and treatment preferences; future studies should account for this by exploring potential differences.

4.3. Strengths and Limitations

Despite the recruitment difficulties, every effort was made to facilitate data collection by including participants with comorbid difficulties (who did not meet exclusion criteria) and allowing for adjustments to be made when required (e.g. reading through the material for an individual with visual impairment). Including participants with comorbidities could have affected our findings by introducing confounding bias; however, comorbidities are common

among individuals with psychosis (Buckley, Miller, Lehrer & Castle, 2009), indicating that our sample is likely to be representative of the actual population.

This study recruited 27 participants, in line with the recommended sample size (i.e. 30) for feasibility studies (Billingham et al., 2013). Furthermore, this study was the first to explore treatment preferences for psychosis using a structured, comprehensive and culturally sensitive tool in the UK. The development of this measure was guided by research on relapse prevention (Birchwood et al., 2000) and literature on pathways to care for migrants with psychosis (Thomson et al, 2015). We aimed to make the tool sensitive to individual background, culture and beliefs about the origins of mental illness. Thus, this tool was the first, to our knowledge, to have included 'formal' (i.e. medical, psychological) and 'informal' interventions (i.e. social support and alternative therapies) as treatment options in this area.

Moreover, the format and administration of the tool via a card-sorting task aimed to increase participation by making the data collection process more interactive and engaging. Anecdotal feedback from participants is that they found the tool useful, relevant to their experiences, and thought provoking. They also reported an increased awareness over the sources of help and support that were either already available to them or that they could access. Nonetheless, participants also highlighted areas for improvement, such as the reduction of items to make the sessions shorter, or inclusion of additional options, such as phoning a help-line, or not using any help. Such feedback should be taken into consideration when refining the tool. Moreover, future studies may benefit from including a qualitative component to capture patient views in a more structured way.

Finally, there was some variation in terms of how service users interacted with the assessment, with some participants being interested in volunteering additional information. For instance, some participants wished to explain how their experience with the treatments they had received had influenced their preferences, or wished to discuss ways that services

could improve to meet the needs of patients with various preferences. Although such knowledge has not been formally captured, service users have provided some helpful information about how the tool could be further refined to include exploration of aspects of treatment that they have found beneficial. Moreover, the interaction of service users with the task was also noted to be different depending on where they were in their recovery journey at the time of the assessment, or their mental health status (e.g. whether they were detained or not). Future studies will benefit from taking account of these user-experience factors to help refine preference assessment tools.

5. Conclusions

More research on the refinement of the GlasMPT is needed, as our findings suggest some sound psychometric properties despite poor construct validity. Future studies should consider whether adding a qualitative component or a different mode of administration (e.g. questionnaire) may improve the tool's validity and reliability. Further testing with a bigger sample comprising of migrants and non-migrants is also needed, as patient preferences may vary significantly across ethnicities.

Our study highlighted difficulties in recruiting migrants. However, it has provided useful information to help future studies improve recruitment. Finally, we found a preference for psychosocial treatments among non-migrants. Although it is unknown to what extent such preferences relate to those of migrants, clinicians should be aware of this and attempt to incorporate patient preferences in treatment planning to increase engagement and up-take of evidence-based treatment.

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Appendices

Appendix 1.1: Author Guidelines for Schizophrenia Research: An International Multidisciplinary Journal of the Schizophrenia International Research Society

Guides for Author
Aims and scope:

Schizophrenia Research provides rapid publication of new international research that contributes to the understanding of schizophrenia and related disorders. The journal brings together previously separated biological, clinical and psychological research on this disorder, and stimulates the synthesis of clinical and research data into cohesive hypthesis.

Types of papers:

(1) Full-length papers: 4000 words (excluding tables, figures and references).(2) Short communications: 1000-1500 words (excluding tables, figures and references).(3) Letters to the Editors: 600-800 words, 10 references, 1 figure or table.(4) Special solicited research and/or reviews.(5) Invited comments or hypotheses.(6) Editorials.(7) Schizophrenia meeting reviews; solicited and/or submitted.(8) Book reviews.

Submission Checklist:

It is hoped that this list will be useful during the final checking of an article prior to sending it to the journal's editor for review. Please consult this Guide for Authors for further details of any item.

Ensure that the following items are present:

•One author designated as corresponding author
•E-mail address
•Full postal address
•Telephone and fax numbers
•All necessary files have been uploaded
•Keywords
•All figure captions
•All tables (including title, description, footnotes)

Further considerations

•Manuscript has been "spell checked"
•References are in the correct format for this journal
•All references mentioned in the Reference list are cited in the text, and vice versa
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PsycINFO via EBSCOhost	S1: TI ((Treat* or Patient* or Client*) N2 (Prefer* or Priorit*)) OR AB ((Treat* or Patient* or Client*) N2 (Prefer* or Priorit*)) OR KW ((Treat* or Patient* or Client*) N2 (Prefer* or Priorit*)) S2: TI (Measur* OR assess* OR investigat* OR evaluat* OR explor* OR elicit* OR identif* OR scale* OR tool* OR interview* OR focus group* OR questionnaire* OR survey*) OR AB (Measur* OR assess* OR investigat* OR evaluat* OR explor* OR elicit* OR identif* OR scale* OR tool* OR interview* OR focus group* OR questionnaire* OR survey*) OR KW (Measur* OR assess* OR investigat* OR evaluat* OR explor* OR elicit* OR identif* OR scale* OR tool* OR interview* OR focus group* OR questionnaire* OR survey*) S3: TI (Psychosis OR Psychoses OR Psychotic* OR schizo*) OR AB (Psychosis OR Psychoses OR Psychotic* OR schizo*) OR KW (Psychosis OR Psychoses OR Psychotic* OR schizo*) S4: De Psychosis or DE Schizophrenia S5: DE Client Attitudes OR DE Client Satisfaction OR DE Preference Measures S6: DE Measurement OR DE Surveys OR DE Questionnaires OR DE Likert Scales OR DE Interviews S7: S3 OR S4 S8: S2 OR S6 S9: S1 OR S5 S10: S7 AND S8 AND S9
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Crowe Critical Appraisal Tool (CCAT) Form (v1.4)

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Research design (add if not listed)

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❑ Historical		...
❑ Qualitative		Narrative | Phenomenology | Ethnography | Grounded theory | Narrative case study | ...
❑ Descriptive, Exploratory, Observational		A. Cross-sectional | Longitudinal | Retrospective | Prospective | Correlational | Predictive | ...
		B. Cohort | Case-control | Survey | Developmental | Normative | Case study | ...
Experimental	❑ True experiment	Pre-test/post-test control group | Solomon four-group | Post-test only control group | Randomised two-factor | Placebo controlled trial | ...
	❑ Quasi-experiment	Post-test only | Non-equivalent control group | Counter balanced *(cross-over)* | Multiple time series | Separate sample pre-test post-test [no Control] [Control] | ...
	❑ Single system	One-shot experimental *(case study)* | Simple time series | One group pre-test/post-test | Interactive | Multiple baseline | Within subjects *(Equivalent time, repeated measures, multiple treatment)* | ...
❑ Mixed Methods		Action research | Sequential | Concurrent | Transformative | ...
❑ Synthesis		Systematic review | Critical review | Thematic synthesis | Meta-ethnography | Narrative synthesis | ...
❑ Other		...

Variables and analysis

Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)

Sampling

Total size		Group 1		Group 2		Group 3		Group 4		Control	
Population, sample, setting											

Data collection (add if not listed)

Audit/Review	a) Primary | Secondary | ... b) Authoritative | Partisan | Antagonist | ... c) Literature | Systematic | ...	Interview	a) Formal | Informal | ... b) Structured | Semi-structured | Unstructured | ... c) One-on-one | Group | Multiple | Self-administered | ...
Observation	a) Participant | Non-participant | ... b) Structured | Semi-structured | Unstructured | ... c) Covert | Candid | ...	Testing	a) Standardised | Norm-ref | Criterion-ref | Ipsative | ... b) Objective | Subjective | ... c) One-on-one | Group | Self-administered | ...

Scores

Preliminaries		Design		Data Collection		Results		Total [/40]	
Introduction		Sampling		Ethical Matters		Discussion		Total [%]	

General notes

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Appraise research on the merits of the research design used, not against other research designs.

