Personal stigma and psychosis: Exploration of lived experience, assessment, and therapeutic intervention.

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

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List of Abbreviations

1:1: one to one

ACWS: Approaches to Coping with Stigma

ADHS: Adult Dispositional Hope Scale

AQ: Attribution Questionnaire

API: Anti-stigma Photovoice Intervention

AS: Affect Scale

B: Baseline

BDI: Beck Depression Inventory

BDI-PC: Beck Depression Inventory for Primary Care

BHS: Beck Hopelessness Scale

BPIS: Birchwood Psychosis Insight Scale

BPS: British Psychological Society

CAMI: Community Attitudes towards Mental Illness Scale

CAQ: Change Assessment Questionnaire

CBT: Cognitive Behavioural Therapy

CCS: Cybernetic Coping Scale

CDS: Calgary Depression Scale

CESD: Centre of Epidemiological Studies Depression

CESQ: Consumer Experiences of Stigma Questionnaire

CGSS: Chinese General Self Efficacy Scale

CMA: Comprehensive Meta-Analysis

CMHT: Community Mental Health Teams

COMIS: Coming Out with Mental Illness Scale

CONSORT: Consolidated Standards for Reporting Trials

COP: Coming Out Proud

CORE: Clinical Outcome and Routine Evaluation Measure

CT: Controlled Trial

CS: Cohort Study

CSC: Coping with Symptoms Checklist

CSSMIS: Chinese Version of the Self-Stigma of Mental Illness Scale

CI: Confidence Interval

DA: Discourse Analysis

DAI: Drug Attitude Inventory

DDS: Devaluation-Discrimination Scale

DH: Department of Health

DISC: Discrimination and Stigma Scale

DPA: Data Protection Act

DSM: Diagnostic and Statistical Manual of Mental Disorders

DSSS: Depression Self-Stigma Scale

EDS: Experience of Discrimination Scale

EIS: Early Intervention in Psychosis Service

EPHPP: Effective Public Health Practice Project tool

ESS: Ending Self Stigma

FEP: First Episode Psychosis

FIA: Freedom of Information Act

GAF: Global Assessment of Functioning

GRADE: Grading of Recommendations, Assessment, Development and Evaluation tool

GSES: General Self-Efficacy Scale

GT: Grounded Theory

HRA: Health Research Authority

HSS: Stigmatisation Scale

ICC: Intra-Class Correlation

ICD: International Classification of Disease

IPA: Interpretive Phenomenological Analysis

IS: Internalised Stigma

ISE: Inventory of Stigmatising Experiences

ISMI: Internalised Stigma of Mental Illness Inventory

ISMI-S: Internalised Stigma of Mental Illness Inventory-Short Form

ISS: Internalised Shame Scale

ITT: Intention to Treat

KIDI: Knowledge of Illness and Drugs Inventory

LSS: Link Secrecy Scale

M: Mean

MANSA: Manchester Short Assessment of Quality of Life

MDT: Multi-Disciplinary Team

MES: Modified Engulfment Scale

MHS: Miller Hope Scale

MIDUS: McArthur Foundation Mindline Development in the United States

MSI: Manualised Stigma Intervention

NAP: Non-Affective Psychosis

NATS: Negative Automatic Thoughts

NECT: Narrative Enhancement Cognitive Therapy

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

OMI: Opinions about Mental Illness Scale

PANSS: Positive and Negative Syndrome Scale

PCA: Principle Components Analysis

PDD: Perceived Devaluation and Discrimination Scale

PE: Psychoeducation

PGRS: Personal Growth and Recovery Scale

PICO: Participant group, Intervention type, Comparator group, Outcome measures

PIS: Participant Information Sheet

PS: Paranoid Schizophrenia

PSS: Perceived Social Support

PSYRATS: Psychotic Symptoms Rating Scale

QLS: Quality of Life Scale

QPR: Process of Recovery Questionnaire

R&D: Research and Development

REC: Research Ethics Committee

RES: Rejection Experiences Scale

RESS: Rogers Empowerment Scale

RESPECT: Reducing Stigma in Psychosis through Engagement in Cognitive Therapy

RP: Recurrent Psychosis

RSE: Rosenberg Self-Esteem Scale

S: Schizophrenia

SA: Schizoaffective Disorder

SAIS: Social Anxiety Interaction Scale

SD: Standard Deviation

SDM: Semantic Differential Measure

SDS: Social Distance Scale

SDS-J: Social Distance Scale-Japan

SESQ: Self-Esteem and Stigma Questionnaire

SERS: Self-Esteem Rating Scale

SES: Self-Efficacy Scale

SIAS: Social Interaction Anxiety Scale

SIMS: Semi-structured Interview Measure of Stigma

SMI: Serious Mental Illness

SMT: Social Mentality Theory

SRER: Self-Reported Experiences of Rejection

SRF: Stigma Related Feelings

SS: Stigma Scale

SSS: Stigma Stress Scale

SSD: Schizophrenia Spectrum Disorder

SSDS: Self-Stigma of Depression Scale

SSMIS: Self-Stigma of Mental Illness Scale

SSRP: Self-Stigma Reduction Programme

SPE: Social Stigma and Psychoeducation

SPSS: Statistical Package for the Social Sciences

SUMD: Scale to Assess Unawareness of Mental Disorders

SURG: Service User Reference Group

TA: Thematic Analysis

TAU: Treatment Usual

TSCS: Tennessee Self-Concept Scale

UK: United Kingdom

USA: United States of America

WHO: World Health Organisation

WLC: Waiting List Control

Thesis Abstract

The University of Manchester
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A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health in 2017.
Thesis Title: Stigma and psychosis: Exploration of measures of assessment, lived experience and therapeutic intervention

This thesis aimed to explore the construct of stigma and its relationship with experiences of psychosis. In particular, it sought to investigate the role of assessment, lived experience, and therapeutic response to stigma, with those who experience psychosis. To achieve these objectives multiple methods were utilised including qualitative interviews, cross-sectional and longitudinal methods, systematic narrative synthesis and meta-analysis, and a feasibility randomised controlled trial. Chapter one provides a review of the stigma literature applied to people who experience psychosis. Chapter two provides an overview of the methodology utilised in this thesis and outlines the six academic papers which comprise the bulk of this thesis. Chapter three (Study 1) describes a systematic narrative synthesis and meta-analysis of psychosocial interventions for internalised stigma in psychosis. This review identified that no current trials of psychosocial intervention improved internalised stigma, but low-quality evidence limited the conclusions drawn. Further research examining psychosocial interventions is required. Chapter four (Study 2; n=79) outlines the development of semi-structured interview measure of stigma (SIMS) in psychosis. A reliable, valid and clinically relevant measure of stigma was developed specifically for people who experience psychosis. Chapter five (Study 3; n=25) outlines a qualitative exploration of stigma experiences with psychiatric inpatients who experience psychosis. This study identified three superordinate themes of 'stigmatising social environments and networks', 'stigmatised person with psychosis', and 'stigma interactions'. Chapter six (Study 4; n=79), explored relationships between stigma and psychological factors in psychosis. It identified that internalised shame and self-esteem were significant mediators between the relationships of experienced and perceived stigma with depression, hopelessness and recovery. Based on the evidence examined in chapters one to six, chapter seven (Study 5) outlined an integrative cognitive model of internalised stigma in psychosis. Chapter eight (Study 6), based on the model described in chapter seven, describes a feasibility randomised controlled trial (n=30) that was conducted examining the efficacy and acceptability of a brief internalised stigma CBT intervention, comparing it to a psychoeducational intervention, with acute inpatients who experience psychosis. The intervention was shown to be feasible and acceptable but a larger definitive trial is required. Finally chapter nine outlines an overall discussion and reflections on the previous chapters.

Declaration

Analysis and write-up

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

The data analysis and write-up of all papers presented have been carried out by the author of this thesis, under the supervision of Professor Anthony P. Morrison and Dr Rory Byrne.

Data

The Semi-Structured Interview Measure of Stigma (SIMS) outlined in Study 2 was initially developed by the author as part of the evaluation of the Reducing Stigma in Psychosis through Engagement in Cognitive Therapy (RESPECT; Morrison et al., 2016) pilot trial, and used with all RESPECT participants (n=29). A further fifty (n=50) participants were recruited to validate this measure for this PhD. Studies 3 and 4 are secondary analyses of data gathered for Study 2. Study 3 only used participants who were recruited for the PhD. Thirty (n=30) further participants were recruited for Study 6. The author was responsible for the design, implementation, analysis and write up of all studies included in this PhD.

Published work

This thesis is submitted in alternative format with six papers. Studies 1 and 2 have been published in *Schizophrenia Research*. Study 3 has been published in *Stigma and Health*. Study 4 is published in *Psychiatry Research*. Study 5 is published in *Behavioural and Cognitive Psychotherapy*. Study 6 id under review at *Psychiatry Research*.

Collaborators and authorship

Supervision for all studies has been conducted by Professor Anthony P. Morrison and Dr Rory Byrne and therefore both are listed as authors on all published papers. Dr Filippo Varese (Lecturer in Clinical Psychology) supervised the meta-analysis of Study 1 and read final proofs, and therefore was an author on the published paper. Eilish Burke (then a Research Assistant) contributed to the data collection (n=29) of Study 2 and 4 and read final proofs of papers so therefore is included as an author. Gabriela Enache contributed to the data collection of Studies 2 (n=20), 3 (n=8), 4 (n=20) and 6 (n=5) and read final proofs of papers and therefore was included as an author on published papers.

Language

The author recognises that the terms and language used in this thesis are not universally endorsed. Although it did not sit with the author's preference, language was used which was reflective of the evidence base being examined. For example, medical terms such as Serious Mental Illness (SMI) were utilised as this was a term used by the existing evidence base. Furthermore, the language in this thesis was also reflective of the journal where the study was being submitted. For example, studies 1, 2, 4 and 6 were submitted to psychiatric journals so the language used in the respective chapters were more medicalised than the language used in the remaining studies. Therefore, the language and terminology throughout the thesis may appear changeable.

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On a personal note, I would like to thank my mum Sue Wood, and my dad Steve Wood, giving me ongoing love and support throughout my PhD. Thank you.

The author

From a young age, I have had regular exposure to mental health difficulties through personal family experiences as well as three generations of my family working within the field. I have wanted to work within, and contribute to the development of, the mental health field since I was young. I have been working in the National Health Service since 2005 where I first undertook a role in mental health services part-time as a Nursing Assistant in a mental health crisis team and community day centre in Colchester, Essex, whilst completing my undergraduate degree in Psychology at the University of Essex. In 2006, I went on to complete a masters degree in research psychology at the University of Manchester and gained employment in 2007 as a Research Assistant at the Psychosis Research Unit (PRU) in Manchester working on a large program of research examining recovery in psychosis. In 2009, I began training as a clinical psychologist on the University of East London (UEL) Doctorate in Clinical Psychology (DClinPsy) Programme. I continued my interest in psychosis research by completing my doctoral thesis on "The Usefulness of Compassion Focused Therapy (CFT) for experiences of psychosis: Exploring the role of relationship experiences, internal fears and external fears in recovery". Upon qualifying in 2012, I gained a position as a Research Clinical Psychologist at PRU working on two research trials examining the efficacy of CBT for Clozapine unresponsive symptoms and internalised stigma in psychosis respectively. I moved back to London in 2014 and gained a role as a Principal Clinical Psychologist in NELFT on an inpatient unit where I continue to work. I registered onto this PhD course in September 2014 part-time, alongside my clinical role. Currently, I continue to work part-time on the inpatient unit, part-time on the University of Essex DClinPsy programme, whilst completing my PhD alongside this. I have been passionate about tackling stigma since the start of my career, and this was my motivation to undertake this thesis topic.

1. Chapter 1: Literature Review

Stigma is a concept which sadly applies to an array of marginalised groups across the globe. These groups include those diagnosed with HIV and AIDS (Mahajan et al., 2008), intellectual disability (Ali, Hassiotis, Strydom, & King, 2012), alcoholism (Schomerus et al., 2010), and Serious Mental Illness (SMI; Link & Phelan, 2001), to name a few. It is a social phenomenon that has been explored in detail by a number of professional groups including sociologists, social psychologists, clinical psychologists, psychiatrists, and epidemiologists, examining it from a variety of different epistemological positions. For this review, the stigma literature regarding SMI, and more specifically psychosis, will be explored. As the author is a clinical psychologist, this thesis has a clinical focus but importantly incorporates the social context of stigma. The broad aim of this thesis is to improve the therapeutic response to stigma experienced by mental health service users with psychosis. Personal stigma is a particular focus for this PhD.

Firstly, this literature review will provide an overview of the current conceptualisation of SMI and psychosis. An overview of the concept of stigma and its definitions, theoretical models and key psychological and social processes will then be outlined. The prevalence and causes of public stigma will be delineated to provide a context to explore personal stigma (impacts and causes) in more detail. The chapter will then go on to explore the research evidence of assessment measures and interventions for stigma (public and personal). Finally, the literature examining stigma and its relevance to psychiatric inpatients with psychosis will be outlined. Clear aims of the thesis will be presented with further and more specific hypotheses being described.

1.1 Defining Serious Mental Illness (SMI), psychosis and schizophrenia

A mental illness has been defined as a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual (American Psychiatric Association, 2013). A Serious Mental Illness (SMI) has been defined as the presence of a mental disorder, as defined by the Diagnostic and Statistics Manual of Mental Disorders (DSM-V), for at least 12 months which causes "severe impairment" (Kessler et al., 2003). SMI is a term which will be utilised throughout this thesis due to the stigma literature being predominantly focused on this broad clinical population. There is much debate in the literature about what diagnostic categories comprise SMI. Some people consider the construct of SMI to typically include diagnostic categories such as personality disorders, depressive disorders, anxiety disorders, schizophrenia-spectrum disorders, and bipolar disorders (American Psychiatric Association, 2013). However, others have operationally defined SMI more narrowly as a diagnosis of a non-organic psychosis (a schizophrenia-spectrum disorder), with a duration of treatment of two years or more, and dysfunction (a score of under 60 as measured by the Global Assessment of Functioning (GAF; Hall, 1999) scale) (Ruggeri, Leese, Thornicroft, Bisoffi, & Tansella, 2000). Consequently, the stigma literature has examined the stigma of SMI utilising both outlined definitions.

As stated, both definitions of SMI are inclusive of psychosis and schizophrenia which are the focus of this thesis. The National Institute of Health and Care Excellence (NICE, 2014) describe psychosis as referring to 'the group of psychotic disorders that includes schizophrenia, schizoaffective disorder, schizophreniform disorder and delusional disorder,' (pg.5). It does not refer to affective psychosis such as bipolar or unipolar disorder. Schizophrenia is defined as 'a major psychiatric disorder (or cluster of disorders) in which a person's perception, thoughts, mood, and behaviour are significantly altered' (pg. 12; NICE, 2014). The recent DSM-V (American Psychiatric Association, 2013) states

that schizophrenia should contain at least two of the following symptoms, present for a significant portion of the time during a one-month period: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, or negative symptoms. There should also be a negative impact on social and occupational function. Both psychosis and schizophrenia are contested terms with some service users and clinicians disagreeing that schizophrenia and psychosis are discrete illnesses or disorders (Boyle, 2002; British Psychological Society, 2014). However, for the purposes of this thesis, these terms will be utilised for ease in describing the collective experiences of hearing voices, culturally unacceptable beliefs (paranoia and other delusional beliefs), and other experiences associated with these presentations. The term 'psychosis' will be used where possible as it is the term preferred by service users (British Psychological Society, 2014), but 'schizophrenia' will also be utilised if more appropriate (for example, if a cited research paper has used it).

It is estimated that 1% of the UK population will experience psychosis across a lifetime (NICE, 2014). The age of onset is typically before the age of 35 with 75% of men and 66% of women having their first episode by this age (Kirkbride, Fearon, Morgan, Dazzan, & Morgan, 2006). The Schizophrenia Commission (2012) have identified that psychosis costs the UK £11.8 billion a year, demonstrating the high level of health care needs that this population has. It has been identified that the annual number of new cases per year per 100,000 people in England is 15 new cases of schizophrenia and 12 cases of affective psychosis demonstrating that it is a relatively common experience (Kirkbride et al., 2012). Therefore, mental health services have a responsibility to understand the needs of this population.

1.1.1. The development and conceptualisation of psychosis and schizophrenia

The condition now known as 'schizophrenia' was initially described by Emil Kraepelin, a German psychiatrist, who developed his conceptualisation based on a number of longitudinal clinical observations of patients who demonstrated a specific pattern of cognitive and behavioural decline (Jablensky, 2010). He originally termed this condition as dementia praecox which is a decay in mental efficiency and rapid cognitive disitegration (Kraepelin, 1919). It had nine different clinical forms, including schizophasia (a confusional speech dementia praecox), and paranoid dementia (where increased paranoia was present). Dementia praecox was considered to be a degenerative brain disorder with little hope for recovery, and with no recognition of social causal factors such as trauma or stressful life events (Jablensky, 2010).

The term schizophrenia was established by Eugen Bleuler (1911, 1950), a Swiss psychiatrist, and taken from Greek language which literally translates into the "splitting" (schizen) of the "mind" (phren). He explained that schizophrenia was not a singular disease but a group of diseases comprising clinical subgroups such as simple schizophrenia, and paranoid schizophrenia. Eugen Bleuler was also the first to group symptoms of schizophrenia into positive and negative subcategories (Tsuang, Stone, & Faraone, 2000). Positive symptoms included hallucinations, delusions and formal thought disorder, and negative symptoms included social withdrawal, loss of volition, affective flattening, and poverty of speech (Jablensky, 2010). Arguably these conceptualisations of schizophrenia are still reflective of our continued understanding today and underpin the current diagnostic definition. Furthermore, the subcategories and distinction between positive and negative symptoms are clearly evident in the most recently published version of the DSM-V (American Psychiatric Association, 2013).

Biogenetic explanations of schizophrenia are still dominant and underpin the rationale for pharmacological treatment for psychosis. A number of theories continue to dominate our understanding of psychosis including the biomedical model of understanding (where psychosis is viewed as a mental disorder caused by biological abnormalities located in the brain; Deacon, 2013), which is underpinned by theories of chemical imbalance (Hess, Bracha, Kleinman, & Cresse, 1987), genetics (Weinberger et al., 2001) and disease (Deacon, 2013). As a result, medical treatment using psychotropic medication is the first line recommended treatment option for psychosis as recommended by current UK guidance (NICE, 2014). The prognosis of psychosis is viewed as relatively poor by the psychiatric profession as it is still considered a long-term illness.

1.1.2. Psychosocial understandings of psychosis and schizophrenia

Importantly, an alternative discourse regarding the conceptualisation of schizophrenia and psychosis has been developing since the 1950's due to the rise of patient human rights, deinstitutionalisation, and the emergence of the anti-psychiatry movement (Kings Fund, 2014). This discourse has incorporated a psychosocial model of conceptualising mental distress which integrates psychological and social factors. Influential social psychiatrists and psychologists such as R.D. Laing and Thomas Szasz began to question whether schizophrenia was a disease or an understandable reaction or coping response to traumatic life experiences, thus acknowledging the important role of social factors (Laing, 1964, 1967; Szasz, 1960). Other systemically informed theories began to emerge recognising the role of the individual's family and social environment in the development and maintenance of psychosis, such as double bind theory (Watzlawick, 1963) and expressed emotion theory (Kavanagh, 1992). Collectively, this has led to a shift in our understanding of psychosis with acknowledgement of the importance of an individual's family and social context.

1.1.2.1.Survivor movement and recovery model

A survivor movement of service user activists also became an influential force in the conceptualisation and prognosis of psychosis (Frese & Davis, 1997). They fought for humane treatments and services that offer an alternative to dominant medical treatments (Everett, 1994). The central concept of recovery underpinned this movement and was promoted to tackle the pessimism of prognosis from the dominant discourse of psychiatry. Service users argued that recovery was a process, not a definitive endpoint, which is possible and achievable and did not have to include the alleviation of symptoms (Chadwick, 1997; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007). A recent systematic review of studies (k=97) which examined personal recovery proposed a conceptual framework of recovery (Leamy, Bird, LeBoutillier, Williams, & Slade, 2011). The review identified three components of the framework; *recovery characteristics*, *recovery processes* and *recovery stages*. *Recovery characteristics* included aspects such as it being active, individual and unique, non-linear, multidimensional, gradual and without cure. *Recovery processes* included connectedness, hope and optimism, positive identity, meaning in life and empowerment. *Recovery stages* reflected the transtheoretical model of change (Prochaska & DiClemente, 1982): precontemplation, contemplation, preparation, action, and maintenance and growth. Leamy et al.'s (2011) review demonstrates the idiosyncratic and psychosocial nature of recovery.

The survivor recovery movement challenged the traditional medical conceptualisations of recovery, which were based on symptom alleviation and remission. The movement has undoubtedly shifted the conceptualisation of psychosis, and psychosocial recovery is now promoted and prevention is implemented (Forchuck, Jewell, Tweedell, & Steinnagel, 2003).

1.1.2.2. The relationship between adversity and psychosis

The role of adversity in the development of psychosis was arguably first documented following World War II when veterans were returning home with post-traumatic stress and symptoms of psychosis (Mander & Kingdon, 2015). This triggered the development of psychosocial models of mental illness, and the acknowledgement of the role of trauma in the development of psychotic symptoms (Boyle, 2002). However, it has only been during the last two decades that extensive research has been conducted to examine the role of adversity in understanding the development of experiences of psychosis. The rate of adverse experiences, such as trauma, have been reported to be experienced by 72% of people with experiences of psychosis (Alsawy, Wood, Taylor, & Morrison, 2015), ranging from between 50% to 98% across research studies demonstrating the prevalence of such adversity (J. Read, van Os, Morrison, & Ross, 2005). It has been established that adverse experiences such as sexual abuse, bullying, migration, exposure to urban environments, social deprivation, racism, neglect, and other forms of trauma all significantly increase the odds of experiencing psychosis (Mander & Kingdon, 2015; Varese et al., 2012). In a large meta-analysis, a dose-response relationship was identified, the greater number of adversities an individual faced the stronger association with their risk of developing psychosis (Varese et al., 2012). The relationship between adversity and psychosis has been clearly established.

More recently, the process by which adversity leads to the development of experiences of psychosis has been examined (R. Bentall, Wickham, Shelvin, & Varese, 2012). A number of psychological factors have been proposed to mediate the relationship, including disruptive attachment patterns, social defeat, poor coping strategies, and poor social support (Larkin & Read, 2008). More recently, J. Read, Fosse, Moskowitz, and Perry

(2014) have developed a traumagenic model of psychosis which outlines a biopsychosocial approach to understanding the pathway from trauma experience to psychosis. Read et al., (2014) argue that trauma and adversity cause neurodevelopmental changes to the brain which can contribute to experiences of psychosis. These changes include an overactive hypothalamic-pituitary axis (HPA), neurotransmitter abnormalities and changes in cognitive function, which can increase the risk of psychosis developing (J. Read et al., 2014). This demonstrates how adversity can influence biological processes, which may lead to psychosis.

R. P. Bentall et al. (2014) conducted a theoretical review to further build upon the hypothesised processes which cause experiences of psychosis to identify specific forms of adversity which could lead to specific experiences of psychosis. They identified associations between communication deviance from parents and thought disorder, childhood sexual abuse and auditory hallucinations, and attachment disrupting events and paranoid symptoms. These specific relationships support findings in a large population-based survey (n=7353) where the same relationships between specific adverse events and psychotic symptoms were identified (R. Bentall et al., 2012). In conclusion, this research evidence demonstrates the significant role of adversity in the development of experiences of psychosis, further supporting the role of psychosocial factors in the development of psychosis.

1.1.2.3.Cognitive models in understanding experiences of psychosis

As a result of the development of psychosocial understandings of psychosis, in particular, the understanding of the role of adversity, cognitive models of psychosis have been developed in order to offer a psychological framework to understand the development and maintenance of psychotic experiences (Mander & Kingdon, 2015). In brief, cognitive

models of psychosis assume that it is the way in which people make sense of an experience, rather than the experience per se which causes people to experience psychotic symptoms (A. Morrison, Renton, Dunn, Williams, & Bentall, 2003). Two complimentary models have been developed to understand experiences of psychosis from a cognitive perspective, an integrative cognitive model of delusions and hallucinations developed by A. P. Morrison (2001), and a positive symptoms model developed by Garety, Kuipers, Fowler, Freeman, and Bebbington (2001). Both models will be outlined in detail below.

The A. P. Morrison (2001) integrative cognitive model of delusions and hallucinations draws upon the cognitive literature for anxiety disorders and hypothesises that experiences of psychosis develop through a similar cognitive route. Morrison (2001) outlines that experiences of psychosis are ultimately intrusions (cognitive, body state, emotional or external information) into awareness that are misinterpreted as experiences which threaten physical or psychological integrity. For example, experiencing a negative and self-critical thought but interpreting this as being from an external source (e.g. the voice of the devil) can lead to someone believing they are experiencing distressing auditory hallucinations. Morrison (2001), drawing upon Wells and Matthews (1994) model of self-regulatory executive functioning (S-REF), outlined that this process is mediated by metacognitive difficulties such as cognitive-attentional biases, ruminative processes and negative core beliefs. Negative misinterpretations have detrimental consequences for our mood, physiology and behaviour. In other words, misinterpretations lead to threatening emotional experiences (e.g. fear and anxiety) and related physiological reactions (e.g. palpitations and chest pains) which we may try to manage through the development of safety behaviours (e.g. escaping from situations which are causing the threatening emotion). It is an individual's biopsychosocial vulnerability (genetic, biological, adversity, and cognitive disruptions), particularly negative early life experiences (e.g. adversity and trauma) which

lead to the development of negative schemas (global and stable beliefs about the self, world and others) making it more likely that misinterpretations will occur and psychotic symptoms are experienced.

The Garety et al. (2001) cognitive model is based on the biopsychosocial model (the integration of biological, psychological and social theories) of understanding psychosis. Garety et al. (2001) argue that individuals may develop a biopsychosocial vulnerability and predeveloped negative schemas which make them likely to develop psychotic experiences. This leads to experiencing positive symptoms of psychosis through two routes; one through problematic cognitive and affective changes, and the other through affective changes alone (although the former is hypothesised to be most common). Cognitive disturbances play an integral role within this model and ultimately cause the psychotic experience to occur. Garety et al. (2001), outline that cognitive disturbances can occur in two ways. The first route is through a weakening of stored past memories, which mean that current experience cannot be interpreted appropriately resulting in ambiguous sensory input. The second route is through difficulty with self-monitoring (i.e. not being able to identify inner experiences which lead to them being experienced as alien or external to one's self). These outlined cognitive disturbances, coupled with emotional distress, lead to anomalous experiences such as auditory hallucinations, paranoia, unusual beliefs and delusions. Cognitive biases, such as jumping to conclusions and external attribution bias, then form and maintain these psychotic experiences.

The Morrison (2001) and Garety et al. (2001) cognitive models of psychosis both clearly demonstrate the role of psychosocial factors in the development and maintenance of psychosis. The role of psychosocial vulnerabilities and cognitive processes has been highlighted as particularly important in understanding experiences of psychosis.

1.1.3. Summary of psychosocial understandings of psychosis

Biological and medical conceptualisations of mental illness have contributed the underlying framework for understanding psychosis in the twentieth century, and continue to prevail within current society. However, psychosocial theories have extensively developed over the last half a century and challenged the traditional medical approaches to psychosis. This has led to psychosocial approaches being integrated into our current understanding of psychotic experiences and indeed into treatment guidelines (NICE, 2014). However, it can be argued that the medical model remains dominant with medical treatment continuing to be the first line treatment for psychosis (NICE, 2014). Moreover, psychiatrists continue to most often bear clinical responsibility for all service users under mental health services, demonstrating the dominance of medical care within our current mental health services (Department of Health, 2010).

Problematically, the medical model and biological understandings of psychosis, and mental health more broadly have been demonstrated to be a potential cause of stigma for people with these experiences (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Kvaale, Gottdiener, & Haslam, 2013). A growing evidence base of both qualitative and quantitative research demonstrates that people with psychosis experience significant stigma, more so than those with other mental health experiences (Caveleti, Rusch, & Vaulth, 2014; Dickerson, Sommerville, Origoni, Ringel, & Parente, 2002; Karidi et al., 2015; G. Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009).

In summary, this section sought to explore the common conceptualisations of psychosis to describe the context within which stigma is explored through the following sections.

1.2. Understanding the construct of stigma within western society

The term stigma originated from Greek word "stizein" which referred to bodily marks or blemishes, which reflected an individual's immoral status. It signified to the public that the person was bad, of lower class, or tainted, for example, the physical branding of slaves by owners (Arboleda-Florez, 2002). To date, the term stigma still reflects a notion that an individual is tarnished and defective in some way; however, stigma is not applied in such a literal manner. It is now associated with a group of marginalised people who are believed to have a set of negative characteristics which set them apart from the 'normal' population (Byrne, 2001).

It is vital to consider the role of the western cultural context in the understanding and development of stigma, in which this thesis is being conducted. An abundance of research has demonstrated that the stigma of SMI and psychosis is widespread and penetrates varying cultures (Dovidio, Major, & Crocker, 2000). However, there are distinct difference across cultures regarding the way SMI and psychosis are conceptualised, which impact on the consequential stigma associated with these presentations (Pescosolido, Olafsdottir, Martin, & Scott Long, 2008). P. W. Corrigan and A. C. Watson (2002) state that the stigma of mental illness may be less severe in non-Western cultures, for example in African and Asian countries, due to SMI not being conceptualised as a medical illness, but an experience which may be within the normal range of human experience (R. P. Bentall, 2004; Fabrega, 1991). As demonstrated, this is in stark contrast to how SMI and psychosis are conceptualised in current western society (Angermeyer et al., 2011). The majority of the stigma research has been conducted within a Western context and within an illness paradigm.

The most prominent stigma theories will now be reviewed here and will be critically examined with the cultural context in mind. For the ease of the reader, a summary table (table 1) of the key stigma theories is presented.

1.2.1. Goffman's conceptualisation of stigma

Stigma, as it is known in the current Western context, was arguably first conceptualised by sociologist Erving Goffman (1963) who was a pioneer in the understanding and conceptualisation of stigma. Since his early writings, stigma research has increased exponentially yet his definition continues to be widely cited throughout the stigma literature (Dinos, Stevens, Serfaty, Weich, & King, 2004; Kleinman & Hall-Clifford, 2009; B. Link & Phelan, 2001). Goffman proposed that all people have a social identity which becomes enacted when any social interaction is undertaken (Goffman, 1963). A social identity allows individuals to anticipate what a person may say, how they may behave, and ultimately whether they are a threat. Goffman (1963) suggested that stigma occurs when a social identity is tarnished and reflects 'an attribute that is deeply discrediting' (pg. 13). He explained that there are three types of stigma: abnormalities of the body, blemishes of individual character, and tribal stigma (referring to race, nationality, and religion). Goffman (1963) explained that stigma is maintained when the stigmatised individual holds the same negative societal beliefs about him or herself.

Goffman's conceptualisation of stigma has arguably underpinned our understanding of stigma today. However, his theory has been criticised for placing the problem of stigma within the individual rather than recognising the complex relational interplay between the stigmatised individual and their stigmatising social environment (B. Link & Phelan, 2001). As a consequence, researchers have attempted to build upon and develop his conceptualisation.

Table 1 – Summary of key stigma theories

Stigma components	Underpinning theories	External components	Internal components
Goffman (1963)	Social identity theory	N/A	Tarnished social identity
Link & Phelan (2001)	Evolutionary theory	Labelling, stereotypes, separation status loss and discrimination	Personal Reactions (passive victim or active challenger)
Corrigan & Watson (2002a)	Social cognitive theory	Public Stigma (stereotypes, prejudice, discrimination)	Self-stigma (stereotypes, prejudice, discrimination) which occurs through a process of stigma awareness, stigma consciousness and stigma agreement
Brohan et al (2010a)	N/A	Experienced stigma	Perceived stigma, internalised (self) stigma
Rusch et al (2009)	Stress-coping model (Lazarus & Folkman, 1984)	N/A	Stigma vulnerability, stigma stress appraisals, cognitive and emotional consequences
Gilbert (2010)*	Social mentality theory, evolutionary theory	Threatening stigmatising social relationships	Internal stigma appraisals/shame, external stigma appraisal/shame, stigma related safety behaviours
Beck (1979)*	Cognitive Behavioural Theory	Experiences of stigma and discrimination, Stigmatising environment	Stigma core beliefs and appraisals, stigma rules for living, stigma safety behaviours, stigma emotional reactions

N/A – Not Applicable, *these theories have been applied to stigma and have not been explicitly developed for this purpose.

1.2.2. Social cognitive conceptualisations of stigma for Serious Mental Illness (SMI)

A significant proportion of the early stigma literature has been contributed to by sociologists and social psychologists. Importantly, a number of these models have been developed specifically to understand SMI stigma. As outlined above, people with an SMI are acknowledged to be one of the most stigmatised groups in current western society (M. C. Angermeyer & H. Matschinger, 2003), and experience significant discrimination from the public (Semrau, Evans-Lacko, Koschorke, Ashenafi, & Thornicroft, 2015). There has been a substantial increase in research examining SMI stigma in the two decades, which has led to attempts to refine and understand the construct in detail (Elaine Brohan, Slade, Clement, & Thornicroft, 2010). Key models and conceptualisations which have contributed to this evidence base of SMI stigma are outlined below.

1.2.3. Link and Phelan's (2001) theoretical model of SMI stigma

Building upon the work of Goffman, Link and Phelan (2001) conceptualised stigma as a five component model which describes the processes which cause stigma to develop. Link and Phelan (2001) stated there was a need to build upon understandings of stigma as the conceptualisations of stigma to date had been poorly defined and not captured the complex social relational nature of stigma. Therefore, they attempted to build upon Goffman's (1963) conceptualisation by making clear relational links between the social network and the stigmatised individual. Link and Phelan (2001) stated that the stigma literature had rarely gone further than developing a robust definition of stigma, for example Crocker, Major, and Steele (1998), did not explain the complex relational aspects of stigma (Link & Phelan, 2001). Moreover, the application of stigma had been broad and not focused on specific marginalised groups who would experience stigma very differently, for example

SMI. Given this, Link and Phelan (2001) developed a stigma model which was specific to SMI.

1.2.3.1.Labelling

As social psychologists, Link and Phelan (2001) underpinned their conceptualisation using evolutionary theory. The first component of their five-component model explains that people are compelled to distinguish and label human difference to make sense of the social world. Many minor human differences are mostly ignored, for example, the colour of one's car, but differences which may pertain to social threat, for example, race, ethnicity, religion, mental health status, are conceptualised and labelled. The use of the word "label" is emphasised as it is a social construct and dependent on the environment in which the label is being given, i.e. SMI stigma may be labelled in one culture but not in another (Link & Phelan, 2001).

1.2.3.2.Stereotypes

Dominant cultural beliefs connect the labelled person to undesirable characteristics, and stereotypes are formed. As human beings, we have an innate tendency to categorise information to process our complex world (Link & Phelan, 2001). We develop generalised social categories, which are influenced by our social context, to facilitate our social interactions with others (Levy, Stroessner, & Dweck, 1998). Stereotypes are an example of this. Stereotypes are considered to be negative generalised beliefs formed about a group of people and are context specific. Regarding SMI in the westernised context, the most prominent stereotypes about individuals with an SMI are an inability to recover, dangerousness and unpredictability (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000).

1.2.3.3.Separation

The labelled person is placed in a distinct category different to members of the general population, and an 'us and them' dynamic is created, which allows for people to emotionally distance themselves from the stigmatised group (Devine, Plant, & Harrison, 1999). Link and Phelan (2001) explained that this occurs due to a human's natural ability to form 'in' groups and 'out' groups to protect themselves from social threat. Therefore, anyone who is a potential social threat will be grouped differently. This distancing and detachment allow the public to apply negative and stigmatising labels to the stigmatised individual without any emotional consequence (for example, guilt).

1.2.3.4.Status Loss and Discrimination

The stigmatised person experiences status loss which is a "general downward placement of a person in a status hierarchy" (pg. 371; Link & Phelan, 2001) . They are viewed, and perceive themselves, as being of lower social ranking than others around them who do not have an SMI. Therefore, due to social, economic and political power, the stigmatised individual experiences disapproval, rejection, exclusion and discrimination. Discrimination can be defined as prejudicial treatment, and occurs at both an individual and structural level, with the stigmatised person being individually rejected and less likely to be offered the same opportunities as others (Link & Phelan, 2001). Individuals with SMI often experience loss of opportunity, problems with accessing housing and employment, and physical and verbal abuse (Semrau et al., 2015).

1.2.3.5.Personal Reactions

Once a person is stigmatised, it is postulated that they will develop appraisals that others will reject and devalue them, which consequently causes emotional distress and impacts on their behaviours causing them to withdraw and avoid social situations (B. G. Link, Yang,

Phelan, & Collins, 2004). B. Link and Phelan (2001) distinguish between the stigmatised person either becoming a passive victim or active challenger. In other words, the individual either adopts a state of learned helplessness or a position of activism and challenges stigma (B. Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999).

1.2.3.6.Summary of Link and Phelan's (2001) model

This conceptualisation clearly outlines how stigma develops and is maintained, and describes the relational nature of stigma. Furthermore, it had built upon the stigma literature by drawing upon evolutionary theory and identifying that status loss is experienced by the stigmatised person which had not been identified previously. Furthermore, Link and Phelan (2001) have made some attempts to identify the personal consequences of stigma regarding cognitions and emotional responses. One of the criticisms of this model is the emphasis placed on the stigmatised individual and that there are no clear sub-components which make explicit the role of society and public in causing and maintaining stigma experiences. Moreover, it could be argued that the personal impacts of stigma are not exhaustively examined within this conceptualisation. Other researchers believe that emphasis should be placed on public and internalised stigma (or self-stigma) and that it is important to develop theoretical understandings which incorporate these elements of stigma (P. Corrigan & A. Watson, 2002; Major & O'Brien, 2005; Rusch, Corrigan, Powell, et al., 2009).

1.2.4. P. Corrigan and A. Watson (2002) model of public and self-stigma

P. Corrigan and A. Watson (2002) went further to focus on and categorise SMI stigma into two subcomponents of public stigma and self-stigma. Their aim was to make distinctions between two separate components, which have facilitated the development of targeted

interventions to address stigma. Arguably their conceptual framework has led to extensive research examining the significant detrimental impacts of stigma upon the individual.

1.2.4.1.Public stigma

Public stigma can be defined as the "negative reactions that the general population has to people with mental illness" (pg. 16; Corrigan & Watson, 2002a) . They outline that public stigma comprises three subcomponents which contribute to its development: stereotypes, prejudice and discrimination. The stereotype component, as described in the B. Link and Phelan (2001) model, explains that culturally dependent stereotypes develop about the stigmatised group, e.g. that they are dangerous, incompetent and have character weakness. Stereotypes are an efficient way to allow an individual to understand any potential social threats from another person (P. W. Corrigan & A. C. Watson, 2002). The presence of stereotypes in society alone does not mean public stigma will develop; Corrigan and Watson (2002a) explain that individual people must agree with them.

Prejudice is developed through an individual's agreement with the stereotypes. This agreement leads to negative cognitive and affective responses towards the stigmatised person. Prejudice has been described as a problem of personal attitudes (G. Thornicroft, Rose, Kassam, & Santorius, 2007). Prejudice involves an individual's negative appraisal or agreement with the stereotypes (for example "Yes I agree that all people with mental illness are dangerous!") which results in a related negative emotional reaction, (for example, fear or anger) towards the stigmatised group.

Discrimination is the negative behavioural response to prejudicial beliefs and negative affect. Discriminatory behaviour can take many forms and include both individual and structural discrimination (B. Link & Phelan, 2001). The discriminatory response will be dependent on the prejudicial belief and affective response; for example, if the prejudicial

response is fear this is likely to lead to avoidance, and if the prejudicial response is anger this may result in physical harm. Discrimination is arguably the most troubling element of public stigma.

1.2.4.2.Self-stigma

Self-stigma, also described as internalised stigma, can be defined as "the prejudice which people with mental illness turn against themselves", which can either be a conscious or unconscious process (pg.16; Corrigan & Watson, 2002a). Self-stigma cannot exist without the presence of public stigma and can be considered as an individual's negative response to public stigma. Corrigan and Watson (2002a) explain that self-stigma also comprises the same three components of public stigma (stereotypes, prejudice and discrimination) but are internalised by the stigmatised individual and applied to oneself.

Self-directed stereotypes occur when the individual becomes aware of the negative beliefs associated with SMI and considers them relevant to their experiences of SMI. The individual is more than likely to have grown up within a context where negative stereotypes of SMI are widely accessible (for example, through the media, parental beliefs). Prejudice occurs when the individual agrees with the stereotype and develops personal negative appraisals (for example, "I am dangerous"). The personal prejudice then leads to a negative emotional reaction (for example shame, hopelessness). Finally, discrimination occurs when the individual behaviourally responds to the prejudice by being self-discriminatory; for example, isolating themselves from others, and not putting themselves forward for beneficial opportunities.

Corrigan and Watson (2002a) explain that there are two dominant consequences of self-stigma: either deterioration in self-esteem or the development of righteous anger. This is dependent on the appraisals an individual has about stigma. For example, if a person

believes that the stereotype applies to them they will develop low self-esteem, and if they believe them to be unfair and unjust, they are more likely to develop righteous anger. Furthermore, they outline that it is also possible for an individual to have an ambivalent cognitive and emotional reactions towards stigma, although this is less common. They explain that individual responses are context-dependent and are influenced by a number of social factors (for example, family support, and social identity).

1.2.4.3.The process of self-stigmatisation

Watson, Corrigan, Larson, and Sells (2007) refined their construct of self-stigma to include a hierarchy of three key cognitive processes which cause and maintain self-stigma: stigma awareness, stigma agreement and self-concurrence. Firstly, self-stigma begins when the stigmatised person develops *stigma awareness* or becomes conscious of public stigma (Watson & River, 2005). This alone is not enough to cause self-stigmatisation and requires the latter two cognitive processes to be present. The second stage of the process is when there is *stigma agreement,* and the individual endorses the negative stereotypes (P. W. Corrigan, A. C. Watson, & L. Barr, 2006). Finally, the process becomes internalised when the person believes the stereotypes are *self-concurrent* and apply them to themselves personally. This model was partially supported when explored quantitatively using regression models (Corrigan, Rafacz, & Rusch, 2011).

1.2.4.4.Summary of Corrigan and Watson's model of public and self-stigma

Corrigan and Watson's (2002a; 2007) model has clearly provided a foundation for the development of understanding and therapeutically responding to stigma for people with an SMI. Their model identifies a cognitive, emotional and behavioural element to internalised stigma which has allowed a more detailed understanding of the psychological impacts of stigma. It continues to be extremely influential in the current conceptualisations of stigma

with public stigma and self-stigma assessment tools and intervention strategies being researched independently (Corrigan & Shapiro, 2010; Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2014). However, there are a number of criticisms which are important to consider.