Category Item	Item descriptors [☑ Present; ☒ Absent; ■ Not applicable]	Description [Important information for each item]	Score [0–5]
1. Preliminaries			
Title	1. Includes study aims ❑ and design ❑		
Abstract (assess last)	1. Key information ❑ 2. Balanced ❑ and informative ❑		
Text (assess last)	1. Sufficient detail others could reproduce ❑ 2. Clear/concise writing ❑, table(s) ❑, diagram(s) ❑, figure(s) ❑		
		Preliminaries [/5]	
2. Introduction			
Background	1. Summary of current knowledge ❑ 2. Specific problem(s) addressed ❑ and reason(s) for addressing ❑		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) ❑ 2. Secondary question(s) ❑		
	Is it worth continuing?	**Introduction [/5]**	
3. Design			
Research design	1. Research design(s) chosen ❑ and why ❑ 2. Suitability of research design(s) ❑		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen ❑ and why ❑ 2. Precise details of the intervention(s)/treatment(s)/exposure(s) ❑ for each group ❑ 3. Intervention(s)/treatment(s)/exposure(s) valid ❑ and reliable ❑		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen ❑ and why ❑ 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) ❑ 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid ❑ and reliable ❑		
Bias, etc	1. Potential bias ❑, confounding variables ❑, effect modifiers ❑, interactions ❑ 2. Sequence generation ❑, group allocation ❑, group balance ❑, and by whom ❑ 3. Equivalent treatment of participants/cases/groups ❑		
	Is it worth continuing?	**Design [/5]**	
4. Sampling			
Sampling method	1. Sampling method(s) chosen ❑ and why ❑ 2. Suitability of sampling method ❑		
Sample size	1. Sample size ❑, how chosen ❑, and why ❑ 2. Suitability of sample size ❑		
Sampling protocol	1. Target/actual/sample population(s): description ❑ and suitability ❑ 2. Participants/cases/groups: inclusion ❑ and exclusion ❑ criteria 3. Recruitment of participants/cases/groups ❑		
	Is it worth continuing?	**Sampling [/5]**	
5. Data collection			
Collection method	1. Collection method(s) chosen ❑ and why ❑ 2. Suitability of collection method(s) ❑		
Collection protocol	1. Include date(s) ❑, location(s) ❑, setting(s) ❑, personnel ❑, materials ❑, processes ❑ 2. Method(s) to ensure/enhance quality of measurement/instrumentation ❑ 3. Manage non-participation ❑, withdrawal ❑, incomplete/lost data ❑		
	Is it worth continuing?	**Data collection [/5]**	
6. Ethical matters			
Participant ethics	1. Informed consent ❑, equity ❑ 2. Privacy ❑, confidentiality/anonymity ❑		
Researcher ethics	1. Ethical approval ❑, funding ❑, conflict(s) of interest ❑ 2. Subjectivities ❑, relationship(s) with participants/cases ❑		
	Is it worth continuing?	**Ethical matters [/5]**	
7. Results			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen ❑ and why ❑ 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen ❑ and why ❑ 3. Suitability of analysis/integration/interpretation method(s) ❑		
Essential analysis	1. Flow of participants/cases/groups through each stage of research ❑ 2. Demographic and other characteristics of participants/cases/groups ❑ 3. Analyse raw data ❑, response rate ❑, non-participation/withdrawal/incomplete/lost data ❑		
Outcome, Output, Predictor analysis	1. Summary of results ❑ and precision ❑ for each outcome/output/predictor/measure 2. Consideration of benefits/harms ❑, unexpected results ❑, problems/failures ❑ 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) ❑		
		Results [/5]	
8. Discussion			
Interpretation	1. Interpretation of results in the context of current evidence ❑ and objectives ❑ 2. Draw inferences consistent with the strength of the data ❑ 3. Consideration of alternative explanations for observed results ❑ 4. Account for bias ❑, confounding/effect modifiers/interactions/imprecision ❑		
Generalisation	1. Consideration of overall practical usefulness of the study ❑ 2. Description of generalisability (external validity) of the study ❑		
Concluding remarks	1. Highlight study's particular strengths ❑ 2. Suggest steps that may improve future results (e.g. limitations) ❑ 3. Suggest further studies ❑		
		Discussion [/5]	
9. Total			
Total score	1. Add all scores for categories 1–8		
		Total [/40]	

Appendix 1.4: Data Extraction Form

Data Extraction Form

General/study characteristics **Study ID: _____**

- Paper Title _____
- First author _____
- Publication year _____
- Origin of study (country) _____
- Design _____
- Method of Analysis _____
- General Study Focus (exploratory, experimental) _____
- Objective(s) (Main, Secondary)

_____
_____

- Outcomes (Primary, Secondary)

_____
_____

Assessment of Bias

- Funding (fully, partly, etc.) & source _____

Population Characteristics

- Condition/Diagnosis _____
- Mean Age _____
- Gender distribution _____
- Ethnicity distribution _____
- Setting (in-/outpatient) _____
- Sample size (including drop outs, treatment & control group sizes) _____

_____

- Sampling approach _____

Aspects of the preference elicitation

- Definition of treatment preferences

_____
_____

- Preference elicitation method(s)

_____
_____

- Categories/options presented for preference elicitation (e.g. choose between treatment interventions /treatment attributes/health states/health domains/other)

_____
_____

- Psychoeducation (i.e. if information was provided about the treatment options/decision-support tool used prior to choice)

_____
_____

• Sources used in option selection, construction of tool and/or development of methodology (e.g. systematic reviews, experts/clinicians, patients/focus groups, family members, staff etc.)

_____
_____

• Purpose of the preference elicitation (e.g. Efficacy of intervention/benefit to individual patients, research prioritisation, other)

_____

Results

• Most preferred choice(s):

_____
_____

• Other Key Findings

_____
_____

• Strengths of elicitation method

_____
_____

• Limitations of elicitation method

_____
_____

• Comparisons of preferences among different sub-groups (Was sub-group analysis performed & what are the results for each subgroup? (if applicable)

_____
_____
_____

• Correlations between patient preferences and demographic variables (if applicable)

_____
_____

Additional Notes

Add Quality Rating (CCAT score) _____

Appendix 1.5: Quality Appraisal of included studies

Study	CCAT Scores									
	Preliminaries	Introduction	Design	Sampling	Data Collection	Ethical Matters	Results	Discussion	Total	Total %
Sumner et al., 2014	5/5	4/5	4/5	2/5	4/5	3/5	4/5	5/5	31/40	78%
Crawford et al., 2004	4/5	5/5	3/5	2/5	3/5	4/5	4/5	5/5	30/40	75%
Moritz et al,. 2017	5/5	4/5	4/5	3/5	4/5	2/5	4/5	4/5	30/40	75%
Farrelly et al., 2014	4/5	5/5	4/5	3/5	4/5	4/5	4/5	5/5	34/40	85%
Haddock et al., 2018	5/5	5/5	5/5	4/5	4/5	4/5	4/5	5/5	37/40	93%
Mendel et al., 2011	4/5	4/5	3/5	2/5	3/5	4/5	4/5	4/5	28/40	70%
Huang et al., 2011	4/5	5/5	4/5	4/5	3/5	1/5	4/5	5/5	30/40	75%
Levitan et al., 2015	5/5	4/5	4/5	5/5	4/5	4/5	4/5	5/5	35/40	88%
Wilder et al., 2010	4/5	5/5	4/5	3/5	4/5	4/5	4/5	4/5	32/40	80%
Caroli et al., 2011	5/5	5/5	4/5	4/5	4/5	4/5	3/5	4/5	33/40	83%
Patel et al., 2009	4/5	5/5	4/5	3/5	2/5	3/5	4/5	4/5	29/40	73%
Khan & Pillay, 2003	3/5	4/5	3/5	3/5	4/5	2/5	3/5	4/5	26/40	65%

Appendix 1.6: Table illustrating strengths and weaknesses of preference elicitation method per study design

		Preference Elicitation Method	Strengths	Weaknesses
Quantitative	**Choice based techniques**	Simple, choice-based, closed questions (as part of a questionnaire/survey)	Structured questions help to ensure comparability of responses and facilitate analysis	May fail to capture the complex nature of preferences
		Decision- making scenarios & discrete choice tasks (e.g. DCE, Vignettes etc)	The decisional situation is preference sensitive. DCE tasks can provide information on the trade-offs	Evaluating cognitive tasks can be cognitively difficult for patients with schizophrenia
	Rating techniques	Likert Scales (separate or as part of a questionnaire/structured interview)	Relatively easy to complete Allow for measuring the strength of preference	Non-validated measures
Qualitative	**Structured interview-based techniques**	Advance Statements (e.g. JCPs or PADs)	The information generated may be richer & more clinically relevant They provide a more formal way to elicit and clearly document treatment preferences	Lengthy process which requires high levels of motivation from participants. The involvement of clinicians in the completion may limit free expression of preferences
		Open-ended questions (as part of a questionnaire/structured interview)	Ensure participants' understanding and allow clarification of reasons for their choices.	More difficult to compare responses across participants and facilitate analysis of preferences.

Appendix 2.1: LMIC List

World Bank Country Classification 2019

Low Income Countries ($1,000 tuition)			
Afghanistan	Ethiopia	Mali	**Syrian Arab Republic**
Benin	Gambia, The	Mozambique	**Tajikistan**
Burkina Faso	Guinea	Nepal	Tanzania
Burundi	Guinea-Bissau	Niger	Togo
Central African Republic	Haiti	Rwanda	Uganda
Chad	Korea, Dem. People's Rep.	Senegal	**Yemen, Rep.**
Comoros	Liberia	Sierra Leone	Zimbabwe
Congo, Dem. Rep	Madagascar	Somalia	
Eritrea	Malawi	South Sudan	

Middle Income Countries ($1,500 tuition)					
Albania	China	Guatemala	Macedonia, FYR	Papua New Guinea	Timor-Leste
Algeria	Colombia	Guyana	Malaysia	Paraguay	Tonga
American Samoa	Congo, Rep.	Honduras	Maldives	Peru	Tunisia
Angola	Costa Rica	India	Marshall Islands	Philippines	Turkey
Armenia	Côte d'Ivoire	Indonesia	Mauritania	Romania	Turkmenistan
Azerbaijan	Cuba	Iran, Islamic Rep.	Mauritius	Russian Federation	Tuvalu
Bangladesh	Djibouti	Iraq	Mexico	Samoa	Ukraine
Belarus	Dominica	Jamaica	Micronesia, Fed. Sts.	São Tomé and Principe	Uzbekistan
Belize	Dominican Republic	Jordan	Moldova	Serbia	Vanuatu
Bhutan	Ecuador	Kazakhstan	Mongolia	Solomon Islands	Venezuela, RB
Bolivia	Egypt, Arab Rep.	Kenya	Montenegro	South Africa	Vietnam
Bosnia and Herzegovina	El Salvador	Kiribati	Morocco	Sri Lanka	West Bank and Gaza
Botswana	Equatorial Guinea	Kosovo	Myanmar	St. Lucia	Zambia
Brazil	Fiji	Kyrgyz Republic	Namibia	St. Vincent and the Grenadines	
Bulgaria	Gabon	Lao PDR	Nauru	Sudan	
Cabo Verde	Georgia	Lebanon	Nicaragua	Suriname	
Cambodia	Ghana	Lesotho	Nigeria	Swaziland	
Cameroon	Grenada	Libya	Pakistan	Thailand	

Appendix 2.2: GlasMPT Items (Problem & Treatment Cards)

The wording of items was checked for clarity using the QUAID tool (Question-Understanding Aid; Graesser, Wiemer-Hastings, Wiemer-Hastings, & Kreuz, 2000b), a web-based tool that assists in identifying potential problems in lay people comprehending the meaning of questions on questionnaires. The following tables included the items that were included in the final version of the GlasMPT.

Problem Items		
Thoughts	**Feelings**	**Behaviours**
P.1 - Hearing Voices	P.7- Experiencing strange sensations	P.16 - Spending too much time alone
P. 2 - Thinking people are against you	P.8 - Feeling helpless	P.17 - Not leaving the house
P.3 - Having difficulty concentrating	P.9 - Feeling anxious or restless	P.18 - Having difficulty sleeping or staying asleep
P.4 -Seeing things others cannot see	P.10 - Feeling tired or lacking energy	P.19 - Neglecting your appearance
P.5 - Worrying that other people can control your thoughts	P.11 - Feeling irritable	P.20 Feeling like not eating or eating more than you used to
P.6 - Thinking that other people can read your mind or you can read theirs	P.12 - Feeling sad or low	P.22 – Drinking or smoking more
P.21 - Having difficulty making decisions	P.13 - Feeling guilty	P.23- Getting into arguments
	P.14 - Feeling forgetful or distractible	
	P.15 - Feeling like you cannot trust other people	

Graesser, A. C., Wiemer-Hastings, K., Wiemer-Hastings, P., & Kreuz, R. (2000). The Gold Standard of Question Quality on Surveys: Experts, computer tools, versus statistical indices. In *Proceedings of the American Statistical Association Section on Survey Research Methods*. American Statistical Association, 459-464.

Treatment Items			
Medical	**Psychological**	**Alternative** **(self-care, spiritual & alternative therapies)**	**Social**
T.1 - Taking tablets/pills	T.8 - Talking to a psychologist about the problem	T.6 - Seeing a faith healer	T.2 - Talking to a friend
T.4 - Seeing a doctor	T.14 - Using relaxation techniques	T.7 - Seeing a priest or imam	T.3 - Getting support from my family
T.5 - Going to the hospital	T.18 - Learning more helpful ways to cope with the problem, by changing my thoughts, feelings and behaviours	T.9 - Using natural remedies such as vitamins & herbs	
T.13 - Receiving ECT		T.10 - Exercising	
		T.11 - Having a healthy diet	
		T.12- Working or being busy	
		T.15 – Meditating	
		T.16 - Wearing lucky charms	
		T.17 - Praying or reading a religious book	
		T.19 - Aromatherapy: using aromatic oils to improve my mood/relax	
		T.20 - Acupuncture/needle therapy	
		T21 - Looking after myself or doing something relaxing (e.g. massage or listening to music)	

Appendix 2.3: Card Sort Form

Card Sorting Task – Record Form

Start: _____ **Subject ID: _____**

End: _____

Thinking Cards	Treatment (*for all cards in 'thinking' category)	Feeling Cards	Treatment (*for all cards in 'feeling' category)	Behaviour Cards	Treatment (*for all cards in 'behaviour' category)
1.		1.		1.	
2.		2.		2.	
3.		3.		3.	
4.		4.		4.	
5.		5.		5.	
6.		6.		6.	
7.		7.		7.	
8.		8.		8.	
9.		9.		9.	
10.		10.		10.	
11.		11.		11.	

12.		**12.**		**12.**	
13.		**13.**		**13.**	
14.		**14.**		**14.**	
15.		**15.**		**15.**	

Comments:

Appendix 2.4: Administration Guidelines & Procedure

General guidelines for administration of the GlasMPT are as follows:

- Prior to commencing the administration process, it is essential that adequate time is spent to build rapport with the service user. This can be facilitated through relating in a warm and empathic manner with the service user and through adopting an open and curious stance when exploring their views.

- Ideally, the task should flow like a conversation and the participant should be praised for their engagement and the effort they are putting in. This will help maintain rapport and maintain participant's motivation.

- To ensure that the participant's safety is maintained, the researcher should not ignore difficult emotions that may arise, when engaging in the task. The researcher should spend some time to explore these feelings with the participant and provide validation and support. The researcher can also offer the participant a break to allow them to manage these feelings prior to continuing with the task. If the participant experiences extreme distress the researcher should allow the participant to discontinue and direct them to agreed sources of support.

- The researcher should also explore any worries that may arise during the task and should address these appropriately. The participants should be reminded that the purpose of the task is to explore their treatment preferences and that this is not a test, nor there is a right or wrong answer.

- If, following this, participants struggle to complete the task, then the researcher should allow them to stop.

- After the task is completed, the researcher should offer the participant some time to go through any questions or worries the participants may have. As above, the researcher should ensure that any strong emotions or concerns are discussed prior to the participant leaving the room.