Although, Corrigan & Watson (2002a) outline that self-stigma would not occur without public stigma, thus demonstrating the role of external factors in the development of self-stigma, the term is still at risk of placing the problem of stigma within the individual. Corrigan (2016) has recently stated that "there is one unintended lesson worth learning in terms of tackling self-stigma. Self-stigma [can be approached] as "the person's problem", rather than a problem of a society that breeds public stigma, prejudice and discrimination" (pg. 71). Moreover, although it may be a reasonable assumption that self-stigma would not exist without the presence of public stigma, to the author's knowledge no empirical research has been conducted to examine whether this is the case. Further empirical cross-cultural research is required to examine whether self-stigma is prevalent when public stigma is not. Corrigan & Watson's (2002a) model also does not offer an explanation as to why some people internalise stigma and other does not. It is acknowledged that about 50% of people with experience self-stigma (Elaine Brohan, Elgie, Sartorius, & Thornicroft, 2010), therefore there are key factors which are not incorporated into this model.

1.2.5. Experienced, perceived and internalised stigma: components of personal stigma

More recently, in a review paper conducted by Elaine Brohan, Mike Slade, et al. (2010) examining personal stigma outcome measures, three key elements of personal stigma were outlined. Personal stigma components are considered to be the individual consequences and impact of public stigma (Gerlinger et al., 2013). The aim of the Brohan et al. (2010)

review was to identify relevant personal stigma measures and examine them for reliability and validity. For their review, Brohan et al. (2010) provided a framework to understand personal stigma experience using previously identified personal stigma concepts. Their framework built upon the concept of self-stigma and included two additional components, which had been identified in previous literature. They distinguished between three subcomponents of personal stigma: experienced stigma, perceived stigma and internalised stigma (Elaine Brohan, Mike Slade, et al., 2010).

1.2.5.1.Experienced stigma

Experienced stigma has been defined as "instances of discrimination ...on the grounds of their perceived unacceptability or inferiority" (pg.33; Scrambler & Hopkins, 1986) . Examples of experienced stigma include verbal abuse, physical abuse, being treated as inferior, and loss of opportunity (Dinos et al., 2004; Semrau et al., 2015). Experienced stigma can occur at different levels from individual, community and structural/organisational (Overton & Medina, 2008).

1.2.5.2.Perceived stigma

Perceived stigma is the extent to which the stigmatised person believes in the negative stereotypes of SMI and how much they believe they are applicable to them (B. G. Link, 1987). Perceived stigma has been identified to contribute to the development of internalised stigma even when experienced stigma is not present. Link and colleagues have outlined the term "symbolic interaction stigma" to explain how perceived stigma can occur without overt experienced stigma (B. G. Link, Wells, Phelan, & Yang, 2015). Link et al. (2015), based on the sociological framework of symbolic interactionism, postulate that people seek to predict how others may interact with them socially as a coping strategy to keep themselves safe in social situations. Therefore, an individual may predict or

anticipate that others may be stigmatising towards them for having an SMI (i.e. perceived stigma). Some constructs capturing the same experience or process of perceived stigma have been identified, such as stigma awareness, stigma consciousness and stigma agreement (Watson et al., 2007).

1.2.5.3.Internalised stigma

Internalised stigma, also termed as self-stigma (Corrigan & Watson, 2002a), is the internalisation of the stereotypes and related cognitive, behavioural and emotional consequences. As described above, it comprises three subcomponents of stereotypes, prejudice and discrimination towards oneself. Brohan et al., (2010) explain that each component of experienced, perceived and internalised warrant examination to understand an individual's personal experience of stigma.

1.2.6. Summary of the social cognitive conceptualisations of stigma

The conceptualisations outlined by Goffman (1963), Link and Phelan (2001), Corrigan and Watson (2002a), and Brohan et al (2010) have provided significant understanding to the conceptualisation of stigma, particularly personal stigma, and have led to significant developments in the field. However, it is important to acknowledge at this stage, the potential difficulties with the concepts of stigma. One of the main criticisms of the stigma theories presented here is the lack of empirical testing in order to examine the proposed components of the models. D.M. Clark (2004) outlines the importance of empirically testing theoretical models through the manipulation of specific components to identify how they relate to one another. However, none of the stigma models presented here have been examined in this way.

One area of development is the refinement of the stigma theories described to ensure they have clinical applicability and include the emotional, clinical and symptomatic consequences of stigma. This will ensure that mental health services can respond appropriately to someone experiencing self-stigma. The lack of clinical application has restricted the models' capacity to include the complex interaction between stigma and pre-existing mental health difficulties (Drapalski et al., 2013). Arguably the stigma of mental health requires a more clinically focused theoretical understanding as people with SMI are "challenged doubly" (p.16) by their SMI and the stigma associated with their psychiatric diagnosis (P. W. Corrigan & A. C. Watson, 2002). Therefore, the inclusion of clinical symptoms within the model would be essential to having a robust understanding of the phenomenon of stigma. This has led to several new conceptualisations being developed which are outlined below.

1.2.7. Psychologically focused models of stigma

More recent developments have led to clinically focused models of internalised stigma to provide a way of understanding the complex relationship between mental illness and emotional distress caused by stigma. Internalised stigma has been the focus of the following models due to it being the component which relates to internal psychological processes and individual manifestations of stigma.

1.2.7.1.Stress-coping model of stigma

The stress-coping model of stigma was initially developed by Major and O'Brien (2005), and further examined quantitatively by Rusch et al. (2009a) and Rusch et al. (2009b) , in order to understand why some people are affected by stigma and others are not. Their model drew upon widely established stress theories used within the health literature

(Lazarus & Folkman, 1984). They describe a model of stigma stress which comprises four main components that cause an individual to internalise stigma as distressing.

The first stage of their model outlines factors that may make an individual vulnerable to stigma stress. These factors include perceived stigma and a number of pre-existing personal factors (including increased sensitivity to rejection, perceived legitimacy of stereotypes, past experiences of discrimination, and identification with the labelled group) (Rusch, Corrigan, Powell, et al., 2009; Rusch, Corrigan, Wassel, et al., 2009). For example, the more a person perceives stigma to be present in their social context, along with an increased sensitivity to rejection, the more likely it is that someone will develop stigma related stress. The second stage occurs when a person develops stigma stress appraisals and applies stigma to one's self (e.g. I am an outcast). A second component to this stage is that the individual believes that perceived harm by stigma outweighs perceived coping resources. This leads to the third stage of cognitive and emotional consequences of stigma such as stress, anxiety, and shame. Finally, this impacts on the behavioural outcomes for the individual, for example as outlined in previous models, avoidance and withdrawal.

A particular focus of this model is to understand the cognitive and behavioural coping responses to stigma which previous models have not focused on. Rusch, Corrigan, Powell, et al. (2009) outline three potential coping responses that a stigmatised individual may adopt to protect themselves from stigma stress. Firstly, a stigmatised individual may devalue factors which their group perform poorly in (for example, work and education) therefore not succeeding in those areas will not impact on self-esteem. Secondly, the stigmatised individual will compare themselves only with fellow members of the stigmatised group as such comparisons are less threatening. Finally, the individual may use

external attributions for negative experience (for example, blame others for stigma rather than themselves).

1.2.7.2.Social Mentality Theory (SMT) and stigma

Given the links already made between stigma and evolutionary theories (Link & Phelan, 2001), a model which may be particularly helpful in understanding the development and maintenance of internalised stigma is Social Mentality Theory (SMT; Gilbert, 2005) . SMT is a theory which underpins Compassion Focused Therapy (CFT; Gilbert, 2010). To date, a theoretical model using SMT has not been specifically developed for understanding stigma, however SMT can be applied to examine how internalised stigma develops. SMT, based within evolutionary psychology theory, outlines a model to understand human's abilities to detect threats within their social environment (Gilbert, 2010). Humans have a range of emotions which orientate them to threat, such as anger and anxiety, which include consequential evolutionary-based behavioural responses such as fight, flight, freeze and faint (Gumley, Braehler, Laithwaite, MacBeth, & Gilbert, 2010). These threat focused emotions offer a means to protect us within our social roles and ultimately maintain our survival. SMT allows the individual to assess the threats, safeness or rewards within a given social relationship. Therefore, to act appropriately in our social roles, our motives, emotions, cognitions and behaviours must be coordinated.

Threatening social relationships, such as those where stigma is present, can cause the stigmatised individual to become focused and hypervigilant towards the threat of stigma. Multiple threats can impair our social rank (our perceived ranking in society) and cause us to experience shame. Shame has been described as either being internally or externally focused. External shame is the negative affect we experience as we believe that *others* perceive us negatively, with contempt and as rejectable (Gilbert, 2010). Internal shame is

the negative affect we experience when we internalised these beliefs and perceive *ourselves* as negative, with contempt and as rejectable (Gilbert & Procter, 2006). Internal shame may be considered an affective component of internalised stigma. Shame impacts upon behavioural responses causing the individual to avoid or be submissive towards the perceived dominant other in order to limit social damage (Matos, Pinto-Gouveia, & Gilbert, 2012).

A relevant model which has used SMT to explain how social anxiety develops in first episode psychosis has been developed by Birchwood et al. (2007). Birchwood et al. (2007) suggest that internalised cultural values of mental illness stigma lead the person to develop an other-to-self focus, i.e. worries that he/she will be judged or rejected by others (external shame). This, in turn, leads to a self-focus (internal shame, e.g. I am worthless), which results in the individual becoming hypervigilant towards how they look or perform in social situations leading to social anxiety (D.M. Clark, 2001). This model partially explains how stigma experiences can cause shaming experiences, and consequential emotional distress.

1.2.7.3.A cognitive approach to understanding internalised stigma

Another dominant model which may help explain the development of internalised stigma is the application of Cognitive Behavioural Therapy (CBT) theory (A. Beck, 1979). Similarly to SMT, a CBT based model of internalised stigma has not been formally developed however the theory is applicable to internalised stigma and can explain the development and maintenance of internalised stigma. Moreover, CBT has been used to underpin a number of interventions to alleviate internalised stigma demonstrating its applicability (P. T. Yanos, Roe, & Lysaker, 2011), and (as outlined) has been applied to understand experiences of psychosis (Garety et al., 2001; A. P. Morrison, 2001).

CBT is based on the assumption that negative appraisals and unhelpful cognitive processes are the core to causing and maintaining emotional distress and consequential mental illness (Beck, 1979). Our appraisals and cognitive processes develop throughout our lives and evolve due to life experiences, particularly those which impact on our early life attachment development (negative experiences include trauma, neglect, and institutional care). Our life experiences contribute to the development of core beliefs or schemas (global and stable beliefs about the self, world and other) which act as a filter through which we view our social world (Fowler et al., 2006). People who experience emotional distress and SMI often have negative, threat focused, core beliefs about themselves, the world and others which underpin their day to day interactions (B. Smith et al., 2006). Core beliefs lead to adaptive rules for living (dysfunctional assumptions about how one should behave in response to our core beliefs) which keep negative core beliefs from being exposed to others in our social context (Dryden & Branchm, 2012). Collectively, our core beliefs and rules for living underpin our current and ongoing cognitions, emotions, behavioural and physiological reactions. Therefore, when a trigger is present (an idiosyncratic threatening experience e.g. discriminatory behaviour), a maintenance cycle of emotional distress (negative cognitions/appraisals (e.g. "I am incapable"), behaviours (e.g. not bothering to apply for a job), emotions (e.g. depression, shame) and physiological reactions (demotivation) ensues (Dryden & Branchm, 2012).

In relation to internalised stigma, it could be hypothesised that experiences of discrimination or lifelong exposure to stigma would potentially lead an individual with SMI to develop stigmatising core beliefs and adaptive rules for living which protect themselves from stigma and discrimination. These would underpin an individual's ongoing cognitions, behaviours, emotions and physiological reactions when any relevant social

interaction or situation occurs. However, to date the application and testing of CBT to internalised stigma in SMI and psychosis has never been formally explored.

1.2.7.4.Summary of the stigma theoretical models

To summarise, these stigma specific conceptualisations and theories have contributed significantly to the understanding of stigma as a social and clinical construct (Elaine Brohan, Mike Slade, et al., 2010; P. Corrigan & A. Watson, 2002; B. Link & Phelan, 2001; Rusch, Corrigan, Wassel, et al., 2009). The different components of stigma have been defined and the relationship between the constructs has been described using relevant social and psychological theory. The models have been able to refine stigma, an extremely broad concept, into meaningful subcomponents. The key components of stigma which have been outlined are public stigma, and its subcomponents of stereotypes, prejudice and discrimination, and personal stigma including experienced stigma, perceived stigma and self-stigma (stereotypes, prejudice and discrimination). Furthermore, they have identified key cognitive, emotional and behavioural processes within relevant stigma components. One area for expansion is to develop a theoretical model with clinical applicability which can be translated into clinical practice. Moreover, the theories which are more clinically relevant such as SMT and CBT have not been used to formally conceptualise internalised stigma. This would be an important focus for future theoretical models of stigma.

A criticism of the stigma theories, which is important to consider in future theory development, is that they all arguably have located the problem of stigma within the individual without sufficient reference to the social and cultural context (Page, 2013). D. Harper and Vakili (2008) outline that current models have turned a social problem to an individual one, which has the danger of absolving responsibility from the public who are doing the discriminating. Page (2013) recommend that models acknowledge the cultural

context and include the impact of social, cultural, economic, human and political processes. It is imperative that future model development incorporates such components.

In summary, these conceptualisations have led to important developments in our understanding of stigma, and to extensive research examining its detrimental impacts, methods of assessment and therapeutic response. These will be explored further within the remainder of this chapter. A focus will be on public and personal stigma, particularly internalised stigma, as these are the areas of interest within this thesis. The concepts outlined within these models (public stigma, and its subcomponents of stereotypes, prejudice and discrimination, and personal stigma including experienced stigma, perceived stigma and self-stigma) will be used to underpin the research evidence explored within the remainder of this chapter.

1.3. Stigma, SMI and psychosis

As outlined in these stigma models, stigma is a prevailing difficulty for SMI in regard to both public and personal stigma. An abundance of research studies have demonstrated that stigmatising beliefs about SMI are endorsed widely by the current western world (Corrigan and Watson, 2002a), and that stigma is experienced by the majority of people diagnosed with an SMI, particularly psychosis (The Schizophrenia Commission, 2012). As a consequence, extensive research has been conducted attempting to examine the public and personal stigma associated with SMI and psychosis through the use of qualitative and quantitative research methods. Therefore, this literature will be explored here in order to understand these aspects of stigma in detail. This thesis is particularly focused on personal stigma, however it is acknowledged that without public stigma, personal stigma would not exist (P. Corrigan & A. Watson, 2002), and therefore it is imperative to understand the

evidence base of public stigma in order to have an appropriate context for the remainder of the chapter. The prevalence and causes of public stigma will be presented here.

1.3.1. Public stigma concerning SMI and psychosis

As outlined, public stigma has been defined as negative stereotypes, prejudicial public attitudes and consequential discrimination towards the stigmatised group (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012). Public stigma towards SMI is a widespread problem with significant levels identified across 15 countries across Africa, Asia, Australasia, Europe and North and South America (Pescosolido et al., 2010). Public stigma has been identified in specific sub-populations of the public including, faith leaders (Mantovani, Pizzolati, & Edge, 2016), school children (Greenwood et al., 2012), the police (B. G. Link et al., 2015) and healthcare providers (B. G. Link et al., 2015). Furthermore, this extends to well-trained health professionals, including those who work in the mental health field (Rao et al., 2009). Public stigma is present towards both adults and adolescents with SMI, and is a universal and disabling problem (Kaushik, Kostaki, & Kyriakopoulos, 2016). Evidence of public stigma pertaining to negative stereotypes, prejudicial attitudes and discrimination components towards people with SMI and psychosis are outlined below.

Research into public stigma has demonstrated wide scale public agreement with the negative stereotypes towards people with SMI and psychosis. The dominant stereotypes includes stereotypes of incompetence, dangerousness and violence, which are consistent across cultures (Parcesepe & Cabassa, 2013). Corrigan and Watson (2002a) described three main stereotypes of those with a mental illness: that they are homicidal maniacs, they are childlike and have childlike perceptions of the world, and they are weak in character. This has been demonstrated in several large scale public attitude surveys. In

another UK-based population survey (n=1725), Crisp, Gelder, Goddard, and Meltzer (2005) found that over half of the sample described people with an SMI (severe depression, panic attacks, schizophrenia, dementia, alcoholism and drug addiction) as unpredictable and hard to talk to. In addition, people diagnosed with schizophrenia were viewed as dangerous by almost two thirds of the sample. This has been identified as an ongoing pattern in two further follow-up surveys using the same measure of attitudes in the UK population (Crisp et al., 2005; Wood, Birtel, Alsawy, Pyle, & Morrison, 2014).

There is further evidence to demonstrate that psychosis is particularly negatively stereotyped. In a public survey conducted in Belgium (n=544) exclusively examining public perceptions of schizophrenia, it was found that respondents believed that people with a schizophrenia diagnosis are unpredictable and have a poor prognosis (Thonon & Laroi, 2016). Furthermore, in another cross-sectional study, it has been demonstrated that negative stereotypes relate to poor public understanding of psychosis. In a survey of attitudes (n= 330) of university students, poor levels of understanding regarding psychosis were identified (V. Smith, Reddy, Foster, Asbury, & Brooks, 2011). Lack of understanding was also associated with less tolerance of those who experience psychosis.

The negative stereotypes associated with having an SMI have resulted in a number of negative emotional responses from the public. Prejudice occurs when the public have negative cognitive and emotional reactions to the stereotypes. Corrigan and Shapiro (2010) outlined that fear, anxiety and anger are common emotional reactions towards people with mental illness. Angermeyer, Holzinger, and Matschinger (2010) examined the emotional reactions towards people with SMI using data they had previously collected from three separate samples (n=3067, Angermeyer et al., 1998; n=2094, Angermeyer et al., 2009; and n=5025, Angermeyer & Matschinger, 2003a). They identified that positive emotional reactions were most prevalent, followed by fear and anger. However, they reported that the

emotional reactions towards people with SMI were worsening. They also found that emotional reactions mediated the relationship between knowledge of SMI and desire for social contact demonstrating the important role of emotion. In a more recent study, Makowski, Mnich, Angermeyer, and von den Knesebeck (2016) conducted a large population survey (n=1,338) and identified negative emotional reactions as a significant part of public stigma towards schizophrenia and depression respectively, with levels of anger and fear being higher towards those with schizophrenia. In particular, they also identified that anger and fear played a significant mediatory role between stereotype agreement and consequential discriminatory behaviour towards both mental illnesses. This demonstrates both the prevalence and important role of negative emotional reactions towards mental illness.

In regard to discrimination, a recent public survey study identified that the public stigma results in social distance and minimal contact with people diagnosed with an SMI. In a recent systematic review conducted in the United States on k=36 studies, prejudicial attitudes towards SMI were identified to lead to social distancing from people with as SMI (Parcesepe & Cabassa, 2013). Furthermore, in a large cross sectional study of people with SMI (n=281) conducted in Canada, it was identified that participants struggled gaining and maintaining employment. In another non-systematic review article, public stigma was demonstrated to also result in discrimination, segregation, reduced autonomy, poor housing or homelessness, restricted employment opportunities and support, restricted financial autonomy and lack of opportunity (Corrigan & Shapiro, 2010). In regard to psychosis-specific discrimination, the large public survey conducted in Belgium (n=544) found that a third (33%) of the sample would distance themselves from those diagnosed with schizophrenia and one fifth (20%) would flee if they came into contact with someone with schizophrenia (Thonon & Laroi, 2016). They also identified that stereotypes of

dangerousness and incompetence were most associated with fleeing responses. Moreover, discrimination was worse for people with schizophrenia compared to those with depression. Furthermore, in a large American sample (n=1280), 62% of the public refused to work closely with people diagnosed with schizophrenia, and 52% would not socialise with them (Pescosolido et al., 2010).

This evidence demonstrates that public stigma is a significant problem for people with SMI. People with psychosis are subject to the most negative stereotypes, worsened negative emotional reactions from the public, and experience the most discriminatory behaviour compared to those with other SMI diagnoses. It is important to note that all studies reviewed here have assumed that the examined stigma factors, e.g. distancing yourself from someone with psychosis, are due to stigma and have not considered that such responses may be understandable from the public if faced with someone with psychosis who does overtly demonstrate dangerous or unpredictable behaviour. Nevertheless, public stigma is a serious issue considering people are already suffering distressing experiences of psychosis, and such public stigma has shown to worsen psychological and emotional well-being (Angermeyer & Matschinger, 2003a). It is important to understand what has caused such public stigma to develop towards people with psychosis in order to attempt to tackle it.

1.3.2. What has caused public stigma to develop?

To date, much of the research and theoretical models have examined the developmental and maintenance processes of stigma (P. W. Corrigan & A. C. Watson, 2002; B. Link & Phelan, 2001). For example, they outline the importance of a person's social context, relational factors, and cognitive, behavioural and emotional consequences of stigma. Furthermore, significant research has been conducted in order to understand the

consequences of stigma. However, what is often most absent from the current research evidence base is an understanding of the social and cultural causes of SMI stigma. The social and cultural factors which contribute to the development of stigma are important to understand in order to prevent stigma from developing. Link and Phelan (2001) outlined the importance of the social context in which stigma occurs in order to understand why it develops. It is imperative to understand why people with an SMI are subject to the most stigma and discrimination compared to other marginalised groups (Crisp et al., 2005). The key factors which have contributed to the stigmatisation of SMI, particularly psychosis, are described.

1.3.2.1.Biogenetic conceptualisation, Asylums and 'Mental Illness'

Researchers from a social constructionist position would argue that the term 'mental illness' is a socially constructed concept with relevance only to the social context in which it was developed (Cromby, Harper, & Reavey, 2013). Therefore, it is important to understand the social construction of 'mental illness' in order to understand its consequential 'stigma'. Within western society, mental distress is socially constructed as an illness and predominantly understood as a biogenetic brain disorder (Walker & Read, 2002). Mental illness is defined as a set of symptoms which are not on the continuum with the normal population and are distinct experiences that only those with a mental illness can have (Boyle, 2002). However, experiences which are considered as symptoms of a mental illness in Western Society are part of the normal sequalae of human experience in other cultural groups (R. P. Bentall, 2004). Others who take a psychosocial positioning also do not agree with the conceptualisation of mental illness and see it as an understandable response to threatening and traumatic life experiences (Boyle, 2006; Laing, 1967). This illustrates that 'mental illness' is not a fixed term in which everyone agrees.

This biogenetic conceptualisation has arguably been present since the birth of the Victorian asylums where people who were identified as having a mental health difficulty were largely locked away for the remainder of their lives (Turner et al., 2015). This was due to experiences of mental distress or illness being misunderstood and considered as a permanent degenerative dementia, in the same category as intellectual disabilities and brain injuries (S. Hill & Laugharne, 2003). Mental illness was seen as only treatable by physicians through medical interventions such as lobotomies, electric shock therapy and in more recent years, psychiatric medication (Turner et al., 2015). In the early 20th century, mental distress or illness was acknowledged to be conceptually different from an intellectual disability or brain injury; however its biological conceptualisation persisted, and to this day, mental health problems are still primarily considered a biogenetic disorder by the majority of western society (Kvaale et al., 2013).

The dominant biogenetic understanding of SMI has arguably contributed to the ongoing stigma and discrimination experienced by people with these experiences. J. Read and Harre (2001) outline that biogenetic explanations of SMI increase the likelihood of the stigmatised person being labelled as different and placed in a distinct social outgroup away from the 'normal' population. This medicalisation allows society to place the individual within a mental illness category distinctively different from them and allows for emotional distancing (B. Link & Phelan, 2001). Research has illustrated that the more the public believe that the person has a biologically conceptualised mental illness, the more likely they are to reject them (Sarbin & Mancuso, 1970). In a recent large systematic review and meta-analysis (n=3469), Kvaale et al. (2013) identified that biogenetic conceptualisations of mental illness reduce blame but increase perceptions of dangerousness, and desire for distance.

1.3.2.2.Segregation through institutionalisation

People with SMI have been locked away and segregated from society for hundreds of years (Boyle, 2002). Erving Goffman was the first to consider the social impact of this in his observational research published in his book *Asylums* (Goffman, 1961). In his research conducted in the United States, he noted that asylum inmates were subject to stigma within the asylum and outside of it. He reported that inpatients were forgotten about by society, misunderstood and viewed as immoral by society (due to treatment for SMI such as "moral therapy"). The nature of asylums meant that society had little social contact with people diagnosed with a SMI. It is widely acknowledged that lack of social contact with a social group will decrease knowledge and understanding, and ultimately increase stigma (London, 2010). Thus many years of isolation and lack of social contact has arguably set the foundation for SMI stigma to be an ongoing social problem for current Western society.

This was particularly evident when stigma became a significant reality during the process of deinstitutionalisation in the UK in the 1980's and 1990's (Kings Fund, 2014). Deinstitutionalisation led to a number of difficulties integrating mental health service users back into the local community with a number of service users having spent the majority of their life in asylums with little contact with the outside social world (Killaspy, 2007). Stigma was highly present in the local communities with community members not wanting service users living in their local area (Killaspy, 2007). Furthermore, Fakhoury and Priebe (2002) outlined that an attempt to promote inclusion of service user back into the community was based on a disability paradigm which alienated and restricted full integration back into the community. Wright, Gronfein, and Owens (2000) examined the impact of deinstitutionalisation on mental health service users and identified an increase in social rejection, which led to an increase in self-depreciation and weakened sense of

mastery. It is arguably the process of deinstitutionalisation which sparked the increased interest in understanding the phenomenon of SMI stigma.

In summary, the medicalisation and institutionalisation of people diagnosed with SMI has set the foundation for SMI stigma as it is experienced in its current context. Furthermore, it has also arguably increased the 'us and them' dynamic as outlined by Link and Phelan (2001), due to distress being labelled as a distinct illness and not on a continuum with the normal population. Therefore, it is unsurprising that stigma has become attached to people labelled as having an SMI.

1.3.2.3.The role of the media in perpetuating mental health public stigma

The media has significant power to impact on public perception due to the widespread availability of media sources within the public domain. It is arguably one of the most influential mediums in our current western society and a primary source of public information (Baun, 2009). A wealth of literature has demonstrated that the media plays a significant role in perpetuating the stigma of SMI (Sarah. Clement, Jarrett, Henderson, & Thornicroft, 2010). It has been identified that the media largely portrays negative or misinformed images and stories of SMI (Baun, 2009; Tartakovsky, 2015). In a review study, Klin and Lemish (2008) identified that the media report SMI in a distorted manner, and present people with SMI as peculiar, different and dangerous. These negative portrayals have been identified in many different forms of media such as television, newspapers, films, and more recently on social media (G. Thornicroft et al., 2007).

The media is particularly problematic in regards to the perpetuation of negative stereotypes of SMI. One of the main sources of this stigma is from newspaper articles. In a large prospective national study, Cloverdale, Nairn, and Claasen (2002) examined media stories

over a four week period which related to SMI and identified 600 relevant stories. Their examination of the articles identified that 61.3% related to dangerousness to others, and 47.3% related to criminality, indicating the media's role in perpetuating the stereotype of dangerousness regarding SMI. In a UK based study A. Thornicroft et al. (2013), examined mental health newspaper stories over a four year period (2008 – 2011) by using content analysis and identified stigmatising stories comprised 43-50% of the total articles examined. They identified that dangerousness was a dominant theme within the media stories (14 – 21%).

Negative portrayals of SMI are also prevalent on television. Oostdyk (2005) conducted a review of studies which examined mental illness stigma portrayed on television and identified that those with SMI are portrayed negatively and shown as violent, villains, and unintelligent. Oostdyk (2005) also identified that attitudes are affected by the number of hours spent watching television, as well as the type of portrayal within television programmes. This demonstrates that televised content can significantly impact on public attitudes towards SMI although this was not a systematic review and therefore should be interpreted with caution. Angermeyer, Dietrich, and Matschinger (2005) conducted a population survey examining the relationship between media consumption and desire for social distance towards people with schizophrenia and identified a significant association between television consumption and desire for social distance. They identified that the relationship between watching television and social distance was stronger than the relationship between reading newspapers and social distance.

A more recent source of potential stigma is the internet and social media which is increasing in popularity and is arguably the dominant source of media available in our current western society. Approximately 90% of the United Kingdom (UK) and United States of America (USA) populations use the internet demonstrating its widespread

availability in our western society (Internet Live Stats, 2016). The internet is a favoured source which people access to gain information about mental health. Powell and Clarke (2006) conducted a population survey to examine the prevalence of internet use for mental health related information seeking and the accuracy of information sourced. Their results identified that 18% of their sample had used the internet to gather information relating to mental health. Of those who did access the internet only 12% identified it as a reliable source of information indicating that there may be misleading and potentially stigmatising information freely available online. Due to the abundance of potential sources of mental health-related information, it is extremely difficult to quantify the prevalence of stigmatising content on the internet. Sources of SMI stigma online have included online chat forums, newspaper stories, social media outlets, and online videos (Time to Change, 2013). Therefore, the internet and social media can also be a source of mental illness stigma.

In summary, the media is a powerful source of stigma which continues to portray negative stereotypes about people with SMI and psychosis across western society. There has been little shift in these negative perceptions across recent years demonstrating that the media continues to be problematic and maintaining the stigma experienced in current western society.

1.3.2.4.Summary of causes of public stigma

To summarise, there are a number of contextual factors which contribute to the development and maintenance of public stigma in our current UK context. Negative stereotypes and public attitudes regarding SMI and psychosis continue to prevail and are arguably maintained by the continuing dominance of the medical model and widespread stigma presence within the media. Therefore, those with SMI or psychosis have to manage

in a context of ongoing stigma and discrimination. It is unsurprising that personal consequences of stigma develop which will be explored further below.

1.3.3. Personal consequences of stigma in psychosis

Extensive research has been conducted to understand the experience of personal stigma (perceived, experienced and internalised stigma). Personal stigma is a highly prevalent problem in people with psychosis. In a recent systematic review, Gerlinger et al. (2013) examined the prevalence rates of personal stigma and identified that 64.5% of individuals with psychosis had experienced some form of personal stigma. To the author's knowledge, prevalence rates of personal stigma across the broader SMI population have not been examined. Both quantitative and qualitative research will be examined to explore the personal consequences of stigma.

1.3.3.1.Quantitative examination of the personal consequences of stigma

High levels of experienced stigma have been demonstrated in people with SMI and psychosis. In a study of individuals with SMI (n=46), Dinos et al. (2004) surveyed participants for the type and prevalence of discrimination and identified that people with an SMI experienced. They identified that verbal abuse, physical abuse, loss of contact, patronising attitudes and discrimination were the most commonly reported experiences. This was worse for people who had a psychosis-related diagnosis. In a large psychosis specific cross-sectional survey (n=732), Thornicroft et al. (2009a) examined service user's experiences of discrimination identified that 47% had difficulty making or keeping friends, 43% experienced discrimination from family members, 29% reported difficulty finding and keeping a job and 27% had difficulty in intimate or sexual relationships.

Perceived stigma for SMI and psychosis has been less explored within the literature but has identified that it is prevalent (Rüsch, Lieb, Bohus, & Corrigan, 2006). Perceived stigma has been demonstrated to be a significant predictor of the development of internalised stigma in a sample (n=127) of people with psychosis (Kleim et al., 2008). In a cross-sectional study of a large sample of individuals with SMI (n=411), Bifftu and Dachew (2014) found that perceived stigma was prevalent in 83.5% of their sample. Moreover, treatment adherence and duration of SMI was associated with perceived stigma. In a recent European cross-sectional survey, E. Brohan, Gauci, Sartorius, and Thornicroft (2010) identified high levels of perceived stigma (71.6%) in people with a diagnosis of bipolar or depression (n=1182). The prevalence of perceived stigma is less in those with mood and anxiety disorders. In another large international cross-sectional survey (n=80,737), levels of perceived stigma were low (13.5%) in those suffering from a depressive or anxiety disorder (Alonso et al., 2011). Therefore, levels of perceived stigma can vary across diagnostic categories.

Arguably, most research has focused on understanding internalised stigma and in particular the psychological and behavioural consequences. Internalised stigma has been identified as a significant issue for people with SMI, and worse for people with psychosis compared to people with other diagnoses. The prevalence rates vary but between one-fifth to one-half of people with an SMI experience internalised stigma, for example, 21.7% in people with bipolar and depression (E. Brohan et al., 2010), 36% in people with SMI (West, Yanos, Smith, Roe, & Lysaker, 2011) and 43.6% in people with psychosis (Picco et al., 2016). In a large European study (n=1229), Brohan et al., (2010) conducted a cross-sectional survey of people with schizophrenia and identified that half the sample (41.7%) reported moderate to high levels of self-stigma Furthermore, in another cross-sectional study (n=120), Karidi et al., (2015) demonstrated that levels of internalised stigma were higher in people

diagnosed with schizophrenia compared to those diagnosed with bipolar disorder. Collectively, this research illustrates that internalised stigma is more prevalent for people with psychosis.

The psychological consequences of stigma are widely noted. In particular, emotional distress has been commonly cited as a consequence of stigma. In a large systematic review and meta-analysis of k=127 studies, Livingston and Boyd (2010) identified that stigma was associated with a poorer sense of self including feelings of hopelessness, lower self-esteem, lowered empowerment, reduced self-efficacy and poorer quality of life. Furthermore, P. W. Corrigan et al. (2006) identified that self-stigma (excluding stereotype endorsement) was associated with poorer self-esteem and self-efficacy in a sample of people with mental illness (n=60). In a quantitative study with 70 participants, B. G. Link, Struening, Neese-Todd, Asmussen, and Phelan (2001) also found that perceived stigma and devaluation was significantly associated with self-esteem. In addition, experiences of shame have been found to be associated with stigma (Rusch et al., 2009). In a cross-sectional study of 85 people with psychosis, Rusch, Corrigan, Powell, et al. (2009) found that stigma stress was significantly associated with shame, which in turn predicted low self-esteem and hopelessness.

Studies have identified that stigma can cause behavioural changes in the individual. Specifically, reduction in help seeking was explored in a recent comprehensive review paper. Clement et al., (2015) conducted an extensive systematic review and meta-analysis (k=144) to identify the impacts of stigma in help seeking in people with mental illness. They identified internalised and treatment stigma was significantly but moderately associated with reduced help-seeking (d=-0.27). Furthermore, stigma was identified as one of the highest ranked reasons as to why people did not seek help for health difficulties.

Reluctance to disclose was identified as one of the most common stigma factors which contributed to reduced help seeking in people with mental illness.

Experiences of stigma have been identified as having negative impacts on psychiatric symptoms. In their large systematic review of 127 studies, Livingston & Boyd (2010) identified that internalised stigma was significantly associated with symptom severity and adherence with treatment. Moreover, research has demonstrated that it can exacerbate existing psychiatric symptoms such as symptoms of psychosis, depression, and anxiety. In a longitudinal study of 80 people with psychosis, Vass et al. (2015) identified that stigma significantly associated with hopelessness, depression, low self-esteem, symptoms of psychosis and poor personal recovery. Moreover, Vass et al. (2015) found that self-esteem and hopelessness mediated the relationship between stigma and depression, personal recovery and psychotic symptoms. In another longitudinal study of n=84 men with an SMI it was identified that stigma had a long-term impact on depression, well-being, and functioning (Link et al, 2001).

Two recent studies have explicitly examined the interaction between stigma and its consequences with pre-existing psychiatric symptoms. Drapalski et al. (2013) proposed and quantitatively examined a model of internalised stigma for SMI which incorporated the impacts on psychiatric symptoms. They explained that discrimination experiences cause a person to self-apply the stereotypes (internalise stigma) and develop a poor self-concept (perceive themselves negatively) and consequently to isolate themselves. An individual's poor self-concept can cause the person to experience low self-esteem and self-efficacy. Furthermore, when a person isolated themselves, this led to long-term withdrawal and alienation. Collectively these factors can worsen and perpetuate psychiatric symptoms such as depression, anxiety and psychosis. Similarly, Schrank, Amering, Hay, Weber, and Sibitz (2014) also proposed a psychosis-specific model which aimed to understand the

relationship between depression, self-stigma, positive symptoms, insight, hope and negative symptoms. Their model suggested that positive symptoms, negative symptoms and insight were associated with self-stigma. Furthermore, depression and hopelessness were key mediatory and dependent factors within the model. Using path analysis (n=284), they identified these hypothesised relationships. These models demonstrate that stigma has a reciprocal relationship with psychiatric symptoms.

1.3.3.2.Qualitative explorations of the experiences of personal stigma

Importantly some studies have focused on examining the subjective experiences of stigma from a service user perspective. This has facilitated an idiosyncratic understanding of personal stigma. A recent review and thematic synthesis of nine qualitative studies conducted by Wood, Burke, Byrne, et al. (2015) examined the personal experiences of stigma of outpatients with psychosis. Two main themes were identified; the 'stigma system' and 'stigma processes'. This review paper will form the basis for the following section.

The theme 'stigma processes' identified the key factors which maintained stigma and discrimination towards psychosis. A number of the subthemes related to what Link and Phelan (2001) described as status loss and discrimination. People described experiencing social exclusion, being devalued, having a lack of power and control, experiencing negative stereotypes and discrimination, and being seen as inferior. Pyle and Morrison (2013), one of the studies included in the review, found that their participants felt judged and experienced a lowered social status as a result. A number of other examples of status loss and discrimination included being restricted and viewed as incapable (Schulze & Angermeyer, 2003), being seen as an illness (Jenkins & Carpenter-Song, 2009), abandonment, and avoidance from others (Buizza et al., 2007).

One of the other factors relevant for understanding the subjective experiences of stigma was shame and emotional distress caused by stigma (Wood et al., 2015a). In a large-scale qualitative study, Dinos et al. (2004) interviewed n=46 service users, to identify the impacts of stigma on people who have a mental illness. They identified that people reported distressing emotional experiences such as anger, depression, fear, anxiety, guilt and embarrassment. Moreover, shame and secrecy were identified as an overarching theme in the review. For example, participants identified shame and embarrassment around treatment (Jenkins & Carpenter-Song, 2009), and personal shame (Pyle & Morrison, 2013).

The second superordinate theme was the 'stigma system' which described the different social groups which were sources of stigma and discrimination (Wood et al., 2015). Stigma was identified from multiple levels of the social system from family, friends, community and society demonstrating penetrating nature of stigma. Regarding society, participants described the media as being an influential factor in maintaining stigma (Dinos et al., 2004), as well as cultural/race factors causing multiple stigmas (Pyle & Morrison, 2013). The community groups identified as causing stigma included health care professionals (Schulze & Angermeyer, 2003), neighbours (Jenkins & Carpenter-Song, 2009), family (Pyle & Morrison, 2013) and friends. Finally, some participants in individual studies acknowledged they too could be a source of their own stigma, i.e. self-stigma (Gallo, 1994).

1.3.3.3.Summary of the evidence of personal stigma

In summary, personal stigma for psychosis has been evidenced using both quantitative and qualitative research. It has been demonstrated that experienced stigma, perceived stigma, and internalised stigma are prevalent in SMI and worsened in those who experience

psychosis. Moreover, clear psychological consequences of stigma have been outlined, including experiences of shame, low self-esteem, depression, hopelessness, anxiety and worsening of psychotic symptoms. From an examination of the qualitative literature, status loss and discrimination are particularly distressing for people with psychosis.

1.3.4. What are the causes of personal stigma?

The causes of public stigma have been outlined, and research has examined this in reasonable detail. However, significantly less research has examined the causes of personal stigma. As outlined, not every individual within a stigmatised group would go on to develop perceived and internalised stigma, even when experienced stigma is present (G. Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). Therefore, there has been increasing interest in understanding what causes people to develop perceived, but particularly internalised, stigma.

In an attempt to figure out why only some people develop internalised stigma, Corrigan and Rao (2013) outline a stage model of self-stigma which suggests why internalised stigma can occur. Corrigan and Rao (2013) reported that levels of perceived stigma (an individual's awareness of public stigma) are significantly associated with the development of internalised stigma. If a person perceives there to be a high level of stigma associated with their mental health experiences, and that the stigma applies to themselves, internalised stigma is likely to be high. Quantitative research has further supported this with large samples, demonstrating that elevated levels of perceived stigma also lead to high levels of self-stigma (Jennings et al., 2015; Kleim et al., 2008).

Pre-existing low self-esteem and low self-efficacy have also been identified as associated with internalised stigma in Corrigan et al.'s (2006) model. Self-esteem has been defined as a cognitive representation of the self which is developed through life experiences (Fennell,

1998). Self-efficacy has been defined as "the psychological mechanisms for positively motivating human resources" (pg. 126; Stajkovic & Luthans, 1979) . Self-esteem and self-efficacy are both essential components of well-being (P.W. Corrigan, A.C. Watson, & L. Barr, 2006). Corrigan outlines that these factors play a significant role in the development of internalised stigma. In a number of cross-sectional studies, low self-esteem and self-efficacy have been found to be associated with higher levels of internalised stigma (P. W. Corrigan et al., 2006; P. H. Lysaker, Tsai, Yanos, & Roe, 2008). Similarly, shame, a key component outlined in SMT, has also been identified as a potential factor which may contribute to the internalisation of stigma (Birchwood et al., 2007). As described in Birchwood et al.'s (2007) model, experiences of stigma lead to internal and external shaming beliefs which cause emotional distress such as anxiety and anger. However, this has not been examined in relevant stigma research.

Insight is widely discussed within the internalised stigma literature and highlighted as a significant risk factor. A lack of psychiatric insight has been defined as "a multidimensional construct composed of unawareness of symptoms, denial/minimization of illness-related consequences, and failure to recognise the need for treatment" (pg. 137; Goldberg et al., 2001) . Insight, or the lack of it, has also been described as a defence mechanism towards coping with having an SMI. It has been suggested that avoiding that an SMI exists can reduce the distress caused by it (Goldberg et al., 2001). A lack of psychiatric insight is common across SMI diagnoses (Cooke et al., 2007), with poor insight being highlighted in those with a diagnosis of schizophrenia in particular (Amador et al., 1993). Psychiatric insight has been demonstrated to have a paradoxical relationship with internalised stigma (Kilk, 2015). P. H. Lysaker, Roe, and Yanos (2007) have identified that having an awareness of one's mental health status can lead service users to experience internalised stigma. They conducted a quantitative study that identified that high insight

resulted in higher levels of internalised stigma. Furthermore, elevated levels of insight and internalised stigma also predicted poorer social functioning, hopelessness, and poor quality of life. This has been identified in similarly designed research demonstrating that insight is a significant risk factor to internalised stigma (Caveleti et al., 2014; Hasson-Ohayon et al., 2012).

The final potential risk factor for internalised stigma which has been documented in the literature is premorbid poor social identity. A social identity has been defined as "a person's sense of who they are based on their group membership" (pg. 1; McLeod, 2008) . Group membership significantly shapes an individual's perceived identity, and positive group membership can bring about a positive sense of belonging in the social world. A poor sense of social identity can lead to psychological consequences such as poor self-esteem, depression, hopelessness, and anxiety (Goffman, 1963; McLeod, 2008). Therefore, if the stigmatised individual has a poor social identity before being diagnosed with an SMI, they may be more likely to experiences internalised stigma when joining the stigmatised group.