Administration Instructions

- Prior to reading out the following instructions, the researcher should ensure that all material (problem cards, treatment cards & pens) are placed on the table or desk.

  - *"In this task, we are going to use **two packs of cards**. One pack describes different types of problems that people may experience. The other pack describes different types of treatments that people would like to get to address their problems.*
  - *As you can see, there are also some blank problem and treatment cards (show the participant the cards). You can use these cards, to write down any other problems you may experience and/or any other types of treatment that you would like to get that are not listed in the cards.*
  - *First, I would like you to take a look at the problem cards and pick the ones which describe the problems you would like most help with.*
  - *Put the cards you have selected on this side of the table, and the cards you don't need here (show the participant where to lay the cards).*

- *You can select up to 15 problem cards.*
  (Once the cards are selected the researcher counts the cards and ensures that the participant is happy with their choices).
- *Great. Now, if we look at the cards you selected, we can see that these problem cards, can be divided into 3 main categories, a) problems with your feelings, b) problems with your thinking and c) problems with your behaviour (i.e. what you do or don't do).*
- *Now I am going to show you the treatment cards. Again, I would like you to take a good look at these cards. For each of the 3 categories of the problem cards you have picked, I would like you to choose at least one treatment card which describes the type of treatment that you would like to get to address the problems in each category.*
- *You can pick two or more treatment cards for one problem category if you wish.*

*Initially, participants were also asked to rank the problem & treatment cards in order of importance. The guidelines were:

Guidelines for the ranking of <u>problem cards</u>, (following selection of problem cards):

- *Now, I would like you to rank the cards in each category, in order of importance, by putting the most important problem for you at the top of each category and the least important at the bottom of the list (demonstrate an example if needed)*

Guidelines for the ranking of <u>treatment cards,</u>(following selection of treatment cards):

- *Now, I would like you to rank the treatment cards in each category, in order of importance, by putting the most important treatment for you at the top of each category and the least important at the bottom of the list (demonstrate an example if needed)*

However, these guidelines were eventually omitted as they increased substantially the duration of the session.

<u>Troubleshooting:</u>

- Check that the participant understands the task and answer any questions that they have.

- Check if the participant requires assistance with reading or writing and if so, make sure you provide assistance (i.e. reading the cards to them and/or writing on the blank cards on their behalf).

- Let the participant know that you will be taking notes during the procedure to ensure that you write down their answers.

- If the participant does not understand or is not familiar with a particular term written in the cards (e.g. a name of treatment) the researcher should provide a few examples to the participants.

Appendix 2.5: Staff Information leaflet

University of Glasgow

NHS Greater Glasgow and Clyde

Staff Information Sheet

A study exploring PReferences for treatment, Internalised Stigma & social defeat among individuals in receipt of care for psychosis from mental health services (PRiorItieS)

Principal Investigator: Foteini Thriskou

Chief Investigator & Academic Supervisor: Professor Hamish McLeod

Local Lead Collaborator: Dr Dannielle Graham

What is this research about?

We are exploring barriers to mental health help-seeking among migrants and non-migrants experiencing psychosis, who are receiving care from mental health services in NHS Greater Glasgow and Clyde. The study comprises of two main components: validation of a new method developed to ascertain mental health treatment preferences that can be used by migrants and non-migrants and 2) comparison of migrants and non-migrants in relation to potential help seeking barriers of social defeat experiences, internalised stigma and treatment preferences for psychosis.

What will the study involve?

Participants will be asked to meet with the researcher and complete some short questionnaires and a card-sorting task designed to ascertain treatment preferences in an engaging and easy to understand way. This will take approximately 30 minutes.

Who is eligible?

All participants must:

- be aged 18 and older
- have lived experience of psychosis (including those who have not yet received a formal diagnosis but whose symptoms are deemed severe enough to require treatment)
- be currently receiving care from your service
- have sufficient command of English to be able to consent and meaningfully engage with the study

Plus, for the migrant group, must be:

- first generation migrants
- coming from Low- and Middle-Income Countries (LMIC)
- staying in the UK legally for the past 6 months or having applied for asylum

For the non-migrant group:

- must be born in the UK
- have British nationality

Participants are not eligible:

- if they cannot provide informed consent, and in particular:
- if substance misuse, head injury or an organic disorder is considered to be the primary cause of psychotic symptoms

Version 1, Date: 19.11.18

- if they have a learning disability or an impairment that affect their meaningful participation
- if they are experiencing an acute psychotic episode that will affect their meaningful participation

****Study flyers should only be provided to service users who meet the criteria above****

How I can help?

- You will be asked to identify potential participants for each group. Please make sure you carefully consider the above criteria when deciding upon someone's eligibility.
- Once you have identified a potential participant, please approach them and provide them with the study flyer, which contains basic information about the study.
- After providing the service user with the study flyer, it is important that they understand what is required of them and have the opportunity to ask questions. Please direct them to the principal investigator (see below for contact information) if these questions cannot be answered by yourself.
- If participants are happy to be contacted by the researcher, please document this on their notes. Please ensure that you have obtained participant's verbal consent prior to contacting the researcher.

If you have any questions, please contact:

Foteini Thriskou
Trainee Clinical Psychologist
Mental Health and Wellbeing
Gartnavel Royal Hospital,
1st Floor, Admin Building,
1055 Great Western Road
Glasgow G12 0XH
Email : f.thriskou.1@research.gla.ac.uk

Thank you for helping out with the above study.

Appendix 2.6: Study Flyer

PRiorItieS:

A study exploring PReferences for treatment, Internalised Stigma & social defeat among individuals in receipt of care for psychosis from mental health services

Invitation to take part in a research study

What is the research about?

We want to find out about some of the things that can make it difficult for you to seek help for your difficulties.

We hope that this will help us to understand the needs of people with psychosis and inform their treatment.

What does taking part involve?

A researcher will initially meet with you to discuss the study and answer any questions you may have. If you decide that you would like to take part, you will attend a session to complete some brief measures at a time that suits. This will take around 30 mins.

Do I have to take part?

No. Your participation is entirely up to you.

Your decision will not affect your care in any way.

If you would like to find more about the study, speak to your key worker or contact:

Foteini Thriskou

Email: f.thriskou.1@research.gla.ac.uk

NHS Greater Glasgow and Clyde

University of Glasgow Institute of Health & Wellbeing

Version 1, Date: 19.11.18

Appendix 2.7: Participant Information Sheet

A study exploring **PR**eferences for treatment, **I**nternalised **S**tigma & social defeat among individuals in receipt of care for psychosis from mental health services **(PRiorItieS)**

Participant Information Sheet

Invitation to Participate in a Research Project

You are being invited to take part in a research study. Before you decide, 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. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who is conducting the research?
The research is being carried out by Foteini Thriskou who is a Clinical Psychologist in training from the University of Glasgow. The research is being supervised by Professor Hamish McLeod from the University of Glasgow. The NHS field supervisor is Dr Danielle Graham, a Clinical Psychologist who works for NHS Greater Glasgow and Clyde.

What is the research about?
This study is designed to improve understanding of mental health help-seeking preferences among people who are currently receiving care via NHS Greater Glasgow and Clyde. This research will help mental health services to develop better ways of helping people to get the help they need. The study is being undertaken by Foteini Thriskou as part of the requirements for a Doctorate in Clinical Psychology at the University of Glasgow.

Who is being asked to take part?
We are asking people who are currently being treated by mental health services in NHS Greater Glasgow & Clyde, and who also have experience of psychosis and other similar disorders, to take part in the study.

Why I have been asked to take part in this study?
A member of the mental health team responsible for your care (e.g. Consultant Psychiatrist, Clinical Psychologist or CPN) has suggested that you might meet the eligibility criteria for the study and could be interested in participating.

What are you asking me to consent to?
If you consent, you will initially meet with a researcher to discuss the study. If, following this, you are still willing to take part, you will meet with the researcher at the service you attend to complete some measures about your experiences and help-seeking preferences. This session is expected to last for approximately half an hour.

You are also being asked to consent to your case notes being reviewed by one of the researchers to collect some relevant information about yourself such as your age, ethnicity, diagnosis etc.

What does taking part involve?
If you have expressed your interest in participating in the study, this means that:

- You have given permission to the clinician who approached you, that your name and contact details can be passed to Foteini Thriskou (researcher) so that she can contact you to discuss the study.
- During your first meeting with Foteini, she will give you more information about the study and answer any questions you may have.
- If you remain willing to take part, you will book a convenient time to meet again with Foteini to complete some brief measures. The measures will ask you questions about your experiences and your mental health seeking preferences.
- During the research session, before you start completing the measures, you will be will be asked to sign a consent form.
- You will be able to take breaks during the sessions if you would like to, and you can decide to stop participating in the study at any time. You don't have to give a reason for this.
- If you need to travel to the service to meet with Foteini, the cost of you travelling there by public transport may be reimbursed for by funds from the University of Glasgow. Please speak to Foteini about this, as some restrictions may apply.
- Your responses will be anonymous – any personal information that could identify you will be removed from the results of the study.
- If answering the questions produces any distress, you will be offered help with managing this.
- Following your participation, you will be given the opportunity to ask any further questions you may have about the research, and discuss any concerns that may arise after the session.

Do I have to take part in this study?
No, participation in the study is entirely voluntary. If you do not wish to take part you do not have to. Your decision whether to take part or not will not affect any treatment you receive.

Can I change my mind?
Yes. You can change your mind and withdraw from the study at any time, and you do not need to give a reason. Your care will not be affected in any way if you change your mind.

Will my information be confidential?
Yes. The information you provide will be treated confidentially and kept safe and anonymous. This means that your name will not be attached to any questionnaires, instead a participant number will be assigned. Your name and any information that could identify you will not appear in any reports and your answers to questions will not be used to inform your relationship with your mental health worker.

The anonymised questionnaires along with the consent forms and other study data will be stored in a password-protected computer on University of Glasgow premises and will be accessible only to the researchers who are directly involved with the research. Study data may be also looked by representatives of the study Sponsor, NHS Greater Glasgow and Clyde, to ensure the study is being conducted correctly. In particular, NHS Greater Glasgow and Clyde is the sponsor for this study based in Scotland. They will act as the data controller for this study for the information you provide and the information gathered from your medical records. This means that they are responsible for looking after your information and using it properly and are bound by the same confidentiality rules as the researchers and your care team.)

With your permission we will also inform your responsible clinician and/or mental health team that you are taking part in the study. If you share information that makes the researcher concerned for your safety or the safety of other people, we may be required to tell others involved in your care (e.g. your keyworker or psychiatrist). We will always make a reasonable attempt to discuss this with you beforehand and explain why we are concerned.

How long will you keep information?

NHS Greater Glasgow and Clyde will keep identifiable information about you for up to 1 year after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at
http://www.nhsggc.org.uk/patients-and-visitors/faqs/data-protection-privacy/

What are the benefits of taking part?
Although there are no direct benefits, we hope that taking part in this study may help improve service options for other people with similar experiences in the future.

Is there a downside of taking part?
Although we do not expect you to become distressed by your participation in the study, it is possible that completion of some questionnaires may stir up some unwanted emotions. If you have any concerns about taking part, you can contact Foteini, Hamish or discuss this with your key-worker or a member of your mental health team in order to access suitable support. There is also a debrief form within the pack which provides the contact details of supportive agencies should you require it.

What will happen to the results of the study?
The results of the study will be reported in Foteini Thriskou's thesis as part of her Doctorate in Clinical Psychology degree. The results may also be published in scientific journals or presented at conferences.

You will not be identified in any report or publication. You are welcome to receive a copy of the findings once the project is complete. Please tell Foteini if you would like this and provide an address to which a summary of the results can be sent to.

Who has reviewed the study?
The study has been reviewed by the University of Glasgow to ensure that it meets standards of scientific conduct. It has also been reviewed by the Research and Development Department in NHS Greater Glasgow and Clyde and by the West of Scotland NHS Research Ethics Committee to ensure that it meets standards of ethical conduct.

Can I speak to someone who is not involved in the study?
Yes. You can speak to Dr Karen McKeown (Tel: +44 (0)141 211 3932 & Karen.McKeown@glasgow.ac.uk) or Professor Tom McMillan (Tel: +44 (0)141 211 0354 & Thomas.McMillan@glasgow.ac.uk), who have reviewed the study but are not involved in the study.

What will happen if there is a problem or if I want to make a complaint?
If you have any concerns about the study, please contact the researchers who will do their best to assist you:

Researchers Contact Details	
Professor Hamish McLeod Professor of Clinical Psychology, Doctorate in Clinical Psychology Programme Director & Honorary Consultant Clinical Psychologist Mental Health & Wellbeing, University of Glasgow Administration Building, 1st Floor Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH Email: Hamish.McLeod@glasgow.ac.uk	Foteini Thriskou Trainee Clinical Psychologist Mental Health & Wellbeing, University of Glasgow Administration Building, 1st Floor Gartnavel Royal Hospital 1055 Great Western Road Glasgow G12 0XH Email: f.thriskou.1@research.gla.ac.uk

If you remain unhappy with the conduct of the study and wish to complain formally, you can do this through NHS Greater Glasgow and Clyde NHS Complaints by telephoning 0141 201 4500 and/or 0141 287 0130 , or by emailing complaints@ggc.scot.nhs.uk.

If you feel distressed following your participation in this study, you can speak to your key worker: .....

Thank you for taking the time to read this

Appendix 2.8: Participant Consent Form

University of Glasgow
Institute of Health & Wellbeing

NHS Greater Glasgow and Clyde

Participant Consent Form

A study exploring **PR**eferences for treatment, **I**nternalised **S**tigma & social defeat among individuals in receipt of care for psychosis from mental health services **(PRiorItieS)**

Chief Investigator: Professor Hamish McLeod
Researcher: Foteini Thriskou
Local Lead Investigator: Dr Dannielle Graham

Please initial the box

1. I confirm that I have read and understand the Participant Information Sheet, dated..... (Version ....) for the above study. ☐

2. I have had the opportunity to ask questions, and I am satisfied with the answers I received. ☐

3. I have received enough information about the study. ☐

4. I understand that my participation is voluntary, and that I am free to withdraw at any time. I understand that I can do so without giving any reason, and without my care being affected. ☐

5. I understand that the researcher will keep the completed questionnaires and notes of my answers. I understand that all personal data will be anonymized and stored in locked drawers and will be destroyed following completion of analysis. ☐

6. I also understand that the study data may be looked by representatives of the study sponsor, NHS Greater Glasgow & Clyde, to ensure the study is being conducted correctly. ☐

7. I agree that fully anonymized data may be used in publications and other materials arising from the study. ☐

8. I understand that if I become upset during the research session the researcher will help me to access appropriate professional support if this is required. ☐

9. I understand that if I say anything that makes the researcher concerned about my safety or the safety of another person this information may be communicated to a third party. I also understand that the researcher will attempt to discuss this with me beforehand. ☐

10. I agree that my RMO, Psychiatrist, Key Worker and/or my Mental Health Team will be informed of my participation in the study. ☐

11. I understand that a member of the research team will examine my case notes to obtain some personal data such as information about my age, diagnosis, ethnicity etc. ☐

11. I agree to take part in the study. ☐

13. I would like to receive a copy of the study results and these can be sent to me via email at _____ or at the following address: ☐

_____

_____

Participant Name	Date	Signature
……	… / … / ……	……
Researcher	Date	Signature
……	… / … / ……	……

1 copy for participant; 1 copy for researcher

Appendix 2.9: Demographic Form

***PR**ior**I**tie**S**; A study exploring **PR**eferences for treatment, **I**nternalised **S**tigma & social defeat among individuals in receipt of care for psychosis from mental health services*

Participant Demographic Form

1. Participant Number: _____ Group: Migrant / Non-migrant

2. Site: Leverndale /Gartnavel/ ESTEEM/ Other: _____

3. Level of Care: Acute/ Rehab / Early Intervention

4. Gender: Male / Female / Prefer not to state

5. Age: _____

6. Country of birth: _____

7. Is English First language? Y/N

8. Has participant received a diagnosis of a psychotic disorder? Y/N
(Please state type of psychotic disorder or relevant symptoms the participant is presenting with)
_____

For the migrant group:

Has participant been living in the UK for the past 6 months? Y / N

Is the participant an asylum seeker? Y/N

For those participants admitted in acute or rehab wards:

Date of Admission: _____

Is the participant detained under any Mental Health Act Section? Y / N
(If yes, please state under which section the patient is detained) _____

---

9. Ethnicity:

White British
White Irish
White other (*please state*) _____

Black African
Black Caribbean
Black other (*please state)* _____

Asian Chinese
Asian Indian
Asian Pakistani
Asian other *(please state*) _____

Mixed White & Asian
Mixed White & Black African

Mixed White & Black Caribbean
Mixed other *(please state*) _____ Prefer not to state

10. Marital status:

Divorced/Civil Partnership Dissolved
Separated
Single
Widowed
Married/Civil Partnership/Common Law
Other *(please state)* _____
Prefer not to state

11. Religion/Belief:

Atheism
Buddhism
Hinduism
Sikhism
Islam
Jehovah's Witness
Judaism
No Religion
Other (*please state*) _____
Prefer not to state
Christianity (*Please indicate denomination*) _____

12. Years of formal education *(& associated qualifications):*

< 6/7 years
7-9 years
10-13 years (e.g. high school or college diploma or secondary education diploma such as A Levels)
14-16 years (e.g. graduate degree)
16-18 (e.g. postgraduate degree such as Masters)
19+ years (e.g. PhD or other Doctoral level degree)

Please consider also the following exclusion criteria prior to proceeding to data collection:

Is the participant under the *influence of any substances* that would affect meaningful participation in the study? Y/N

Has the participant had a *brain injury* that would affect meaningful participation in the study? Y/N

Does the participant have a *learning disability* that that would affect meaningful participation in the study? Y/N

Appendix 2.10: Research Ethics Committee approval

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Professor Hamish McLeod
Mental Health and Wellbeing, University of Glasgow
1st Floor, Admin Building, Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH

West of Scotland REC 4
Research Ethics
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ
(Formerly Yorkhill Childrens Hospital)

Date 17 January 2019
Direct line 0141 232 1808
E-mail WoSREC4@ggc.scot.nhs.uk

Dear Professor McLeod

Study title:	**PRiorItieS; A study exploring PReferences for treatment, Internalised Stigma & social defeat among individuals in receipt of care for psychosis from mental health services**
REC reference:	**19/WS/0005**
Protocol number:	**n/a**
IRAS project ID:	**242138**

The Research Ethics Committee reviewed the above application at the meeting held on 11 January 2019. Thank you for attending to discuss the application along with Miss Foteini Thriskou.

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 favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request.
Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

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

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

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

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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

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

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

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

Ethical review of research sites

NHS Sites

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

Extract of the meeting minutes:

- **Social or scientific value; scientific design and conduct of the study**

  The Committee was of the opinion that this was an important area of study since psychosis was more common in those who had migrated from one area to another. It would be useful to find out why some individuals were less likely to seek treatment and what the barriers were. They asked the applicants why a new tool was needed.

  The applicants explained that after undertaking a literature review, it appeared that there was no existing tool to measure treatment preferences. This was currently done via interviews, focus groups or questionnaires. For people with psychosis, there was nothing more standardised than these options. The aim was to develop a more standardised method to establish preferences which would aim to understand the barriers to seeking help. It was hoped that the card-sorting tool would be less intimidating and more accessible for those with language barriers. The aim was to find out what preferences people had and how these matched/contrasted with the management options available. It may also assist with managing expectations as well.

  The Committee asked how this new tool would be tested.

  The applicants stated that it would be compared with the general help-seeking questionnaires.

  The Committee accepted this.

  The Committee asked about the definition of "*low and middle income countries*" as per A13 of the IRAS form.

  The applicants stated that these countries were classified by the World Bank and clinicians would be aware of this in relation to the inclusion/exclusion criteria.

  The Committee thanked them for this clarification.

- **Recruitment arrangements and access to health information, and fair participant selection**

  The Committee asked the applicants to describe how participants would be recruited.

  The applicants explained that recruitment would be undertaken across NHS Greater Glasgow & Clyde (Leverndale and Gartnavel Royal Hospitals and also ESTEEM). Local collaborators would brief their staff about the study and the inclusion/exclusion criteria. These staff would approach potential participants from their caseloads in each of the centres. They would give out flyers to those interested and Miss Thriskou would then visit any individuals interested in participating to discuss it further and issue the PIS.

  The Committee enquired as to why only the flyer would be given out to begin with, and not the PIS as well.

  The applicants explained that they wanted to give only a small amount information initially to establish if people were interested or not. This would give people more

time to consider. They did not want to give out the PIS at the outset in case people felt overwhelmed by too much information.

The Committee accepted this response.

The Committee observed that those who did not speak English would be excluded and asked for more information about this.

The applicants acknowledged that valuable information may be lost in excluding those with no ability to understand English but were aware of the limitations of a feasibility study. In future studies they planned to try and include non-English speakers.

The Committee was content with this.

The Committee enquired about those who lacked capacity to consent.

The applicants responded that this would be assessed and those lacking capacity to consent would be excluded from participation.

The Committee was reassured by this answer.

- **Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)**

  The Committee was of the opinion that the study was low risk and that any potential risks to participants had been anticipated, with strategies in place to deal with these during and after completion of the questionnaires. All patients were under the care of psychiatric services in Greater Glasgow & Clyde and had an established diagnosis.

  There was some discussion around the titles of the questionnaires (defeat, entrapment, stigma) and whether these could cause distress to participants. It was observed that in this patient group, these would be familiar as they were commonly used. This was accepted.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Study Flyer]	1	19 November 2018
GP/consultant information sheets or letters [Notification Letter to RMO]	1	19 November 2018
IRAS Application Form [IRAS_Form_14122018]		14 December 2018
Other [Participant Debrief Sheet]	1	19 November 2018
Other [Study Information Leaflet for Clinicians]	1	19 November 2018

Document	*Version*	*Date*
Other [Participant Demographic Form]	1	19 November 2018
Other [CV- Danielle Graham (local collaborator)]		30 July 2018
Other [Supplemmentary Info about the non-validated tool]	1	19 November 2018
Other [GlasMPT - Online Survey Feedback Form]	2	11 December 2018
Participant consent form [Consent Form]	1	19 November 2018
Participant information sheet (PIS) [Participant Information Sheet]	1	19 November 2018
Research protocol or project proposal [Research Protocol- Priorities]	1	19 November 2018
Summary CV for Chief Investigator (CI) [CV CI Hamish McLeod]		23 September 2018
Summary CV for student [CV - Student Foteini Thriskou]		04 August 2018
Validated questionnaire [Questionnaire Booklet]	1	19 November 2018

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

HRA Training

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

19/WS/0005	Please quote this number on all correspondence

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

Yours sincerely

On behalf of
Dr Ken James
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Ms Emma-Jane Gault
Mrs Kayleigh McKenna, NHS Greater Glasgow and Clyde
Miss Foteini Thriskou, University of Glasgow
nhsg.NRSPCC@nhs.net

Appendix 2.11: Research and Development Department Approval

Administrator: Mrs Elaine O'Neill
Telephone Number: 0141 232 1815
E-Mail: elaine.o'neill2@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
West Glasgow ACH
Dalnair Street
Glasgow G3 8SW

15 February 2019

Miss Foteini Thriskou
Inst of Health and Wellbeing
Gartnavel Royal
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Miss F Thriskou,

Study Title:	**A study exploring PReferences for treatment, Internalised Stigma & social defeat among individuals in receipt of care for psychosis from mental health services**
Principal Investigator:	**Miss Foteini Thriskou**
GG&C HB site	**Gartnavel Royal Hospital**
Sponsor	**NHS Greater Glasgow and Clyde**
R&D reference:	**GN18MH606**
REC reference:	**19/WS/0005**
Protocol no:	**V1; 19/11/18**

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004

    a. During the life span of the study GGHB requires the following information relating to this site
        i. Notification of any potential serious breaches.
        ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
   a. Recruitment Numbers on a monthly basis
   b. Any change of staff named on the original SSI form
   c. Any amendments – Substantial or Non Substantial
   d. Notification of Trial/study end including final recruitment figures
   e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Pp Mrs Elaine O'Neill

Mrs Kayleigh McKenna
Senior Research Administrator

Appendix 2.12: Notification letter to Responsible Medical Officer

A study exploring PReferences for treatment, Internalised Stigma & social defeat among individuals in receipt of care for psychosis from mental health services (PRiorItieS)

Letter of Notification to Responsible Clinician

Dear Dr _____

Re: (Patient name) _____, D.O.B. _____

This is to inform you that the above named person has agreed to participate in a research study, which is being carried out by Foteini Thriskou, who is a Clinical Psychologist in training from the University of Glasgow. The study is supervised by Professor Hamish McLeod, Professor of Clinical Psychology, DClinPsy Programme Director & Honorary Clinical Psychologist from the University of Glasgow, and Dr Danielle Graham, Principal Clinical Psychologist, who works for NHS Greater Glasgow and Clyde (GG&C).