1.4. The assessment of stigma

The assessment of stigma has been identified as essential to understanding public attitudes, beliefs and behaviours (public stigma) as well as the personal impacts that stigma has on the individual (personal stigma). Assessment measures play a major role in research by monitoring change within research trials, collecting data about the efficacy of an intervention, gathering data about participant's subjective experiences and attitudes, and are psychometrically robust. Assessment measures play an integral role in quantitative research as they can be used to collect information regarding a specific topic area relatively quickly, can be administered to a large sample, and are generalizable (Carmines & Zeller,

1979). In regard to a clinical setting, assessment measures are necessary to guide treatment decisions, monitor improvement and gather assessment information (Nordel, 2012). Furthermore, assessment measures present the individual with validated information regarding a topic (through questionnaire items) and can prompt the extraction of information. Therefore, assessment measures of stigma play a major role in the development of the research evidence base, as well as understanding the clinical impacts of stigma. The available measures of public stigma and personal stigma will be examined here. Again, the focus of this thesis is personal stigma however to have a sound understanding of personal stigma and its related measures; it is helpful also to understand what the available public stigma measures are and identify the constructs of stigma that they measure.

Two systematic review papers were utilised to examine the assessment measures of public stigma (Yang & Link, 2015) and personal stigma (Elaine Brohan, Mike Slade, et al., 2010) respectively. The review searches were updated by the author to identify recently published measures. Both review papers used the same search terms ('mental AND ill*' OR 'mental AND distress' AND 'stigma* OR prejudice* OR discriminat*) and databases (MEDLINE, PSYCINFO, and British Nursing Index) outlined in Brohan et al., (2010c). The author utilised the same search criteria from 2010 – 2016 to update their searches which identified 11,600 initial papers. Due to the excessive volume, the author added additional terms in order to refine the search (measure OR scale OR interview OR outcome) which led to 518 papers. These were screened at title and abstract and left three studies. One final study was identified and measured internalised stigma (Barney, Griffiths, Christensen, & Jorm, 2010). No further measures of public stigma were identified.

1.4.1. Assessment of public stigma

There is a wealth of measures developed to assess public stigma in SMI in different target populations. For this section, public measures are considered to be measures of stigmatising attitudes, beliefs and behaviours in the general population (Yang & Link, 2015). Public stigma measures have been developed for specific sub-populations within the public realm such as with children, the police force and health professionals (Parcesepe & Cabassa, 2013). However, as this is a brief overview, only general public measures will be examined here. The available measures of public stigma and examination of their psychometric properties will be briefly summarised.

Yang and Link (2015) conducted a systematic and narrative review of assessment measures which examined attitudes, beliefs and behaviours of the public towards people with mental health problems. They identified six measures which examined a variety of dimensions of public stigma: the Social Distance Scale (SDS; Bogardus, 1925), Community Attitudes toward Mental Illness (CAMI) Scale (J. Cohen & Struening, 1962; Struening & Cohen, 1963), Semantic Differential (SD) measure (Osgood, Suci, & Tannenbaum, 1957), Opinions about Mental Illness (OMI) scale (Cohen & Struening, 1962; Struening & Cohen, 1963), Attribution Questionnaire (AQ; Van Boekel et al., 2013) , and the Affect Scale (AS; Angermeyer & Matschinger, 1996) . Two of the measures examined desire for social distance (Bogardus, 1925; Taylor & Dear, 1981), three measured stereotype agreement/attitudes (J. Cohen & Struening, 1962; Osgood et al., 1957; Van Boekel et al., 2013), and one measured negative emotional responses (Angermeyer & Matschinger, 1996). All available measures demonstrated good internal consistency (Cronbach alpha = 0.74 – 0.89) and did reasonably well on other measures of reliability and validity. Their review concluded that there are psychometrically robust measures available which measure different components of public stigma. It also

demonstrated that social distance and public attitudes are the most measured elements of public stigma.

1.4.2. Assessment of personal stigma

The personal impacts of stigma (experienced, perceived, and internalised stigma; Brohan et al., 2010c) on people who experience psychosis are detrimental. As a consequence, researchers and clinicians have identified the importance of assessing stigma through the use of assessment measures. They have been developed for arguably two main purposes; to be utilised within research which aims to examine personal stigma, and also to be used in clinical practice to understand the personal impacts of stigma (Boyd, Otilingam, & DeForge, 2014). As a consequence, the available outcome measures for examining personal stigma will be explored here.

Personal stigma is understood as the components of perceived, experienced and internalised stigma (Brohan et al., 2010c). Therefore, a brief overview of available measures of perceived, experienced and internalised stigma will be given. A recent review examined the available measure of personal stigma and scrutinised their utility and psychometric properties (Brohan et al., 2010c), and will be used to guide the examination of available assessment measures. They identified 57 relevant studies which had utilised 14 available assessment measures. All measures were self-report measures. Seven of the measures examined perceived stigma as part of their measure; ten examined experienced stigma and five measures examined internalised stigma.

Perceived stigma was the most frequently addressed construct of personal stigma. The seven available measures which examined perceived stigma at least as a component of their measure was the Perceived Devaluation and Discrimination Scale (PDD; Link et al, 1987) , Self-Stigma of Mental Illness Scale (SSMIS; Corrigan et al., 2006), Depression

Self-Stigma Scale (DSSS; Kanter et al., 2008) , the Inventory of Stigmatising Experiences (ISE; Stuart et al., 2005) , Self-Esteem and Stigma Questionnaire (SESQ; Hayward et al., 2002) , Stigmatisation Scale (HSS; Bagley & King, 2005) , and the Discrimination and Stigma Scale (DISC: Thornicroft et al., 2009) . The most commonly used measure was the PDD which measured perceived stigma exclusively. The rest of the measures examined perceived stigma as a sub-component. Elaine Brohan, Mike Slade, et al. (2010) identified that none of the perceived stigma measures met all of their reliability and validity criteria (content validity, internal consistency, construct validity, test-retest reliability, and floor/ceiling effects). The SSMIS was identified as the most reliable and valid measure (by meeting content validity, construct validity, and test-retest reliability) all other measure met only one or two criteria.

Brohan et al. (2010c) identified ten measures of experienced stigma: the Internalised Stigma of Mental Illness Inventory (ISMI: Boyd et al., 2014; Ritscher & Phelan, 2004) , Consumer Experiences of Stigma Questionnaire (CESQ; Wahl, 1999) , Rejection Experiences Scale (RES; Bjorkman et al., 2007) , Depression Self-Stigma Scale (DSSS; Kanter et al., 2008) , Self-Reported Experiences of Rejection (SRER; Link et al., 1997) , Stigma Scale (SS; King et al., 2007), the Inventory of Stigmatising Experiences (ISE; Stuart et al., 2005), McArthur Foundation Midline Development in the United States (MIDUS; Kessler et al., 1999) , Discrimination and Stigma Scale (DISC; Thornicroft et al., 2009), and Experience of Discrimination Scale (EDS; Thompson et al., 2004) . A number of sub-components of experienced stigma were examined, discrimination experiences (Kessler et al., 1999; J.B. Ritsher & Phelan, 2004; Wahl, 1999), stigma experiences (Kanter et al., 2008; King et al., 2007; Stuart et al., 2005; Wahl, 1999) and rejection experiences (Bjorkman et al., 2007; B. G. Link et al., 1997) . Out of all the available measures of experienced stigma, the ISMI was identified as the most widely used and

psychometrically robust measure by meeting four of the five reliability and validity criteria (content validity, internal consistency, construct validity, and test-retest reliability). However, none of the measures met all outlined criteria.

Finally, Brohan et al., (2010c) identified five measures which examined internalised stigma: the Internalised Stigma of Mental Illness Inventory (ISMI; Boyd et al., 2014; Ritscher & Phelan, 2004), the Self-Stigma of Mental Illness Scale (SSMIS; Corrigan et al., 2006), the Depression Self-Stigma Scale (DSSS; Kanter et al., 2008), the Stigma Scale (SS; King et al., 2007), and the Inventory of Stigmatising Experiences (ISE; Stuart et al., 2005). As with perceived stigma, the ISMI was identified as the most reliable measure of internalised stigma but did not meet all reliability and validity criteria (floor and ceiling effects). All of the measures examined different components of internalised stigma such as stereotype endorsement/agreement (P. W. Corrigan et al., 2006; J.B. Ritsher & Phelan, 2004), alienation (J.B. Ritsher & Phelan, 2004), social withdrawal (J.B. Ritsher & Phelan, 2004), stereotype self-concurrence (P. W. Corrigan et al., 2006), self-esteem (P. W. Corrigan et al., 2006), secrecy/disclosure (Kanter et al., 2008; King et al., 2007), and general self-stigma (Kanter et al., 2008). The additional search conducted by the author of this thesis identified one further measure of internalised stigma which was not included in the Brohan et al., (2010) review, the Self-stigma of Depression Scale (SSDS; Barney et al., 2010) . This measure is a self-report measure which examined aspects of internalised stigma not examined in previous measures such as shame, self-blame and social inadequacy. It demonstrated adequate reliability and validity.

Brohan et al.'s (2010c) review indicated that there are no available measures of the personal stigma that meet all of the required reliability and validity criteria. All measures to date are self-report measures and do not have the necessary flexibility to explore the subjective experiences of stigma from a service user perspective. Also, self-report

measures have limitations such as ensuring credibility, issues of social desirability, cultural constraints, and other response biases such as pattern responding (Paulhus & Vazire, 2007). All measures to date have been for broad SMI experiences, and therefore may lack the specificity required to examine nuanced stigma experiences specific to different psychiatric diagnoses. There appears to be a need to develop a semi-structured outcome measure for personal stigma for specific SMI presentations.

1.5. Interventions for stigma

Given the detrimental impacts of stigma, researchers and clinicians have developed and refined interventions to tackle stigma at a public and personal level. A stigma intervention can be defined as "an intervention which aims to reduce stigma or discrimination" (pg.3; Loufty et al., 2015) . The aim of stigma interventions is to alleviate the stigma faced by the stigmatised group. Public interventions have focused on increasing the understanding and knowledge of the public about SMI through education and social contact interventions to alleviate stigma (Corrigan et al., 2012). Personal stigma interventions, have largely focused on internalised stigma and used therapeutic strategies borrowed largely from Cognitive Therapy (M. D. Knight, Wykes, & Hayward, 2006; P. T. Yanos, Lucksted, Drapalski, Roe, & Lysaker, 2014). The evidence base is reasonably developed for both public and internalised stigma. The evidence base for both areas of stigma will be examined here, however, the primary focus is on internalised stigma interventions.

1.5.1. Public stigma interventions

A public stigma intervention can be considered to be an intervention which attempts to tackle stigma at a public level (Mehta et al., 2015). Public stigma campaigns are usually conducted through mediums such as the media or through teaching/training workshops to challenge widespread public attitudes (Parcesepe & Cabassa, 2013). On the whole, they

aim to promote public knowledge and understanding of SMI. Many public stigma interventions have been implemented for SMI across a number of countries. A consensus study was conducted with a panel of mental health experts (n=32; professionals and service users) to examine what messages should be included in public stigma interventions (Sarah. Clement et al., 2010). Clement et al. (2010) identified that public stigma interventions should include messages of recovery, seeing the person, social inclusion, and the high prevalence of mental health issues. Furthermore, messages should also counteract otherness and ideas of difference, and not include problematic messages referring to aetiology.

A number of systematic and narrative reviews have been conducted examining the efficacy of public stigma interventions. In a recent systematic review, Mehta et al. (2015) examined the types and effectiveness of public stigma interventions which have been implemented to target public stigma (80 studies, n=422,653). They included a number of target groups for public stigma interventions such as university students, health care professionals, the general public, school students and armed forces. They identified a number of broad approaches to intervention: social contact, first person narratives, and development of mental health knowledge through a number of methods (videoed play, role plays, educational courses). Social contact interventions aim to increase the public's interactions with people with an SMI. They are underpinned by the belief that face-to-face contact allows the individual to challenge stereotypes and prejudicial attitudes, and have been illustrated to improve attitudes (S. Clement et al., 2012). First person narrative interventions involve personal stories of SMI to be shared and discussed with the public which hopes to increase empathy, to help the public identify a self-other overlap, and cause a shift in attributions (i.e. remove blame from the individual) (Mann et al., 2008) . Finally, educational based interventions aim to improve the knowledge and understanding of the

public towards people with SMI, which has been demonstrated to reduce stigmatising attitudes (Pinfold et al., 2003).

Mehta et al., (2015) identified in their meta-analysis that there is reasonable evidence to demonstrate that public stigma interventions improve knowledge and reduce stigmatising attitudes in the medium term. Having social contact with individuals with SMI was not significantly superior to the other available forms of interventions. The individual studies included in the review rarely examined changes in behaviours (i.e. acts of discrimination) therefore it is unable to be determined whether public stigma interventions improve such outcomes. In summary, public stigma interventions are reasonably effective in improving public attitudes.

1.5.2. Therapeutic interventions for personal stigma

Although less examined, some therapeutic interventions have been developed for internalised stigma in SMI. Internalised stigma interventions can be considered to be therapeutic interventions which attempt to alleviate internalised stigma (P. T. Yanos et al., 2014). A number of reviews have been conducted to examine the efficacy of therapeutic interventions for internalised stigma (Gerlinger et al., 2013; Mittal et al., 2014; Tsang et al., 2016; P. T. Yanos et al., 2014). It is important to note that the reviews did not follow best practice guidance outlined by the Cochrane Collaboration (J.P.T Higgins et al., 2011).

The reviews have identified a number of types of interventions which have focused on reducing internalised stigma. Six group interventions were identified; Healthy Self-Concept (E. McCay et al., 2007), Ending Self Stigma (Lucksted et al., 2011), Coming Out Proud (Corrigan, Kosyluk, & Rusch, 2013), Narrative Enhancement Cognitive Therapy (Yanos et al., 2011), and other CBT informed group interventions (Fung, Tsang, & Cheung, 2011). Healthy Self-Concepts was a 12-week group programme based on the

principles of CBT which aimed to improve engulfment and self-esteem. Ending Self-Stigma was a 9-session group intervention also based on the principles of CBT which aimed to improve internalised stigma, empowerment, recovery orientation, perceived social support and beliefs about societal stigma. Narrative Enhancement Cognitive Therapy was a 20 session group intervention designed to facilitate participants' developing a narrative/story regarding their stigma experiences, as well as utilising CBT strategies to tackle internalised stigma. A CBT model was utilised by two studies in a group format, one 8-session group intervention focusing on stigma and self-esteem (M. D. Knight et al., 2006), and the other a 12 group session (4 individual follow-up sessions) focused on internalised stigma (Fung et al., 2011). As outlined, these interventions either drew upon CBT (a psychological intervention, which aims to alleviate distress through targeting cognitions and behaviours; Beck, 1979) as part of their interventions, or aimed to enhance storytelling and disclosure. All interventions to date have been group interventions.

The reviews demonstrate that there have been a number of approaches applied to the alleviation of internalised stigma. To date, the interventions have found inconsistent findings across studies, and therefore the efficacy of internalised stigma interventions is inconclusive. Problematically, there has not been a robust review undertaken utilising systematic review strategies as suggested by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Liberati et al., 2009) and the Cochrane guidance for systematic reviews (J.P.T Higgins et al., 2011). Moreover, the efficacy of the interventions has not been examined specifically for people who experience psychosis.

1.6. Stigma of inpatients with psychosis

It is clearly established that people who experience psychosis are stigmatised by their social network, and they suffer from experienced stigma, perceived stigma and internalised

stigma (Gerlinger et al., 2013; G. Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). However, the evidence base examining the stigma of being an acute psychiatric inpatient with psychosis has been minimally examined, with the majority of research being conducted in outpatient settings.

Psychiatric inpatient units provide acute and intensive care to people in mental health crisis across the UK (Royal College of Psychiatrists, 2015). They provide support to people experiencing severe and acute mental distress who are at high risk to themselves and others (Royal College of Psychiatrists, 2010). The presentation of inpatients has changed dramatically over the last century due to the widespread closure of large asylums and significant reductions made in numbers of beds and a move towards community care (A. Thompson et al., 2004). Psychiatric inpatients beds have reduced from 155,000 in 1954 to 27,000 in 2008 (Tyrer, 2011). Due to the significant reduction in beds, inpatient services now only take on the most high-risk patients. The vast majority of inpatients admitted to a psychiatric ward have either had suicide intent or attempted to commit suicide (Royal College of Psychiatrists, 2010). People who experience psychosis make up to one-third to one-half of patients currently admitted to UK psychiatric hospitals. A total of approximately 27,000 people with psychosis are admitted to psychiatric hospitals each year and have the longest inpatient admissions (Thompson et al., 2007).

Stigma has been identified to be associated with a psychiatric inpatient admission since the development of the early psychiatric asylums (Goffman, 1961). The process of deinstitutionalisation has led to researchers being interested in the public perceptions of psychiatric hospitals and the patients being discharged from a hospital setting. It is widely established that the public holds negative attitudes towards those diagnosed with a mental illness and view them as dangerous, unpredictable and unlikely to recover (Crisp et al., 2005), and desire social distance from them (Angermeyer et al., 2005). One study

examined the public's perception of recently discharged inpatients and demonstrated that they viewed the patients as having poor communication, bizarre behaviour, poor social skills, aggressive behaviour, and behaviour which is disturbing to the public (Reda, 1996). The author concluded that inpatients are highly likely to experience public stigma following discharge.

As outlined, psychiatric inpatients are usually admitted to an inpatient ward following thoughts of attempting suicide or an attempt at ending their life (Royal College of Psychiatrists, 2015). In a large survey of n=4859 suicide cases in England, it was identified that 16% of total suicides occurred during an inpatient admission, and 23% took place within three months of being discharged from an inpatient hospital (with the two weeks post discharge being the most vulnerable time for patients) (Meehan et al., 2006). This demonstrates the high risk of suicide associated with an inpatient admission. Stigma has been shown to be a significant contributing factor to suicide (Pompili, Mancinelo, & Tatarelli, 2003). Pompili et al., (2003) demonstrated that stigma could prevent people from seeking treatment which exposes them to greater risk of suicide. Therefore, individuals who are admitted to inpatient units are more likely to be more stigmatised before admission. Moreover, in a large study across 25 European countries, social acceptance of a person was significantly associated with suicide rates (Schromerus et al., 2015). The authors concluded that stigma is a stressor which contributes to suicidality and that social isolation resulting from stigma also increases the risk of suicide. Therefore, this demonstrates that stigma has a role in causing and maintaining suicidality. Addressing the personal stigma experienced by psychiatric inpatients with psychosis appears imperative to reduce risk following discharge.

Psychiatric inpatient admissions are likely to cause stigma for two reasons: firstly the stigma from being admitted to a psychiatric inpatient ward, and secondly the stigma

experienced within an inpatient unit (Lloyd-Evans et al., 2010). Inpatient admissions have been noted to cause extreme distress to service users which can be considered a form of stigma. The dominant treatment available in psychiatric inpatient hospitals is arguably underpinned by the medical model with first line interventions being medical treatments such as anti-psychotic medication (Kings Fund, 2007). Although, psychosocial interventions are recommended they are not implemented as first line treatments and are secondary to medical care (Killaspy, 2007).

As previously outlined, the dominant use of the medical model can cause and perpetuate stigmatising beliefs due to the 'us and them' dynamic (Angermeyer et al., 2011). This is even more likely with 'professional staff' caring for 'patients' where a power imbalance is often present (S. Henderson, 2003). Although the subjective experience of stigma related to an inpatient admission has not been explored recently, subjective experience of inpatient admission has been explored quite extensively. A recent systematic review and thematic synthesis of the subjective experience of inpatient admission identified that inpatients had little control over their care, were offered medical treatment as a first line intervention, forced treatment practices, and poor relationships with staff (Wood & Alsawy, 2016). Moreover, inpatient admissions, particularly sectioned and forced ones, have been described by service users as traumatic and cause re-traumatisation due to the physical force sometimes utilised by staff (A. P. Morrison, Frame, & Larkin, 2003). This treatment could be reflective of discriminatory behaviour which may stem from prejudiced attitudes. This demonstrates that stigma could be a potential difficulty which would need to be explored further in acute psychiatric inpatients with experiences of psychosis. It is important to understand this further to support people in inpatient settings who are experiencing stigma.

The subjective experiences of being admitted to a psychiatric inpatient unit from a service user perspective are relatively unknown, especially for people who experience psychosis. To the author's knowledge, only one study has examined the experiences of stigma of an acute inpatient admission with patients experiencing an SMI (n=30; McCarthy et al., 1995). The study found that patients were more likely to keep their admission a secret due to stigma, and were often unsure about their diagnosis and reason for admission. This study is arguably out of date for current practice within UK inpatient services. As stated, there has been a significant decrease in bed numbers meaning the nature of inpatient admission has changed. Inpatients are more likely to present with complex presentations, multiple difficulties, and have briefer admission (Killaspy, 2007). Therefore, the stigma experience of current psychiatric inpatients with psychosis needs to be explored further.

1.7. Summary of the literature

SMI, and more specifically psychosis have been outlined to be constructs of mental distress widely understood as mental illnesses predominantly treated with first line medical treatment (NICE, 2014). Psychosis has been demonstrated to be one of the most stigmatised mental health problems worldwide which has significant long-term personal and social consequences for the individual. Evidence for SMI and psychosis has been presented to demonstrate significant levels of public stigma (Corrigan & Shapiro, 2010) in the form of negative stereotypes (P. W. Corrigan & A. C. Watson, 2002), prejudicial attitudes (G. Thornicroft, Brohan, Rose, Sartorius, Leese, et al., 2009) and discrimination (Parcesepe & Cabassa, 2013). Evidence has also been presented to demonstrate high levels of experienced stigma (Dinos et al., 2004), perceived stigma (Gerlinger et al., 2013), and internalised stigma (G. Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). Furthermore, these experiences have been demonstrated to be worse for people who experience

psychosis, as they are associated with the most stigma (Caveleti et al., 2014; Karidi et al., 2015; G. Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009).

1.8. Thesis Rationale

Tackling the stigma associated with SMI is a current UK government priority. In the recent "No Health without Mental Health" document (Her Majesty's Government, 2011) one of the six objectives was that "fewer people will experience stigma and discrimination". Most recently, tackling stigma has been identified as one of three main priorities by the Independent Mental Health Taskforce (2015). In the Deputy Prime Minister's 2014 strategy "Closing the Gap: Priorities for Essential Change in Mental Health", one of the priorities was to "stamp out discrimination around mental health" (Department of Health, 2014). This has led to increased funding and the development of initiatives aiming to reduce SMI stigma such as Time to Change. The government has pledged over £16,000,000 towards tackling mental health stigma (Department of Health, 2014). Therefore, reducing stigma for people who experience SMI, particularly people with psychosis, is essential.

The majority of government investment, and also research evidence, has focused on the public stigma interventions (Time to Change, 2014). However, people with psychosis continue to suffer the consequences of public stigma, and it is imperative that they be supported to manage the personal impacts of stigma. Therefore, further therapeutic developments should be made to help people with psychosis manage personal stigma. As described, a number of internalised stigma interventions are available for people who experience SMI, but a rigorous systematic review and meta-analysis has not been conducted to examine the relevance of such interventions for people with psychosis.

Secondly, the examination of available assessment measures for personal stigma demonstrated that there are no available measures that meet all reliability and validity criteria (Brohan et al., 2010c). They were all self-report measures and designed for people with SMI. This demonstrates that there is a need to develop an interview measure which is intended to understand the stigma experiences of people who specifically experience psychosis, and meets all relevant reliability and validity criteria. This will allow for the assessment and exploration of personal stigma for people with psychosis, which can be utilised in both research and clinical practice.

There is relatively little understanding of the subjective stigma experiences of acute inpatients who experience psychosis with only one study being conducted over 20 years ago (McCarthy, Prettyman, & Friedman, 1995). As outlined, being admitted to hospital is an incredibly stigmatising experience both within the hospital and from the public due to being admitted to a psychiatric inpatient unit (Goffman, 1961). Stigma is a significant contributing factor to suicide, which is usually the cause of admission, and a risk factor during admission, and post-discharge (Pompili et al., 2003). Therefore, understanding the subjective experiences of stigma for people with psychosis who are currently admitted to a UK psychiatric unit would be important to inform therapeutic support.

The quantitative examination of personal stigma experiences for people with psychosis is relatively under-researched. The relationship between perceived, experienced, and internalised stigma in people with psychosis has not been examined. Moreover, the role of internalised shame (as a subcomponent of internalised stigma) has been demonstrated to have a role in the internalisation of stigma (Rusch, Corrigan, Powell, et al., 2009) but it has never been examined for its relationship with perceived and experienced stigma. SMT would suggest that internalised shame would play an integral role in understanding an individual's personal stigma experiences (Gilbert, 2010). It is imperative that the

relationship between perceived stigma, experienced stigma and established consequences of internalised stigma (depression, hopelessness, internalised shame, low self-esteem and personal recovery) are examined for their relationship to better understand personal stigma experiences in people who experience psychosis.

Also, a number of theoretical models have been developed to understand the construct of stigma within SMI which has extended the understanding of its experience significantly (P. Corrigan & A. Watson, 2002; B. Link & Phelan, 2001). However, all have lacked clinical applicability and have not been developed for people who experience psychosis. CBT interventions have been applied to SMI stigma but have lacked a theory-driven formulation to underpin the intervention. Therefore, a clinically relevant model which specifically explained personal stigma experiences for people with psychosis needs to be developed.

Finally, it would be important to understand whether an internalised stigma therapeutic intervention is feasible and acceptable for acute inpatients with psychosis. As demonstrated, all internalised stigma interventions have been developed for people who are outpatients, and none have been examined for their efficacy with inpatients. Therefore, the development of a brief inpatient-specific intervention which focuses on internalised stigma would be of importance.

1.9. Aims of the thesis

Due to the outlined rationale, the aims of this thesis were:

1. To conduct a systematic review of psychosocial interventions for internalised stigma in psychosis. To meet this aim, narrative synthesis and meta-analysis methodologies were utilised. Study 1 addressed this aim and was titled "Psychosocial interventions for internalised stigma in people with a schizophrenia-

spectrum diagnosis: a systematic narrative synthesis and meta-analysis" (Chapter 3).

2. To develop a reliable and valid semi-structured interview measure of internalised stigma for people who experience psychosis. This aim was addressed by developing a measure, in consultation with service users, and to examine its psychometric properties using quantitative methodology. Study 2 "Semi-structured Interview Measure of Stigma (SIMS) in psychosis: Assessment of psychometric properties" (Chapter 4) addressed this aim. It was hypothesised that the SIMS would be a reliable and valid measure of personal stigma in psychosis.

3. To examine and understand the subjective experiences of stigma for acute inpatients that also experience psychosis. This was achieved using qualitative methodology, specifically thematic analysis, to examine participant experiences. This was achieved by Study 3 "Acute inpatients' experiences of stigma from psychosis: A qualitative exploration" (Chapter 5).

4. To examine the relationship between experienced stigma, perceived stigma and its relationship with psychological variables self-esteem, internalised shame, personal recovery, depression and hopelessness. Further, it aimed to explore the role of self-esteem and internalised shame as potential mediators. Study 4 achieved this aim, "The impact of stigma on emotional distress and recovery from psychosis: The mediatory role of internalised shame and self-esteem" (Chapter 6). It was hypothesised that experienced and perceived stigma would be significantly associated with the psychological variables. Moreover, it was hypothesised that

internalised shame and self-esteem would both be identified as mediators in this relationship.

5. To develop a cognitive model of internalised stigma in psychosis to explain experiences of internalised stigma using clinically relevant theory. Furthermore, it aimed to develop a model which could underpin a CBT intervention to alleviate internalised stigma in psychosis. This aim was examined by Study 5 "An integrative cognitive model of internalised stigma in psychosis" (Chapter 7).

6. To examine the feasibility and acceptability of a CBT-based internalised stigma intervention for inpatients that experience psychosis, based on the cognitive model developed in Study 5. This aim was achieved through Study 6 titled "A brief cognitive therapy intervention for internalised stigma in acute inpatients who experience psychosis: A feasibility randomised controlled trial" (Chapter 8). It was hypothesised that the intervention would be feasible and acceptable to participants.

2. Chapter 2: Methodology

The aim of this chapter is to provide an overview of the methodology utilised within this thesis. It will outline the rationale, decision-making processes, strengths and limitations of the methodologies employed. As an alternative format was chosen in order to present the PhD, the description of the methodology within individual papers was limited due to the word count outlined by the respective journals. Therefore, this chapter will provide a more detailed overview of the methodology utilised within individual studies.

2.1. Peer review of thesis research studies

All studies (except Study 6) have been peer reviewed. Studies 1 – 5 have been submitted for publication and received peer review feedback which was utilised to inform the write up of the respective studies. Furthermore, studies 2, 3, 4 and 6 received individual peer review from academics working within the Research and Development (R&D) department as part of the approval process. These were also used to inform the development of the individual studies.

2.2. Epistemological considerations

Before outlining my methodology, it is imperative to consider the epistemology underpinning this thesis. Epistemology has been described as the theory of knowledge and is an area of philosophy that aims to understand how knowledge is developed and how we come to believe things to be true (Barker, Pistrang, & Elliot, 2016). The way in which a researcher develops and interprets their data is dependent on their epistemological positioning. Hamlyn (1970) argues that there are four fundamental epistemological positions which will be described before outlining my epistemological position.

Realism is an approach that believes there is an objective world which is measurable and exists, which is independent of our subjective perceptions of it (Niiniluoto, 2002). It outlines that scientific research can reliably measure and examine the objective world. Arguably this approach has been the dominant position for most psychological research during the early development of the profession. This position was traditionally adopted by scientists who favoured empirical research but has, over recent decades, evolved into a critical realist approach to the social sciences. Critical realism adopts a position that a real world exists, however, we can never realistically understand it with complete certainty (Willig, 2001). The critical realist approach emphasises the importance of aiming to achieve reliability and validity in research for the research to test the real world with optimal efficacy. Critical realism is a popular position for clinical psychology, with research often testing psychological components such as cognitions, behaviours and emotions, which are assumed to be tangible constructs which exist and are measurable.

Constructionism has challenged the critical realist position and outlines that there is not an objective world and only subjective interpretations of it (Barker et al., 2016). It describes that there are multiple realities which are idiosyncratic and dependent on the perspective of the observer. Given the multiple realities and perspectives, it is tough to examine or measure the world from this position reliably. Therefore, within this approach, it is the examination of perspectives, which is the focus of constructionist research. A social constructionist approach has a particular emphasis on the social context and social relationships of the individual which play an integral role to the idiosyncratic perceptions of the world (Burr, 2003). In regard to research, social constructionism would outline that the researcher is an integral part of the process and part of the construction of knowledge.

2.2.1. Determining an epistemological position: important considerations

Considering an epistemological position was essential to undertaking this PhD research. Epistemological considerations can often be overlooked when researchers are undertaking quantitative research from a realist or critical realist positioning due to the approaches broadly assuming that constructs are measurable, stable, and can be reliably examined through empirical research. As a consequence, the need to consider the social context of certain constructs or critically evaluate them becomes less important. Despite this, more recent recommendations stipulate that researchers should consider their epistemological positioning despite their methodological preferences (Morgan, 2007). Therefore, the author placed importance in exploring an epistemological position.

Mixed-methods research, which this PhD is undertaking, requires researchers to position themselves epistemologically which can be a significant challenge when undertaking potentially diverse research methodologies. Mixed method researchers have to decide whether they are going to adopt a single epistemological position or adopt multiple positions reflecting individual subcomponents of their research (Cameron, 2011). The favourable option is to pick a position, which is consistent throughout the research programme (Greene & Caracelli, 2003). To this end, the author considered the aims of the research, the proposed methodology, and the author's personal beliefs regarding epistemology and determined that a critical realist position met the needs of this thesis. The critical realist position assumes that individuals interpret their reality but that there are constructs which are observable and measurable. Therefore, an individual's interpretation of reality is changeable but something that can be measured (Barker et al., 2016).

The topic of stigma itself was an important motivator in considering epistemology. Stigma is a construct which is embedded within the social environment in which it occurs (Goffman, 1963). Stigma is dependent on the cultural context, and stigma components

such as stereotype development, and forms of discrimination have been identified as culturally defined (B. Link & Phelan, 2001). In the current westernised UK context, within which this PhD was undertaken, stigma is considered a social concept but deemed to have specific components such as public and internalised stigma (P. Corrigan & A. Watson, 2002). This PhD was particularly concerned with internalised stigma and the personal experiences of stigma. Therefore, the research within this thesis was focused on examining and measuring specific stigma components. However, as with most areas of psychological research, these components are not observable positivistic concepts which can be discretely measured with full reliability and validity. The author believes that these components of stigma exist but are changeable and dependent on individual perceptions. Therefore this approach lends itself to a critical realist position. A critical realist position was adopted throughout this thesis and informed the subsequent decision making outlined in the remainder of this chapter.

2.3. Patient "service user" involvement

Patient and public involvement (PPI) is widely encouraged within the research field to increase the validity of research being conducted. PPI has been defined as "an active partnership between patients and/or members of the public and researchers" where they are "contributing to the research as advisors and possibly as co-researchers" (pg. 3; NIHR, 2014) . PPI is now an expectation for all large research programmes and considered best practice in smaller scale research. Given this, service user (patient) involvement was included wherever possible within this PhD thesis.

The author had a post-doctoral service-user researcher as one of her academic supervisors (RB). RB was involved in the design, planning, supervision, implementation and dissemination of all studies included within this PhD. In particular, RB has played an

important role in the qualitative analysis in Study 3 ensuring that themes were reflective of a service user perspective, and Study 5 where a theoretical model was developed.

In addition, an independent Service User Reference Group (SURG), which was funded and facilitated by the Psychosis Research Unit (PRU), Greater Manchester West NHS Foundation Trust, was also consulted about some studies within this PhD. The SURG comprise eight service users with lived experience of psychosis and mental health services. This group was integral in the development of the Semi-Structured Interview Measure of Stigma (SIMS) outlined in Study 2. They provided comments on the initial draft of the interview measure and provided feedback regarding the measure content and structure. Also, they provided feedback on the measures utilised for studies 2, 4 and 6.

2.4. Ethical considerations

This thesis followed the ethical guidance outlined by the British Psychological Society (BPS; 2010) throughout the design, development, implementation, and dissemination of all research studies. The consideration of ethics within a research capacity is essential to minimise risk and avoid harm to research participants. Given the sample populations within this thesis, consideration of ethics was of utmost importance to protect a potentially vulnerable group of people. The BPS outlines the importance of considering risk, consent and confidentiality which are explored in more detail below.

The BPS (2010) have defined risk as "the potential physical or psychological harm, discomfort or stress to human participants that a research project may generate" (pg. 15). It is imperative to identify and assess all possible risks when undertaking research. The main risk to participants in this thesis was being exposed to psychological stress or harm by being asked about potentially distressing experiences of stigma and discrimination. However, this risk was minimised by ensuring participants had a full understanding of the

nature of questions before consenting to participate, allowing participants to withdraw at any point, being offered emotional support by the researcher through the utilisation of their therapeutic skills during the research process. The risk to the researcher was also minimised by conducting the majority of the research sessions within the inpatient unit and local risk procedures being adhered to. Supervision was also utilised if the distressing emotional content was discussed within the research sessions.

Informed consent has been described as an individual being able to make an informed choice about participating in research by being given adequate information regarding purpose and procedures (BPS, 2010). Participants in the studies described here were presented with Participant Information Sheets (PIS; Appendix 1 & 2) approved by the Research Ethics Committee (REC) and Health Research Authority (HRA) respectively and given time to read through the information sheets with the researcher and have questions answered. The information sheets included all recommended components: descriptions of the aims of the project, types of data to be collected, methods of data collection, confidentiality, anonymity, compliance with the Data Protection Act (DPA: Great Britain, 1998), and time commitments. Therefore, valid informed consent was achieved with all participants included in this thesis. Consent was also documented with consent forms (Appendix 3 & 4), which were also approved by the REC and HRA. Participants were given a copy of the consent form as well as one being kept by the researcher. The consent forms were stored separately from the research data in locked NHS premises to ensure anonymity and confidentiality were maintained.

Confidentiality has been defined as a "duty of confidence which arises when one person discloses information to another (e.g. patient to the clinician) in circumstances where it is reasonable to expect that the information will be held in confidence" (pg. 7; Department of Health, 2003) . Confidentiality is a legal obligation and is underpinned by legislation such

as the DPA (Great Britain, 1998) and Caldicott Principles (The Caldicott Committee, 1997). Confidentiality must be provided to all participants undertaking research and only broken if the duty of care requires it (e.g. if participants express an intention to harm to themselves or others). This thesis adhered to principals of confidentiality throughout the research process. Confidentiality was only broken when participants expressed an intention of or actual harm to themselves or others, as outlined by NHS guidance (Department of Health, 2003). No identifiable information was utilised within the write-up of this thesis or through the publication of any data.

2.4.1. Ethical approval

Ethical approval was sought for all studies which involved participants. Studies 2, 3 and 4 gained NHS ethics approval (ID: 14/LO/2164; Appendix 5), R&D approval (Appendix 6) and full sponsorship from the University of Manchester (Appendix 7). As the procedures for ethical approval changed on the 1st April 2016, Study 6 received full ethical approval (ID: 16/NW/0332; Appendix 8), NHS HRA approval (ID: 187857; Appendix 9), R&D approval (Appendix 10) and sponsorship from the University of Manchester (Appendix 11).

2.5. Research Design and Procedures

The remainder of this chapter will focus on the design and procedures of the research papers (studies 1 – 6) outlined in Chapter 3.

2.5.1. Quantitative and Qualitative Methods

Quantitative and qualitative approaches are the two dominant subcategories of research methodology. In a basic sense, qualitative analysis is "concerned with describing the constituent properties of an entity, while quantitative analysis is involved in determining

how much of the entity there is" (pg. 20; Smith et al., 2009) . Both approaches are also arguably distinguishable by their epistemological positioning, with quantitative analysis mostly reflecting a realist or critical realist position, and qualitative analysis sitting within a constructionist or social constructionist position, although there are exceptions to this, e.g. thematic or content analysis where some degree of numerical or objective analysis may be used (Barker et al., 2016). Traditionally within research, qualitative and quantitative methods were employed independently to meet the required research aims. However, a pragmatic approach is now recommended to examine given research aims which often results in mixed-methods approaches being implemented (Creswell & Plano-Clark, 2011).

Mixed-methods approaches have been defined as "an approach to knowledge (theory and practice) that attempts to consider multiple viewpoints, perspectives, positions, and standpoints (always including the standpoints of qualitative and quantitative research)" (pg. 113; Burke Johnson et al., 2007) . More recent policy and guidance for health research also advocate for the use of mixed-methods research and acknowledge the value of both quantitative and qualitative research methodology (Creswell, Klassen, Plano Clark, & Clegg-Smith, 2012). Mixed-methods research allows for methodological variety which reflects the diverse nature of the complex health problems within current society. Therefore, a mixed-methods approach allows for more nuanced examination of health phenomena such as stigma and psychosis. Furthermore, a mixed-methods approach is aligned with the critical realist positioning of the author and therefore seemed an appropriate choice towards analysis.

A mixed-methods approach, one which combines both quantitative and qualitative approaches, was employed to meet the aims of this PhD. A mixed-methods approach was used across the thesis; studies 2, 4 and 6 were quantitative, and Study 3 was qualitative,

Study 1 used both qualitative and quantitative methodology, and Study 5 was a theoretical paper. The chosen methodologies will be described in subsequent sections.

2.5.2. Systematic narrative review and meta-analysis

The first example of a mixed-methods approach to analysis can be found in Study 1 where the use of a systematic narrative review and meta-analysis were utilised. To meet the first aim of the thesis, which was to review the available research studies which examined the efficacy of a psychosocial intervention for people who experience psychosis, the author considered a systematic narrative synthesis appropriate. However, the available review methodologies will be examined to justify the choice made.

A systematic review can be considered as "a summary of available carefully designed health care studies which provides a high level of evidence of the effectiveness of healthcare interventions" (pg. 1; Higgins et al., 2011) . Systematic reviews can gather evidence and give robust support of the efficacy of health care interventions. Problematically, systematic reviews in the traditional sense, in particular, methodologies outlined by Cochrane (J.P.T Higgins et al., 2011), can only be conducted when there are rigorous Randomised Controlled Trials (RCTs) available for analysis and do not work well when there are smaller, methodologically heterogeneous studies available. Furthermore, they do not function well when the aim of the review is not to examine the effectiveness of the intervention, but to ask other important questions such as *why* the intervention was helpful (Snilstveit, Oliver, & Vojtkova, 2012). This is when narrative approaches may be useful.

There a number of alternative approaches to reviews which can potentially be utilised such as thematic synthesis (Thomas & Harden, 2008), framework synthesis (Koehlmoos, Gazi, Hossain, & Rashid, 2011), meta-ethnography (Atkins et al., 2008), content analysis (Mays,

Pope, & Popay, 2005), realist synthesis (Greenhalgh, Kristiansson, & Robinson, 2007) and narrative synthesis (Popay et al., 2006). The former four are primarily concerned with synthesising qualitative literature and quantitative non-trial studies which were not the aim of Study 1 and therefore not relevant here, but the latter two are used to review research trials and therefore will be considered in more detail. Snilstveit et al. (2012) state that the type of review methodology used will be dependent on the research aims, nature of evidence, time and resources. These will be kept in mind when considering the following methods of synthesis.

2.5.2.1.Realist synthesis

As suggested by the name, realist synthesis is an approach to systematic review which is based on realist appraisals and focuses on examining the mechanisms of how interventions work. Snilstveit et al. (2012) outline that realist approaches are theory driven and the approach begins by outlining the key theories of how interventions work. It utilises theory to explore intervention change mechanisms within individual studies and draws together the similarities. It aims to provide an exploratory analysis of how interventions work within particular contexts or settings (Pawson, Greenhalgh, Harney, & Walshe, 2004). A strength of the approach is that it can inform how, why and where interventions work and identify specific effective change mechanisms (Snilstveit et al., 2012). However, it has been identified as less effective when applied to smaller studies with weaker designs, which are heterogeneous. This is problematic given the small evidence base available for the internalised stigma interventions relevant to this thesis. Furthermore, there is a relative lack of published rigorous guidance for the other outlined methods of synthesis, which may limit the reliability of the approach. As a result, realist synthesis was not considered the best-placed approach for the systematic review.

2.5.2.2.Narrative synthesis

Narrative synthesis is an approach developed by Popay et al. (2006) which allows the review of studies to tell a coherent story about a given topic area. It has four main elements: "to develop a theory of how an intervention works, why and for whom, to develop a preliminary synthesis of findings of included studies, to explore relationships in the data, and to assess the robustness of the synthesis" (pg. 11; Popay et al., 2006). It allows the user to review findings from multiple studies when the individual study designs do not allow for formal systematic review and meta-analysis of all study data. Narrative synthesis is often utilised when there is a small emerging evidence base for a given topic area. This is so a story can be told about a target topic area to provide readers with a meaningful summary about a given evidence base. An example where it is most often used is the examination of the efficacy of therapeutic interventions for a given population (Popay et al., 2006). Narrative synthesis is a flexible approach and allows for the use of multiple methods of data synthesis depending on the individual study data. Therefore methods of analysis such as vote counting and meta-analysis can be utilised within narrative synthesis.