The study is designed to improve understanding of mental health help-seeking preferences among individuals with experiences of psychosis who are currently receiving care via NHS GG&C. As part of their participation, individuals will be asked to meet with the researcher and complete some brief questionnaires and a card-sorting task.

We hope that this study will inform prevention strategies and help mental health services develop more targeted interventions for adults experiencing psychosis.

If you have any questions about this work, please do not hesitate to contact me: Foteini.Thriskou@glasgow.ac.uk.

Thank you for your help

Yours sincerely,

Foteini Thriskou
Trainee Clinical Psychologist

Under the supervision of:

Prof. Hamish McLeod
Professor of Clinical Psychology

(Please note that the study has been reviewed by the University of Glasgow, the Research and Development Department (R&D) in NHS GG&C and by the West of Scotland NHS Research Ethics Committee (REC) to ensure that it meets standards of ethical conduct).

Version 1, Date: 19/11/18

Appendix 2.13: Reliability Analysis (Internal Consistency of Scales)

The following table summarizes the internal consistency (Cronbach's alpha) values for the Social Defeat, Entrapment, ISMI, GHSQ and GlasMPT, presented overall (where applicable) and separately by subscales. Alpha values range from 0.00 to 1.00. Higher values provide evidence for strong reliability.

Scale/Subscale	**N of items**	**N**	**α value**
Social Defeat Scale	16	27	.89
Entrapment Scale			
- Internal Entrapment	10	27	.84
- External Entrapment	6	27	.90
ISMI			
- Alienation Subscale	6	26	.82
- Stereotype Endorsement	7	26	.74
- Discrimination Experience	5	26	.74
- Social Withdrawal	6	26	.72
- Stigma Resistance	5	26	.70
GHSQ			
- Emotional Problems (-Q10)	9	26	.77
- Suicidal thoughts (-Q10)	9	24	.82
Problem scale – GlasMPT (overall)	23	25	.68
- Thinking problems category	7	25	.53
- Feeling problems category	9	25	.55
- Behavioural problems category	7	25	.53
Treatment Scale – GlasMPT			
Treatment options selected for:			
- Thinking Problems	21	24	.75
- Feeling Problems	21	23	.61
- Behavioural Problems	21	22	.77
Medical treatment (GlasMPT) selected for:			
- Thinking problems	4	24	.69
- Feelings problems	4	23	.56
- Behavioural problems	4	22	.52
Social support (GlasMPT) selected for:			
- Thinking problems	2	24	.40
- Feeling problems	2	24	-.14
- Behavioural problems	2	22	.40
Psychological treatment (GlasMPT) selected for:			
- Thinking problems	3	24	.55
- Feeling problems	3	24	.39
- Behavioural problems	3	22	.42
Alternative treatment (GlasMPT) selected for:			
- Thinking problems	12	24	.62
- Feeling problems	12	24	.60
- Behavioural problems	12	22	.75

Note. N= Sample size used in the analysis. Note that differences in sample sizes, reflect exclusion of scores for those participants who either did not respond to a certain question or item of a scale, or did not complete the whole questionnaire. These participants were excluded from the analysis.

Appendix 2.14: Major Research Project Proposal

An exploration of barriers to help-seeking among migrants experiencing psychosis

Abstract

Background: Research suggests that migrants are at greater risk of developing psychosis than non-migrants. One hypothesis is that pathways to care are more prolonged for migrants. Post-migratory factors such as internalised stigma, experiences of social defeat and preference for non-medical treatment could contribute to delays in help seeking, by worsening mental health problems due to longer duration of untreated illness.

Aims: This study will explore the role of internalised stigma, social defeat and treatment preferences in help-seeking among migrants and non-migrants experiencing psychosis who are presenting to early intervention, acute, rehabilitation, and trauma services in Glasgow. Treatment preferences will be explored using a newly developed questionnaire.

Methods: A cross-sectional design will be employed to compare differences between migrants and non-migrants. Psychometric properties of the newly developed measure will be also investigated.

Applications: This study will help improve our understanding of barriers to help-seeking and will inform prevention and intervention strategies for psychosis. We also hope to establish a reliable measure of treatment preferences for use with individuals experiencing psychosis.

Introduction

A growing body of research (Bhugra & Jones, 2001; Cantor-Graae, Zolkowska, & McNeil, 2005) indicates higher prevalence of non-affective and affective psychoses in first and second-generation immigrants compared with indigenous populations. These studies suggest a link between foreign migration and higher risk for the development of psychotic disorders, although the procedures underlying this relationship remain ambiguous.

Several hypotheses have been employed to explain this relationship, including the selective migration of predisposed individuals or the tendency of clinicians to misdiagnose schizophrenia in individuals of certain ethnicity (Ödegaard, 1932; Sashidharan, 1993). Other studies have proposed that pre- or peri-migratory exposure to trauma could instead account for the high incidence of psychoses in refugees (Kinzie & Boehnlein, 1989; Leao et al., 2006).

It also appears that the pathways into care are different for migrant groups, with several studies indicating that certain ethnic groups have more adverse and complex pathways (contact with police or accident and emergency services before admission) to care than native residents (Bhui et al., 2003; Morgan et al., 2005a) or may experience significantly longer delays for accessing treatment (Boonstra, Sterk, Wunderink et al., 2012).

Longer duration of untreated psychosis has been associated with poorer prognosis and treatment outcomes (Birchwood, Todd, & Jackson, 1998). While some delays occur because of failure of services in detecting psychotic prodromes (Etheridge, Yarrow & Peet, 2004), there is also a delay in seeking treatment in those who are already in contact with services when they develop psychotic symptoms (Norman, Malla, Verdi, Hassall & Fazekas 2004).

It is possible that a range of risk factors are potentiated within the period between migration and the onset of recognised psychotic symptoms requiring care, which increases

the risk for developing psychosis (Cantor-Graae, Pedersen, McNeil, 2003). Factors such as stigma, experiences of social defeat (stress produced after prolonged exposure to social adversity) post-migration and a preference for non-medical treatments can contribute to delays in help seeking (Cantor-Graae & Selten, 2005; Thomson, Chaze, George & Guruge, 2015). Therefore, understanding better the factors which impede treatment seeking among migrants is essential to improve prevention and early intervention strategies for psychosis.

Aims & Hypotheses

This study will explore internalised stigma (e.g. when a person considers stereotypes about mental illness to be self-relevant), experiences of social defeat, and treatment preferences among migrants and non-migrants being seen in out-patient clinics and treatment wards. The study will also evaluate the psychometric properties (reliability and validity) of a new measure of treatment preferences; the Glasgow Treatment Preferences Scale (GTPS). This measure was developed as, to date, there are no known measures assessing treatment preferences in British migrants. The following questions are posed:

1) What are the treatment preferences of migrants and non-migrants experiencing psychosis?
2) Is GTPS a valid and reliable measure of treatment preferences?
3) Are there any differences between migrants and non-migrants in terms of internalised stigma, social defeat experiences and treatment preferences?

We hypothesize that a) the GTPS will be a valid and reliable measure of treatment preferences for individuals experiencing psychosis and b) migrants will report experiencing greater internalised stigma, social defeat and greater preference for accessing non-medical therapies than non-migrants.

Plan of Investigation

Participants

The sample will consist of individuals with lived experience of psychosis who are currently presenting to early intervention services (i.e. ESTEEM), acute and long-term rehabilitation services across Glasgow. Participants presenting with psychotic symptoms (migrants and non-migrants) will be also recruited from the NHS GG&C trauma service (i.e. 'the Anchor') as trauma has been associated with the emergence of psychosis in adult life (Bendall, Jackson, Hulbert, & McGorry, 2008).