2.5.2.3.Strengths and limitations of narrative synthesis and meta-analysis

Narrative synthesis was chosen as the approach to reviewing psychosocial interventions for internalised stigma in psychosis for several reasons. The evidence base is small and diverse and with studies not being RCTs they are not easily synthesised in a traditional systematic review and meta-analysis (J.P.T Higgins et al., 2011). Furthermore, a number of sub-aims within the review were best achieved with the use of narrative synthesis. For example, as the evidence base had not been previously reviewed specifically for a psychosis population, there was neither a published summary of interventions provided for

internalised stigma nor an examination of outcome measures available. A narrative summary of these points were important aims of the review. Moreover, narrative synthesis allowed for the use of meta-analysis to quantitatively examine the efficacy of internalised stigma interventions on a number of outcomes.

One of the limitations of narrative synthesis, compared to traditional approaches to systematic review, is the potential lack of transparency and clarity regarding the methods its user often adopt (Snilstveit et al., 2012). However, Popay et al. (2006) have responded to the criticism by publishing standardised guidance about how to conduct a narrative synthesis. Study 1 used Popay et al.'s (2006) guidance to inform the review process which hopefully alleviated some of these potential confounding factors.

2.5.2.4 Development of the systematic review design and aims

The design and the reporting of Study 1 followed guidance outlined in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Liberati et al., 2009). The review protocol was published in the Prospective Register of Systematic Reviews (PROSPERO) website before undertaking the review as recommended by PRISMA (PROSPERO 2014: CRD42014015161; Appendix 12).

As recommended by PRISMA, the design of the systematic review questions and aims were informed by the use of the Participant Intervention Comparator and Outcome (PICO) tool (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014). The PICO criteria also informed the search criteria, inclusion and exclusion criteria. The PICO tool provides four areas which the researcher needs to consider when designing a review; *Participant group, Intervention type, Comparison group,* and *Outcomes* examined (PICO). These were considered individually as outlined below.

The *participant group* was chosen to be people with psychosis due to the broader aims of the thesis focusing on stigma experiences of this group specifically. This involved the inclusion of psychosis and schizophrenia as defined by the DSM-V (American Psychiatric Association, 2013) but also those who did not have a formal diagnosis but were experiencing their first episode of psychosis. This definition had been used in similar relevant studies (e.g. Morrison et al., 2016). In regard to *intervention,* its conceptualisation was kept relatively broad, within inclusion of all psychosocial interventions which aimed to reduce internalised stigma for people with psychosis. A psychosocial intervention was considered to be an intervention which used strategies which targeted psychological or social factors to improve internalised stigma. Therefore, this essentially allowed for the inclusion of any non-medical interventions. It was not required for the study to have a *comparator*, and if there was a comparator, no restraints were placed on what this comparator was. Finally, regarding *outcome,* all studies had to examine internalised stigma as an outcome to be included in the review. There are a number of available measures which examine internalised stigma as an outcome (Elaine Brohan, Mike Slade, et al., 2010).

Based on the PICO criteria, the aims of the review were:

1. To examine the efficacy of psychosocial internalised stigma interventions for people with psychosis on the primary outcome (internalised stigma) and other secondary outcomes.
2. To examine individual study quality and risk of bias.
3. Examine the psychosocial internalised stigma interventions for their key mechanisms of change
4. Scrutinise study outcomes and measures used to assess outcome.

2.5.2.5. Development of inclusion and exclusion criteria

The development of the inclusion and exclusion criteria was based upon the PICO criteria and the broader thesis inclusion and exclusion criteria (section 2.6.1.4.). To be included in the review, individual studies had to have "≥50% of participants who met criteria for (i) a schizophrenia-spectrum diagnoses (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, psychotic disorder not otherwise defined by any criteria) or (ii) threshold for Early Intervention in Psychosis (EIP) services (to allow for diagnostic uncertainty)", in order to ensure the sample was primarily those with a schizophrenia spectrum diagnosis or psychosis presentation.

Studies also had to "examine internalised stigma or self-stigma as an outcome" to scrutinise the efficacy of the intervention on this outcome. The inclusion criteria of studies "which examined a psychosocial intervention which aimed to reduce internalised stigma" ensured that the review was focused on internalised stigma interventions rather than generic interventions which had reduced internalised stigma as a secondary outcome e.g. A. P. Morrison et al. (2011). Furthermore, this allowed for the examination of the important change mechanisms in internalised stigma interventions. The final noteworthy inclusion criteria were the inclusion of trials "with an RCT, controlled trial or cohort study design of effectiveness and efficacy" to capture the smaller studies with potentially weaker designs.

Minimal limitations were placed regarding exclusion criteria, again due to the potentially small heterogeneous studies available. However, no observational studies were included and studies with ≥50% participants with psychosis as a secondary diagnosis. This was to ensure the exclusion of potentially high risk and biased studies and studies which are not relevant to the target population respectively.

2.5.2.6. Development of search terms and strategy

The development of the search terms were guided by previous relevant systematic review papers (Griffiths, Carron, Parsons, & Reid, 2014; Livingston & Boyd, 2010; Mittal et al., 2014; P. T. Yanos et al., 2014) and the PICO criteria (Methley et al., 2014). A cluster of search terms were developed which reflected the sample population and both the constructs schizophrenia and psychosis. Individual psychotic symptoms were also examined in case interventions focused on the alleviation of symptoms. It also included the use of Boolean operators to allow for multiple uses of terms (e.g. schizophrenia, schizophrenic, schizotypy). Therefore the search terms regarding population were as follows, *Schizo**, OR *Psychosis*, OR *psychotic*, OR *delusion**, OR *hallucinat** OR *voices*. A group of search terms were also created for the intervention utilised. Given the researcher's awareness of the evidence base and that there were some Cognitive Behaviour Therapy (CBT) interventions, CBT related terminology was used. To identify other sorts of interventions more generic terms were used. Therefore, the following search terms were developed, *intervention*, OR *therapy*, OR *CBT*, OR *trial*. Given the paucity of literature about this topic, search terms were not defined for comparator or outcome. Finally, the search term *stigma* was also utilised as a third subgroup. Therefore, the search terms for sample, interventions and stigma were combined and inputted. Search terms were examined for in the title, abstract, and keywords of papers.

The OVID database was utilised which collectively searched PsycINFO, Embase, and Medline. These databases were chosen to access both psychological and psychiatric journals. Trial registries were also examined, the Cochrane Central Register of Controlled Trials (CENTRAL) and the Clinical Trials Registry (clinicaltrials.gov). This was to ensure the identification of potentially unpublished research which is best practice (J.P.T Higgins et al., 2011). The search strategy also followed guidance by PRISMA (Liberati et al., 2009)

and the relevant diagram was developed (Figure 1). Details of the search strategies are outlined in Chapter 3 (Study 1).

2.5.2.7. Assessment of bias and methodological quality

For systematic reviews, the Cochrane Grading of Recommendations, Assessment, Development and Evaluation (GRADE) risk of bias tool is the recommended tool for examining methodological bias within individual studies (J.P.T Higgins et al., 2011). However, this tool is only suitable for RCTs, which was not reflective of the studies included in this current review. To the author's knowledge, there were no formal Cochrane tools for assessing bias in non-randomised and non-controlled studies at the time the review was conducted but since this time two tools have been published which do meet these requirements (Sterne, Higgins, & Reeves, 2016; J. A. C. Sterne et al., 2016). As a consequence, the Effective Public Health Practice Project (EPHPP) tool was utilised (Armiji-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012) which allowed for the concurrent assessment of all studies included in this review.

2.5.2.8. Methods of data synthesis

As outlined, narrative synthesis and meta-analysis were utilised to analyse the studies identified within the review process. A description of strategies utilised is described here.

The narrative synthesis followed the guidance outlined by Popay et al. (2006) and was underpinned by the four outlined stages of the process. The review considered the first element of the synthesis which was to develop a "theory of change" regarding why an intervention may be helpful (Popay et al., 2006). As the review was examining psychosocial interventions for internalised stigma, there was not one theoretical model that was drawn upon. However, one of the aims of the review was to understand how the

psychosocial interventions may facilitate change, and tentatively reflected upon this within a CBT framework given that most of the interventions were informed by this model.

Popay et al. (2006) outlined the importance of developing a preliminary synthesis by drawing together the key components of the included studies. The aim of this stage is to describe the effects of the intervention and what may be causing these effects. The review achieved this by synthesising the descriptions of the interventions, intervention types, modalities and other descriptive factors. Popay et al. (2006) explain that this can be done through summary tables and descriptive paragraphs of the included studies, which was undertaken by the review. Furthermore, examination of the common intervention change mechanisms utilised across interventions and the use of outcome measures also contributed to stage 2.

The methodological quality of studies also has to be examined which is particularly important as the review included small and low quality studies (IntHoult, Ioannidis, Borm, & Goeman, 2015). As described, this was examined through the use of the EPHPP tool (Armiji-Olivo et al., 2012). Finally, the relationships between studies needs to be explored (Popay et al., 2006). This is where themes or effects across studies are drawn together. This was done using meta-analysis with eligible studies. Meta-analysis was conducted using Comprehensive Meta-Analysis (CMA) software, version 3 (Borenstein, Hedges, Higgins, & Rothstein, 2009). All available data from RCTs was utilised for examination of efficacy on primary and secondary outcomes. The detail of the meta-analysis is described in section 3.3.6. Popay et al. (2006) also describe the importance of completing sub-group analyses; however, this was not possible with the small studies included within this review.

2.5.3. The development of an integrative cognitive model of internalised stigma in psychosis

Study 5 aimed to develop a theoretical model of internalised stigma in psychosis drawing upon cognitive theory and SMT. This model utilised both qualitative and quantitative research to inform its development. This study followed guidance in developing theoretical CBT models from D.M. Clark (2004). D.M. Clark (2004) outlined the importance of drawing together theories and experimental science to inform treatment development. He outlined six key stages in developing treatments which are described below:

1. To use clinical interviews and cognitive psychology paradigms to identify core cognitive appraisals contributing to the target problem.
2. To construct a theoretical account that explains why the negative cognitive appraisals do not self-correct.
3. To test the hypothesised maintaining factors in rigorous experimental studies.
4. To develop specialised cognitive treatments which aim to reverse the empirically validated maintaining factors.
5. To test the efficacy of the treatments in RCTs.
6. To help make the treatments more broadly available through dissemination studies.

This current thesis attempted to incorporate these stages in the development of the theoretical model outlined in Study 5. Prior to undertaking the six stages, a comprehensive literature review and systematic review (Study 1) was undertaken to develop a thorough understanding of the evidence base of internalised stigma interventions in psychosis. Moreover, a literature review was conducted examining relevant social cognitive models of stigma (P. Corrigan & A. Watson, 2002; B. Link & Phelan, 2001), qualitative literature examining service user experiences of stigma (Burke, Wood, Zabel, Clark, & Morrison, 2016; Wood, Burke, Wardle, Chapman, & Morrison, 2015), and quantitative research

examining the relevant cognitive, emotional and behavioural components and consequences of stigma (Livingston & Boyd, 2010).

To meet point 1, clinical interviews were undertaken in Study 3 using the SIMS (Wood et al, 2016) examining internalised stigma with people who experience psychosis. Moreover, previous qualitative research examining outpatients' perspectives were also included to ensure the model was relevant to a broad psychosis population (Burke et al., 2016; Wood, Burke, Byrne, et al., 2015). Furthermore, two relevant cognitive models of psychosis and SMT were reviewed to help develop a conceptualisation of internalised stigma from a cognitive perspective (Garety et al., 2001; Morrison, 2001; Gilbert, 2010). From this, as well as drawing upon the relevant stigma literature, the proposed maintaining factors of internalised stigma in psychosis could be identified for point 2 ('construct theoretical account'). To consider point 3, these maintaining factors were examined in some detail in Study 4 where the relationships between key variables were scrutinised using correlation, regression and mediation analysis. Once the theoretical model was developed, point 4 and 5 ('develop and test treatment') were achieved through the implementation in the feasibility study outlined in Study 6. Point 6 was not examined in this thesis but should be considered for future research.

2.6. Clinical research with participants

Studies 2, 3, 4 and 6 involved collecting data from participants who were mental health service users with experiences of psychosis. Therefore, this section will describe the methodological considerations for these studies.

2.6.1. Quantitative research design

2.6.1.1.Cross-sectional design

To achieve a number of the aims outlined in studies 2 and 4, a cross-sectional design was implemented. A cross-sectional design is a study design which collects data at one time point from a chosen sample population (C. J. Mann, 2003). Cross-sectional designs are often utilised when questionnaire data is being collected. Cross-sectional studies have a number of benefits including the ability to study multiple outcomes concurrently, determining prevalence, and examine the psychometric properties of newly developed outcome measures. Therefore, it was a methodological design which was best suited to achieving the majority of the aims of studies 2 and 4. In regard to Study 2, the factor analysis, internal consistency, interrater reliability, content validity, criterion validity, construct validity and floor and ceiling effects were examined using the cross-sectional design. Study 4's aims were fully met using a cross sectional design.

2.6.1.2.Longitudinal design

A longitudinal design was utilised for some elements of Study 2, and for Study 6. A longitudinal study has been defined as a study which examines the same participants over a set period of time on repeated outcome variables (Barker et al., 2016). In regard to health studies, longitudinal studies usually involve participants being "followed over time with continuous or repeated monitoring or risk factors or health outcome or both" (pg.1; British Medical Journal, 2016) . In regards to Study 2, the longitudinal design was utilised to psychometrically examine test-retest reliability and sensitivity to change. Two additional time points were utilised to measure test retest reliability at 4 months (N= 25) and to measure sensitivity to change at 7 months (n=28). Study 6 utilised a longitudinal design in a more traditional sense to examine the efficacy of a psychological intervention. It included

participant assessments using repeated outcome measures as baseline, post therapy and at follow-up.

2.6.1.3.Participants and recruitment

Participants were recruited from two sources for the purposes of this thesis research. N=29 participants were recruited from Greater Manchester West NHS Foundation Trust (GMW). Participants were recruited from mental health services across Bolton, Salford and Trafford and either from Early Intervention Services (EIS) or Community Mental Health Teams (CMHT). Participants were recruited as part of a pilot RCT of CBT for internalised stigma in psychosis (A. Morrison et al., 2016). These participants contributed to the sample for studies 2 and 4. The remainder of participants for studies 2, 3, and 4 (n=50) were recruited from a psychiatric inpatient unit in North East London Foundation Trust (NELFT). A total of five acute inpatient wards (three male and two female) were utilised as recruitment sites. For the purposes of Study 6, a further n=30 participants were recruited from the same inpatient services as studies 2, 3 and 4. All participants for the purposes of this thesis research met the same inclusion criteria as outlined below (section 2.6.1.4).

All participants were recruited via their care coordinator or keyworker. The researcher (EB, GE, or LW) presented at the mental health service team business meetings to describe each study using respective study leaflets (Appendices 13 & 14). The purposes of each study, and their inclusion and exclusion criteria were clearly outlined. Clinicians were asked to inform their service users about the study and approach potential participants to explain the study. The clinician would either give the researchers' details to the potential participants for them to initiate contact with the researcher or, with their verbal consent, pass on potential participants' name and contact number to the researcher. The researcher would contact the potential participant to go through the relevant PIS with them

(Appendices 1 & 2). They had the opportunity to ask any questions they wished. The potential participant had a minimum of 24 hours to decide whether they wanted to take part in the research or not. Once a participant agreed to take part, written informed consent was taken (Appendices 3 & 4).

2.6.1.4.Inclusion and Exclusion Criteria

Participants met the following inclusion criteria for all studies included in this thesis:

(a) Participants were aged between 18 and 65 to identify an adult sample.

(b) Participants met ICD-10 criteria for schizophrenia, schizoaffective disorder or delusional disorder, or met criteria for an early intervention service to allow inclusion of first episode service users without a diagnosis.

(c) For studies 3 and 6, participants also had to be currently admitted to an acute psychiatric inpatient unit.

Exclusion criteria for this thesis were:

(a) Moderate to severe learning disability due to the aims of the thesis focusing on experiences of psychosis as the primary presentation.

(b) Organic impairment as this may be the cause of the experiences of psychosis and has a different aetiology to the psychosis examined within this thesis.

(c) Not having the capacity to consent to research participation as informed consent was required for the purposes of this study

(d) Non-English speaking participants as (i) the majority of self-report measures utilised in this thesis were only validated in English and (ii) this thesis did not hold a budget for a translator

(e) Severe thought disorder as this may have impacted on their ability to (i) complete the research requirements and (ii) their ability to give informed consent**.**

(f) A primary diagnosis of drug and alcohol dependency due to it being a confounding factor in the cause and maintenance of psychosis.

2.6.1.5. Sample size

A sample size was calculated for the purposes of studies 2, 4 and 6. Studies 2 and 4 utilised the same sample and the calculation was based on the required analyses for these studies, and the largest required sample size was chosen. Firstly, a sample size calculation was undertaken for both correlation and regression analyses. Using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009) with alpha as 0.05 and power as 0.8, the sample size required for a medium effect size (J. Cohen, 1988) was calculated for correlation analysis (n=67) and regression analysis (with two predictor variables; n=61). Factor analysis, utilised in Study 2, requires three to ten participants per questionnaire item (Nunnally & Bernstein, 1994), and n=71 participants are required to identify a moderate effect size in mediation analysis (Fritz & MacKinnon, 2007). Therefore, the aim of these studies was to recruit n=80 participants to meet the requirements of all analyses and to allow for dropouts.

Study 6 utilised the recommended sample size for feasibility studies therefore a sample size calculation was not required. Lancaster, Dodd, and Williamson (2004) recommend a sample size of 30 for the examination of feasibility which was applied to Study 6.

2.6.1.6.Outcome measures

Studies 2, 4 and 6 all utilised similar outcome measures and these are described below. These measures were chosen, in consultation with the SURG described above, as appropriate outcome measures to meet the relevant aims of the individual studies. The

SURG felt strongly that inclusion of a measure of psychotic symptoms (e.g. Positive and Negative Syndrome Scale; Kay et al., 1987) would contradict the de-stigmatising aims of the research and therefore a measure of psychotic symptoms was not included within this thesis.

2.6.1.6.1. **Semi-structured Interview Measure of Stigma in psychosis (SIMS)**

The SIMS (Appendix 15) was utilised within studies 2 and 4 but with different purposes (Wood, Burke, Byrne, Enache, & Morrison, 2016). Study 2 describes its development and validation, and Study 4 utilises the subscales of *perceived* and *experienced* stigma to explore their relationship with other psychological variables. As the development and validation of the SIMS is described in detail in study 2 (section 4.3.1.) only a brief overview of the measure will be given here. The SIMS was developed in consultation with the SURG and aimed to examine subjective experiences of personal stigma. It is an 11-item (10 scored items) semi-structured interview measure of personal stigma for people with experiences of psychosis. It examines experienced stigma, perceived stigma, and internalised stigma (impacts of stigma on self-esteem, relationships, emotions, behaviours, recovery, treatment, and positive consequences of stigma). Participants' responses are rated on a scale of 0 (no experiences/impact of stigma) to 4 (severe impact/experiences of stigma) by the interviewer. The interview takes approximately thirty to forty-five minutes to complete. The measure demonstrates good internal consistency (Cronbach alpha = 0.87). The SIMS measures the impact of stigma over the past month. This was to ensure the SIMS could identify change in personal stigma within RCTs (A. Morrison et al., 2016).

As stated, this measure was utilised in studies 2 and 4 only. It was not included in Study 6 due to concerns regarding participant burden. Participants within Study 6 were asked to complete a baseline assessment, two-hour therapy intervention, and a post-therapy follow-

up assessment within a two week period. The author and supervisors were concerned that the addition of the SIMS would be burdensome for participants. Secondly, the SIMS measures change across a one month period therefore the timeframe of Study 6 was too short for the SIMS to measure change across this period.

2.6.1.6.2. **Internalised Stigma of Mental Illness Inventory (ISMI)**

The ISMI is a 29-item scale (Ritsher et al., 2003) examining internalised stigma (Appendix 16). Internalised stigma is defined as "the process by which a person with SMI loses previously held or hoped for identities (e.g., self as student or worker) and adopts stigmatizing views held by many members of the community (e.g., self as dangerous, self as incompetent)" (pg. 16; Mashiach-Eizenberg et al., 2013) . It has five subscales of alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance. Following feedback from the SURG, the wording of items on the measure were changed. The term 'mental illness' was replaced by 'mental health problems' as members of the group thought 'mental illness' was too stigmatising. Items on the measure included: 'I am disappointed in myself for having mental health problems', and 'I can't contribute to society because I have a mental health problem'. Participants were asked to rate items on a scale from 1 (strongly disagree) to 4 (strongly agree). It was developed with a sample of 127 mental health outpatients. The ISMI had excellent internal consistency (Cronbach alpha=0.90) and test-retest reliability (r=0.92). This ISMI was utilised in Study 2 as a primary comparator measure. Firstly, in a large systematic review of stigma measures it was considered to be the most reliable and valid tool available to measure stigma, and therefore the highest-quality comparator measure with which to examine the construct validity of the SIMS (Elaine Brohan, Mike Slade, et al., 2010).

2.6.1.6.3. **Internalised Stigma of Mental Illness Inventory– Short version (ISMI-S)**

The ISMI-S (Boyd et al., 2014; Appendix 17) is a 10-item version of the original 29-item measure (Ritscher et al., 2003). It includes two items from each original subscale. It also demonstrates good internal consistency (Cronbach alpha=0.94). As with the original ISMI, the term mental illness was changed to mental health problems in order to be less stigmatising. Study 6 utilised the short 10-item version of the ISMI as it is an equally reliable but briefer measure.

2.6.1.6.4. **Stigma Scale (SS)**

The SS is a 28 item self-report scale which aims to measure experiences of stigma (King et al., 2007; Appendix 18). It has three subscales of discrimination (experiences of stigma), disclosure (willingness to discuss mental health problems) and positive aspects of mental illness (development of understanding and acceptance). Individual items for this measure were originally developed from semi-structured interviews examining service users subjective experiences of mental health stigma taken from another study (Dinos et al., 2004). Items on the measure include 'having had mental health problems has made me a more understanding person', 'people have been understanding of my mental health problems', and 'I am scared of how other people will react if they find out about my mental health problems'. Participants rate their level of agreement on a five-point scale from strongly agree to strongly disagree. The measure demonstrates good internal consistency (Cronbach Alpha = 0.87), as do individual subscales (discrimination =088; disclosure =0.85; positive aspects = 0.64).

For the purposes of this study only the collective total of the disclosure and positive aspects subscales were utilised. This was due to the remaining subscale (discrimination) being considered as unreliable in identifying changes in stigma (A. Morrison et al., 2016).

This measure was utilised in studies 2, 4 and 6. It was chosen as a measure of stigma due to being cited as one of the most reliable and valid measure available (Brohan et al., 2010), and developed from interviews with service users about their stigma experiences (Dinos et al., 2004).

2.6.1.6.5. **Beck Depression Inventory for Primary Care (BDI-PC)**

The BDI-PC (A. T. Beck, Guth, Steer, & Ball, 1997) is a 7 item self-report measure of depression (Appendix 19). Depression has been defined as "a wide range of mental health problems characterised by the absence of a positive affect (a loss of interest and enjoyment in ordinary things and experiences), low mood and a range of associated emotional, cognitive, physical and behavioural symptoms" (pg.13; NICE, 2009) . It was developed as a brief version of the original 21 item measure (A. T. Beck, Steer, & Brown, 1996). It measures symptoms of depression on a 4-point likert scale from 0 – 3. It asks participants to rate items in relation to how they have been feelings over the last two weeks. Each individual item has responses unique to it; for example, to measure suicidality participants are asked to choose from 0 -'I don't have any thoughts of killing myself', 1-'I have thoughts of killing myself, but I would not carry them out, 2-'I would like to kill myself', and 3- 'I would kill myself if I had the chance'. Participants can score between 0 – 27 with scores over 4 indicating a major depressive disorder. The measure demonstrates good internal consistency (Cronbach alpha = 0.86).

This measure was utilised in studies 2, 4 and 6 as it is considered one of the most robust measure of depression available (Lako et al., 2012). Furthermore, the short version demonstrates good reliability in comparison to the original BDI (A. T. Beck et al., 1997). Depression was chosen as an outcome as research has widely demonstrated a strong relationship between stigma and depression (Livingston & Boyd, 2010).

2.6.1.6.6. **Beck Hopelessness Scale (BHS)**

The BHS (Beck et al., 1974) is a twenty item self-report measure examining levels of hopelessness (Appendix 20). Beck et al. (1974) outline that hopelessness is a core characteristic of depression and other conditions such as suicide, schizophrenia, and alcoholism therefore an important component to examine. The scale includes items such as 'I might as well give up because there is nothing I can do about making things better for myself', 'I have enough time to accomplish the things I want to do', and 'All I can see ahead of me is unpleasantness rather than pleasantness'. Participants rate their agreement on items by either choosing 'true' or 'false'. Participants can score a total of twenty points with scores between 0 and 3 indicating minimal hopelessness, scores between 4 and 8 indicating mild hopelessness and scores between 9 and 14 indicating moderate hopelessness, and scores between 15 and 20 indicating severe hopelessness. This measure demonstrates good internal consistency (Cronbach alpha = 0.93).

This measure was utilised in studies 2 and 4 to measure hopelessness as it is one of the most reliable and valid measures of this construct (A. Beck, Weissman, Lester, & Trexler, 1974). Furthermore, the relationship between stigma and hopelessness is widely established (Livingston & Boyd, 2010). The BHS was not utilised in Study 6 as, following peer review, it was replaced with stigma specific measures, which were thought to be more likely to identify change in the intervention.

2.6.1.6.7. **Self-Esteem Rating Scale – short form (SERS)**

The SERS (Appendix 21) is a twenty item self-report measure of self-esteem (T. Lecomte, Corbiere, & Laisne, 2006). Self-esteem has been described as "neither a static trait nor a transient state but rather a self-concept that can fluctuate with social feedback and self-evaluations" (pg. 100; Lecomte et al., 2006). The SERS includes items such as 'I get angry

at myself over the way I am', 'I feel that I get pushed around more than others', and 'I feel ashamed about myself'. It has two subscales of positive self-esteem and negative self-esteem. Participants rate their agreement on individual items on a scale from 1 (never) to 7 (always). Participants can score between 20 and 140 with higher scores indicating higher self-esteem.

This measure of self-esteem was utilised in studies 2, 4 and 6 due to self-esteem being widely documented as being impacted upon by stigma (P. Lysaker, Yanos, Outcalt, & Roe, 2010). Furthermore, the SERS is demonstrated to be a reliable and valid measure examining self-esteem with people who experience psychosis and has been utilised in a number of related research studies (M. D. Knight et al., 2006; Vass et al., 2015).

2.6.1.6.8. **Process of Recovery Questionnaire (QPR)**

The QPR (Law et al., 2014) is a 15 item self-report measure examining subjective experiences of recovery from psychosis (Appendix 22). It is a brief version of the original 22-item QPR (Neil et al., 2009). The authors have defined recovery as the rebuilding of self, rebuilding of life and hope for a better future and can occur despite the presence of ongoing psychotic symptoms (Pitt et al., 2007). The measure was developed from semi-structured qualitative interviews with service users about their experiences of recovery (Pitt et al., 2007). Statements on the questionnaire include: 'I feel able to take chances in life', 'I feel better about myself', 'I can recognise the positive things I have done' and 'my experiences have changed me for the better'. Participants are asked to rate these statements on a 5-point likert scale from 'disagree strongly' to 'agree strongly' and to consider how they have felt about the items over the last week. The QPR has been found to be a reliable and valid measure (Cronbach alpha = 0.93).

The QPR was chosen as a measure of recovery due to the nature of its development. It was developed in partnership with service user researchers, and from interviews conducted with and by service users with experiences of psychosis (Pitt et al., 2007; Neil et al., 2009). Therefore, it was assumed that this outcome measure was most likely to represent service users' personal recovery in comparison to other standard recovery outcome measures. The SURG also stated it was important that a measure of user defined recovery was included in all relevant thesis studies.

Personal recovery was also chosen as an important factor to measure due to the service user led recovery literature widely citing stigma as a significant hurdle in the recovery process (Pitt et al., 2007). Moreover, quantitative research has also demonstrated similar findings (Vass et al., 2015). Therefore, personal recovery was considered an important outcome. This measure was utilised in studies 2, 4 and 6.

2.6.1.6.9. **Internalised Shame Scale (ISS)**

The ISS (Cook, 1987) is a 30 item self-report measure of internalised shame (Appendix 23), originally developed in a sample recruited from alcohol recovery programmes. This measure was utilised in studies 2 and 4 to examine subjective perceptions of internalised shame. It is a measure of shame proneness and internalised shame and does not measure the affect of shame. Participants rate on a 5-point likert scale from 1 ('never') to 5 ('almost always'). Example items on this measure include 'I feel smaller than a pea', 'I feel somehow left out', and 'I feel intensely inadequate and full of self-doubt'. It demonstrates good internal consistency (Cronbach alpha = 0.90). Participants can score between 0 – 96 with higher scores indicating higher levels of internalised shame.

Internalised shame was chosen for the aims of studies 2 and 4 because it has been demonstrated to be associated with stigma (Rüsch et al., 2014). More specifically, this

measure was chosen as it is the best available measure of internalised shame (J. Harper, 2011). However, the measure has been criticised for not reliably examining internalised shame as conceptualised in more recently developed third-wave CBT models; rather it examines trait shame and not the affective-cognitive states which underpin the concept (Goss, Gilbert, & Allan, 1994). Given this criticism, and the additional informal feedback from participants in studies 2 and 4 that the ISS was too long and that the questions were worded in an unhelpful way (e.g. items such as 'I feel smaller than a pea'), it was not included in Study 6.

2.6.1.6.10. **Attitudes towards Mental Health Problems scale (AMHP)**

The AMHP scale (Appendix 24) is a 35-item self-report measure which examines different aspects of shame in relation to having a mental health problem (Gilbert et al., 2007). For the purposes of this research, the sub-scale relating to stigma awareness was utilised. There were three relevant sub-sections regarding how respondents view themselves, how their family view them, and how their community view them. Participants are asked to rate their agreement on items from 0 (strongly disagree) to 3 (strongly agree). Example statements included 'I think my community would look down on me', 'I think my family would see me as inferior' and 'I would see myself as a weak person'. It has good internal consistency on all subscales (Cronbach alpha = 0.85 and 0.97; Gilbert et al., 2007).

This questionnaire was not utilised in studies 2 and 4 as it was not required to meet the aims of those studies. It was included as an outcome measure of Study 6 following a peer review of the protocol for Study 6 suggesting that an extra measure of attitudes relating to mental health stigma should be included. This measure was chosen by the author as it was a brief measure (minimising participant burden) that allowed for the examination of personal, family and community stigma attitudes.

2.6.1.7.Non-validated measures

2.6.1.7.1. Demographics sheet

A demographics sheet (Appendix 25) was developed in order to gather demographic information from study participants. This was utilised in studies 2, 3, 4, and 6. Participants were asked for their age, gender, ethnicity, religious beliefs, psychiatric diagnosis, education level, employment status, marital status, diagnosis, length of contact with mental health services, and current mental health service use. Number of admissions to psychiatric inpatient wards, admission status and the length of current admission, was also extracted for inpatient participants. Only data deemed as important contextual information for the relevant studies was extracted as per the Caldicott Principles (Institute of Health Records and Information Management; IHRIM, 1999) .

2.6.1.7.2. Feedback questionnaire

For the purposes of Study 6, a feedback questionnaire was developed examining the participant's experiences of the study as well as of the intervention (Appendix 26). The feedback questionnaire was designed to gather feasibility data and asked participants about the positive and negative elements of the intervention, positive and negative elements of taking part in the research, further suggestions for change, and disclosure following the intervention.

2.6.1.7.3. Feasibility data collection sheet

A data collection sheet was developed to collect the required feasibility data for Study 6 (Appendix 27). The data collected included: recruitment rates, recruitment timeframe, willingness of clinician's to recruit participants, consent rates, willingness of participants to be randomised, dropout rates, time needed to undertake the research study, adherence to treatment, types of intervention change mechanisms used, and serious adverse events.

2.6.1.8.Procedure

Once a potential participant for a study was identified, and informed consent had been attained, participants completed a demographics sheet examining their personal characteristics. Participants were then given the battery of study measures in a random order to minimise practice effects and assessment fatigue impacting upon specific measures (Paulhus & Vazire, 2007). Each assessment session took approximately thirty to forty-five minutes to complete. Participants went through the individual questionnaires alongside the researcher and had the opportunity to ask questions if they wish (studies 2, 3, and 4). For Study 6, in an attempt to uphold blindness, participants were asked to complete the questionnaires independently but where this was not possible the researcher would complete the questionnaires with them. Once the assessment was complete, the researcher took time to answer any final questions or queries from the participant. For studies 4 and 6 participants would repeat this battery of assessments at further time points in order to meet the aims of the respective studies.

2.6.1.9.Methods of evaluation and analysis

The methods of analysis and evaluation for studies 2, 4 and 6 are outlined separately below. Within these sections, decisions will be described about methods of analysis or evaluation chosen. Where applicable, all data analysis was conducted using the Statistical Package for the Social Sciences (SPSS) version 23 (IBM Corp, 2015). For all studies, if or when missing data was less than 20%, it was replaced with the questionnaire mean.

2.6.1.10. Psychometric validation of the SIMS

The aim of Study 2 was to develop and examine the psychometric properties of the SIMS. Validation of the SIMS measure followed guidelines for the testing of psychometric properties of health based measures outlined by Terwee et al. (2007). An initial factor

analysis was conducted to explore the factor structure of the SIMS, as recommended when developing a new measure (Nunnally & Bernstein, 1994). A principal components analysis was conducted as there was not a predefined structure given to the measure. Once a factor structure was established the examination of psychometric properties was undertaken, underpinned by the principles of reliability and validity which are outlined below.

2.6.1.10.1. **Examination of reliability**

Reliability can be defined as "the extent to which an experiment, test, or any measuring procedure yields the same result on repeated trials" (pg. 11; Carmines & Zeller, 1979) . Reliability has a number of important subcomponents, which are essential to examine when developing a new health measure.

Firstly, internal consistency was examined which was the "extent to which the items in a questionnaire are correlated thus measuring the same concept" (pg. 36; Terwee et al., 2007) . Internal consistency is inspected by examining the relationship of individual measure outcomes with one another. Internal consistency was examined in Study 2 using Cronbach's alpha statistic and intra-class correlations (ICCs), recommended statistical procedures (Nunnally & Bernstein, 1994). ICCs are most suitable for continuous measures but arguably Cronbach's alpha is the most widely used, therefore both were utilised (Terwee et al., 2007). Landis and Koch (1977) outline that 0.01 – 0.2 indicates slight agreement, 0.21-0.4 indicates fair agreement, 0.41-0.6 indicates moderate agreement, 0.61 – 0.8 indicates substantial agreement, and 0.81 to 1.00 indicates perfect agreement.

Test-retest reliability is "the degree to which repeated measurements in a stable person provide similar answers" (pg. 36; Terwee et al., 2007). Therefore, scores on the SIMS were examined at baseline and with a subsample of participants at a 4-month follow-up. Usually, an intervening period of between one to several weeks is recommended to

examine test-retest reliability. However the SIMS examines stigma experiences over a month timeframe, and a 4 month test-retest period was chosen for convenience as this was the follow-up period of the RESPECT study (A. Morrison et al., 2016). An ICC was calculated comparing participant scores on the SIMS at baseline and at follow-up.

As the SIMS is a semi-structured interview measure, inter-rater reliability was an important component of reliability to examine. Inter-rater reliability has been described as the level of agreement between raters on a given questionnaire or interview (McHugh, 2012). Raters' scores were compared on three randomly selected interviews in order to calculate an overall ICC score.

2.6.1.10.2. **Examination of validity**

The examination of validity in research "determines whether the research truly measures that which it was intended to measure or how truthful the research results are" (pg. 598; Joppe, 2000) . Content validity examines "the extent to which the concepts of interest are comprehensively represented by the items in the questionnaire" (pg. 35; Terwee et al., 2007). For content validity to be achieved, Terwee et al. (2007) states that the aim of the questionnaire has to be clearly established, the target population has to be defined, concepts that the questionnaire is measuring have to be clearly outlined, item selection and reduction has to be justifiable and service user led, and items have to be easily understood by the target population. To develop the SIMS measure, service user involvement was essential and is outlined in section 2.3.1 above. In particular, the group supported the development of the items and commented upon the wording of these. It was ensured that these comments were all considered, and are explicitly discussed in the study paper.

Criterion validity has been defined as "the extent to which scores on a particular instrument relate to a gold standard" (pg. 36; Terwee et al., 2007). It was imperative for the SIMS to

be compared to an established measure of stigma. For this current thesis study, the gold standard chosen was the best available measure of stigma, the ISMI (J. B. Ritsher, Otilingam, & Grajales, 2003), as identified by a recent systematic review of available stigma measures (Elaine Brohan, Mike Slade, et al., 2010). A Pearson's correlation coefficient was produced to examine the strength of the relationship between the SIMS and ISMI.

Construct validity is the "extent to which scores on a particular instrument relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning concepts that are being measured" (pg. 36; Terwee et al., 2007). The relevant research literature was examined to identify constructs relevant to the concept of stigma (with available outcome measures) which could be used to examine construct validity. The following psychological constructs are regularly reported to be associated with stigma and therefore were chosen: depression, hopelessness, shame, and personal recovery. Pearson's correlation coefficients were calculated between the SIMS and relevant measures.

In relation to construct validity, sensitivity to change was also calculated. Sensitivity to change has been defined as a measure's ability to identify change in its target construct. This is especially important if the identification of change is a primary aim of the measure (Terwee et al., 2007). It is examined by calculating mean change in all variables and examining their relationship over a set time period. For the analysis described here, this was done using a Pearson's correlation coefficient with the same construct utilised for the examination of criterion validity. It was calculated with a sub-sample (n=28) participants utilising a seven-month follow-up point in the RESPECT study (Morrison et al., 2016).

2.6.1.10.3. **Floor and ceiling effect**

It is essential that assessment measures do not have floor or ceiling effects, in other words that the full range of participant scores can be captured by a given measure. Terwee et al. (2007) outline that no more than 15% of respondents can score the highest or lowest score on a given measure. For this study, this was calculated by examining the frequencies of participants' scores on the SIMS measure.

2.6.1.11. Mediation analysis: Exploration of relationship between stigma and psychological variables

The aim of Study 4 was to explore the relationship between stigma (experienced and perceived) with psychological factors (internal shame, self-esteem, hopelessness, depression, and personal recovery), and to explore the role of internal shame and self-esteem as potential mediators. To meet these aims, correlation, regression and mediation analysis were conducted. These methods of analysis were used to examine the relationship between independent variables (a manipulated variable which causes change in a dependent variable) and dependent variables (an outcome variable which is impacted by the independent variable) (Field & Hole, 2003). Correlation analysis is utilised to explore the relationships between variables, and does not distinguish between independent or dependent variables (Field, 2009). Within Study 4, it was utilised to make initial explorations of the relationship between all included variables. As data was continuous and normally distributed, Pearson's correlation analysis was utilised to investigate these relationships.

Regression analysis builds upon correlation analysis and can investigate the nature of the relationship and identify associations between variables (Logan, 2010). Regression analysis is unable to identify causality or the predictive ability of any variables. To conduct

regression analyses, data has to meet a number of assumptions. These include homoscedasticity, independent and normally distributed errors, variables being independent of one another, and absence of multicollinearity (Field, 2009). Data in Study 4 met all these assumptions except for the mediator variables (this is discussed in the study paper in Chapter 6). Multiple linear regression analysis was utilised within Study 4 to examine the associations between the stigma variables (independent variables) and psychological variables (dependent variable). Moreover, regression analysis was utilised to do some preliminary explorations for the presence of potential mediation (Baron and Kenny 1996). Mediation can be defined as the exploration of the impact of an intermediate variable in the relationship between an independent and dependent variable (Kenny, 2016).

Baron and Kenny (1986) described a stage method to identify mediation. Firstly, they explain that the independent variable must predict the dependent variable in a regression model. In the second stage, the independent variable must predict the mediator variable in an independent regression model. Thirdly, the independent variable and mediator variable are entered into a regression model together and for mediation to be present the mediator has to predict the dependent variable but the independent variable becomes a non-significant predictor.

More recent developments in mediation analysis have led to bootstrapping techniques (A. F. Hayes & Preacher, 2010), and this approach was also utilised within this thesis to ensure that a robust analysis was conducted. Hayes & Preacher (2010) have critiqued Baron & Kenny's (1986) approach for being dependent on sample size and therefore at risk of a type-1 error with large sample sizes, and type-2 errors with small sample sizes. They argue that Baron and Kenny's (1986) method has low statistical power and that their bootstrapping approach overcomes this problem (Hayes & Preacher, 2010). Furthermore, they argue that one of the stages of the Baron and Kenny (1986) approach (the independent

variable needing to predict the DV) is not required to demonstrate mediation. A number of mediation models were run with stigma as the independent variable, self-esteem and internalised shame proposed as mediator variables, and the other psychological variables as dependent variables. Hayes and Preacher's (2010) mediation analysis method was only utilised when suggested by the preliminary regression models.

2.6.1.12. Examining feasibility in a randomised controlled trial

The aim of Study 6 was to conduct a feasibility RCT of a brief CBT intervention for internalised stigma with acute inpatients who experience psychosis. A protocol was published on the clinicaltrials.gov website prior to study commencement (NCT02853396; Appendix 28). The trial was developed on the basis of recommendations from Eldridge et al. (2016) and the Consolidated Standards for Reporting Trials (CONSORT) statement for the design and development of feasibility trials (Thabane et al., 2016). Both documents have reported widespread confusion between feasibility and pilot studies within the research community, and have published clear guidance to inform trial development.

Study 6 adhered to the National Institute of Health Research (NIHR) definition, "feasibility studies are pieces of research done before a main study in order to answer the question "can this study be done?". They are used to estimate important parameters that are needed to design larger future study" (pg. 1; NIHR, 2015) . A feasibility study can be distinguished from a pilot study as a pilot study is "a smaller version of the main study used to test whether the components of the main study can all work together. It is focused on the processes of the main study, for example to ensure that recruitment, randomisation, treatment, and follow-up assessments all run smoothly" (NIHR, 2015).

A feasibility trial was chosen as the specific intervention being tested is novel and has therefore not been previously examined for feasibility or acceptability. Therefore, the

feasibility study examined the following indicators as recommended by Thabane et al., (2016): willingness of participants to be randomised, willingness of clinicians to recruit participants, number of eligible patients, examination of suitable outcome measures, follow-up rates, response rates, adherence rates, compliance rates, and the time needed to collect and analyse data. Data on participant experiences of the interventions, and the research process more broadly, was also gathered through a feedback questionnaire. Thabane et al., (2016) recommend that feasibility data is presented in descriptive form and thematic comparisons can be made between intervention arms.

In addition to the feasibility data, Study 6 also examined relevant primary and secondary outcome measure to examine for efficacy. To do this, firstly an intention to treat principle was applied to the data. Intention to Treat (ITT) has been described as including all randomised participants in the data analysis regardless of treatment adherence, withdrawal or anything else that happens post randomisation (Gupta, 2011). ITT removes bias from analysis and avoids overestimates or inflation of positive findings. It is recommended by CONSORT and should be undertaken by any RCT (Boutron et al., 2008). There are a number of methods available to conduct ITT analysis including last observation carried forward, multiple imputation, and sensitivity analysis (White, Horton, Carpenter, & Pocock, 2011). For the purposes of Study 6, last observation carried forward method was utilised as the other methods were deemed too complex for a small feasibility trial.

In order to identify any group differences; Analysis of Covariance (ANCOVA) was conducted. ANCOVA is a method of quantitative analysis which allows the comparison of multiple means across groups over time. In addition to traditional Analysis of Variance (ANOVA), ANCOVA allows for the control of relevant confounding variables. In Study 6, ANCOVA was utilised to compare the differences in outcomes across groups whilst controlling for the baseline outcome data. In addition, effect sizes and confidence intervals

were also reported. Effect sizes are an objective and standardised measure of the magnitude of the observed effect and can demonstrate whether the difference between two means is meaningful (Field, 2009). There are a number of measures of effect sizes available which broadly fall into two groups; those which examine the effect of standardised mean difference, and those which examine the strength of association (Lakens, 2013). Cohen's *d*, including its confidence intervals, was utilised as a measure of effect size for Study 6 as it is widely used and appropriate for small sample sizes (Sullivan & Feinn, 2012). It is recommended that effect sizes and confidence intervals are reported for feasibility studies as they are more reliable measures of effect in small studies (Thabane et al., 2016).

2.6.2. Qualitative methodology

Qualitative methods were employed to meet the aims of Study 3 which examined experiences of stigma from the perspective of psychiatric inpatients with experiences of psychosis. This aim was not hypothesis driven but attempted to explore the subjective experiences of stigma of participants. Qualitative methods were chosen as it was assumed that it would be best placed to examine the subjective and idiosyncratic lived experiences of stigma. A number of qualitative methods of analysis are available to meet the aim including discourse analysis, grounded theory, interpretative phenomenological analysis and thematic analysis. These will all be outlined, critiqued within the context of the aim, and the chosen approach will be justified.

2.6.2.1.Discourse analysis

Discourse Analysis (DA) is a method of qualitative analysis, which is usually embedded within a social constructionist perspective, and has developed in popularity since the 1980s. Discourse has been defined as "systems of meaning that are related to the

interactional and wider sociocultural context and operate regardless of the speakers' intentions" (pg.1; Georgaca & Avdi, 2011) . Therefore, DA is concerned with understanding the use of language and the communication of personal beliefs and understandings within a sociocultural context (Willig, 2001). DA can take a number of forms with arguably the two most popular forms being discursive psychology and Foucauldian DA. Both are concerned with language but are underpinned by different theory and therefore have differing aims. Discursive psychology DA is more focused on how people construct meaning within their social context. Foucauldian DA has more focus on understanding the social context and how reality is constructed through language.

Given the epistemological positioning of the researcher as well as the aim of this thesis being to understand the subjective experiences of stigma from the perspective of service users who experience psychosis, it was felt that DA was not best placed to achieve these aims. Furthermore, DA would focus on the dialogue and social construction of meaning making which is not the aim of Study 3.

2.6.2.2.Grounded theory

Grounded Theory (GT) is a qualitative methodology developed in the 1960s which has been defined as "the discovery of theory from data systematically obtained from social research" (pg. 2; Glaser & Strauss, 1967) . GT is underpinned by social interactionism, an idea that human beings behave and are guided by their underlying goals and values which are shaped by social interactions that one has with others. GT has a number of key features such as: it being an inductive process, simultaneous collection and analysis of data, code development based on data rather than pre-existing theory, extraction of data pertaining to social processes, and the writing of analytical notes throughout the analysis process.

GT was deemed inappropriate for the purposes of this study for a number of reasons. Firstly, the epistemological position was at conflict to the author's and consequently did not seem the most appropriate choice. Secondly, the aim of this study was not to generate a theory regarding stigma but to understand individual personal experiences, and finally the pre-developed structured format of the SIMS interview schedule meant that the data collection methods were not best suited to this approach.

2.6.2.3.Interpretative phenomenological analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative approach which sits within a critical realist position. IPA was developed by J. Smith et al. (2009) and is concerned with understanding people's subjective experiences. It is outlined as a process involving 'double hermeneutics' where it is made explicit that the researcher is unescapably involved within the research process and analysis. In other words, the analysis of participant data is dependent on the interpretation of the researcher and can only be analysed through this lens. It is also concerned with symbolic interactionism which takes into account the individual's personal and social context and how this impacts on their experience and sense making of research data.

IPA was not chosen for the purposes of Study 3 due to the use of the data collection method. The data was collected using the SIMS and therefore could not offer the flexibility required to truly examine participants' experiences from their subjective perspective.

2.6.2.4.Framework analysis

Framework Analysis (FA) is a method of qualitative analysis which was initially developed for use in large-scale policy research but is now widely used in health research

(Ritchie & Lewis, 2003). Unlike some other qualitative methods, FA is a flexible approach which does not assume a particular epistemology or theory (Parkinson, Eatough, Holmes, Stapley, & Midgley, 2016). FA requires the user to make decisions about how it is used, for example, how a theme is identified, whether the analysis will be inductive or deductive, and the epistemological positioning of the user. FA is a highly structured and systematic approach and is useful when using large datasets and developing a descriptive overview of the data (Gale, G., Cameron, Rashid, & Redwood, 2013). FA's distinguishing features are its structured outputs such as development of a matrix output and indexing approaches which succinctly presents data analysis.

Framework analysis would be a potentially useful approach for Study 3 given its suitability in working with larger dataset, its flexibility in being applied inductively or deductively (which would fit well with the already gathered data SIMS data), and its rigorous systematic methods. However, framework analysis has been criticised for being overly systematised which can lead to the inadvertent loss of idiosyncrasies of personal experiences within the data (Barnett-Page & Thomas, 2009). It is for this reason that framework analysis was not chosen for the purposes of Study 3.

2.6.2.5.Thematic analysis

Thematic Analysis (TA) is a qualitative methodology developed by Braun and Clarke (2006), which can be used to code and extract themes within qualitative data. Similarly to FA, TA is also a flexible approach which is not underpinned by a epistemological position. Instead, it requires the researcher to make a number of important decisions to guide how it is used. Best practice requires researchers to be explicit regarding the decisions they made about using TA (Braun & Clarke, 2006). The decisions that researchers are require to make are: what counts as a theme, whether the research is a rich description of the full data set or

a detailed account of one aspect, whether to use inductive or theoretical analysis, whether to identify semantic or latent themes, whether to adopt a realist or constructionist position, and to ensure clear questions for the analysis are identified.

It was felt that the flexible and pragmatic approach of TA allowed for the approach to fit with the epistemological positioning underpinning this thesis research. Furthermore, the use of the SIMS appeared less problematic for the TA approach. The SIMS is a theory driven outcome measure embedded within a cognitive framework and was not developed for the primary purposes of qualitative data gathering. TA has the required flexibility in order to analyse such data. Therefore, TA was adopted for the purposes of examining aim 3 (Study 3).

2.6.2.6.Reflexivity

It is imperative in qualitative research for the researcher to consider their positioning in relation to the research topic and aims. This is to ensure that there is transparency in regards to any potential interpretations and biases that could influence the researcher's analysis. Therefore, the author has explored their positioning below. This section is informed by the underpinning epistemology outlined in section 2.2.

I have approached this thesis as both a researcher and clinical psychologist who has worked with people who experience psychosis for almost ten years. I am passionate about improving psychological therapies and treatments for people who experience psychosis, and about promoting service user perspectives. Stigma has been something that I have witnessed both in my clinical role, but also within the public realms, and in broader society. Therefore, I have come into this research with a passion to tackle the stigma that people with psychosis experience. In addition, prior to conducting this study and broader thesis, I worked on the RESPECT pilot research trial examining the effectiveness of CBT

for internalised stigma in psychosis (A. Morrison et al., 2016). Therefore, I had already been immersed into personal stories regarding experiences of stigma in relation to psychosis. I come to this research practising clinically from a CBT perspective, therefore I may have been influenced by this method of understanding people's distress in relation to stigma. I may have considered stigma experiences within the context of constructs such as cognitions, emotions and behaviours. I kept this in mind when conducting the data analysis.

2.6.2.7.Sampling methods and procedures

The participant sample used in Study 3 were a sub-set of participants taken from Study 2, therefore the sampling methods and recruitment procedures outlined in section 2.6.1.3 applied. The sample was taken from the n=50 participants recruited from the inpatient setting. The sample for this qualitative sample was convenience and comprised the first twenty five participants of the fifty recruited. The participant sample as a whole were assumed to be homogenous given that they all had experiences of psychosis, were from inner London, and were admitted to an acute inpatient ward. The sample size was determined by guidance outlined by J. Smith et al. (2009); that is, sampling was considered complete once no new themes emerged in the ongoing data analysis.

2.6.2.8. Interview schedule and analysis

Data was collected for Study 3 using a semi-structured interview schedule. For the purposes of this specific study the SIMS was utilised. Data previously collected from the SIMS (Study 2) was utilised, partly as the pragmatic secondary use of this qualitative data reduced overall participant burden. As outlined in section 4.3.1.3, the SIMS measure

enquires about experiences during the previous month regarding experienced stigma, perceived stigma and the impacts of stigma on self-esteem, emotions, behaviours, relationships, treatment, recovery, psychosis and the positive aspects of stigma. For the purposes of the qualitative interview, prompts were added to each sub-section in order to enquire about inpatient-specific experiences. However, the researcher attempted to be flexible in order to maximise exploration of their subjective experiences.

As outlined, TA requires the author to make six key decisions to guide the data analysis. The first decision is what constitutes a theme, particularly in regard to the frequency in which it needs to occur, and the 'keyness' of the theme (Braun & Clarke, 2006). For the purposes of the aim of this PhD, due to it being a relatively novel area of research with inpatient-specific populations, no specifications were pre-determined in regards to required frequency of themes. However, the number of participants who contributed to the theme was clearly recorded in the analysis. 'Keyness' of a theme was deemed to be any theme which appeared to relate to participants' experiences or consequences of stigma.

The second decision of TA requires the author to decide whether they want to have a rich description of the data set, or a detailed account of specific parts of the data (Braun & Clarke, 2006). Again, as this is a relatively novel study, the full dataset was used for analysis. No predefined hypotheses were made regarding what themes may be important to inpatients with psychosis, therefore no restrictions were placed on the data which was analysed. This is recommended when examining an under-researched area or where themes are unknown (Braun & Clarke, 2006).

The researcher is also required to decide whether an inductive or theoretical approach to analysis is taken (Frith & Gleeson, 2004). An inductive analytic approach is closely linked to the data and is a data-led method of analysis, whereas a theoretical approach is driven by

a pre-existing theory. Although the research cannot be completed free of theoretical knowledge, the author attempted to take an inductive approach to analysis and to not be led by pre-existing theory.

Researchers using TA must also decide whether the proposed themes reflect a semantic or latent level of interpretation (Braun & Clarke, 2006). Sematic level interpretation extracts codes and themes at the surface level and analysis is not intended to explore beyond this. However, latent interpretation requires the researcher to go beyond the spoken word of the participant and take a more interpretative stance. The author adopted a semantic level of interpretation which is consistent with previous decisions.

The final decision requires the researcher to make a decision regarding their epistemological positioning. As outlined, the researcher has adopted a critical realist position and all outlined decisions reflect this epistemology.

The author followed guidance for the practical undertaking of analysis outlined by (Braun & Clarke, 2006) whilst keeping these six key decisions in mind. Five randomly selected transcripts were cross-checked in order to ensure accuracy of transcription. Analysis was conducted on the computer software NVivo9 (QSR, 2012). Transcripts were read at least twice before coding commenced in order for the author to be immersed in the data. Transcripts were coded line by line by LW and identified as “nodes” within the NVivo9 software. Nodes were grouped together into emerging themes once each interview transcript was fully coded. Therefore, once 25 interviews were complete; it was evident that no new emergent themes were being identified.

2.6.2.9.Quality criteria for the qualitative methodology and analysis

There is increasing importance placed on ensuring transparency and rigor in qualitative research with guidelines being published to ensure quality. As with quantitative research, guidelines have been offered to ensure researchers meet the best-practice guidance for the employment of qualitative methodology. Thomas et al. (2003) offer a checklist of 12 criteria which qualitative studies should meet to ensure research bias is minimised as much as possible. These criteria were carefully considered and addressed by the author, and are described further below.

The first sub-section of criteria outlined by Thomas et al. pertains to the quality of reporting. Firstly, it is essential that research aims and objectives are clearly reported: these have been outlined in this thesis both in the stated 'PhD aims' and within the study paper. It is essential that there is an adequate description of the context of the study. This includes description of recruiting services, context of where the research was being carried out: these have also been made explicit in the study paper. The description of the participant sample is clear, with explicit inclusion and exclusion criteria described. Data collection methods should be adequately described, including the design and development of interview schedule (Chapter 4). Finally, data analysis methods should be adequately described with key decision-making processes being outlined.

The second sub-section of Thomas et al's (2003) quality criteria relates to reliability and validity. Reliability and validity of data collection methods are outlined as essential. *Reliability* of data collection materials relates to the ability of the interview schedule to gather data in a consistent manner across multiple interviews. The semi-structured interview measure utilised in this case (SIMS) is atypical of a standard qualitative measure as it has been developed as an outcome measure and examined for reliability and validity. Whilst this may have negative impacts on other areas of the quality criteria (e.g.

idiosyncratic data collection and issues of validity), the author believes that it increases the reliability of the qualitative data collection. The SIMS interview measure demonstrated good inter-rater reliability, test retest reliability, and internal consistency. Additionally, the *validity* of data collection methods was also ensured in the following ways. The interview measure was developed from a systematic review of qualitative studies (n=9) which examined service user experiences of stigma related to psychosis (Wood, Burke, Byrne, et al., 2015), and was further refined with a service user consultation panel. As such it is hoped that the interview measure suitably integrates service user perspectives of stigma related to psychosis.

Reliability of qualitative data analysis was achieved through several means. Firstly, five randomly selected transcripts were checked against audio recordings to ensure no errors were identified. The first author coded every interview within the study; however GE and RB checked the quality of the analysis by coding two randomly selected transcripts. Coding was deemed to be reliable as there were no large differences in the quantity of codes identified, and no new themes were identified. Coding was conducted on NVivo 9 (QSR, 2012) where 'nodes' were identified within each transcript providing a robust method of counting and tracking coding. Validity of the analysis was achieved through supervision with RB who has lived psychosis and stigma experience. Furthermore, three randomly selected participants were approached to comment on the analysis once the initial theme structure was developed. Overall, these participants felt the analysis was reflective of their interviews and only offered minor suggestions to the proposed analysis. For example, participants offered some suggestions for changing the wording of themes into simpler lay language, emphasising (more) that stigma is not just confined to an inpatient admission and in fact penetrates all areas of their lives, and ensuring the relational nature of stigma was emphasised, i.e. its detrimental impacts are mainly caused by others.

The final subsection of bias assessment relates to qualitative findings being rooted within service user perspectives. Firstly, Thomas et al. (2003) outline the importance of data collection methods being suitable for service users to express their views. One of the drawbacks of the SIMS interview measure was that it was a predefined measure examining broad experiences of stigma; this allowed less flexibility than an iteratively developed interview measure with more targeted aims. Therefore, this may limit the interview measure's ability to fully allow service users to express their views. The second criterion was that appropriate measures were used to ensure that data analysis was grounded in the views of service users. In this case, as stated, service users were consulted regarding the analysis. Finally, it was imperative that service users were involved in the design and conduct of the study. This was achieved as RB was involved in all aspects of the research development.

2.7. Dissemination of thesis studies

Dissemination of research is becoming increasingly recognised as an essential part of the research process (Schillinger, 2010) . In addition to peer reviewed publication, the author attempted to disseminate the findings from this thesis to diverse audiences, which will be described here. Firstly, Study 1 was presented at a stigma conference for clinicians and service users (Stigma in Psychosis: Advances in Theory and Practice Conference, 4th March 2016, Greater Manchester West NHS Foundation Trust). Study 2 and 5 were (a) integrated into a clinical workshop for clinicians and service users (Stigma in Psychosis: Advances in Theory and Practice Conference, 4th March 2016, Greater Manchester West NHS Foundation Trust) and (b) presented at a Time to Change and University of Manchester stigma conference (Time to Join Forces: An Interdisciplinary Approach to Fighting Mental Health Stigma, 6th September 2016). Study 5 was further presented at two

other conferences; Beckfest 19th Annual Meeting of CBT for Psychosis (20th May 2016) and the IEPA international network for early intervention in mental health annual conference (IEPA 10, 21st October 2016). Finally, studies 1 – 5 were integrated into a lecture on the UCL psychosis top-up course and delivered to psychologists working within EIS services across London and Essex (5th October, 2016).

In addition to conference presentations and lectures, studies 2, 3 and 4 have been disseminated locally and presented to ward staff and psychology teams, and written feedback was given to participants. Study 6 will be presented at a relevant conference and disseminated locally to clinical teams and participants.

3. Chapter 3: Study 1 - Psychosocial interventions for internalised stigma in people with a schizophrenia-spectrum diagnosis: a systematic narrative synthesis and meta-analysis

This paper has been published in Schizophrenia Research:

Wood, L., Byrne, R, Varese, F., & Morrison, A. (2016) Psychosocial interventions for internalised stigma in people with a schizophrenia-spectrum diagnosis: a systematic narrative synthesis and meta-analysis. *Schizophrenia Research*. 176 (2-3), 291 – 303.

3.1. Abstract

It is acknowledged that people with a schizophrenia-spectrum diagnosis experience higher levels of stigma compared to any other mental health diagnosis. As a consequence, their experience of internalised stigma is likely to be the most detrimental and pervasive. Internalised stigma interventions have shown some benefits in those who experience serious mental illness including those diagnosed with a schizophrenia-spectrum diagnosis. A systematic narrative review and meta-analysis were conducted examining the efficacy of internalised stigma interventions for people with a schizophrenia-spectrum diagnosis. Randomised Controlled Trials (RCTs), controlled trials, and cohort studies were included and assessed against quality criteria. The search identified 12 studies; 7 randomised controlled trials, 3 cohort studies and 2 controlled trials. A variety of psychosocial interventions were utilised with the majority employing Cognitive Behaviour Therapy (CBT), psychoeducation and social skills training. The core outcomes used to examine the efficacy of the intervention were internalised stigma, self-esteem, empowerment, and functioning. The meta-analysis revealed an improvement in internalised stigma favouring the internalised stigma intervention but was not significant (5 RCTs, n=200). Self-efficacy and insight were significantly improved favouring the internalised stigma intervention. Internalised stigma interventions show promise in those with schizophrenia-spectrum diagnoses. Existing interventions have demonstrated small effects and employed small samples. Large scale RCTs are required to further develop the evidence base of more targeted interventions.

3.2. Introduction

Stigma was originally defined as an "attribute that is deeply discrediting" which turns a person from "a whole and usual person to a tainted, discounted one", (pg. 3; Goffman, 1963). Stigma is pervasive amongst people diagnosed with a mental health difficulty in our current society (Wood et al., 2014). P. Corrigan and A. Watson (2002) explained that stigma comprises two distinct components; public stigma and self-stigma. Public stigma consists of negative stereotypes (a specific negative belief about a group), prejudice (agreement with belief) and discrimination (negative behavioural response) from the public towards the stigmatised group. Self-stigma, often described as internalised stigma interchangeably, is becoming aware of the negative stereotypes, agreeing with it and applying it to one's self (Corrigan et al., 2010). The term internalised stigma will be used henceforth throughout this review. Internalised stigma can be extremely detrimental to service users who experience severe mental illness (SMI). Livingston and Boyd (2010) conducted a systematic review of the consequences of internalised stigma and found that it was associated with poorer self-esteem, hopelessness, reduced self-efficacy and disempowerment. It can also exacerbate existing mental health problems, increase social avoidance and impair recovery (P. Corrigan & A. Watson, 2002).

Arguably, those with a schizophrenia-spectrum diagnosis experience higher levels of internalised stigma compared to other SMI diagnoses (Holzinger, Beck, Munk, Weithaas, & Angermeyer, 2003). A number of large-scale studies have identified that those diagnosed with schizophrenia are viewed most negatively by the public (Wood et al, 2014), experienced the most discrimination (Dinos et al., 2004), and experience the most rejection (Lundberg, Hansson, Wentz, & Bjorkman, 2008). High levels of internalised stigma were reported by almost half (41.7%) of a large European sample of people with a

schizophrenia-spectrum diagnosis and two thirds (69.4%) reported moderate or high perceived discrimination (Elaine Brohan, Rodney Elgie, et al., 2010). Moreover, compared to bipolar disorder, people diagnosed with schizophrenia reported significantly higher rates of internalised stigma with significant impacts on their social life and overall functioning (Karidi et al., 2015; Sarisoy et al., 2013). Furthermore, in a large sample (n=261), internalised stigma was identified as conceptually different in schizophrenia compared to depression and bipolar disorders (Oliveria, Esteves, & Carvalho, 2015). Internalised stigma in schizophrenia was characterised by dissatisfaction with social relationships, high levels of stereotyping, withdrawal and alienation (Oliveria et al., 2015). Furthermore, they found that internalised stigma was a risk factor for social isolation only in individuals with schizophrenia, which may worsen the course of the disorder.

There is an increasing interest in the development of interventions to reduce internalised stigma. A number of pilot studies and small scale trials have been conducted examining the efficacy of these interventions. These studies have found some promising finding such as significant improvements in engulfment, hopelessness, quality of life, self-esteem and personal recovery (Fung et al., 2011; E. McCay et al., 2007; A. Morrison et al., 2016). However, a number of these studies have reported no impact on their primary outcome measures of internalised stigma and other secondary outcomes (Fung et al., 2011; B. G. Link, Stuening, Neese-Todd, Asmussen, & Phelan, 2002; A. Morrison et al., 2016; P. T. Yanos et al., 2011) .

A handful of systematic reviews have been conducted examining the efficacy of internalised stigma interventions for SMI. Although the evidence base is relatively small, examination of studies which meet rigorous criteria for inclusion in a systematic review and meta-analysis allows conclusions to be drawn regarding the efficacy of such interventions (Moher, Liberati, Tetzlaff, Altman, & The PRISMA group, 2009). Griffiths

et al. (2014) conducted a systematic review of three randomised controlled trials (RCTs) of internalised stigma interventions for SMI (Fung et al., 2011; Luoma, Kohlenberg, Hayes, & Fletcher, 2012; P. T. Yanos et al., 2011) but their pooled mean effect sizes were not statistically significant. Two further systematic reviews conducted by Mittal et al. (2014) and P. T. Yanos et al. (2014) examined internalised stigma interventions for SMI using a narrative synthesis methodology. Mittal et al. (2014) reported that only two of seven studies examining participants with a diagnosis of schizophrenia-spectrum diagnosis reported significant improvements post intervention. Yanos et al. (2014) examined internalised stigma interventions in detail and considered their effective change mechanisms. They concluded that psychoeducation and cognitive challenging were the most important elements of an intervention. Both reviews did not follow rigorous criteria for the conduct of systematic reviews and meta-analysis as outlined by, for example, the Cochrane Collaboration (J.P.T. Higgins & Green, 2011).

The use of meta-analysis with small, potentially heterogeneous studies is a topic of much debate. The systematic review and meta-analysis of small studies has been illustrated to increase methodological heterogeneity, error rates, and the chances of identifying a false statistically significant finding (Borenstein et al., 2009; IntHoult et al., 2015; IntHout, Ioannidis, & Borm, 2012) However, in an area with a limited evidence base, the meta-analysis of small studies can provide informative effect sizes as long as sensitivity analyses is considered (Borenstein et al., 2009; IntHoult et al., 2015). To date, no systematic reviews have been conducted examining the efficacy of internalised stigma interventions for people with a schizophrenia-spectrum diagnosis. It is important that such interventions are examined within a systematic review in order to determine whether they are efficacious in this population. There has been no examination of study quality and risk of bias of internalised stigma intervention studies. Furthermore, a narrative exploration of change

mechanism would offer important information on what may bring about change in internalised stigma interventions. There also appears to be no agreement on outcome measures used to assess the efficacy of an internalised stigma intervention. Finally, data from internalised stigma RCTs have not been subject to a meta-analysis to examine for overall efficacy. Given the limited literature, a systematic narrative review (Colliver, Kucera, & Verhulst, 2008) and meta-analysis will be conducted. The review will aim to examine study quality and risk of bias of included trials, compare and contrast internalised stigma interventions for their key mechanisms of change, and scrutinise study outcomes and measures used to assess outcome. The meta-analysis will aim to examine the efficacy of the internalised stigma interventions on the primary outcome of internalised stigma, and other secondary outcomes.

3.3. Methodology

3.3.1. Study protocol

The review protocol was published online at the PROSPERO website on the 25th November 2014 (http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014015161#.VLflgNEfzIU).

3.3.2. Inclusion and exclusion Criteria

This review included studies (a) where ≥50% of participants meet criteria for (i) a schizophrenia-spectrum diagnoses (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, psychotic disorder not otherwise specified defined by any criteria) or (ii) threshold for Early Intervention in Psychosis services (to allow for diagnostic uncertainty), in order to ensure the sample was primarily those with a schizophrenia spectrum diagnosis or psychosis presentation (b) which examined internalised stigma or self-stigma as an outcome (c) which examined a psychosocial intervention which aimed to reduce internalised stigma (d) in English language, (e) with a sample of adults aged 16–65 (f) with a randomised control trial (RCT), controlled trial (CT) or cohort study (CS) (an observational study which follows participants over time) (CS) (g) of effectiveness and efficacy. Exclusion criteria were defined by (a) studies which include ≥50% of participants with psychosis as a secondary diagnosis (e.g. to alcohol use, learning disability) (b) observational studies. No criteria are specified in regard to severity and/or duration of illness.

3.3.3. Search strategy

Three electronic databases, Embase, Medline and PsycInfo were utilised for the search. Two trial registries were also examined, the Cochrane Central Register of Controlled Trials (CENTRAL) and the Clinical Trials registry, to identify any unpublished or soon to be

published studies in peer review journals. The initial search was conducted between November 2014 and March 2015 by the first author (LW) using the following key words: (Schizo* OR psychosis OR psychotic OR Delusion* OR Voices OR Hallucinat* OR Mental Illness) AND (Stigma) AND (Intervention OR Therapy OR CBT OR Trial). Initially titles and abstracts were screened. For relevant studies full texts were sourced. Authors of conference abstracts were followed-up. All corresponding authors of the final studies included were contacted to identify any further published or unpublished work. References of included studies were also examined for any further papers. Recent reviews examining internalised stigma for SMI, Livingston and Boyd (2010), Mittal et al. (2014), Yanos et al. (2014) and Griffiths et al. (2014) were also examined for relevant studies.

3.3.4. Data extraction

Individual study data was extracted by the first author (LW) into pre-defined tables with uncertainties discussed with AM and RB. RB crosschecked 25% of data extraction and no errors were identified. A number of study characteristics were extracted, including type of intervention, intervention modality (group or individual therapy), duration of treatment, number of prescribed sessions, duration of treatment period (weeks), control condition (e.g. treatment as usual), number of arms of study, demographics (age, gender, diagnosis), consent rates, dropout rates, percentage of participants who had the full amount of sessions, length of sessions, and pertinent statistical information (means, standard deviation, N from each assessment time point (e.g. baseline, post therapy, follow-up points) on specific outcomes of interest. Analysis of any available relapse, rehospitalisation and adverse events was also extracted. If any data were not available in the published report, corresponding authors were contacted. The above data were obtainable from the majority of studies. Two studies (B. G. Link et al., 2002; E. McCay et

al., 2007) were unable to provide usable data for meta-analysis, but these reports still contributed to the narrative synthesis of the review.

3.3.5. Methodological quality and risk of bias of included studies

A detailed examination of the quality of the studies was undertaken using the Effective Public Health Practice Project (EPHPP) tool (Armiji-Olivo et al., 2012). This tool was chosen over the GRADE risk of bias tool (J.P.T Higgins et al., 2011), which was outlined in our submitted proposal, as it allowed assessment of quantitative studies with a variety of methodologies. It examined six key areas of potential bias; selection bias, study design, confounders, blinding, data collection methods, and withdrawals and dropouts (see measure for more detail). Studies can score weak, moderate or strong with weak scores illustrating high risk of bias and strong scores reflecting a low risk of bias. Quality assessments were carried out by the first author (LW) and were reviewed with other authors in supervision (AM, RB). Risk of bias assessments are outlined in table 3.

3.3.6. Data Analysis

The inclusion of non-RCTs meant data analysis was informed by the procedures of narrative synthesis (Popay et al., 2006). Narrative synthesis offered a framework for structuring a systematic review which includes non-RCT studies. It outlined four key elements to the process; developing a theory of how the intervention works, why and for whom, developing a preliminary synthesis of findings of included studies, exploring relationships in the data, and assessing the robustness of the synthesis. Initially, the review compared and contrasted the types of therapies employed within the included studies. Individual study outcome measures were examined and described. A vote counting tool, as recommended by Popay et al. (2006), was implemented to visually illustrate when a study reported a positive effect, a negative effect or did not report for a given outcome.

Meta-analysis was used to integrate available effects extracted from the RCTs included in the review. Meta-analysis was conducted using Comprehensive Meta-Analysis (CMA) software, version 3 (Borenstein et al., 2009). As all available data was continuous, data from different outcome measures were combined using the standardised mean difference, Hedges g (J.P.T. Higgins & Green, 2011). Effect sizes were calculated using post therapy and follow-up data provided in the included studies, based on means, standard deviations and sample sizes extracted from the primary studies. A meta-analysis was conducted where at least two RCTs contributed to the examined outcome. Fung et al. (2011) was the only study with multiple follow-up points (two, four, six months) so, in order to be conservative, the middle follow-up point (four months) was extracted. Where there was more than one measure for an examined outcome with a study, and aggregated effect was estimated based on the procedure outlined by Borenstein et al. (2009). Effects were integrated using a random effects model.

3.4. Results

3.4.1. Study selection

The process of study selection followed study extraction guidance from Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) , as outlined in figure 1. The initial search, after removing duplicates, identified 3176 papers and conference abstracts. The majority of studies were excluded through title and abstract screening for being irrelevant, leaving twenty studies. The full-texts for these studies were sourced and examined against the inclusion and exclusion criteria. This led to a total ten of studies being identified from the database searches. Two further studies were identified from, (a) the reference list of an already included study (B. G. Link et al., 2002) and (b) another identified by a contacted author (Roe et al., 2014). A final twelve studies were included in the review. Excluded studies are identified in appendix 29.

3.4.2. Study characteristics

Study characteristics and baseline demographics are outlined in table 2. A total of seven studies used a Randomised Controlled Trial (RCT) design (Fung et al., 2011; B. G. Link et al., 2002; E. McCay et al., 2007; A. Morrison et al., 2016; Rusch et al., 2014; Russinova et al., 2014; P. T. Yanos et al., 2011) and five were Controlled Trials (CTs) or Cohort Studies (CSs) (M. D. Knight et al., 2006; Lucksted et al., 2011; Roe et al., 2014; Sousa, Marques, & Queiros, 2012; Uchino, Maeda, & Uchimura, 2012). All studies were relatively small with the biggest sample including sixty six participants. Only four studies included participants exclusively with a schizophrenia-spectrum diagnosis. In terms of these participants, ten studies examined those with SMI, one included a combination of SMI and early onset presentations, and one examined first episode psychosis only. The majority of participants were male and middle aged. All studies were conducted in outpatient settings.

Figure 1 –PRISMA diagram of search strategy

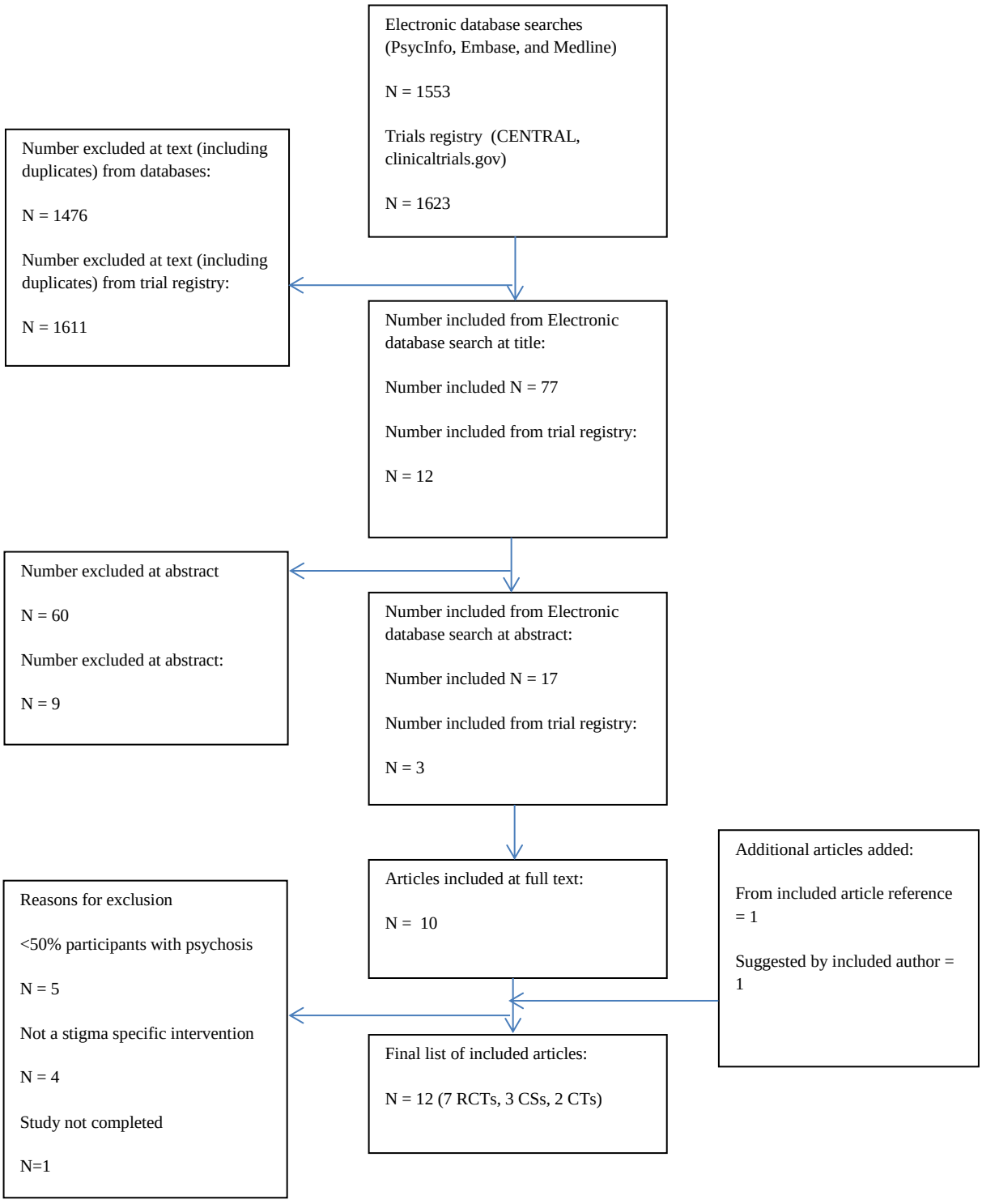


Table 2 – studies included in the systematic review

Randomised controlled trials									**Baseline demographics (total sample)**			
Author	**Study design**	**Intervention**	**Number randomised**	**Dropouts (at ET)**	**Modality**	**Sessions offered (weeks)**	**Primary measure of self-stigma**	**Location (city)**	**Schizophrenia related Diagnosis, n (%)**	**Age(years), Mean (SD)**	**Female, n (%)**	**Follow-up data available**
Link et al (2002)	RCT	SPE Control	88 N/R	18 (20.45%)	Group	16 (8)	PDD	USA	S, 36.4% NAP, 13.6%	40.9 (n.s.)	34 (38.6%)	B, ET, 18m
McKay et al (2007)*	RCT	MSI TAU	41 26	12 (29.3%) 8 (30.8%)	Group	12 (12)	MES	Canada (Toronto)	FEP 100%	25.07 (4.86) 26.17 (7.03)	9 (31.0%) 4 (22.2%)	B, ET
Yanos et al (2011)	RCT	NECT TAU	21 18	5 (23.8%) 2 (11.1%)	Group	20 (20)	ISMI	USA (New York, Indiana)	S, 28.2%, SA, 48.7%	47.14 (7.86) 48.06 (6.78)	7 (33.3%) 4 (22.2%)	B, ET, 3m
Fung et al (2011), Tsang et al (2014)	RCT	SSRP NRG	34 32	0 (0.0%) 2 (6.3%)	Group	16, 12 group, 4 1:1 (16)	CSSMIS	Hong Kong	S 100%	43.91 (10.38) 46.91 (8.92)	16 (47.1%) 13 (40.6%)	B, ET, 2, 4, 6m
Rusch et al (2014)**	RCT	COP TAU	16 11	2 (12.5%) 0 (0.0%)	Group	3 (3)	ISMI	Switzerland (Zurich)	SSD 100%	44.69 (11.62) 38.36 (7.22)	8 (50.00%) 5 (38.46%)	B, ET, 3wk
Russinova et al (2014)**	RCT	API WLC	14 14	1 (7.1%) 2 (14.3%)	Group	10 (10)	ISMI	USA	SSD 100%	46.32 (12.66) 48.14 (11.39)	10 (71.4%) 10 (71.4%)	B, ET, 3
Morrison et al (2016)	RCT	CBT TAU	15 14	2 (13.3%) 1 (7.1%)	Individual	12 (16)	ISMI	UK (Manchester)	S, 31%, FEP 47% RP 3%	39.00 (13.50) 29.36 (10.02)	3 (20.0%) 3 (21.4%)	B, ET, 3
Controlled trials and cohort studies									**Baseline demographics (total sample)**			
Author	**Study design**	**Intervention**	**Number allocated**	**Dropouts**	**Modality**	**Sessions offered (weeks)**	**Primary measure of self-stigma**	**Location (country)**	**Schizophrenia related diagnosis, n (%)**	**Age(years), Mean (SD)**	**Female, n (%)**	**Follow-up data available**
Knight et al (2006)	Time series	CBT	21	2 (9.5%)	Group	7 (7)	PDD	UK (London)	S 38.%, PS 57.1%, SA 4.8%	39.32 (8.79)	10 (47.6%)	B, ET, 6wk
Lucksted et al (2011)	Cohort	ESS	50	16 (32.0%)	Group	9 (9)	ISMI	USA	S 41.17%, SA, 8.82%, P 5.88%	51.56 (7.18)	3 (18.8%)	B, ET
Sousa et al (2012)*	Cohort	SD&EL	21	4 (19.0%)	Group	15 group, 15 online	ISMI	Portugal	S 100%	38.1 (8.7)	2 (11.77%)	B, ET
Uchino et al (2012)	Controlled trial	PE SC	29 27	NR	Group	6 (6)	SDS-J	Japan	S 92.9%, SA, 7.1%	35.6(10.4) 32.8 (10.5)	NR	ET
Roe et al (2014)*	Controlled trial	NECT TAU	137 85	74 (54.0%) 29 (34.1%)	Group	20 (20)	ISMI	Israel	Author approximates majority	39 (12.1) 44 (12.3)	33 (52%) 32 (57%)	B, ET

API Antistigma Photovoice Intervention, B Baseline, CBT Cognitive Behaviour Therapy, CCMIS Chinese Version of the Self-stigma of Mental Illness Scale, COP Coming Out Proud, DDS Devaluation-Discrimination Scale, EL E-Learning, ESS Ending Self-Stigma Intervention, ET End of Therapy , FEP First Episode Psychosis , ISMI Internalised Stigma of Mental Illness Inventory, m month, MSI Manualised Stigma Intervention, MES Modified Engulfment Scale, NAP Non-Affective Psychosis , NECT Narrative Enhancement Cognitive Therapy, N/R Not Reported, NRG Newspaper Reading Group, PDD Perceived Devaluation and Discrimination Scale, PE Psychoeducation, PS Paranoid Schizophrenia, RCT Randomised Controlled Trial, RP Recurrent Psychosis, SA Schizoaffective Disorder, SC Standard Care, SD Sociodrama, SDS-J Social Distance Scale Japan, SPE Social Stigma and Psychoeducation, SSD Schizophrenia Spectrum Disorder, SSRP Self-Stigma Reduction Programme, TAU Treatment As Usual, UK United Kingdom, USA United States of America, wk week, WLC Waiting List Control, S Schizophrenia, 1:1 one to one

**Baseline demographics do not include drop outs, **Data reported is only for the participants diagnosed with a schizopreniform diagnosis*

3.4.3. Risk of bias

All studies were assessed for bias using the EPHPP tool. Summary scores and ratings are outlined in table 3. All studies were assessed on six key areas outlined by the EPHPP tool; *selection bias, study design, confounders, blinding, data collection, withdrawals and dropouts* (Armiji-Olivo et al., 2012). *Selection bias* was examined and only one study rated strongly in this category as they sampled participants from a variety of services (A. Morrison et al., 2016), whereas all other studies were either not randomised and/or recruited participants from one or two clinics, and therefore scored moderately. All RCTs were rated as strongly on *study design* because investigators would have no way of predicting the allocation of participants to groups thus minimising bias. The CTs were rated moderate as they had a control group; however participants were not randomly allocated. All other studies which did not have a control group were rated as weak. The RCTs also scored strongly on *confounders*, except B. G. Link et al. (2002) as confounders were not described. All other studies scored weakly on this variable as confounders were not controlled for in the design or data analysis. Only two RCTs explicitly described *blinding* procedures, either in their published paper or through further contact with the author, whereas all the other papers did not comment on blinding procedures. All other studies were unblinded so were scored weakly. All studies scored strongly on *data collection methods* as they all employed widely used outcome measures which have been validated with people who experience SMI. All RCTs, except Yanos et al (2011) and Link et al (2002), rated strongly on drop outs. One CT was rated as weak on this factor with over 50% of drop outs (Roe et al., 2014), the rest of the studies rated moderately. Overall, the global ratings of bias expectedly found the RCTs as strong and all other studies as weak.