Inclusion and Exclusion Criteria

Individuals will be eligible if they are currently in receipt of care from the above services. Experience of psychosis will be defined as presentation to clinical services with psychotic symptoms of sufficient severity and/or distress to require treatment. This will involve participants with a diagnosis of schizophrenia, schizoaffective, schizotypal or delusional disorder as defined by the ICD-10 (International Classification of Diseases of the World Health Organization, Tenth Edition), (World Health Organization; WHO, 1992), as well as participants who have not yet received a diagnosis but whose symptoms are of clinical concern.

Additional inclusion criteria include participants living in the Glasgow area and being over the age of 18 years old. Participants will be excluded if they are not eligible for consent (e.g. if substance misuse, head injury or an organic disorder is considered to be the primary cause of psychotic symptoms, if they have a learning disability, or if they experiencing an acute psychotic episode).

Measures

Experience of Psychosis: A file diagnosis of a schizophrenia spectrum disorder by ICD-10 criteria (WHO, 1992), will be completed to confirm experience of psychosis and/or presentation of psychotic symptoms. *Treatment Preferences:* a draft questionnaire exploring treatment preferences has been developed under supervision of the academic supervisor of this project. This measure asks participants to rate their experience of certain types of treatment on a 10-point Likert scale (with *1=no experience at all and 10=a great deal of experience*), across a range of domains (e.g. medical, psychological or social). Participants are then asked to indicate their views on how beneficial each of the treatments presented may be for them (see Appendix A). The questionnaire will be reviewed by experts in the field and following receipt of their feedback, it will be refined and tested in the clinical setting.

Internalised Stigma will be measured with The Internalised Stigma of Mental Illness Scale (ISMI; Ritsher, Otilingam, & Grajales, 2003), a 29-item scale that assesses service users' experiences of *self-stigma*. The measure has strong internal consistency ($\alpha = 0.90$) and test–retest reliability($r = 0.92$) (Ritsher and Phelan, 2004). The Perceived Devaluation and Discrimination Scale (PDD) will be also used to measure *felt stigma,* which is the individual's estimation of how the society may view a mental health service user (Link, 1987). This scale also has excellent psychometric properties (Link, Mirotznik & Cullen, 1991).

Experiences of social defeat will be measured using two brief self-report questionnaires, the Social Entrapment and Defeat Scales (Gilbert & Allan, 1998). Both scales are administered together as they assess the same construct and have demonstrated good psychometric properties (Taylor, Wood, Gooding, Johnson, & Tarrier, 2009). The Social

Comparison Scale will be also used to assess participants' view of themselves in relation to others (Allan & Gilbert, 1995).

Design

This study will employ a correlational (i.e. exploring associations between variables), cross-sectional (i.e. one time point of assessment), between groups design, as we aim to a) determine the psychometric properties of the GTPS, and b) to explore differences between migrants and non-migrants.

Research & Recruitment Procedures

This study will consist of two phases:

Phase 1. An expert panel, which will consist of clinicians working with individuals with experiences of psychosis, will be asked to provide their views on the GTPS. Following receipt of the feedback, the measure will be refined before its psychometric properties are tested in the clinical setting.

Phase 2. Staff at each service will identify eligible participants and will alert them to the study. Service users who express an interest in finding out more will be introduced to the researcher who will provide information about the study and obtain written consent. Participants will then attend for one data collection session and complete the GTPS, plus measures of social defeat and internalised stigma. It is estimated that the questionnaires will take approximately 30-45 minutes to complete.

Data Analysis

All data – including sociodemographic data such as gender, age etc. - will be collected and stored using a Statistical Package for Social Sciences (SPSS) dataset. Data will be then

analysed using descriptive and inferential statistics generated by IBM SPSS version 25.0 and will be summarised in written, graphic or tabular format.

During phase 1, psychometric properties (e.g. internal consistency, face and/or content validity etc.) of the GTPS will be investigated. If the sample size is sufficient, exploratory factor analysis will be used to explore the factor validity of the questionnaire.

In phase 2 of the study, independent-samples *t*-tests for continuous data and Chi-squared tests for categorical data will be used to examine differences between groups (e.g. treatment preference in migrants vs. nom-migrants). Mann Whitney U tests will be used for data that are not normally distributed. If our hypotheses are supported, analysis will highlight significant differences between the two groups.

Justification of sample size

As this is a pilot study, power and sample size calculations are tentative. There are several rules of thumb for feasibility studies attempting to estimate a parameter for use in a sample size calculation, such as Julious's (2005) recommendation of a minimum of 12 participants per group, or Browne's (1995) suggestion of a total sample size of 30 or greater.

G*Power (v.3.1.5. Faul, Erdfelder, Lang, & Buchner, 2007) was used to estimate the effect size for our study, if we recruited 12 participants per group. For a power of ≥0.8, α err prob = 0.05 and 12 participants per group, an effect size of 1.0 was calculated. Therefore, recruiting a sample of 12 participants per group, will be sufficient for our study as it will yield a large effect size.

Settings and Equipment

The study will take place across outpatient and inpatient settings in the area of Glasgow. Early intervention services for psychosis (i.e. ESTEEM), acute, rehabilitation and

trauma services (i.e. 'the Anchor') will be approached to recruit participants. Self-report measures, consent forms, information and debriefing sheets will be used during the recruitment period. An encrypted laptop or computer with access to SPSS will be used to analyse data.

Health and Safety Issues

Participant safety issues:

As part of the informed consent process, participants will be advised of how to access support should they experience distress following their participation to the study. This will include a statement of the researcher's obligation to inform appropriate agencies if they believe the individual, or a third party, to be at risk of harm.

Researcher safety issues:

Research interviews will be conducted within staffed NHS sites during normal working hours (between 9 and 5pm). The researcher will become familiar with local health & safety protocols and have an awareness of how to access support if needed.

Ethical Issues

The study will be conducted only after ensuring favourable ethical approval by the West of Scotland Research and Ethics Committees. Management approval will be also sought from the NHS Greater Glasgow and Clyde Research and Development Office.

Participants will be recruited only after providing their informed written consent. Participants who lack capacity to consent will not be included in the study. Prior to participating, named clinicians will be contacted to confirm each participant's capacity for consent. Thereafter, individuals will be asked to read an information sheet about the project and then complete a consent form.

During data collection, completed questionnaires will be stored in a locked drawer on each site. Data will be then coded and entered in a password encrypted SPSS file, in line with the, University of Glasgow and NHS GG&C data protection, confidentiality and research ethics guidelines and in line with the Data Protection Act 1998. All cases will be anonymised to ensure confidentiality and will be assigned a unique case number. Data will be stored on an encrypted computer throughout the data collection and analysis period. Only the researcher will have access to data stored in the computer and following the analysis the data will be destroyed. Finally, the right of withdrawal will be explained fully to service users before taking part in the study.

Financial Issues

Stationary costs for copies of self-report measures, consent forms and information and debriefing sheets will be incurred. Use of NHS GG&C translation services will be also required for those participants who can't read or speak English. Finally, travel expenses may be reimbursed to assist participants from outpatient settings attending the data collection session (see Appendix B).

Timetable

Time	Major Task/s
September 2017	Submission of the MRP outline to the Academic Supervisor. Begin Literature Review.
December 2017	Submission of the draft proposal to the Academic Supervisor
February 2018	Submission of the MRP Proposal to the Academic Supervisor

May 2018	Submission of the Final Approved MRP Proposal & Submission of ethics forms to the NHS REC (Research & Ethics Committee)
May- August 2018	Obtain ethics approval from West of Scotland REC and begin writing background and literature chapters.
August 2018 – March 2019	Data collection and analysis. Begin writing analysis and discussion chapter.
March 2019	Submit first draft of thesis
July 2019	Revise first draft and submit final MRP project

Practical Applications

The proposed study will make a significant contribution to the current understanding of barriers to help-seeking in migrants experiencing psychosis and it will help inform interventions and improve prevention strategies for psychosis. We also hope to establish a reliable measure of treatment preferences for use with individuals experiencing psychosis.

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