Table 3– Assessment of bias

Study	Selection Bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals /drop outs	Global rating
Randomised controlled trials							
Link et al (2002)	M (2)	S (1)	W(3)	W(3)	S (1)	M (2)	**W(3)**
McKay et al (2007)	M (2)	S (1)	S (1)	M (2)	S (1)	S (1)	**S (1)**
Yanos et al (2011)	M (2)	S (1)	S (1)	S (1)	S (1)	M (2)	**S (1)**
Fung et al (2011), Tsang et al (2014)	M (2)	S (1)	S (1)	M (2)	S (1)	S (1)	**S (1)**
Rusch et al (2014)	M (2)	S (1)	S (1)	M (2)	S (1)	S (1)	**S (1)**
Russinova et al (2014)	M (2)	S (1)	S (1)	M (2)	S (1)	S (1)	**S (1)**
Morrison et al (2016)	S (1)	S (1)	S (1)	S (1)	S (1)	S (1)	**S (1)**
Controlled trials and cohort studies							
Lucksted et al (2011)	M (2)	W(3)	W(3)	W(3)	S (1)	M (2)	**W(3)**
Sousa et al (2012)	M (2)	W(3)	W(3)	W(3)	S (1)	S (1)	**W(3)**
Uchino et al (2012)	M (2)	M (2)	W(3)	W(3)	S (1)	M (2)	**W(3)**
Knight et al (2006)	M (2)	W(3)	W(3)	W(3)	S (1)	S (1)	**W(3)**
Roe et al (2014)	M (2)	M (2)	W(3)	W(3)	S (1)	W(3)	**W(3)**

W – Weak, M-Moderate, S-Strong

3.4.4. Characteristics of self-stigma interventions used

The average number of sessions offered by the RCTs was 12.71 sessions (range 3 – 20), and 11.4 (range 6-20) by other studies. The majority of studies included in this review utilised a group format intervention (91.67%) and one study offered individual therapy (Morrison et al., 2016). The majority of studies (66.67%) used some form of psychoeducation and/or CBT. Two studies explicitly identified CBT as the basis of their intervention (M. D. Knight et al., 2006; A. Morrison et al., 2016). M. D. Knight et al. (2006) drew upon two main cognitive models for their CBT intervention; group treatment for auditory hallucinations (Wykes, Parr, & Landau, 1999) and, 'I am super' group treatment for self-esteem (T. Lecomte et al., 1999). Morrison et al's (2016) 12 session intervention was underpinned by the CBT for psychosis theoretical model (A. P. Morrison, 2001) and used techniques from Morrison et al's (2008) self-help manual.

Two studies delivered an adapted CBT approach titled Narrative Enhancement Cognitive Therapy (NECT) for their group intervention (Roe et al., 2014; P. T. Yanos et al., 2011). NECT is a 20 session manualised intervention based on principles of CBT but aims to help participants gain a positive narrative about their mental health experiences through story telling with their peers (Roe et al., 2014). It consisted of four modules, an introduction, psychoeducation, cognitive restructuring, and narrative enhancement.

Two studies combined psychoeducation, CBT and social skills training to develop their respective 16 session group interventions (Fung et al., 2011; Lucksted et al., 2011). Fung et al. (2011) developed a therapeutic framework consisting of psychoeducation about schizophrenia, CBT for irrational ideas of self-concept and abilities, motivational intervention to promote change, and social skills training. Lucksted (2011) used CBT skill to challenge self-stigmatising thinking, strengthening positive aspects of self, creating a

belongingness to their local community, family and friends, and responding to overt experiences of stigma and discrimination.

Two studies developed peer-led group interventions (Rusch et al., 2014) which were 3 and 10 sessions in length respectively. Coming Out Proud (COP; Rusch et al., 2014) is a 3 two hour session manualised group programme to support people with a diagnosis of mental illness in their decisions around disclosing their diagnosis to others. The sessions examined advantages and disadvantages of disclosure, different ways to disclose, and how to disclose their personal mental health journey in an idiosyncratic way. The photovoice intervention (Russinova et al., 2014) aimed to help participants develop a personal narrative regarding stigma and discrimination, and means for recovery through the use of photography. Throughout the group process, participants developed coping strategies for managing stigma, such as challenging stigma in social situations and challenging internalised stigma through strategies similar to cognitive restructuring.

The remaining studies used: six session group psychoeducation to teach participants accurate non-stigmatising perceptions of schizophrenia with an emphasis on violence and criminal activity (Uchino et al., 2012); 16 session group psychoeducation focusing on developing awareness of stigma, recognising the possibility of internalising stigma, and identifying stigma in social interactions and learning how to cope (B. G. Link et al., 2002); 15 session group sociodrama, where participants discuss their experiences and understanding of stigma and act out related scenes, alongside online educational classes about stigma (Sousa et al., 2012); and a 12 session recovery focused group which helped participants develop a healthy self-concept through acceptable appraisals of psychosis, minimising self-stigmatising attitudes, developing hope and future goals (E. McCay et al., 2007).

3.4.5. Characteristics of outcomes used

Each study was examined for the outcomes utilised to measure the efficacy of their interventions. As this is a relatively novel area, there is no agreement regarding the types of outcome measures to reliably assess the efficacy of an internalised stigma intervention apart from internalised stigma itself. The outcome measures used by each study are outlined in table 4. The primary outcome of internalised stigma was measured using a diverse number of self-report questionnaires across studies which arguably conceptualise internalised stigma differently. The Internalised Stigma of Mental Illness (ISMI) Inventory (J. B. Ritsher et al., 2003) and the Chinese self-stigma scale (Fung, Tsang, Corrigan, Lam, & Cheung, 2007) are the only measures designed specifically to examine internalised stigma. Other measures used such as the perceived discrimination and devaluation (PDD) scale (B. G. Link et al., 2002) and the modified engulfment scale (MES; McCay & Seeman, 1998) are arguably not measuring the same construct of stigma. In a systematic review of outcome measures, Brohan et al. (2010) distinguished between perceived stigma (how individuals think the public perceive people with mental health difficulties, and they view them personally) and internalised stigma (internalisation of cognitions and emotions in response to public stigma) and explain how they are conceptually different. Therefore, the PDD scale may be measuring aspects of both perceived and internalised stigma. Furthermore, Brohan et al., (2010) found that the PDD scale only met one (construct validity) of five reliability and validity criteria. The primary measure, the ISMI (J.B. Ritsher & Phelan, 2004), was used within most of the studies and met four (content validity, internal consistency, construct validity, test-retest reliability) of their five outlined criteria (not floor/ceiling effects). Brohan et al. (2010) identified that there are no

acceptable measures of internalised stigma currently available. In addition, these measures have been validated in SMI and not specifically with those who have a schizophrenia-spectrum diagnosis who may have experienced internalised stigma differently. Therefore, the reliability and validity of the internalised stigma measures is questionable.

There was little consistency in the secondary outcomes utilised by studies. The most frequently examined secondary outcomes were self-esteem (50%), coping skills (41.7%), empowerment (41.7%) and functioning (41.7%). In order to develop the evidence base of internalised stigma interventions, consistent core measures should be employed.

Table 4 – Outcomes measured and tools used

Author	Self-stigma	General stigma	Stigma Stress	Coping skills	Recovery	Functioning	Psychopathology	Depression	Hopelessness	Anxiety	Self-Esteem	Empowerment	Self-efficacy	Shame	Knowledge	Treatment adherence	Insight	Social Support	Change	Total outcomes
Link et al (2002)	PDD SRF	SRER	-	ACWS	-		-	CESD	-	-	RSES	-	-	-	-	-	-	-	-	**6**
McKay et al (2007)	MES PDD		-	-		QLS GAF	PANSS	-	MHS	-	RSES	TSCS	SES	-	-	-	-	-	-	**9**
Yanos et al (2011)	ISMI	-	-	CSC		QLS	PANSS	-	BHS	-	RSES	-	-	-	-	-	SUMD	-	-	**7**
Fung et al (2011), Tsang et all (2014)	CSSMIS	-	-	-	-			-	-	-	-	-	CGSS	-	-	-	SUMD	-	CAQ	**4**
Rusch et al (2014)	ISMI	-	SSS	LSS COMIS	-		-	-	-	-	-	RESS	-	-	-	-	-	-	-	**5**
Russinova et al (2014)	ISMI	-	-	ACWS	PGRS		-	CESD	-	-	-	RESS	SES	-	-	-	-	-	-	**6**
Morrison et al (2016)	ISMI SIMS	SS	-	-	QPR-S		-	BDI-PC	BHS	SIAS	SERS	-	-	ISS	-	-	-	-	-	**9**
Controlled trials and cohort studies																				
Lucksted et al (2011)	ISMI	-	-	-	MHRM		-	-	-	-	-	RESS	-	-	-	-	-	PSS	-	**4**
Uchino et al (2012)	SDS	-	-	-		GAF	-	-	-	-	-	-	-	-	KIDI	DAI	BPIS	-	-	**5**
Sousa et al (2012)	ISMI	-	-	-		CORE (F)	CORE (S)	-	-	-	-	-	-	-	-	-	-	-	-	**2**
Knight et al (2006)	PDD	-	-	CCS	-		PANSS	BDI	-	-	ISE	RESS	-	-	-	-	-	-	-	**6**
Roe et al (2014)	ISMI	-	-	-		MANSA	-	-	ADHS	-	RSES	-	-	-	-	-	-	-	-	**4**
N (%) studies examining outcome	**12 (100)**	**2 (16.7)**	**1 (8.3)**	**5 (41.7)**	**3 (25)**	**5 (41.7)**	**4 (33.3)**	**4 (33.3)**	**4 (33.3)**	**1 (8.3)**	**6 (50)**	**5 (41.7)**	**3 (25)**	**1 (8.3)**	**1 (8.3)**	**2 (16.7)**	**3 (25)**	**1 (8.3)**	**1 (8.3)**	

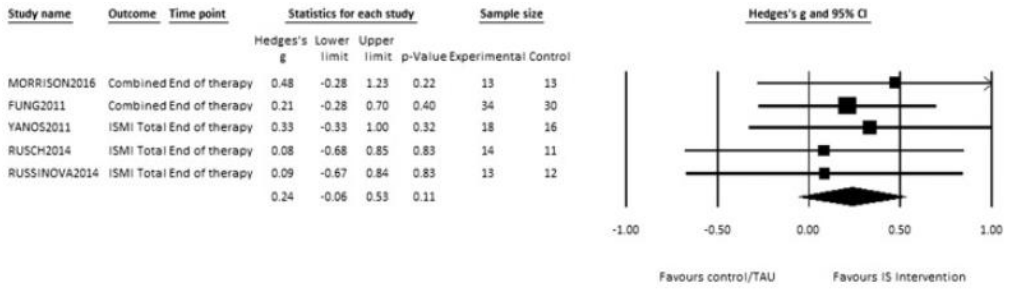
ACWS – Approaches to Coping with Stigma (B. G. Link et al., 2002), ADHS – Adult Dispositional Hope Scale (Snyder et al., 1991), BDI – Beck Depression Inventory (A. T. Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), BDI-PC – Beck Depression Inventory for Primary Care (Winter, Steer, Jones-Hicks, & Beck, 1999), BHS – Beck Hopelessness Scale (A. Beck et al., 1974), BPIS – Birchwood Psychosis Insight Scale (Birchwood et al., 1994), CAQ – Change Assessment Questionnaire (Hilburger, 1995), CCS – Cybernetic Coping Scale (Edwards & Baglioni, 1993), CESD – Centre of Epidemiological Studies Depression (Radloff, 1977), CGSS – Chinese General Self Efficacy Scale (Chiu, 2004), COMIS – Coming Out with Mental Illness Scale (Corrigan et al., 2010), CORE – Clinical Outcome and Routine Evaluation Measure (Evans et al., 2000), CSC- Coping with Symptoms Checklist (P. T. Yanos, Knight, & Bremer, 2003), CSSMIS – Chinese Self-Stigma of Mental Illness Scale (Fung et al., 2007), DAI – Drug Attitude Inventory (Hogan, Awad, & Eastwood, 1983), GAF – Global Assessment of Functioning (Endicott, Spitzer, Fleiss, & Cohen, 1976), GSES – General Self-Efficacy Scale (Scwarzer & Jerusalem, 1995), ISMI - Internalised Stigma of Mental Illness Inventory (J.B. Ritsher & Phelan, 2004), ISS – Internalised Shame Scale (Cook, 1987), KIDI – Knowledge of Illness and Drugs Inventory (Maeda, Mukasa, Ogoh, & Mukasa, 1992), LSS – Link Secrecy Scale (B. G. Link et al., 2002), MANSA – Manchester Short Assessment of Quality of Life (Priebe, Huxley, & Knight, 1999), MES - Modified Engulfment Scale (E. A. McCay & Seeman, 1998), MHRM – Mental Health Recovery Measure (Young, Ensing, & Bullock, 1999), MHS – Miller Hope Scale (Miller & Powers, 1988), PANSS – Positive and Negative Syndrome Scale (Kay, Fiszbein, & Opler, 1987), PDD – Perceived Devaluation-Discrimination scale (B. G. Link, Mirotznik, & Cullen, 1991; B. G. Link et al., 2002), PGRS – Personal Growth and Recovery Scale (Russinova et al., 2014), PSS – Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988), QLS – Quality of Life Scale (Henrichs, Hanlon, & Carpenter, 1984), QPR-S – Process of Recovery Short Form (Law, Neil, Bunn, & Morrison, 2014), RESS – Rogers Empowerment Scale (Rogers, Chamberlin, Ellison, & Crean, 1997), RSE – Rosenberg Self-Esteem Scale (Rosenberg, 1979), SDS – Social Distance Scale (Whatley, 1959), SERS – Self-Esteem Rating Scale (T. Lecomte et al., 2006), SES- Self-Efficacy Scale (Sherer et al., 1982), SIAS – Social Interaction Anxiety Scale (Mattick & Clarke, 1998), SIMS – Service user Interview Measure of Stigma (Wood et al., 2016), SRER – Self-Reported Experiences of Rejection (B. G. Link et al., 2002) , SRF – Stigma Related Feelings (B. G. Link et al., 2002), SS –Stigma Scale (King et al., 2007), SSS – Stigma Stress Scale (Lazarus & Folkman, 1984), SUMD – Scale to Assess Unawareness of Mental Disorders (Amador et al., 1993), TSCS – Tennessee Self-Concept Scale (Fitts & Warren, 1996).

3.4.6. Examination of primary and secondary outcomes

3.4.6.1.Primary outcome Internalised stigma

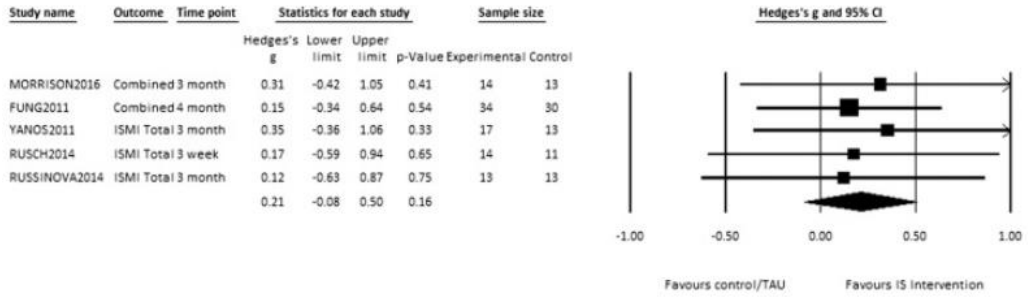
Internalised stigma was examined by all studies included in the review. Both CTs and one pre/post CS found significant improvements in internalised stigma individually, and no RCTs found significant individual improvements. A meta-analysis was conducted with five RCTs (n=200) that had available data (figure 2 and 3). Analysis did not suggest a significant difference in internalised stigma between groups at end of therapy, although analysis was favouring the internalised stigma intervention (Hedges' g 0.24, 95% CI -0.06 to 0.53, p = 0.11). Heterogeneity between studies was low (Q=0.783, P=0.941, I^2 = 0.000). Similarly, at follow-up (ranging from 3 weeks to 4 months) there was no significant difference in internalised stigma between groups, although the analysis favoured the internalised stigma intervention (Hedges' g 0.21, 95% CI -0.08 to 0.50, p=0.16). Heterogeneity was also low for this time point (Q=0.352, P=0.986, I^2 = 0.000).

Figure 2 – Internalised Stigma (IS) meta-analysis output for end of therapy



Study name	Outcome	Time point	Hedges's g	Lower limit	Upper limit	p-Value	Experimental	Control
MORRISON2016	Combined	End of therapy	0.48	-0.28	1.23	0.22	13	13
FUNG2011	Combined	End of therapy	0.21	-0.28	0.70	0.40	34	30
YANOS2011	ISMI Total	End of therapy	0.33	-0.33	1.00	0.32	18	16
RUSCH2014	ISMI Total	End of therapy	0.08	-0.68	0.85	0.83	14	11
RUSSINOVA2014	ISMI Total	End of therapy	0.09	-0.67	0.84	0.83	13	12
			0.24	-0.06	0.53	0.11		

Figure 3 – Internalised Stigma (IS) meta-analysis output for follow-up



Study name	Outcome	Time point	Hedges's g	Lower limit	Upper limit	p-Value	Experimental	Control
MORRISON2016	Combined	3 month	0.31	-0.42	1.05	0.41	14	13
FUNG2011	Combined	4 month	0.15	-0.34	0.64	0.54	34	30
YANOS2011	ISMI Total	3 month	0.35	-0.36	1.06	0.33	17	13
RUSCH2014	ISMI Total	3 week	0.17	-0.59	0.94	0.65	14	11
RUSSINOVA2014	ISMI Total	3 month	0.12	-0.63	0.87	0.75	13	13
			0.21	-0.08	0.50	0.16		

3.4.5.2. **Secondary outcomes**

In order to focus on the most important secondary outcomes, outcomes which had at least three or more studies contributing to an outcome were examined narratively, and at least two were required for the meta-analysis. Table 5 outlines the outcomes examined and whether the individual studies found a significant or non-significant result favouring the intervention.

Table 5 – Significant outcomes (total scores) of internalised stigma intervention end of therapy

Author	Self-stigma	Coping skills	Recovery	Functioning	Pathology	Depression	Hopelessness	Social Anxiety	Self-Esteem	Empowerment	Self-efficacy	Insight
Link et al (2002)	×	×	-	-	-	NR	-	-	NR	-	-	-
McKay et al (2007)	×	-	-	✓	NR	✓	-	-	NR	NR	NR	-
Yanos et al (2011)	×	✓	-	×	×	-	×	-	×	-	-	×
Fung et al (2011)	×	-	-	-	-	-	-	-	×	-	✓	✓
Rusch et al (2014)	×	✓	-	-	-	-	-	-	-	×	-	-
Russinova et al (2014)	×	✓	×	-	-	×	-	-	-	×	✓	-
Morrison et al (2016)	×	-	✓	-	-	✓	✓	×	×	-	-	-
Controlled trials and cohort studies												
Lucksted et al (2011)	✓	-	✓	-	-	-	-	-	-	×	-	-
Uchino et al (2012)	✓	-	-	×	-	-	-	-	-	-	-	✓
Sousa et al (2012)	×	-	-	✓	×	-	-	-	-	-	-	-
Knight et al (2006)	×	×	-	-	✓	✓	-	-	✓	×	-	-
Roe et al (2014)	✓	-	-	✓	-	-	×	-	✓	-	-	-

NA-Data not in published paper as study used <50% people with psychosis, NR – Not reported, ✓- Significant result favouring stigma intervention, × - non significant difference, - outcome not examined

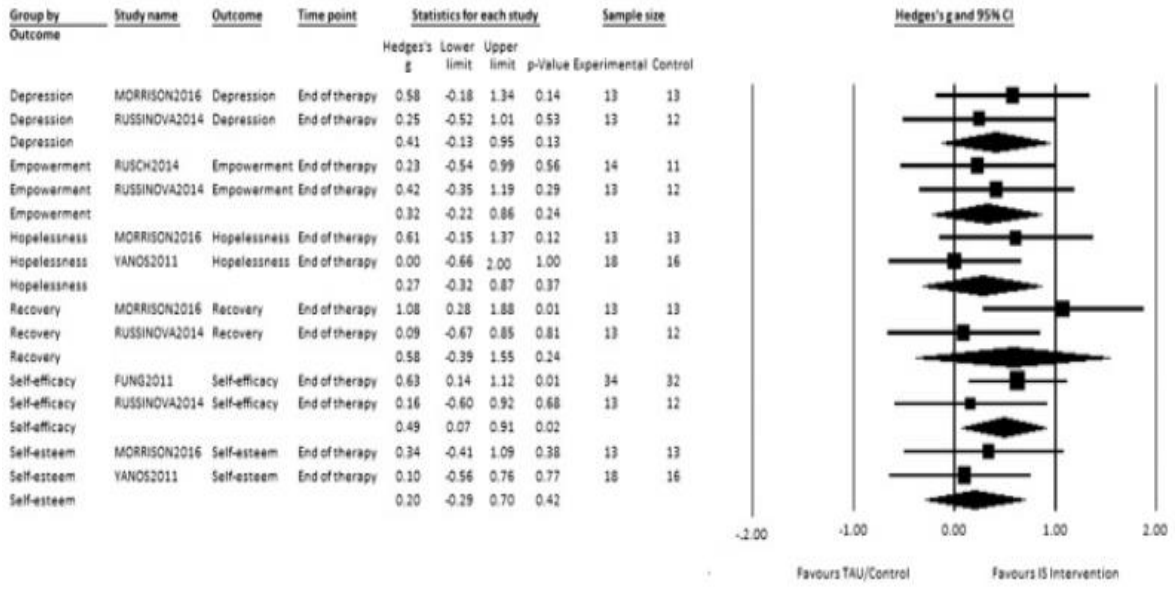
The random effects models and effect sizes for the secondary outcomes are outlined in figures 4 – 7. RCTs examining depression, empowerment, hopelessness, recovery and self-esteem were entered into a meta-analysis. No significant findings were identified.

Self-efficacy was examined by three RCTs, two found a significant improvement in self-efficacy at the end of therapy. Two RCTs with available data (N= 89) were entered into a meta-analysis. Self-efficacy was shown to significantly favour the internalised stigma intervention following therapy (Hedges' g 0.49, 95% CI 0.07 to 0.91, p=0.02). This was not maintained at follow-up but the effect was favouring the intervention (Hedges' g 0.31, 95% CI -0.10 to 0.71, p=0.14).

Insight was examined by three studies, two RCTs and one CT. The CT and one RCT found an individual significant difference favouring the intervention. The two RCTs (N=70) were entered into a meta-analysis. At the end of therapy there was a significant outcome favouring the internalised stigma intervention (Hedges' g 0.43, 95% CI 0.04 to 0.83, p=0.03). This significant treatment effect was not maintained at follow-up (Hedges' g 0.28, 95% CI -0.12 to 0.68, p=0.17).

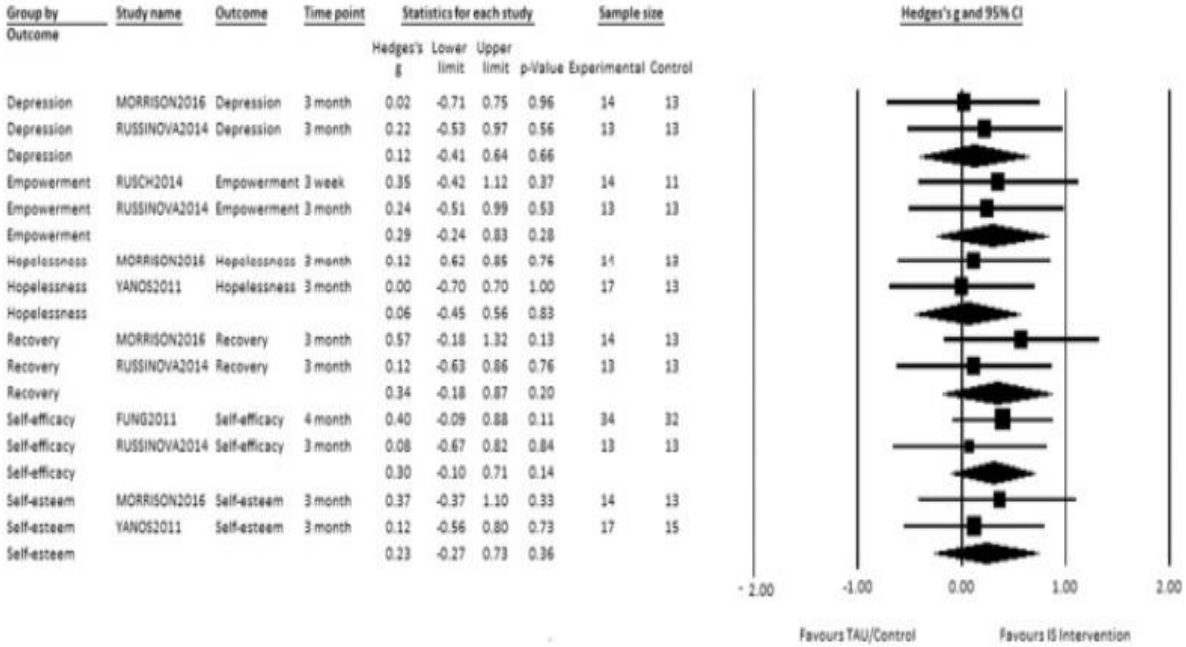
Coping skills included outcomes which examined ways people responded and coped with stigma and their related mental health difficulties. The outcomes examined varied quite considerably across included studies. Studies looked at outcomes such as secrecy, withdrawal, distancing, educating, positive views of disclosure, problem solving and avoidance coping. These outcomes were not entered into a meta-analysis due to the variability in outcomes.

Figure 4 – Random effects model of secondary outcomes at end of therapy



Group by Outcome	Study name	Outcome	Time point	Hedges's g	Lower limit	Upper limit	p-Value	Experimental	Control
Depression	MORRISON2016	Depression	End of therapy	0.58	-0.18	1.34	0.14	13	13
Depression	RUSSINOVA2014	Depression	End of therapy	0.25	-0.52	1.01	0.53	13	12
Depression				0.41	-0.13	0.95	0.13		
Empowerment	RUSCH2014	Empowerment	End of therapy	0.23	-0.54	0.99	0.56	14	11
Empowerment	RUSSINOVA2014	Empowerment	End of therapy	0.42	-0.35	1.19	0.29	13	12
Empowerment				0.32	-0.22	0.86	0.24		
Hopelessness	MORRISON2016	Hopelessness	End of therapy	0.61	-0.15	1.37	0.12	13	13
Hopelessness	YANOS2011	Hopelessness	End of therapy	0.00	-0.66	2.00	1.00	18	16
Hopelessness				0.27	-0.32	0.87	0.37		
Recovery	MORRISON2016	Recovery	End of therapy	1.08	0.28	1.88	0.01	13	13
Recovery	RUSSINOVA2014	Recovery	End of therapy	0.09	-0.67	0.85	0.81	13	12
Recovery				0.58	-0.39	1.55	0.24		
Self-efficacy	FUNG2011	Self-efficacy	End of therapy	0.63	0.14	1.12	0.01	34	32
Self-efficacy	RUSSINOVA2014	Self-efficacy	End of therapy	0.16	-0.60	0.92	0.68	13	12
Self-efficacy				0.49	0.07	0.91	0.02		
Self-esteem	MORRISON2016	Self-esteem	End of therapy	0.34	-0.41	1.09	0.38	13	13
Self-esteem	YANOS2011	Self-esteem	End of therapy	0.10	-0.56	0.76	0.77	18	16
Self-esteem				0.20	-0.29	0.70	0.42		

Figure 5 - Random effects model of secondary outcomes at follow-up



Group by Outcome	Study name	Outcome	Time point	Hedges's g	Lower limit	Upper limit	p-Value	Experimental	Control
Depression	MORRISON2016	Depression	3 month	0.02	-0.71	0.75	0.96	14	13
Depression	RUSSINOVA2014	Depression	3 month	0.22	-0.53	0.97	0.56	13	13
Depression				0.12	-0.41	0.64	0.66		
Empowerment	RUSCH2014	Empowerment	3 week	0.35	-0.42	1.12	0.37	14	11
Empowerment	RUSSINOVA2014	Empowerment	3 month	0.24	-0.51	0.99	0.53	13	13
Empowerment				0.29	-0.24	0.83	0.28		
Hopelessness	MORRISON2016	Hopelessness	3 month	0.12	0.62	0.86	0.76	14	13
Hopelessness	YANOS2011	Hopelessness	3 month	0.00	-0.70	0.70	1.00	17	13
Hopelessness				0.06	-0.45	0.56	0.83		
Recovery	MORRISON2016	Recovery	3 month	0.57	-0.18	1.32	0.13	14	13
Recovery	RUSSINOVA2014	Recovery	3 month	0.12	-0.63	0.86	0.76	13	13
Recovery				0.34	-0.18	0.87	0.20		
Self-efficacy	FUNG2011	Self-efficacy	4 month	0.40	-0.09	0.88	0.11	34	32
Self-efficacy	RUSSINOVA2014	Self-efficacy	3 month	0.08	-0.67	0.82	0.84	13	13
Self-efficacy				0.30	-0.10	0.71	0.14		
Self-esteem	MORRISON2016	Self-esteem	3 month	0.37	-0.37	1.10	0.33	14	13
Self-esteem	YANOS2011	Self-esteem	3 month	0.12	-0.56	0.80	0.73	17	15
Self-esteem				0.23	-0.27	0.73	0.36		

Figure 6 - Random effects model of insight at end of therapy

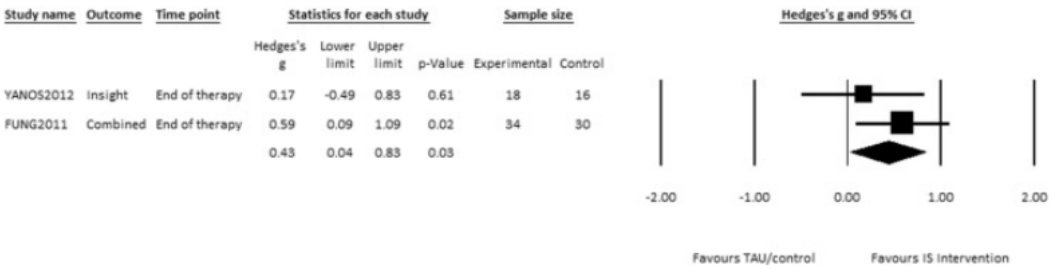
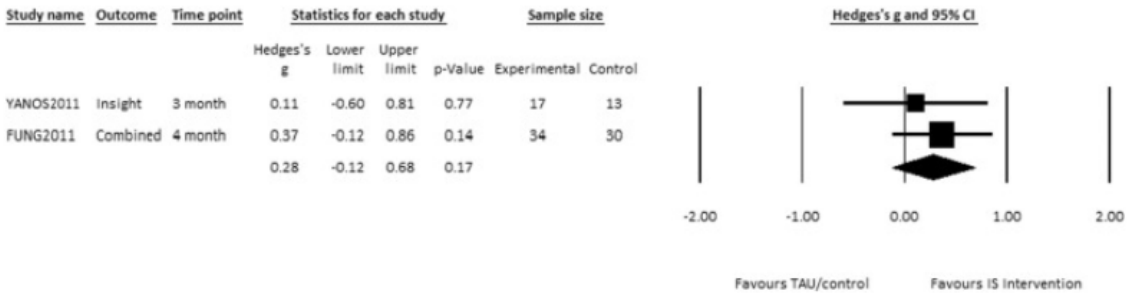


Figure 7 - Random effects model of insight at follow-up



3.5. Discussion

This study aimed to conduct a systematic narrative review and meta-analysis of psychosocial interventions for internalised stigma with schizophrenia-spectrum diagnoses. A total of 12 studies were included in the review, 7 RCTs, 3 CSs and 2 CTs. This review is the first of its kind examining the efficacy of internalised stigma interventions specifically in schizophrenia-spectrum diagnoses. The review has to be interpreted tentatively due to the relatively small number of studies with small sample sizes which were included.

Examination of the interventions revealed that psychoeducation, thought challenging, connecting with peers and social skills training were the most commonly used techniques within the psychosocial interventions. It was beyond the scope of this review to statistically examine which interventions significantly predicted outcome due to the paucity of studies. In a recent narrative review of internalised stigma interventions for SMI, Yanos et al (2014) similarly found that psychoeducation and cognitive challenging were key components of all interventions. Furthermore, in a recent examination of service user perspectives of participation in the A. Morrison et al. (2016) internalised stigma CBT intervention, a number of specific change mechanisms were highlighted as essential in the therapeutic process (Wood, Burke, Byrne, & Morrison, 2016). Psychoeducation and normalisation were identified by service users as important mechanisms within therapy. The review findings tentatively support the use of previously identified change mechanisms.

Few of the interventions were specifically designed for people with a schizophrenia-spectrum diagnosis. The majority of internalised stigma studies were for SMI rather than those with a schizophrenia-spectrum diagnosis per se. Less than half of studies included in this review had specific interventions for this group. Other studies included participants

who experienced chronic depression, anxiety, bipolar disorder and personality disorders (B. G. Link et al., 2002; Lucksted et al., 2011; Roe et al., 2014; Rusch et al., 2014; Russinova et al., 2014; P. T. Yanos et al., 2011). As outlined, the stigma experienced by those with schizophrenia-spectrum diagnosis is likely to be conceptually different to those with other psychiatric diagnoses (Oliveria et al., 2015). Moreover, psychological interventions are commonly developed for specific presentations in order to maximise their efficacy. For example, the cognitive models of psychosis (A. P. Morrison, 2001) and bipolar (Mansell, 2007) have distinctive differences in the conceptualisation of their respective presentations. This has a number of potential consequences for the efficacy of the intervention as a) people with a schizophrenia-spectrum diagnosis may have not felt as comfortable sharing their experiences with the group, especially if they were in the minority, and b) the intervention itself may have not been tailored to their specifics needs in relation to internalised stigma.

The A. Morrison et al. (2016) study was the only one to offer individual CBT for internalised stigma; all others offered a group intervention. There are a number of advantages of an individual therapy which may be helpful in alleviating internalised stigma. A particular advantage is the ability to develop an idiosyncratic formulation. A formulation has been highlighted as an essential part of CBT by therapists ensuring that therapy goals are targeted to a service user's individual needs (A. Morrison & Barratt, 2010). Exploration of service user experiences of the A. Morrison et al. (2016) intervention indicated that flexible goal setting was essential to the efficacy of the intervention (L. Wood, E. Burke, R. Byrne, & A. Morrison, 2016). Further RCTs are required examining the efficacy of individual interventions for internalised stigma.

The primary outcome of internalised stigma was found to be significantly improved by two CTs and one pre/post CS but not significant in the meta-analysis at end of therapy or

follow-up. The most methodologically robust study found the largest effect favouring the internalised stigma intervention (A. Morrison et al., 2016). Internalised stigma has been highlighted to be extremely prevalent in those with mental health difficulties, including schizophrenia-spectrum diagnoses (Elaine Brohan, Rodney Elgie, et al., 2010). It has been highlighted as an important factor negatively impacting on people's mental health, self-esteem, levels of depression and hopelessness (Livingston & Boyd, 2010) and therefore is an important outcome to target in psychological therapy. It is essential this is continued to be examined as a primary outcome in internalised stigma interventions.

This meta-analysis identified that internalised stigma, self-esteem, and empowerment illustrated an overall effect favouring the internalised stigma intervention, and self-efficacy and insight had a significant effect after the internalised stigma intervention. This would suggest that these outcomes are important in capturing the efficacy of an internalised stigma intervention. Although the overall effect did not near significance for other outcomes, depression, hopelessness and recovery were found to have a small effect favouring the internalised stigma intervention in the Morrison et al. (2016) study. This study found an individual significant effect for personal recovery measured on the process of recovery questionnaire (Neil et al., 2009). This study was found to be the most methodologically robust study with little bias detected indicating that these outcomes may also be important in assessing the efficacy of an internalised stigma intervention.

One of the limitations of the review was the small studies that were included. In a meta-analysis, small studies can fail to detect a modest intervention effect due to the lack of power within each individual study (Borenstein et al., 2009). Conversely, small studies can also have "small-study effects" as small studies are likely to suffer from publication bias and only be published if they are significant (Hutton & Taylor, 2014). Small studies are also more likely to suffer from methodological flaws. This review included studies

which illustrated heterogeneity although the small study numbers did not facilitate reliable examination of heterogeneity. Examination of the funnel plots highlights large confidence intervals and variability in effect sizes illustrating clinical and methodological heterogeneity respectively. The small number of studies within this review also meant that tests for publication bias could not be performed. Ioannidis and Trikalinos (2007) recommend at least 10 trials for enough power to perform such analysis. There were only 5 studies eligible for the meta-analysis and these were all with small samples (N range 27 – 66). Nevertheless, meta-analysis of small studies within a limited evidence base is advantageous as long as sensitivity analyses are considered (IntHoult et al., 2015).

The comprehensive synthesis of a limited evidence base of internalised stigma interventions for schizophrenia-spectrum diagnosis was a considerable strength of the review. The review synthesised data on outcome measures, key mechanisms of change within internalised stigma interventions, and meta-analysed a relatively large sample to identify effect sizes of internalised stigma interventions. This facilitated the identification of a number of recommendations for future trials of internalised stigma interventions.

3.5.1. Future research

In terms of the population examined, over half of the studies included in this review did not exclusively examine participants with a schizophrenia-spectrum diagnosis. It would be important to examine the efficacy of an internalised stigma intervention in large scale RCTs exclusively with this presentation, such as people who experience first episode psychosis, severe and enduring psychosis, and at risk groups as stigma is a prevalent issue in all these groups (E. McCay et al., 2007; A. Morrison et al., 2016).

The review tentatively suggests that the development of more targeted interventions for internalised stigma may be helpful. The majority of interventions to date have not directly

targeted internalised stigma idiosyncratically through the development of a formulation. A number of large scale RCTs are required to examine the efficacy of the diverse psychosocial interventions included in this review. All studies included in this review had relatively small sample sizes and did not have enough power to find significant results on the internalised stigma outcome. All intervention types would benefit from further examination in a large-scale trial. Potentially, one of the most important interventions to examine is CBT given that it is the first line recommended psychological intervention for people with a schizophrenia-spectrum diagnosis (NICE, 2014). As stated, psychoeducation, normalisation, and cognitive restructuring of stigma were the most frequently used change mechanisms with study interventions, all of which are encompassed within a CBT approach.

The refinement and validation of an internalised stigma outcome measure which is specific to people with a schizophrenia-spectrum diagnosis and meets all reliability and validity (Terwee et al., 2007) could also improve outcome. As Brohan et al. (2010) stated, there is not a measure of internalised stigma which meets all reliability and validity criteria required for an outcome measure. Being able to identify the efficacy of an internalised stigma intervention would depend on a measure which is sensitive and specific to change. Best practise also states that outcome measures should also be developed in consultation with service users (Trivedi & Wykes, 2002).

In conclusion, internalised stigma interventions could show promise in alleviating internalised stigma in people with a schizophrenia-spectrum diagnosis. However the studies were limited by the small sample size, small effect sizes, and the lack of methodological rigor in some of the studies included in the review. Further large-scale RCTs need to be conducted in order to examine the efficacy of internalised stigma interventions exclusively with people with a schizophrenia-spectrum diagnosis. Outcome

measures should include measures of internalised stigma, recovery, self-esteem, empowerment, self-efficacy, and coping skills.

4. Chapter 4: Study 2 - Semi-structured Interview Measure of Stigma (SIMS) in psychosis: Assessment of psychometric properties

This paper has been published in Schizophrenia Research:

Wood, L., Burke, R., Byrne, R., Enache, G., & Morrison, A. (2016) Semi-structured interview measure of stigma (SIMS) in psychosis: Assessment of psychometric properties. *Schizophrenia Research.* 176 (2-3), 398 – 403.

4.1. Abstract

Stigma is a significant difficulty for people who experience psychosis. To date, there have been no outcome measures developed to examine stigma exclusively in people with psychosis. The aim of this study was to develop and validate a semi-structured interview measure of stigma in psychosis. An eleven item (ten rateable items) semi-structured interview measure of stigma (SIMS) was developed in consultation with service users who have experienced psychosis. 79 participants with experience of psychosis were recruited for the purposes of this study. They were administered the SIMS alongside a battery of other relevant outcome measures to examine reliability and validity. A one-factor solution was identified for the SIMS which encompassed all ten rateable items. The measure met all reliability and validity criteria and illustrated good internal consistency, inter-rater reliability, test retest reliability, criterion validity, construct validity, sensitivity to change and had no floor or ceiling effects. The SIMS is a reliable and valid measure of stigma in psychosis. It may be more engaging and acceptable than other stigma measures due to its semi-structured interview format.

Key words: stigma, psychosis, schizophrenia, semi-structured interview, psychometrics

4.2. Introduction

Many outcome measures have been developed to assess the impacts of stigma on service users diagnosed with a serious mental illness (SMI). However, a recent systematic review of individual outcome measures of stigma identified that all of the available measures are self-report measures and not specific to psychosis (Brohan et al., 2010). Brohan et al (2010) identified that the three most widely-used self-report measures of stigma were; the Perceived Devaluation and Discrimination Scale (PDD: B. G. Link, 1987), the Internalised Stigma of Mental Illness Inventory (ISMI; Ritscher et al., 2003), and the Self-Stigma of Mental Illness Scale (SSMIS; Corrigan et al., 2006). Brohan et al (2010) identified that these outlined measures each lacked some form of reliability and validity; for example, none met requirements for floor and ceiling effects. Furthermore, as stated, these measures were developed for use with individuals experiencing SMI. Arguably not all SMI's are comparable in terms of their experiences of stigma which will also hinder reliability and validity of stigma measures. For example, those with a schizophrenia spectrum disorder are viewed most negatively by the public (Crisp et al., 2005; Wood et al., 2014), are most discriminated against (Dinos et al., 2004; G. Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009), have the most intense internalised stigma beliefs, worst social exclusion and significantly lower levels of functioning, compared to those with a diagnosis of bipolar disorder and depression (Karidi et al., 2015; Oliveria et al., 2015).

The aim of this study was to develop a reliable and valid semi-structured interview measure of stigma (SIMS) in psychosis, in consultation with service users, which can be used to assess and monitor change in the personal impacts of stigma in psychosis. A semi-structured interview measure also provides diversity in a saturated pool of self-report measures. Furthermore, the semi-structured format of the interview measure offers the flexibility in questioning to identify culturally specific aspects of stigma, the lack of which

has been a criticism of existing self-report measures (Semrau et al., 2015). Outcomes on the semi-structured interview measure of stigma (referred to henceforth as the SIMS) were compared to the ISMI (J. B. Ritsher et al., 2003) and Stigma Scale (SS; King et al., 2007) to examine its ability to measure stigma. Furthermore, it was also compared to outcome measures of self-esteem, depression, hopelessness, internalised shame and recovery, since research indicates that these psychological variables are also related to stigma and thus assist with validation (Birchwood et al., 2007; P. W. Corrigan et al., 2006; B. G. Link et al., 2001; Livingston & Boyd, 2010; Michail & Birchwood, 2013; Rüsch et al., 2014). The psychometric properties of the SIMS were examined and it was hypothesised that there will be good validity in comparison to other relevant measures. Specifically, it was hypothesised that the SIMS will be positively correlated with existing measures of stigma, and with measures of depression, hopelessness and shame, and negatively correlated with measures of self-esteem and recovery.

4.3. Methods

4.3.1. Development of the SIMS

4.3.1.1.Literature review and initial development

Item generation for the SIMS was derived from a systematic review of qualitative literature examining service user perspectives of stigma in psychosis, as described in Wood, Burke, Byrne, et al. (2015). Eight studies were included in this review and were analysed using thematic synthesis (Thomas & Harden, 2008). A total of 96 initial codes were identified in the data (coding for the SIMS was conducted separately from analysis published in the systematic review due to differing aims). Codes were reviewed by the research team and grouped into nine subordinate themes as follows; experienced stigma, perceived stigma, internalised stigma (comprising self-esteem, emotions, safety behaviours/avoidance, relationships, impacts on experiences of psychosis, treatments, and recovery). All items related to the stigma caused by experiencing psychosis.

Scoring criteria for the SIMS was developed through examination of a sample of current semi-structured measures utilised in psychosis. The Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987) , the Psychotic Symptoms Rating Scale (PSYRATS; Haddock et al., 1999) , and the Calgary Depression Scale(CDS; Addington, Addington, & Maticka-Tyndale, 1994) were consulted as they offer an array of scoring criteria for consideration. Questions and prompts were developed for each theme to assist interviewers in collecting relevant stigma-related information pertaining to each theme, in a consistent manner across interviewees.

4.3.1.2.Service user consultation and piloting

A draft version of the SIMS was reviewed by a Service-User Reference Group (SURG) to enhance content validity. The SURG comprised eight service users with lived experience of psychosis. The SURG suggested that the SIMS should include two additional areas of questioning; one concerning service users' understanding of stigma and one regarding the positive impacts of stigma. In addition, the SURG offered the following suggestions: to provide standard definitions of stigma; to make language more understandable and acceptable to service users; and to offer service users an interview agenda in advance to allay any fears about questioning. The SURG also made suggestions regarding the scoring of the SIMS preferring a likert scale rating which could be applied to each individual item. The SIMS was piloted with two service user researchers in order to further refine questions and prompts, to estimate duration of interview and to get feedback regarding the experiences of being interviewed using the SIMS.

4.3.1.3.Final measure and scoring

The final SIMS comprised eleven sections, one of which is not scored: understanding of stigma (not scored), perceived stigma, experienced stigma, internalised stigma (self-esteem, safety behaviours/avoidance, relationships, impacts on experiences of psychosis, treatments, positive impacts of stigma, and recovery). All items enquired about the impacts of stigma related to experiences of psychosis. The interview is designed to collect quantitative data based on the subjective accounts reported by the interviewee. Each section is rated on a five-point likert scale (0-4) by the interviewer where 0 indicates no impact/experience of stigma and 4 indicates a severe impact/experience of stigma. When rating, the interviewer must take into consideration the frequency, duration, amount of distress, intensity of distress, and impacts on day to day functioning. All items are rated on

the interviewees experiences in the past month. Comprehensive guidance to support inter-rater reliability is incorporated into the measure.

4.3.2. Participants

Participants were recruited from two sources. Participants were either recruited from (a) the Reducing Self-stigma in Psychosis through Engagement in Cognitive Therapy (RESPECT) trial, A. Morrison et al. (2016) or (b) an inner London acute psychiatric inpatient unit. In both (a) and (b) participants were either identified by their care coordinator or via the nursing staff on the participating wards. Participants were included if they were (i) aged between 18-65, and (ii) met ICD-10 criteria for schizophrenia, schizoaffective disorder or delusional disorder or met criteria for an Early Intervention Service (EIS). Exclusion criteria were moderate to severe learning disability, organic impairment, not having the capacity to consent to research participation, insufficient proficiency with spoken English, severe thought disorder**,** and a primary diagnosis of drug and alcohol dependency. Severe thought disorder was determined by the referring clinician.

4.3.3. Additional outcome measures

The Internalised Stigma of Mental Illness Inventory (ISMI; Ritsher et al., 2003) is a 29-item questionnaire assessing internalised stigma. This measure was revised by the research team in partnership with SURG such that the term ‘mental illness’ in its original form was replaced with ‘mental health problems’. Higher scores indicate increased internalised stigma.

The Stigma Scale (SS) short version (King et al., 2007). The SS is a 16-item measure of stigma. This shortened version included the subscales of ‘disclosure’ and ‘positive

aspects', but not the 'discrimination' subscale which is less likely to capture change over time (Morrison et al., 2016). Higher scores demonstrate higher levels of stigma.

The Process of Recovery Questionnaire – Short form (QPR; Law et al., 2014) was used to measure user-defined recovery. This is a 15-item questionnaire which was developed collaboratively with service users and which measures subjective recovery. Increased scores illustrate higher levels of perceived recovery.

The Beck Depression Inventory for Primary Care (BDI- PC; Beck et al., 1997) is a 7-item measure of depression. Higher scores indicate increased levels of depression.

The Beck Hopelessness Scale (BHS; Beck et al., 1974) is a 20-item measure of hopelessness. Higher scores show increased hopelessness.

Self-esteem was measured using the Self-Esteem Rating Scale – Short form (SERS-S; Lecomte et al., 2006) , a 20-item questionnaire with higher scores indicating higher self-esteem.

Finally, internalised shame was measured using the Internalised Shame Scale (ISS; Cook, 1987), a 30-item questionnaire with higher scores indicating higher levels of shame.

A measure of psychotic symptoms was not included on the basis of feedback from the SURG, who felt that a focus on such symptoms would provide an inconsistent message regarding stigma.

4.3.4. Procedure

This study was carried out in three stages of assessment. A participant information sheet was given and written informed consent was taken before participants took part in the study. Stage one baseline assessments involved participants (n=79) completing the SIMS

alongside all other measures. Data from stage 1 was used to carry out the factor analysis, internal consistency, inter-rater reliability, and concurrent validity of the SIMS. The second stage follow-up involved a proportion of participants (n=25) completing the SIMS again at a 4 month time point to examine for test-retest reliability. Stage 3 followed up stage 2 participants (n=28, including 3 additional participants who were unavailable at stage 2), completing the SIMS and all other measures at a 7 month time point in order to examine for sensitivity to change. All participants at stage 2 and 3 had been included in the RESPECT study (A. Morrison et al., 2016).

4.3.5. Statistical Analysis

All data analysis was conducted using IBM SPSS version 23 (2015). Where whole outcome measures were missing, data would be excluded pairwise for the respective analysis. Where less than 20% of individual items were missing from outcome measures, these would be replaced with the measure mean. Data was initially checked for normality through examination of skewness and kurtosis (Kim, 2013).

Initially, individual SIMS items were compared using the Pearson's correlation coefficient to ensure that no items were either extremely highly or poorly correlated. All SIMS items were entered into an exploratory Principal Components Analysis (PCA) with Direct Oblimin rotation, and internal consistency was examined for the identified factor's items. Test-retest reliability was tested for by examining the Pearson correlation coefficients between the SIMS total scores at stage 1 and 2. The SIMS was compared to the ISMI to examine for criterion validity using Pearson's correlation analysis. The ISMI was chosen as it is currently the most reliable measure of stigma (Brohan et al., 2010). Construct validity was examined through comparisons of the SIMS to all other measures using Pearson's correlation analysis. Sensitivity to change was calculated by comparing the

change score (stage 1 mean score minus the stage 3 mean score) of the SIMS to change score of all other measures. Where relevant, correlation coefficients were compared for significance using the Fishers z calculation. Floor and ceiling effects were determined as present if more than 15% of the sample scored the minimum (0) or maximum (40) score on the SIMS (Terwee et al., 2007).

4.4. Results

4.4.1. Participant demographics

A total of 79 participants took part in the study. Demographics can be seen in table 6.

Table 6- Sample Demographics

Demographic	**Mean (Standard Deviation)**	**Range**
Age	36.489 (11.69)	18-62
	Category	**N**
Patient status	Inpatient	47
	Outpatient	32
Gender	Male	59
	Female	20
Ethnicity	Black heritage	12
	White heritage	52
	Asian heritage	10
	Other	5
Diagnosis	Schizophrenia	25
	Paranoid Schizophrenia	18
	Psychotic episode	19
	First Episode Psychosis	10
	Schizoaffective Disorder	2
	Recurrent Psychosis	2
	Persistent Delusional Disorder	2
	Drug Induced Psychosis	1

4.4.2. Initial data scrutiny

Individual items from the SIMS were initially screened for their relationship with one another (table 7). If items were either high or low item correlations (<.200 or>.900) they would be removed, but none met this criteria. Items 9 (0.142 to 0.417) and 10 (-0.175 to -0.296) had the lowest item correlations. Items 9 and 10 also had the lowest endorsements (table 7) but all ten items were included in the factor analysis.

4.4.3. Examination of reliability

4.4.3.1. Principal Components Analysis

The examination of the scree plot (figure 8) and eigenvalues led to only one factor being identified. This factor explained 51.97% of the variance. Factor loadings are shown in table 7. As a consequence of the one factor solution, no sub-categories were identified within the interview measure. The full ten items will therefore be used for subsequent reliability and validity analysis.

Figure 8 – Scree plot of eigenvalues for Principal Components Analysis

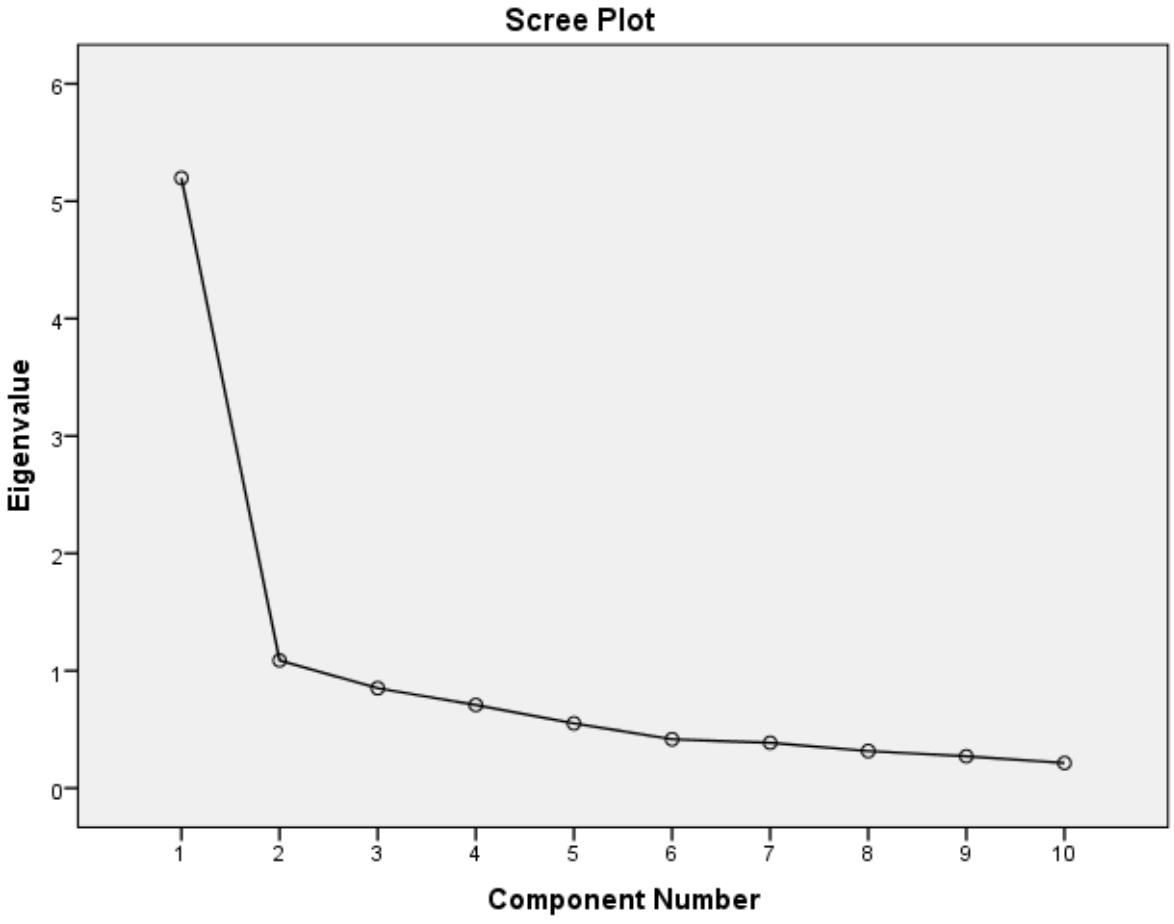


Table 7 – Pearson correlation coefficients, descriptive statistics and factor loadings for SIMS items

Item	1	2	3	4	5	6	7	8	9	M	SD	Min	Max	S	K	Factor Loading
1Percived										2.44	1.059	0	4	-.245	-.212	.762
2Experienced	.527**									1.57	1.195	0	4	.201	-.943	.683
3Self-esteem	.612**	.472**								2.05	1.290	0	4	-.243	-.999	.844
4Emotions	.531**	.511**	.685**							2.41	1.296	0	4	-.547	-.747	.790
5Behaviours	.542**	.398**	.750**	.604**						2.10	1.307	0	4	-.263	-.954	.816
6Relationships	.544**	.603**	.578**	.599**	.533**					1.96	1.275	0	4	-.118	-1.156	.794
7 Symptoms	.580**	.345**	.599**	.449**	.651**	.513**				1.22	1.346	0	4	.598	-1.103	.743
8Treatment	.142	.417**	.255*	.270*	.274*	.336**	.229*			.90	1.069	0	4	.916	-.207	.429
9Positive Impacts	-.257*	-.175	-.240*	-.212	-.213	-.257*	-.296**	-.019		.95	.904	0	3	.421	-.970	-.354
10Recovery	.550*	.446**	.623**	.603**	.656**	.608**	.543**	.388**	-.243*	1.84	1.381	0	4	-.056	-1.296	.810

*p<0.05, ** p<0.01

4.4.3.2. Internal Consistency

Internal consistency was examined through the use of the Cronbach's Alpha statistic. The SIMS items showed excellent internal consistency with a Cronbach's Alpha score of α=0.87 (Nunnally & Bernstein, 1994). Intraclass Correlations (ICCs), using a two way mixed model, were also examined to test for reliability. The measure had a fair ICC of 0.391 (CI: .307 - .489, $p<0.001$).

4.4.3.3. Inter-rater Reliability

The SIMS was also shown to have good inter-rater reliability across three raters. Authors LW and GE rated three interviews and had an ICC of 0.874, LW and EB also rated three interviews and had an ICC of 0.959, both illustrating almost perfect agreement (Landis & Koch, 1977).

4.4.3.4. Test-retest Reliability

Participants (n=25) scored a mean total of 23.76 (SD: 6.66) at stage 1 and a mean of 20.03 (SD: 8.02) at stage 2. The SIMS showed good test-retest reliability with a significant ICC of 0.563 (CI: 0.214 - 0.784, $p<0.01$).

4.4.4. Examination of Validity

Means and standard deviations for all measures used to examine validity are shown in table 8. The Pearson correlation coefficients for each measure are also shown in table 9.

Table 8– Descriptive of outcome measures at baseline and follow-up

	Baseline						Follow-up (7-months)					
Item	**M**	**SD**	**Min**	**Max**	**S**	**K**	**M**	**SD**	**Min**	**Max**	**S**	**K**
1SIMS	19.53	8.73	2	36	-.082	-1.011	17.26	7.91	3	29	-.497	-.836
2ISMI	69.85	16.74	32	104	-.458	-.157	65.47	19.02	0	98	-1.429	4.349
3SS	31.03	10.93	9	58	-.024	-.420	35.80	8.92	13	51	-.591	.381
4BDI	7.29	5.66	0	21	.475	-.686	6.88	4.82	0	14	-.109	-1.343
5BHS	8.41	6.42	0	20	.459	-1.168	9.85	6.83	0	19	.010	-1.502
6SERS	85.74	27.58	36	134	-.064	-1.045	78.16	27.34	33	131	.565	-.681
7ISS	60.60	29.87	1	120	-.136	-.949	63.80	26.52	6	102	-.822	-.210
8QPR	36.31	14.20	0	60	-.658	.098	35.28	12.94	7	60	-.319	.214

K=Kurtosis, M = Mean, Max = Maximum Score, Min = Minimum Score, S=Skewness, SD=Standard Deviation,

Table 9– Pearson correlation coefficients and descriptive statistics of outcome measures at baseline

	N	1	2	3	4	5	6	7
1SIMS	79							
2ISMI	78	.752**						
3SS	76	.666**	.681**					
4BDI	77	.689**	.646**	.533**				
5BHS	76	.603**	.566**	.515**	.800**			
6SERS	77	-.775**	-.800**	-.653**	-.788**	-.754**		
7ISS	63	.741**	-.830**	.678**	.808**	.719**	-.908**	
8QPR	75	-.531**	-.433**	-.517	-.668**	-.777**	.657**	-.688**

*p<0.05, ** p<0.01

4.4.4.1. Criterion validity

The SIMS illustrated a significant strong positive correlation with the ISMI (table 9). The coefficient was above 0.7 illustrating that it meets the gold standard of criterion validity (Terwee et al., 2007).

4.4.4.2. Construct validity

The SIMS illustrated significant correlations with all other outcomes (table 9). The SIMS and SS were highly correlated illustrating that the SIMS is valid in measuring the broad construct of personal stigma. The SIMS was also highly correlated with the BDI and BHS highlighting the relationship between stigma, depression and hopelessness as highlighted in the literature (B. G. Link et al., 2001; P. H. Lysaker et al., 2007). The SIMS was also highly correlated with the SERS and ISS showing a strong relationship between stigma,

shame and low self-esteem (B. G. Link et al., 2001). The SIMS illustrated a significant positive correlation with the QPR.

4.4.4.3. Sensitivity to Change

Pearson correlation coefficients and follow-up descriptive statistics for all measures can be found in table 10 and 8 respectively. The SIMS was found to have significant correlations with all measures. The strongest relationship of change related particularly to the ISS and SERS indicating that changes in stigma relate most strongly to internalised shame and self-esteem. It also has a strong relationship with the BDI, BHS and QPR. The correlations highlight that the SIMS had larger sensitivity to change correlation coefficients against all outcomes compared to the ISMI, with the SERS, ISS and QPR being statistically significant (BDI: Fishers $z=0.88$, $p=0.190$; BHS: Fishers $z=1.34$, $p=0.090$; SERS: Fishers $z= -2.5$, $p<.01$; ISS: Fishers $z= 1.73$, $p<.05$; QPR: Fishers $z=-.659$, $p<.05$). The SIMS also had larger sensitivity to change correlation coefficients with the SERS, ISS, and QPR compared to the SS but the difference was not statistically significant (SERS: Fishers $z= -1.41$, $p=0.0793$; ISS: Fishers $z= 0.18$, $p=0.428$; QPR: Fishers $z= 0.352$, $p=0.703$).

4.4.5. Floor and Ceiling effects

The SIMS did not illustrate any floor or ceiling effects. No participants scored the minimum score of 0 and no participants scored the maximum score of 40. As shown in table 8, the minimum score on the SIMS was 2 and the maximum was 36.

Table 10 – Pearson correlation coefficients and follow-up descriptive statistics for sensitivity to change analysis

	N	1	2	3	4	5	6	7
SIMS change	23							
ISMI change	28	.479*						
SS change	25	.571**	.420*					
BDI change	25	.482*	.255	.595**				
BHS change	25	.453*	.083	.550**	.713**			
SERS change	25	-.819**	-.380	-.622**	-.544**	-.689**		
ISS change	25	.759**	.439*	.735**	.592**	.716**	-.867**	
QPR change	25	-.659**	-.140	-.590**	-.654**	-.681**	.747**	-.731**

*p<0.05, ** p<0.01

4.5. Discussion

The aim of this study was to develop and examine the psychometric properties of the SIMS. Analysis demonstrated that it is a reliable and valid tool to assess change in personal stigma in psychosis. The SIMS was relatively quick to administer compared to other semi-structured tools and appeared to have high content validity. The SIMS is developed to be the first stigma measure specifically for people who experience psychosis. Having a specific target population increases the validity of the measure (Terwee et al., 2007). This may explain why the SIMS was shown to have better sensitivity to change and concurrent validity than the other comparable stigma measures. Targeting this population enabled specific questions to be included examining the impacts of stigma on auditory hallucinations and unusual beliefs. Results illustrated that this was an important subscale which contributed to the reliability and validity statistics. This accords with other research in the field as internalised stigma has also been found to be associated with both positive symptoms (Caveleti et al., 2014) and negative symptoms (K. Hill & Startup, 2013) of psychosis. At the same time the SIMS examined impacts of stigma which could potentially be important to people with other mental health experiences, however this would need to be examined for reliability and validity in future research.

One of the strengths of the SIMS is that it utilises a semi-structured interview format where most previous measures are self-report in nature (Brohan et al., 2010). An interview measure has a number of advantages over standard self-report measures. It improves the reliability since interviewers are on-hand to clarify questions and concepts for interviewees, and improves participant engagement (Phellas, Bloch, & Seale, 2011), which is likely to be of particular importance when discussing issues of a sensitive nature, such as personal accounts of stigma. The SIMS can be used by clinicians as a meaningful clinical tool to assess stigma and offers various prompts to engage service users in a

meaningful discussion about stigma. Talking about stigma has been shown to reduce stigma (Corrigan et al., 2013), therefore administration of the measure alone may be of therapeutic benefit and reduce the internalised stigma of interviewees.

The SIMS is also the first outcome measure to delineate and examine the specific psychological impacts of stigma. The SIMS can extract rich information regarding the psychological functioning of service users. This is valuable information since it can enable clinicians to offer appropriate psychological support. For example, the SIMS scrutinises safety behaviours, emotional responses and impacts on relationships which are fundamental to psychological models. An increasing number of clinical trials have been conducted examining the efficacy of stigma based interventions, mainly drawing upon Cognitive Behavioural Therapy (CBT) theory, and with varying results (M. D. Knight et al., 2006; Lucksted et al., 2011; A. Morrison et al., 2016). One criticism of these studies is the lack of specificity in the outcome measures they use in regard to psychological mechanisms (Wood, Byrne, Varese, & Morrison, 2016). The SIMS may fill this gap by examining specific psychological mechanisms relevant to stigma.

There were a number of limitations in this study. One of the limitations was the time points in which the test retest and sensitivity to change follow-ups were conducted. Usually for test-retest reliability it is recommended that the measure is repeated one to two weeks after it was initially administered (Nunnally & Bernstein, 1994). However, for convenience the test-retest was conducted four months after the initial administration as part of the RESPECT trial follow-up assessment (Morrison et al., 2016). This measure examines stigma over the last month so a longer test-retest period is expected, however four months may have been too long. As the SIMS is time intensive, the researchers were conscious of not overburdening the participant by completing an additional semi-structured interview. Similarly, for the sensitivity of change analysis a seven month time period was utilised as

part of the RESPECT study (Morrison et al., 2016). Although there is not as much explicit guidance on duration for sensitivity to change analysis, seven months is a long duration. A further limitation was the moderate sample size used for psychometric testing. Test-retest reliability and sensitivity to change analysis used only 25 and 28 participants respectively. Furthermore, the factor analysis was carried out with n=79 participants when it is often recommended that 10 times per number of variables are advantageous.

In conclusion, the SIMS is a reliable and valid outcome measure of stigma in psychosis. As it is a semi-structured interview measure, it offers an important alternative to all of the other self-report outcome measures.

5. Chapter 5: Study 3 - Acute inpatients' experiences of stigma from psychosis: A qualitative exploration

This paper has been published in Stigma and Health:

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5.1. Abstract

Stigma is a common difficulty for those who experience psychosis as they are viewed as most dangerous, unpredictable and least likely to recover. In particular, experiences of stigma are yet to be explored with inpatients admitted to psychiatric hospital. The aim of this study was to examine subjective experiences of stigma with acute psychiatric inpatients who experience psychosis. Twenty five (n=25) psychiatric inpatients with experiences of psychosis were interviewed using a semi-structured interview measure to examine their subjective experiences of stigma. The interview schedule enquired about their experiences of stigma and discrimination and the personal impacts this has had. Thematic analysis was employed to analyse the qualitative data. The analysis identified three superordinate themes, 'stigmatising social environment and networks', 'stigmatised person with psychosis', and 'stigma interactions'. These themes reflected experiences of stigma during the inpatient stay as well as in the community. A graphical representation of these themes and their interaction was developed. Stigma is a concern for acute psychiatric inpatients with psychosis. This concern should be explored in future research, and where appropriate addressed during admission to an acute psychiatric inpatient hospital.

Key words: inpatient, stigma, thematic analysis, interviews, psychosis, schizophrenia

Declaration of interests: None

Practitioner points:

- Stigma is a concern for people admitted to a psychiatric inpatient ward that experience psychosis both during admission as well as in the community.
- Participants identified sources of stigma within the inpatient unit from staff, and more broadly as a result of the regimented and medicalised environment.

- Participants identified emotional, cognitive, and behavioural responses to stigma which impact on their mental health difficulties.
- Stigma, where appropriate, needs to be discussed and addressed during an admission to an acute psychiatric inpatient unit.

5.2. Introduction

Stigma is a mark of disgrace associated with a specific characteristic or quality that a person possesses (B. G. Link et al., 1997). Stigma is highly associated with schizophrenia-spectrum diagnoses, as these in turn are highly associated with perceived dangerousness and unpredictability by members of the public (Crisp et al., 2005). The detrimental impact of stigma on an individual's well-being and recovery has been extensively researched through quantitative research (P. W. Corrigan et al., 2006; B. G. Link et al., 2001; B. G. Link et al., 1997). Researchers have also attempted to understand these detrimental impacts from a service user perspective using qualitative research (Buizza et al., 2007; M. T. D. Knight, Wykes, & Hayward, 2003; Pyle & Morrison, 2013; Schulze & Angermeyer, 2003). In a recent qualitative study conducted by Burke et al. (2016), stigma equated to misunderstanding and discrimination from others and led to negative impacts on self, emotions, behaviours and recovery. Moreover a systematic review of the qualitative literature (studies which examined the subjective experiences of stigma through semi-structured interviews or focus groups) identified two important stigma factors (Wood, Burke, Byrne, et al., 2015). Firstly, stigma was identified as a socially ubiquitous issue penetrating all layers of participants' social systems. Secondly, key processes were identified which could potentially tackle stigma, and these included: education and understanding, acceptance, disclosure, and communication.

To date, the majority of qualitative studies of stigma associated with schizophrenia-spectrum diagnoses have been conducted with community-based participants rather than individuals in inpatient settings (Wood, Burke, Byrne, et al., 2015). Being admitted to an acute psychiatric inpatient ward can often be a distressing experience, particularly if the service user is admitted involuntarily (Gilburt, Rose, & Slade, 2008). Service users have reported feeling unsafe and described experiences of verbal and physical abuse (MIND,

2004). The most recent UK national Care Quality Comission (2009) survey illustrated that these issues are still of concern as almost half of inpatients were not always involved in decisions around their care and 20% of inpatients reported that they were not always treated with dignity and respect. Arguably, these reported experiences of acute inpatient admission echo the stigma experiences identified in previous qualitative research (Dinos et al., 2004; Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2007). A possible explanation for this is that the dominant biomedical model of treatment underpinning inpatient care for people experiencing psychosis has been shown to perpetuate stigma. A number of studies have illustrated that biogenetic explanations cause the belief that people with mental ill-health are different and thus increase desire for social distance and emotional detachment (Angermeyer et al., 2011; J Read, Haslam, Sayce, & Davies, 2006).

To the authors' knowledge there has been minimal exploration of inpatients' subjective experiences of stigma. One study by McCarthy et al. (1995) aimed to examine subjective stigma by interviewing sixty inpatients about their knowledge of their diagnosis, attitudes to admission and having their social network involved in their care. They found that families of psychiatric inpatients were unlikely to know about their care, and that service users are reluctant to disclose their diagnosis and details of their admission. However this study is arguably not reflective of current psychiatric inpatient services. Given the ongoing need to improve inpatient services (Care Quality Comission, 2009), it would seem imperative to explore inpatients' perspectives of stigma. Therefore, this study aimed to examine the subjective experiences of stigma in service users with a schizophrenia-spectrum diagnosis and who are currently admitted to an acute psychiatric inpatient unit. It will utilise a semi-structured interview measure which has been successfully used to assess

stigma among community-based individuals with psychosis experiences (Burke et al., 2016).

5.3. Method

5.3.1. Participants

Convenience sampling was undertaken to recruit participants for this study. Participants were recruited from an inner London acute psychiatric inpatient unit and identified via nursing staff. Participants were included if they were (i) aged between 18-65, (ii) were currently admitted to a psychiatric inpatient ward, and (iii) met ICD-10 criteria for schizophrenia, schizoaffective disorder or delusional disorder or met criteria for an early intervention service to allow inclusion of first episode service users without a diagnosis. Exclusion criteria were moderate to severe learning disability, organic impairment, participants not having the capacity to consent to research participation, non-English speaking participants, severe thought disorder**,** and a primary diagnosis of drug and alcohol dependency.

5.3.2. Interview Schedule

Participants were interviewed using the semi-structured interview measure of stigma (SIMS; Wood et al., 2016). The SIMS was developed through a systematic review of qualitative literature and in consultation with a service user group. It has been used successfully as a qualitative interview schedule with a community sample who experience psychosis (Burke et al., 2016). The SIMS examined three areas of stigma: experienced stigma, perceived stigma, and internalised stigma (Brohan et al., 2010). Please see table 11 for questions included in the SIMS. These questions asked about lifetime experiences as well as experiences specific to hospital admission in order to provide space for participants to speak about the most pertinent stigma experiences. Interviews were designed to last

between thirty to forty-five minutes. The semi-structured interview offered consistency in topics but also allowed flexibility for the interviewer to be led by participants' responses. Participants were also invited to discuss stigma issues that were not elicited by the interview questions. As the interviews were undertaken, the SIMS evolved and additional questions were added regarding experiences of stigma or discrimination within the psychiatric inpatient setting.

Table 11 – SIMS interview questions

	Question
1.	What does stigma mean to you?
2.	How do you think a person with psychosis is viewed by society? Prompt. Inpatient experience
3.	Have you had any direct experiences of stigma because you have experienced psychosis? What are they? Prompt. Inpatient experience.
4.	How do others' views about psychosis and/or your experience of stigma make you feel about yourself?
5.	Have you experienced difficult emotions as a result of stigma? What?
6.	Has stigma impacted on your daily life? How? Prompt. Inpatient experience.
7.	Has stigma affected your relationship with others? How? Prompt Inpatient experience.
8.	Has stigma impacted upon your experiences of psychosis?
9.	Has stigma affected you accessing mental health services/treatment? How? Prompt. Inpatient Experience.
10.	Has stigma had any positive impacts on your day to day life? Prompt Inpatient Experience.
11.	Has stigma impacted on your recovery? Prompt. Inpatient Experience.

5.3.3. Procedure and Data Analysis

Full ethical approval was sought for this study from the NHS Research Ethics Committee (14/LO/2164) and the study was sponsored by the University of Manchester. To ensure quality control, the study protocol followed guidance outlined by Thomas and Harden (2008) for the methodology and reporting of the research. Interviews were conducted by the first author LW (n=17) and third author GE (n=8) who are both trained and experienced in qualitative research data collection methods. All interviews took place within the acute psychiatric inpatient ward in a quiet side room. Participants gave written informed consent and completed a demographics sheet prior to completing the interview. The interviews themselves lasted on average 30.48 minutes (range 11.47-48.02).

Interviews were recorded and transcribed verbatim by authors LW and GE. Quality checks of transcription were undertaken by comparing five randomly selected transcripts with recordings. Analysis was undertaken using NVivo software version 10 (QSR, 2012). Transcripts were analysed using procedures for thematic analysis outlined by Braun and Clarke (2006). Thematic analysis was chosen as it is well-suited for working with data gathered using a pre-developed semi-structured interview measure. Thematic analysis requires decisions to be made about the epistemological position that the analysis will take. These decisions were made to best achieve the aims of the study. A realist approach was adopted to work with the data which assumes a directional relationship between meaning, experience and participants' language. Themes were extracted inductively and were strongly linked to the data. Themes were identified by examining the explicit meaning of the data and not looking beyond what the participant has said.

Analysis was conducted concurrently with data collection in order to achieve saturation, and was an iterative process. Saturation was deemed to be achieved when the research team agreed that no new themes had been identified. First author LW coded all interviews

included in the study. Authors GE and RB examined consistency of coding by coding two randomly selected transcripts respectively. Agreement was achieved if the subsequent coding did not identify any new codes not identified by the initial analysis.

Initially 1219 codes were identified, and were then collapsed with overlapping codes to form 201 potential themes. These themes were reviewed and finalised within a triangulation meeting involving the full research team (to minimise risk of individual biases in interpretation), where individual themes were discussed and grouped together to form superordinate and subordinate themes. A final thematic structure to represent study findings was then decided upon. The themes were shared with three randomly selected participants to gain feedback and changes were made accordingly. Overall, participants thought the themes made sense and applied to them. Participant's suggestions for changes included: amending the wording of themes into simpler lay language; emphasising (more) that stigma is not just confined to a psychiatric admission but rather may penetrate all areas of their lives; and ensuring that the unirelational nature of stigma was emphasised, i.e. that it's mainly caused by others but has detrimental impacts on them.

5.4. Results

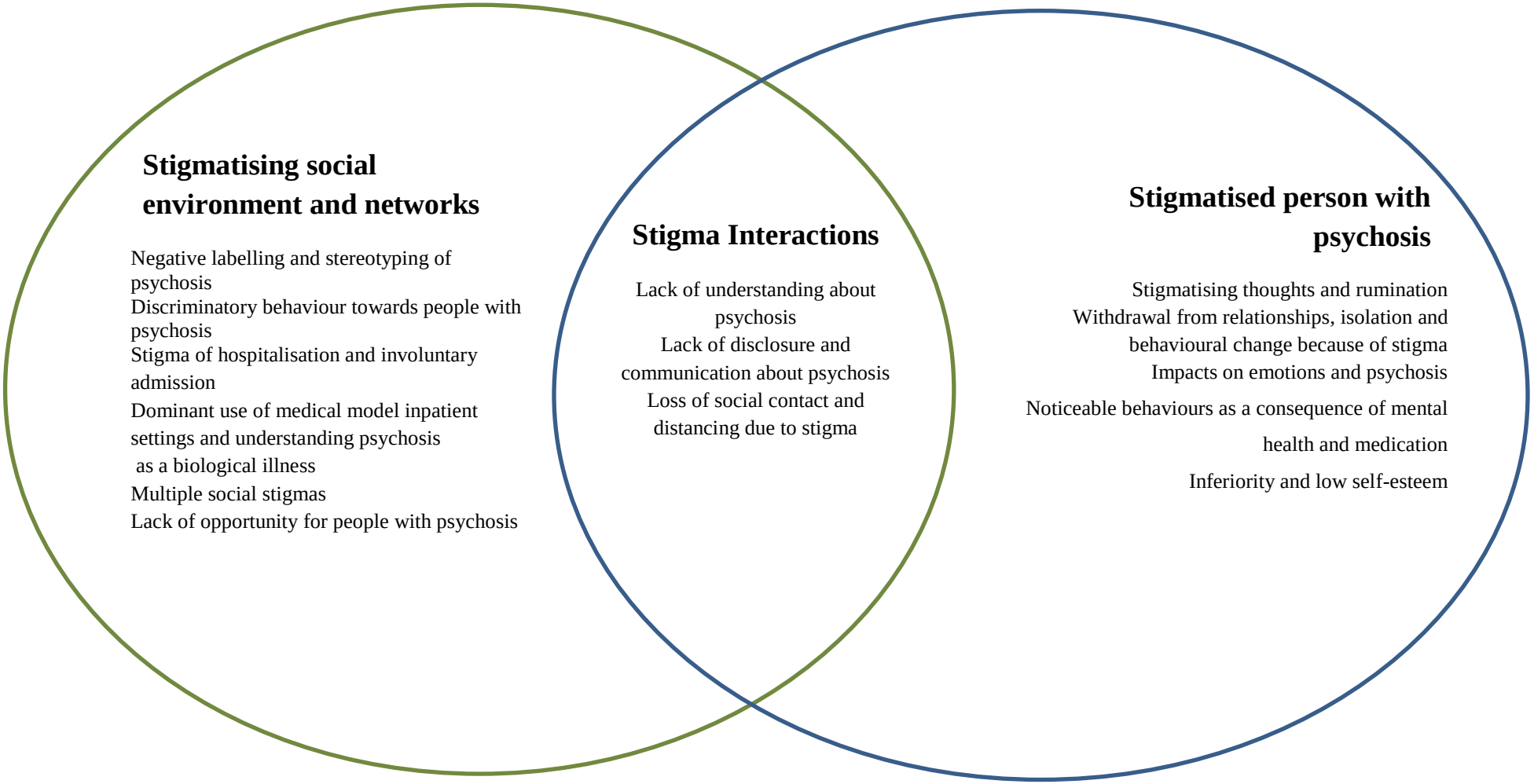
Twenty five individual interviews were included in the analysis. Participant characteristics can be seen in table 12.

Table 12 – Sample demographics

Demographic	**Mean (Standard Deviation)**	**Range**
Age	36.48 (9.98)	21- 58
Hospital Admissions	4.72 (3.70)	1-5
Length of Mental Health Service Contact (years)	10 (7.96)	1-30
	Category	**N**
Gender	Male	20
	Female	5
Employment status	Employed	4
	Unemployed	19
	Student	2
Ethnicity	Black heritage	5
	White heritage	10
	Asian heritage	7
	Mixed heritage	2
	Other	1
Education level	Secondary	4
	Further	8
	Higher	13
Marital status	Single	22
	Married	2
	Divorced/separated	1
Diagnosis	Schizophrenia	16
	Psychotic episode	8
	Persistent Delusional Disorder	1

The thematic analysis identified three superordinate themes, 'stigmatising social environment and networks', 'stigmatised person with psychosis', and 'stigma interactions'. These themes are represented graphically in figure 9.

Figure 9 - Graphical representation of stigma



All themes reflected experiences that participants had during hospitalisation as well as in the community, as both were outlined by participants as equally important. Where appropriate each theme has a specific subsection which pertains to inpatient-specific examples. All quotes below which are not explicitly related to stigma were in direct response to a stigma-related question (table 11), thus given the realist method of analysis were taken as themes of stigma.

5.4.1. Stigmatising social environment and networks

The superordinate theme of 'stigmatising social environment and networks' described the social setting surrounding the individual and the types of stigma which occur within this context. There are multiple types which range from negative labelling to marginalisation. This theme reflects the pervasive nature of stigma for individuals with psychosis.

5.4.1.1.Negative labelling and stereotyping of psychosis

All twenty five participants identified negative labelling and stereotyping of psychosis as something they are aware of and had experience of. Participants felt that media portrayals were the main perpetuators of negative labelling and stereotyping. The most common labels identified by participants were being dangerous and unpredictable: "People just have that one view that schizophrenics are highly dangerous and murderers!" (Participant 18), seen as crazy and abnormal: "seen as crazy people doing crazy things" (participant 7), as inadequate or a failure and as a druggie or drunk: "the manager in the bed and breakfast, when I used to talk to her she used to dismiss me used to say I am drunk 'go away you are drunk' even though I'm not drunk 'don't talk to me'" (participant 30).

Two participants went as far as to compare a diagnosis of schizophrenia to a horror movie: “if you say to someone you’ve got schizophrenia, they step back. Or your psychosis, the film comes into mind like Psycho, like I’m going to kill them or something… That film psycho, that I am a mass murderer” (participant 32).

Negative labelling and stereotyping of psychosis occurred within all of the participants’ social networks including friends and family: “I've had friends that have seen me in that way, I'm a schizophrenia, schizophrenic so must be a murderer. A friend did see me in that way” (participant 2).

All participants felt that negative labelling and stereotyping was maintained by negative portrayals in the media. This included news stories: “I remember the stories in the news a while ago with a man who was hacking up children and the teacher protected them” (participant 16) as well as popular television programmes: “you know like that episode of EastEnders where you know that woman with bipolar, before that that lady Stacey relapsed, the way they are portrayed in the acting” (participant 20). Participants reported that the way their social network viewed them was influenced by the media: “Most people just follow what's in the media and its only a few people in the minority who can see where you're coming from and see your story” (participant 5).

5.4.1.1.1. **Inpatient specific examples**

Negative labelling and stereotyping was identified as prevalent in the inpatient setting. Primarily, participants identified that they are viewed as an illness and not a person by some inpatient staff: “you are mentally ill, so that's how some of the [inpatient ward] staff perceive you” (participant 30). Furthermore, participants explained that the inpatient admission itself increased the likelihood of negative stereotyping occurring: “you know,

[they say] look at yourself, you're useless, you're worthless you haven't done, that you haven't achieved. You're in a mental hospital. You're crazy" (participant 26)

5.4.1.2.Discriminatory behaviour towards people with psychosis

Nineteen participants described experiencing discriminatory behaviour as a consequence of their psychosis. The most common forms of discrimination were verbal abuse: "they come up to me and say 'oh yeah, you're mental'… I've had it before", and being treated like a child: "I feel that I am treated more like a child erm, than my siblings, …But even with friends, [they] push me around" (participant 15), and being continuously judged: "all they [family] do is judge, it's all conditional, no unconditional positive regard" (participant 19), and being ignored: "my sister, the thing is I'm not really in touch of my family at the moment apart from my dad. They sort of ignore me… like I don't exist" (participant 13).

Participants who did not describe any discriminatory behaviour were those who were experiencing their first episode of psychosis: "I haven't [had any experiences of discrimination], I haven't had this [psychosis] long enough" (participant 4).

5.4.1.2.1. Inpatient specific examples

Participants explained that they had experienced discriminatory behaviour which directly related to their experiences of hospital admission, "One person said 'go back to the psychiatric ward'" (participant 5). Another participant described the staff as treating them in a discriminatory way, "you would assume that people working in mental illness would care, but some people don't" (participant 24).

5.4.1.3.Stigma of hospitalisation and involuntary admission

Psychiatric hospitalisation was described by twenty-one participants as being a stigmatising experience. Firstly, participants explained they had experiences of stigma and discrimination during their admission from ward staff: "*Interviewer (I):* Have you experienced any stigma whilst you were on the ward, on here? *Participant (P):* Sometimes, yes…because the staff dismissed me…I just think that they are discriminating against me at times because of my illness" (participant 30). Participants explained that medical treatment was too quickly offered which they perceived as stigma: "*I:* So you quite feel that maybe doctors, psychiatrists, are stigmatising? *P:* Yeah, and some of the nurses as soon as I say I'm hearing voices, I can't cope, they will all make me, quick take this medication, rather than sitting and talk to me" (participant 32). Participants also referred to the perceived stigma attached to being admitted to a psychiatric hospital: "once that people know that you know, that you have been into a mental home that's it, you just got a label there and then" (participant 36).

5.4.1.4.Dominant use of the medical model in inpatient settings and understanding psychosis as a biological illness

Six participants commented upon the dominant use of the medical model in the inpatient setting and how this maintained stigma. Diagnostic labels such as schizophrenia and psychosis were deemed to have negative connotations: "All of it [medical diagnosis] is so wrong. Even psychosis is wrong because it's got psycho in it. Paranoid schizophrenic…there is no good connotations anyway" (participant 6). Participants also spoke about the over-reliance of medical treatment as a form of stigma: "*I:* Do you think staff see you as incapable then? *P:* Yeah I think erm, people should receive encouragement to take care of themselves, like, erm people come round and help them with their cooking

or…. It's very much based on, I'll give you a tablet, I'll give you medication. It's very erm, the treatment seems very harsh sometimes that people in here receive" (participant 15).

5.4.1.5.Multiple social stigmas

Six participants, all from ethnic minority groups explained that mental health stigma worsened when you had to face additional stigmas such as racism: "racism. It's like people judging people about their race, is that kind of thing really. You're such a minority" (participant 17), and negative cultural understanding of psychosis: "the cultural bits you know. We are worthless, don't deserve respect, things like that [due to experiences of psychosis]" (participant 28), not meeting gender requirement: "especially with men you are supposed to take your problems and deal with them and not let them get to you so that is why you know mental health is seen very differently" (participant 26).

5.4.1.5.1. Inpatient specific examples

Participants from ethnic minority groups outlined that their cultural differences meant that hospital admissions were more stigmatising than it would be if they were from a different cultural group: "especially in my kind of culture, there is a lot of that so even being in a psychiatric hospital could be a problem, everyone saying 'he is crazy because he is in hospital'" (participant 26).

5.4.1.6.Lack of opportunity for people with psychosis

Ten participants described having a reduction in opportunities, and limits set on their life due to stigma associated with psychosis. Lost opportunities primarily concerned gaining meaningful employment and not being exploited: "so this thing about job experience is a load of rubbish. They just use you, they used my friend in [UK supermarket] and just used

to and when the job applications came up he wasn't invited to go for a job. That's discrimination, very much so" (participant 18), and other social issues such as lack of secure housing due to stigma from neighbours: "the main one was the phone call from the neighbour [to the council to evict participant]. The people who live in the flat above. That is definitely stigma" (participant 17).

5.4.1.6.1. **Inpatient specific examples**

Participants explained that it was lack of opportunity and social discrimination which often contributed to their mental health worsening which often led to an inpatient admission: "no, apart from work. I don't think my boss was too sympathetic... he just kept bringing me in for more and more interviews when I was supposed to be off sick…this made me worse" (participant 4).

5.4.2. Stigmatised person with psychosis

The second superordinate theme 'stigmatised person with psychosis' reflected the personal impacts and internalisation of stigma. This theme highlighted the cognitive, behavioural and emotional impacts that stigma has on the individual with psychosis.

5.4.2.1.Stigmatising thoughts and rumination

Seventeen participants reported that stigma impacted on their cognitive processes and content in a detrimental way. Participants discussed the content of their cognitions being stigmatising and self-critical: "just really critical and yeah, really aware that the person might not think I am normal, or they might have a bad judgement" (participant 8). Participants would also internalise the negative labels: "I feel like a failure!" (participant 32). Participants also spoke about often worrying about what others think of them: "The

hate from people…. I was worried that people can see through me and know that I [have psychosis], make fun of me" (participant 26).

5.4.2.1.1. **Inpatient specific examples**

The majority of participants reported that they would ruminate and dwell on stigma specific to an inpatient admission: "I start thinking thoughts of people don't like me, then I see other people, I think I'm an outcast in society and I'm different and I'm in hospital" (participant 17). Participants would particularly worry about what others thought of them: "you've been in a mental home, that's it, you just got a label there and then, once you go into a mental institute people automatically assume a mental institute is for the coo coo crazy" (participant 36).

5.4.2.2. Withdrawal from relationships, isolation and behavioural change due to stigma

Twenty participants reported some behavioural change as a result of stigma. The most significant changes were avoidance of people: "yeah, I just keep to myself and avoid socialising in general. I was definitely keeping myself to myself and keeping quiet, and I knew people were going to ask me about it [mental health] so I just avoided it" (participant 7), and situations: "I also avoid places where people might think that I'm unemployed [due to stigma]. I used to go to the gym in the morning when people would've thought I was unemployed so. So I stick to in the afternoon and early morning" (participant 6). Participants had also developed their own idiosyncratic coping mechanisms to manage stigma such as ignoring stigma: "I will just try to ignore it [when people are saying stigmatising things] or just smile" (participant 5), putting on a façade: "I have to put on a façade…. So blend in, I have to put an act on. Yeah" (participant 19), and not letting the

media portrayals affect you: “You see things on the news all the time. Like a guy with schizophrenia and the police. Me, I think rationally I think logical” (participant 8).

5.4.2.2.1. **Inpatient specific examples**

Avoidance was prevalent during the hospital admission due to stigma. Participants explained that they avoided therapy groups: “I avoided some group activities because of it [stigma]” (participant 8), and staying in communal areas: “I started the queue for food, I get worried about people around me, and you know it just added to my anxiety. Because then if it’s not one issue that I’m worried about, it’s the other [stigma], I eat quickly so I could just get to my room” (participant 26).

5.4.2.3.Impacts on emotions and psychosis

Stigma was a source of significant emotional distress for twenty-two participants. This could either be as a consequence of a direct experience of stigma or from perceived stigma. Depression and low mood were the most commonly cited emotional consequences for over half of participants: “it [stigma] just makes it worse, it [stigma] makes me feel pretty low. It’s just another layer on it” (participant 26). Worry and anxiety about stigma was also referred to by half of participants: “yes it [stigma] does worry me a lot. I don't go out sometimes because I'm afraid people will ask me what I do for living” (participant 6). Participants also explained that they experienced shame and embarrassment as a result of stigma: “stigma suppose it’s like erm, the kind of thing you don’t want to talk about something that’s like embarrassing or shameful” (participant 15).

Over half of participants explained that stigma impacted on their experiences of psychosis. Participants reported that it could make them feel more paranoid when they were out in social situations: “the pub can be difficult because, sometimes, sit on my own in the pub,

I'm paranoid anyway and I've got schizophrenia and I'm paranoid, I think the old men don't like me cos I'm ill" (participant 17). Auditory hallucinations were also impacted upon by stigma, they worsened due to stigma but also had stigmatising content: "it's the voices that give me the stigma. If I don't hear the voices, I'm okay" (participant 1).

5.4.2.3.1. **Inpatient specific examples**

Distressing emotions as a result of stigma were also prevalent within the inpatient hospital environment: "it [stigma] just makes it worse, its makes me feel pretty low right now [in hospital]. It's just another layer on it" (participant 3), and particularly upon discharge "I am worrying a bit more [about stigma] because I am about to be, to get back out there" (participant 8).

5.4.2.4.Noticeable behaviours as a consequence of mental health and medication

Nineteen participants explained that their behaviours when experiencing psychosis made it obvious to their social network that they have psychosis which can cause stigma: "If you start going into a room on your own when you only start hearing voice people will look at you and notice you they will think you're going mad" (participant 6). Participants also explained the side effects of the medication made them a target of discrimination: "yes, they do the behaviour changes. One thing is that you have an illness and on top of that you have a truck load of medication that alters your behaviour, you know like I started to put on weight" (Participant 30). It was also stated that there was some truth to the negative stereotypes, such as some people actually being dangerous: "She works for the ambulances, and she was taking someone through to [mental health hospital] actually and he turned on her" (participant 32).

5.4.2.5.Inferiority and low self-esteem

Finally, sixteen participants reported that stigma impacted on their self-esteem and confidence: "yeah, I have had low self-esteem and not good enough to talk to people and been more critical after talking to people as well" (participant 8). Participants also spoke about feelings of inferiority compared to others who didn't have psychosis: "*I:* have you felt more inferior due to stigma then? *P:* yeah, I have had low self-esteem and not good enough to talk to people and been more critical after talking to people as well, how it went and stuff". Participants also described a sense of defeat in relation to stigma: "pretty bad. I mean there is nothing I can do about it [stigma] so that makes it even more, it makes you feel pretty bad about yourself because it is hard to know" (participant 26).

5.4.2.5.1. Inpatient specific examples

Participants explained that their self-esteem was also impacted upon due to being admitted to hospital and that the process of admission contributed to feelings of inferiority: "so when I start thinking thoughts….I'm different and I'm in hospital, it starts to affect my self-esteem" (participant 17).

5.4.3. Stigma interactions

The third superordinate theme 'stigma interactions' encompasses the relationship between the individual with psychosis and their stigmatising social environment. They are dual processes meaning that these difficulties come from both sides of the relationship.

5.4.3.1.Lack of understanding

Nineteen participants explained that lack of understanding about psychosis was one of the most significant maintaining factors of stigma. The lack of understanding was predominantly about the cause and maintenance of psychosis, as well as the reason people

with psychosis behaved in certain ways, e.g. respond to voices. Participants explained that they themselves may not understand psychosis: “people might not necessarily understand it that much themselves and neither might not the person who is suffering from it” (participant 10), and neither did their social network: “I remember in the community that people don’t understand their illness. They don’t understand so they will think that they are a highly, highly dangerous person” (participant 8).

5.4.3.1.1. **Inpatient specific examples**

Problematically, this lack of understanding also came from mental health staff on the inpatient ward: “yes, they [ward staff] said it’s all in your head. In no terms like that, it's all in your head” (participant 2). This lack of understanding often resulted in discriminatory behaviour: “people don't understand or have their own interpretation of it causes you a lot of problems in society” (participant 18).

5.4.3.2. Lack of disclosure and communication about psychosis

Lack of disclosure and communication about psychosis was also reported to be an extremely prevalent concern for twenty-one participants. All participants described some difficulty in disclosing their experiences of psychosis due to fears of stigma: “no not a lot really. It is not easy to talk about. I can't talk about it” (participant 13). When disclosure did occur it was predominantly to immediate family and mental health professionals: “I've told me mum, don't tell anybody until I am well. So I will only talk to my immediate family and professionals” (participant 28). Participants also explained that disclosure often led to negative responses and lack of understanding from their network: “I remember in the community that people don’t understand the illness. They don’t understand, they will think they are a highly, highly dangerous person” (participant 21).

The other main difficulty regarding lack of disclosure is that participants' social networks also found disclosure difficult and discouraged participants from disclosing due to feelings of shame and embarrassment: "My family have said, said erm don't talk about that [psychosis] now, and things like that but I'm one of those people who isn't like that I don't care, who knows just to save face or whatever" (participant 15). When family members have disclosed about their psychosis, the family members themselves have faced stigma: "she [my daughter] became friends with one girl and she had told her about me…something went missing from the girls room, and she accused my daughter of it and … [she] says she should have gone to prison like me and … you are as crazy like your dad" (participant 26).

5.4.3.2.1. **Inpatient specific examples**

Lack of disclosure was also a prevalent problem in the inpatient setting. Participants explained that staff were not receptive of their needs: "nobody [inpatient staff] listens to me… nobody has a positive comment about me, about my recovery" (participant 30). Stigma clearly prevented some participants from disclosing to staff members: "well, the nurses, the nursing system, the whole, I'm not telling my problems to my nurses because of stigma, it's not the only reason but it's definitely an element" (participant 17).

5.4.3.3.Loss of social contact and distancing due to stigma

Loss of social contact and distancing was also a significant concern for nineteen participants. Participants explained that different people in their social network would distance themselves from them when they found out about their psychosis: "they will visit a relative who's got cancer but they don't give me any time. So they don't understand it" (participant 18). Participants explained that they had superficial relationships: "I'm on Facebook, and everyone leaves a comment: 'Oh, I hope you are ok, and blah blah', and

everyone says ‘You’ve got a lot of friends’, but they do not call me, or ever come to see me…” (participant 32). Participants explained that they lost relationships completely: “I’ve had mental health problems then you worry that they aren’t going to like you so I don’t have friends because of that really. Great big gap in my life really, I don’t have any friends” (participant 17).

Participants also explained that because of fears of stigma they isolated themselves from others: “I keep myself to myself all the time. Always. Always.” (participant 16). They explained that the stigma goes away if you self-isolate: “you know if I'm in my room and I haven’t been out, stigma goes away” (participant 26).

5.4.3.3.1. **Inpatient specific examples**

Participants explained that being in hospital prevented the ongoing social support required for their recovery and contributed to the loss of social contact due to its regimented approach to visitation: “it’s harder for my friends to come and see me [in hospital]. They would just call me and be like ‘I can come now’, but now that bit of freedom has gone so it’s once in a while” (participant 7). Participants also explained that once they were in hospital that friends and family didn’t come and visit them due to stigma: “No its been the same here as no one has come to see me... its only my mum that comes to see me, none of my children” (participant 32).

5.5. Discussion

This study aimed to explore the subjective experiences of stigma from the perspective of acute inpatients with experiences of psychosis. Stigma was identified as a prominent issue embedded within the social networks of the participant which was particularly challenging to change. This was evident in the inpatient setting as well as in the community. This study identified that stigma is a prominent issue for psychiatric inpatients with psychosis.

The superordinate and subordinate themes identified in this review broadly reflect themes identified in the recent thematic synthesis of service user perspectives of stigma in psychosis (Wood, Burke, Wardle, et al., 2015). Within the review, the stigmatised individual was identifies as being stigmatised by their social network. The review identified key processes important in tackling stigma, such as increased disclosure and compassion, education and understanding, and social support. The theme structure described by Wood et al. (2015) also reflected themes identified by Burke et al. (2016) who used the same interview tool with outpatients, but importantly also identified some key differences. In particular, the emphasis on hospitalisation, involuntary admission, and the medicalisation of psychosis. This indicates that inpatients' priorities for stigma do not conceptually differ from service users in the community who experience psychosis. However, it does highlight that the psychiatric hospital may perpetuate the stigma found for service users in the community.

The current study identified stigma as a prominent issue for participants during hospital admissions. Participants reported a number of incidents of experienced stigma during their stay on the ward, as well as the internalisation of the stigma associated with admission to a psychiatric hospital. Staff delivering psychiatric inpatient care have been found to experience high levels of burnout, compassion fatigue and exhaustion in staff due to the high pressured environment (Hansson & Berglund, 1992). Such emotional exhaustion

could contribute to staff treating patients in a stigmatising manner by reducing their capacity to deliver person-centred care. Furthermore, the psychiatric ward environment is usually highly medicalised; as mentioned above, biomedical conceptualisations of psychosis have been shown to be associated with higher levels of stigma (J. Read & Harre, 2001). This suggests that providing non-medicalised stigma interventions for staff working on psychiatric inpatient wards is of importance. This study has highlighted the continued need to reduce the stigma associated with being admitted to a psychiatric hospital. Public education on psychiatric inpatient wards would be beneficial to reduce the stigma associated with admission.

There were a number of limitations to the study. A number of participants struggled to define stigma despite definitions being given to them, and therefore it is not certain that all participants' accounts relate specifically to stigma rather than other negative experiences not caused by stigma. However, given the method of analysis, all quotations were taken at surface level and included in the analysis. Some participants were also experiencing acute symptoms of psychosis as well as having been administered high dosages of anti-psychotic medication. As a consequence a number of participants found it very difficult to remember and concentrate on interview questions. Furthermore, the inpatient environment can be very noisy which meant, at times, both parties were distracted from the interview process. One other limitation was the use of a predefined interview measure, the SIMS. The validity of the study would have been improved if interview questions were developed specifically for the aims of this study (i.e. experience of stigma associated with acute inpatient admission). Additionally, the interviews were relatively short which may be reflective of the interview measure utilised and the context in which it was used. It is recommended that qualitative interviews last between thirty to sixty minutes (J. Smith et

al., 2009), but in this current study interview durations were at the lower end of this recommendation.

In conclusion, stigma is a prominent issue for inpatients, the experiences of which does not conceptually differ from experiences reported by outpatients. Further interventions are required to reduce or prevent stigmatising experiences during inpatient admissions.

6. Chapter 6: Study 4 - The impact of stigma on emotional distress and recovery from psychosis: The mediatory role of internalised shame and self-esteem

This paper has been submitted to Psychiatry Research:

Wood, L., Byrne, R., Burke, E., Enache, G., & Morrison, A.P. (under review) The impact of stigma on emotional distress and recovery from psychosis: The mediatory role of internalised shame and self-esteem. *Psychiatry Research.*

6.1. Abstract

Internalised shame and self-esteem have both been proposed to play an integral role in the relationship between stigma and its negative psychological sequalae in people who experience psychosis, but there has been little quantitative exploration to examine their roles further. The aim of this study was to examine the relationship of stigma (experienced and perceived) with emotional distress and recovery in psychosis, and to examine internalised shame and self-esteem as potential mediators. A total of 79 participants were included for the purposes of this study. Participants were administered a battery of assessment measures examining experienced and perceived stigma, internalised shame, self-esteem, depression, hopelessness, and personal recovery. Results illustrated that stigma (experienced and perceived) was significantly associated with internalised shame, low self-esteem, depression, hopelessness and poor personal recovery. Stigma (experienced and perceived) and its relationship with depression, hopelessness and personal recovery was mediated by both internalised shame and low self-esteem. In conclusion, stigma can have significant negative emotional consequences and impede recovery in people with psychosis. This may indicate that stigma needs to be addressed therapeutically for people with psychosis with a particular emphasis on addressing internalised shame and low self-esteem.

6.2. Introduction

Stigma is a significant difficulty for individuals who experience psychosis with 87% of a large surveyed sample reporting experiences of stigma (The Schizophrenia Commission, 2012). Common stereotypes about people with psychosis, such as dangerousness and unpredictability, cause stigmatising beliefs and behaviours to develop within the public (Corrigan et al., 2012). Therefore, individuals with psychosis have to cope with both the distressing experiences of psychosis and stigma and discrimination from their social system (P. Corrigan & A. Watson, 2002). A study which conducted qualitative interviews with individuals who experience psychosis identified that experiences of discrimination, including physical abuse, verbal abuse, and being patronised, are frequently reported (Dinos et al., 2004).

Researchers have attempted to conceptualise stigma and have developed a number of important sub-components in order to understand why stigma occurs and how it impacts on the individual (P. Corrigan & A. Watson, 2002; B. Link & Phelan, 2001). P. Corrigan and A. Watson (2002) distinguished between public stigma, the negative stereotypes, beliefs and discriminatory behaviours held by the public, and self-stigma, the internalisation of negative stereotypes, beliefs and discriminatory behaviours. A more recent conceptualisation focused specifically on the personal impacts of stigma. Elaine Brohan, Mike Slade, et al. (2010) outlined personal stigma as having three components of experienced, perceived and internalised stigma. Experienced stigma can be understood as overt acts of discrimination which occur towards the individual, such as abuse, bullying and lack of opportunity (B. Link & Phelan, 2001). Perceived stigma occurs when an individual believes they belong to a stigmatised group, and also that the negative stereotypes associated with this group apply to themselves (Kleim et al., 2008). These can both lead to internalised stigma, which is the sum of negative cognitive, behavioural and

emotional consequences resulting from experienced and perceived stigma (P. Corrigan & A. Watson, 2002). These consequences include low self-esteem, internalised shame, depression, hopelessness, and poorer personal recovery (Birchwood et al., 2007; B. G. Link et al., 2001; Livingston & Boyd, 2010).

The way in which experienced and perceived stigma leads to internalised stigma, i.e. the internalisation of shame, blame, hopelessness, guilt, and fear of discrimination resulting from stigma (P. Corrigan & A. Watson, 2002), has been of particular interest to researchers. One main hypothesis is that self-esteem mediates the relationship between experienced and perceived stigma and the personal impact of stigma (B. G. Link et al., 2001; Vass et al., 2015). Watson et al. (2007) suggest that agreement with, and self-application of, the negative stereotypes decreases self-esteem and self-efficacy which lead to emotional distress. Furthermore, Vass et al. (2015) identified self-esteem as a mediator between experienced stigma with positive symptoms of psychosis and personal recovery. Drapalski et al. (2013) have also highlighted that self-esteem plays a mediatory role between poor self-concept, resulting from stigma, and emotional distress such as depression, anxiety and psychiatric symptoms. It has been suggested that internalised shame (a painful affect associated with perceptions that one has personal attributes that others will find undesirable; Gilbert, 2000) may play a similar role in explaining the impacts of experienced stigma and discrimination in people who experience psychosis (Birchwood et al., 2007), although this has not been investigated as thoroughly as self-esteem. Based on social mentality theory (SMT), Birchwood et al. (2007) outlined that stigma is a social threat which challenges the stigmatised person's social ranking, leading them to feel inferior to others. This perception of being of low social rank can lead to feelings of internalised shame (Gilbert, 2010). Internalised shame has been acknowledged

to be a sub-component of internalised stigma in a number of research studies examining the phenomenon (Barney et al., 2010; B. G. Link et al., 2015; J.B. Ritsher & Phelan, 2004).

As outlined, internalised shame and self-esteem have been identified as potential mediators in the relationship between experienced stigma and emotional distress in psychosis (Birchwood et al., 2007; Watson et al., 2007). Both internalised shame and self-esteem have been found to be associated with depression, hopelessness, and a poorer prognosis for personal recovery in people with experiences of psychosis and stigma (Birchwood et al., 2007; Vass et al., 2015). As stated, internalised shame has been acknowledged as a component of internalised stigma (B. G. Link et al., 2015), but its relationship as a mediator between stigma (experienced and perceived) and its personal consequences (recovery and emotional distress) has not been examined in the same manner as self-esteem.

Internalised shame and low self-esteem both reflect intrinsic feelings about oneself which manifest at a deep emotional level (Fennell, 1998; Gilbert, 2010). However, they have been proposed to be the negative emotional consequences of different emotional systems (the drive and compassion systems respectively; Gilbert, 2009). Therefore, the identification of their roles would provide potentially useful information regarding the psychological mechanisms underpinning the negative personal consequences of stigma. The aim of this study was to examine the relationship between stigma (experienced and perceived) with internalised shame, self-esteem, emotional distress (depression, and hopelessness), and personal recovery. Firstly, it examined whether experienced and perceived stigmas are predictors of depression, hopelessness and personal recovery in psychosis. Secondly, internalised shame and self-esteem were examined as mediators within these relationships.

6.3. Method

6.3.1. Participants

Participants for this current study were recruited from the sample (n=79) of the semi-structured interview measure of stigma (SIMS) study (L. Wood, E. Burke, R. Byrne, G. Enache, et al., 2016). Participants were either recruited from (a) an inner London acute psychiatric inpatient unit and identified via nursing staff or (b) a trial examining the efficacy of Cognitive Therapy for internalised stigma in psychosis (A. Morrison et al., 2016). Participants were included if they were (i) aged between 18-65, and (ii) met ICD-10 criteria for schizophrenia, schizoaffective disorder or delusional disorder or met criteria for an Early Intervention service to allow for diagnostic uncertainty. Exclusion criteria were moderate to severe learning disability, organic impairment, not having the capacity to consent to research participation, non-English speaking, severe thought disorder**,** and a primary diagnosis of drug and alcohol dependency.

6.3.2. Materials

6.3.2.1.Independent variables

The SIMS was used as a measure of stigma (L. Wood, E. Burke, R. Byrne, G. Enache, et al., 2016). It is an eleven item semi-structured interview which examines interviewee's experienced stigma, perceived stigma and internalised stigma. It is conducted by an interviewer who rates participant responses on a scale of 0 (no stigma present) to 4 (severe stigma present). It has good internal consistency (Cronbach's Alpha =0.87) and high interrater reliability (Intraclass Correlations of 0.87 – 0.94). Only the experienced stigma and perceived stigma items were used for the purposes of the analysis. Higher scores indicate higher levels of stigma.

6.3.2.2.Mediator variable

Internalised shame was measured using the Internalised Shame Scale (ISS; Cook, 1987), a 30-item questionnaire with responses scored on a 5-point Likert scale from 'never' to 'almost always'. Example items include 'I feel like I am never quite good enough' and 'I feel somehow left out'. The measure has good reliability, Cronbach's Alpha score of α=0.95. Higher scores indicate higher levels of internalised shame.

Self-esteem was measured using the Self-Esteem Rating Scale – Short form (SERS; Lecomte et al., 2006), a 20-item questionnaire with responses scored on a 7-point Likert scale from never to always with higher scores indicating higher self-esteem. It has good internal consistency of Cronbach's Alpha score of α=0.77. The SERS illustrated good validity with people who experience psychosis.

6.3.2.3.Dependent variables

The Process of Recovery Questionnaire – Short form (QPR; Law et al., 2014) was used to measure user-defined recovery. This is a 15-item questionnaire which was developed collaboratively with service users and which measures subjective recovery. Items are scored on a 5-point Likert scale, from 'disagree strongly' to 'agree strongly'. Increased scores illustrate higher levels of perceived recovery. The QPR illustrated good reliability and internal consistency (intrapersonal subscale, Cronbach's Alpha =0.94; interpersonal subscale, Cronbach's Alpha =0.77).

The Beck Depression Inventory for Primary Care (BDI-PC; Beck et al., 1997) was used to measure depression. It is a 7-item scale and a score of greater than 3 indicates a probable diagnosis of major depressive disorder. Higher scores indicate increased levels of depression. It has good internal consistency (Cronbach's Alpha =0.85).

The Beck Hopelessness Scale (BHS; Beck et al., 1974) was used to measure hopelessness. It consists of 20 true/false items covering three factors: 'feelings about the future', 'loss of motivation'; and 'future expectations'. Internal consistency of scores was satisfactory (Cronbach's Alpha = .88). Higher scores show increased hopelessness.

6.3.3. Procedure

Full ethical approval was sought for this study from the NHS Research Ethics Committee (14/LO/2164) and the study was sponsored by the University of Manchester. Once informed consent was obtained, participants were administered a battery of outcome measures. The SIMS was conducted by the authors (LW, EB and GE) with the participants. For the rest of the measures, the participant was given a choice of completing the measures with the researcher or on their own, in order to reduce participant burden.

6.3.4. Statistical Analysis

Data analysis was conducted with IBM SPSS version 23 (2015). Missing data (<20%) for individual outcome measure items was replaced with the mean. Missing measures were excluded pairwise. Data was checked for normality through examination of skewness and kurtosis. All data were normally distributed. Missing data was excluded pairwise for all regression analysis.

Exploratory data analysis was conducted through examination of the Pearson correlation coefficient (one-tailed) in order to examine relationships between variables. Independent analysis was conducted to examine the role of self-esteem and internalised shame as mediators respectively. In order to examine the relationships between the independent

variables (IV), mediator variable (M) and dependent variables (DV), a number of multiple linear regression analyses were conducted following guidance by Baron and Kenny (1986) to examine if potential mediation was present. All models met the assumptions required for a regression analysis, including assumptions required to ensure multicollinearity was not present (Variance Inflation Factor: VIF). Firstly, the IV was entered as a predictor variable to M and the DV respectively, as recommended by Baron and Kenny (1986). The IV and M were subsequently entered together to predict the DV. If the IV became non–significant, it was assumed the mediation was likely. Mediation analysis was conducted using the procedures outlined by A. F. Hayes and Preacher (2010) using the SPSS macro. Mediation analysis was conducted only when suggested by the regression analysis. Significant indirect effects were examined using the bootstrapped bias-corrected confidence intervals of 1000 bootstraps. Mediating effects were considered present when 0 did not fall between the confidence intervals.

6.4. Results

A total of 79 participants took part in the study, the average age of the sample was 36.49 (SD: 11.69; range: 18-62). Further demographics can be found in table 13.

Table 13 – Sample demographics

Demographic	Category	N
Patient status	Inpatient	47
	Outpatient	32
Gender	Male	59
	Female	20
Ethnicity	Black heritage	12
	White heritage	52
	Asian heritage	10
	Other	5
Diagnosis	Schizophrenia	25
	Paranoid Schizophrenia	18
	Psychotic episode	19
	First Episode Psychosis	10
	Schizoaffective Disorder	2
	Recurrent Psychosis	2
	Persistent Delusional Disorder	2
	Drug Induced Psychosis	1

6.4.1. Exploratory data analysis

Pearson correlation coefficients and descriptive statistics can be found in table 14. The mean scores of the outcome variables illustrate a sample with moderate levels of stigma (L. Wood, E. Burke, R. Byrne, G. Enache, et al., 2016). The sample is experiencing relatively high levels of internalised shame (>50 indicating a problematic level (Cook, 1987), along with moderate depression and hopelessness (A. Beck et al., 1974; A. T. Beck et al., 1996). Furthermore the sample has a low personal recovery score indicating that the sample is not recovered (Law et al., 2014).

The correlation coefficients indicate that experienced (SIMS-E) and perceived (SIMS-P) stigma are highly correlated to internalised shame, hopelessness, depression and negative

correlated to personal recovery. Furthermore, internalised shame is also highly correlated with hopelessness and depression, and negatively correlated with personal recovery.

6.4.2. Linear Regression

All multiple linear regression analysis coefficient descriptives can be found in table 15. To follow guidance outlined by Baron and Kenny (1986), both IV's were regressed with both mediator variables to ensure a significant relationship was identified which was essential for further exploration of mediation. Experienced stigma significantly predicted self-esteem (F (1,75) = 46.635, r^2=0.383, p<0.001) and internalised shame (*F* (1,61) = 39.652, r^2=0.394, *p*<0.001). Similarly perceived stigma also significantly predicted self-esteem (*F* (1,75) = 25.154, r^2=0.251, p<0.001) and internalised shame (*F* (1,61) = 18.764, r^2=0.235, *p*<0.001).

To further explore the relationships between the IVs, DVs, and potential mediators, a number of linear regression analyses were conducted. These analyses aimed to (i) explore the relationships between variables to meet the required aims of the study, and (ii) to identify where potential mediatory relationships may be present.

Experienced stigma predicted depression (*F* (1, 75) =19.161, r^2=0.203, *p*<0.001), and the model significantly improved when self-esteem was included as a predictor (*F* (2, 74) =61.044, r^2=0.623, *p*<0.001) with experienced stigma becoming insignificant. Internalised shame had the same impact when entered as a predictor (*F* (2, 60) = 57.461, r^2=0.657, *p*<0.001), with experienced stigma becoming insignificant. The same was found with perceived stigma (*F*(1,75)=16.919, r^2=0.184, *p*<0.01) when self-esteem was then entered as a predictor (*F*(2,74)=60.887, r^2=0.622, *p*<0.001), and internalised shame (*F* (2, 60) = 56.441, r^2=0.653, *p*<0.001) respectively. This suggests mediation is present within all models.

Table 14– Pearson correlation coefficients and descriptive statistics of outcome measures

Measure	*N*	*1*	*2*	*3*	*4*	*5*	***6***	*M*	*SD*
1. SIMS -E	*79*	-	-	-	-	-	-	2.44	1.06
2. SIMS-P	*79*	*0.527***	-	-	-	-	-	1.57	1.20
3. ISS	63	0.628**	0.485**	-	-	-	-	60.60	29.87
4. SERS	77	-0.619**	-0.501**	-0.908**	-			85.74	27.58
5. BHS	77	0.402**	0.358**	-0.719**	-0.754**	-	-	8.41	6.42
6. BDI	76	0.451	0.429**	-0.808**	-0.788**	0.800**	-	7.29	5.67
7. QPR	75	-0.264*	-0.238	-0.688**	0.657**	-0.777**	-0.688**	36.31	14.20

*BDI = Beck Depression Inventory – Primary Care Version, BHS = Beck Hopelessness Scale, ISS = Internalised Shame Scale, M=Mean, QPR – Process of Recovery Questionnaire, SD=Standard Deviation, SERS = Self-Esteem Rating Scale, SIMS-E = Semi-structured Interview Measure of Stigma in Psychosis – Experienced Stigma Subscale, SIMS-P = Semi-structured Interview Measure of Stigma in Psychosis – Perceived Stigma Subscale, *=p<0.05, **=p<0*

Experienced stigma significantly predicted hopelessness (F (1, 74) =14.298, r^2=0.162, p<0.01), and the model improved when self-esteem was entered into the model (F (2, 73) =49.345, r^2=0.575, p<0.001) with experienced stigma becoming an insignificant predictor. The same occurred when internalised shame was entered alongside experienced stigma (F (2, 59) = 31.836, r^2=0.519, p<0.001). Perceived stigma significantly predicted hopelessness (F (1, 74) =10.851151, r^2=0.128, p<0.05) and the model improved when self-esteem was entered into the model (F (2, 73) =48.229, r^2=0.569, p<0.001) and perceived stigma became a non-significant predictor. The same occurred when internalised shame was entered as a predictor alongside perceived stigma (F (2, 59) = 32.105, r^2=0.521, p<0.001). Again, all models suggested mediation was present.

Experienced stigma significantly predicted personal recovery (F (1, 74) = 5.484, r^2=0.070, p<0.05). When self-esteem was also entered as a predictor to the model improved and explained more variance (F= (2, 73) =31.289., r^2=0.465, p<0.001) and experienced stigma became a less significant predictor indicating that it may be a potential mediator. The same occurred when internalised shame was entered as a predictor alongside experienced stigma (F (2, 58) = 26.354, r^2=0.476, p<0.001). Similarly, perceived stigma significantly predicted personal recovery (F (1, 74) =4.384, r^2=0.057, p<0.05), and when self-esteem was also entered into the model, the model significantly improved (F (2, 53) =28.282, r^2=0.441, p<0.001) and perceived stigma became a non-significant predictor (table 14). This occurred when internalised shame was entered alongside perceived stigma (F (2, 58) = 26.610, r^2=0.479, p<0.001). All models suggest that mediation may be present.

Table 15 – Multiple regression analysis coefficient descriptives

Regression Model		***B***	***SE (B)***	***Beta***
Experienced stigma				
	Self-esteem	*-15.974*	*2.339*	*-0.619***
	Internalised shame	*17.191*	*2.730*	*0.628***
Perceived stigma				
	Self-esteem	*-11.639*	*2.740*	*0.485***
	Internalised shame	*11.871*	*0.321*	*-0.501***
Experienced stigma				
	Depression	*2.390*	*0.546*	*0.451***
	Hopelessness	*2.403*	*0.635*	*0.402***
	Recovery	*-3.475*	*1.484*	*-0.264**
Perceived stigma				
	Depression	*2.046*	*0.497*	*0.429***
	Hopelessness	*1.922*	*0.584*	*0.358**
	Recovery	*-2.843*	*1.358*	*-0.238**
Depression				
Model 1: Experienced stigma	*Experienced stigma*	*2.390*	*0.546*	*0.451***
	Experienced stigma	*-0.315*	*0.482*	*-0.059*
	Self-Esteem	*-0.169*	*0.019*	*-0.824***
	Experienced stigma	*-0.453*	*0.514*	*-0.086*
	Internalised shame	*0.166*	*0.019*	*0.862***
Model 2: Perceived stigma	*Perceived stigma*	*2.046*	*0.497*	*0.429*
	Perceived stigma	*0.218*	*0.394*	*0.046*
	Self-Esteem	*-0.157*	*0.017*	*-0.765***
	Experienced stigma	*-0.108*	*0.411*	*-0.023*
	Internalised shame	*0.158*	*0.017*	*0.819***
Hopelessness				
Model 1: Experienced stigma	*Experienced stigma*	*2.403*	*0.635*	*0.402***
	Experienced stigma	*-0.633*	*0.581*	*-0.106*
	Self-Esteem	*-0.192*	*0.023*	*-0.819***
	Experienced stigma	*-0.399*	*0.708*	*-0.056*
	Internalised shame	*0.170*	*0.026*	*0.754***

Model 2: Perceived stigma	*Perceived stigma*	*1.922*	*0.584*	*0.358**
	Perceived stigma	*-0.227*	*0.482*	*-0.042*
	Self-Esteem	*-0.182*	*0.021*	*-0.775***
	Perceived stigma	*-0.396*	*0.567*	*-0.073*
	Internalised shame	*0.171*	*0.024*	*0.756*
Recovery				
Model 1: Experienced stigma	*Experienced stigma*	*-3.475*	*1.484*	*-0.254**
	Experienced stigma	*3.083*	*1.447*	*0.235**
	Self-Esteem	*0.421*	*0.058*	*0.803***
	Experienced stigma	*0.976*	*1.592*	*0.075*
	Internalised shame	*-0.359*	*0.060*	*-0.735***
Model 2: Perceived stigma	*Perceived stigma*	*-2.843*	*1358*	*-0.238*
	Perceived stigma	*1.345*	*1209*	*0.113*
	Self-Esteem	*0.374*	*0.053*	*0.712***
	Perceived stigma	*1.021*	*1.271*	*0.087*
	Internalised shame	*-0.356*	*0.053*	*-0.729***

B=unstandardized regression coefficients, SE (B) =standard error B, *=p<0.05, **=p<0.01

6.4.3. Mediation analysis

As suggested by the regression analysis, internalised shame and self-esteem were suggested as potential mediators between stigma (experienced and perceived) with depression, personal recovery and hopelessness. In order to explore these relationships, A. F. Hayes and Preacher (2010) SPSS macro was utilised to examine the mediatory role of internalised shame and self-esteem respectively. Mediation descriptives for internalised shame and self-esteem can be found in table 16. Both self-esteem and internalised shame were found to mediate the relationships between experienced and perceived stigma, with each of depression, recovery and hopelessness. The kappa statistic suggested moderate effect sizes for all mediators.

Table 16 - Total, direct, and indirect effects of stigma on all dependent variables

Mediator	*Stigma Type*	*Dependent Variable*	*B*	*SE (B)*	*P*	*95% BCa CI*	
						LL	*UL*
		Depression					
Internalised Shame	*Experienced stigma*	*Total effect*	*2.408*	*0.603*	*0.000*	*-*	*-*
		Direct effect	*-*	*0.514*	*0.381*	*-*	*-*
		Indirect effect	*0.453*	*0.451*	*-*	*2.066*	*3.857*
		K^2	*2.861*	*0.059*	*-*	*0.413*	*0.649*
			0.530				
	Perceived stigma	*Total effect*	*1.770*	*0.561*	*0.003*	*-*	*-*
		Direct effect	*-*	*0.411*	*0.793*	*-*	*-*
		Indirect effect	*0.108*	*0.439*	*-*	*1.150*	*2.846*
		K^2	*1.878*	*0.077*	*-*	*0.275*	*0.577*
			0.441				
		Hopelessness					
Internalised Shame	*Experienced stigma*	*Total effect*	*5.091*	*1.033*	*0.000*	*-*	*-*
		Direct effect	*1.661*	*1.137*	*0.149*	*-*	*-*
		Indirect effect	*3.430*	*0.951*	*-*	*1.635*	*5.343*
		K^2	*0.337*	*0.090*	*-*	*0.156*	*0.504*
	Perceived stigma	*Total effect*	*2.550*	*1.041*	*0.017*	*-*	*-*
		Direct effect	*-*	*0.919*	*0.703*	*-*	*-*
		Indirect effect	*0.352*	*0.835*	*-*	*1.561*	*4.753*
		K^2	*2.903*	*0.085*	*-*	*0.192*	*0.519*
			0.346				
		Recovery					
Internalised Shame	*Experienced stigma*	*Total effect*	*-*				
		Direct effect	*5.044*			*-*	
		Indirect effect	*0.976*	*1.562*	*0.002*	*-*	*-*
		K^2	*-*	*1.592*	*0.542*	*-*	*-*
			6.019	*1.307*	*-*	*8.793*	*-3.806*
			0.416	*0.832*	*-*	*0.251*	*0.572*
	Perceived stigma	*Total effect*	*-*				
		Direct effect	*3.074*			*-*	
		Indirect effect	*1.020*	*1.480*	*0.042*	*-*	*-*
		K^2	*-*	*1.270*	*0.425*	*-*	*-*
			4.094	*1.340*	*-*	*7.122*	*-2.013*
			0.360	*0.121*	*-*	*0.147*	*0.601*
		Depression					
Self-Esteem	*Experienced stigma*	*Total effect*	*2.390*				
		Direct effect	*-*	*0.546*	*0.000*	*-*	*-*
		Indirect effect	*0.315*	*0.482*	*0.516*	*-*	*-*
		K^2	*2.705*	*0.460*	*-*	*1.833*	*3.653*
			0.496	*0.061*	*-*	*0.369*	*0.608*
	Perceived stigma	*Total effect*	*2.046*	*0.498*	*0.000*	*-*	*-*
		Direct effect	*0.218*	*0.394*	*0.581*	*-*	*-*
		Indirect effect	*1.828*	*0.381*	*-*	*1.114*	*2.617*
		K^2	*0.411*	*0.062*	*-*	*0.280*	*0.526*

		Hopelessness					
Self-Esteem	*Experienced*	*Total effect*	*2.402*	*0.635*	*0.000*	*-*	*-*
	stigma	*Direct effect*	*0.633*	*0.581*	*0.280*	*-*	*-*
		Indirect effect	*3.036*	*0.562*	*-*	*2.061*	*4.220*
		K^2	*0.481*	*0.063*	*-*	*0.346*	*0.586*
	Perceived	*Total effect*	*1.922*	*0.583*	*0.002*	*-*	*-*
	stigma	*Direct effect*	*0.227*	*0.482*	*0.639*	*-*	*-*
		Indirect effect	*2.150*	*0.445*	*-*	*1.394*	*3.241*
		K^2	*0.415*	*0.065*	*-*	*0.289*	*0.548*
		Recovery					
Self-Esteem	*Experienced*	*Total effect*	*-*	*1.484*	*0.021*	*-*	*-*
	stigma	*Direct effect*	*3.474*	*1.447*	*0.037*	*-*	*-*
		Indirect effect	*3.083*	*1.413*	*-*	*9.682*	*4.283*
		K^2	*-*	*0.075*	*-*	*-*	*-*
			6.558			*0.313*	*0.5991*
			0.450				
	Perceived	*Total effect*	*2.843*	*1.358*	*0.040*	*-*	*-*
	stigma	*Direct effect*	*1.345*	*1.210*	*0.270*	*-*	*-*
		Indirect effect	*4.188*	*1.049*	*-*	*6.683*	*2.434*
		K^2	*0.354*	*0.0944*	*-*	*0.192*	*0.559*

B=unstandardized regression coefficient, SE=standard error, p=significance level,

CI=Confidence Interval, LL=Lower Level, UL=Upper Level, K^2 *=Kappa (effect size)*

6.5. Discussion

This study demonstrated that stigma was significantly associated with internalised shame, low self-esteem, depression, hopelessness, and poorer personal recovery, supporting previous research (B. G. Link et al., 2001; Vass et al., 2015). The data was also consistent with internalised shame and self-esteem both being mediators in their respective relationships between stigma (experienced and percieved) and depression, hopelessness and personal recovery in psychosis. This indicates that there are potentially different psychological mechanisms underpinning emotional distress caused by stigma.

The analysis demonstrated that internalised shame mediated the relationship between stigma and depression, hopelessness and recovery respectively. To the authors' knowledge, the relationship between stigma and internalised shame has not previously been quantitatively examined in people who experience psychosis. Internalised shame is widely noted as an integral part of mental distress and occurs due to threatening and traumatic life experience (Gilbert, 2010). Therefore, given that stigma is a threatening social experience which causes devaluation and loss of social status (B. Link & Phelan, 2001), it is unsurprising that internalised shame has been identified as a mediator between stigma and negative emotional consequences. Importantly, internalised shame played a mediatory role with both IVs of stigma and all DVs which demonstrates that it has a role in understanding stigma experiences. As stated in the introduction, internalised shame can be differentiated from self-esteem due to it being a prototypical emotion experienced as a result of a lowering of social status and perceived inferiority (Gruenewald, Kemeny, Aziz, & Fahey, 2004), whereas self-esteem is not explicitly defined as a relational concept and is considered to be a personal attitude about the self (Heatherton & Wyland, 2003).

This study also identified that self-esteem mediated the relationships between stigma and depression, hopelessness and personal recovery. This supports the previous findings from Vass et al. (2015) who identified that self-esteem mediated the relationship between experiences of stigma and personal recovery. Self-esteem has been identified in the service user-informed recovery literature as an important component of recovery (Andreasen, Oades, & Caputi, 2003). For example, in the Pitt et al. (2007) user-led study qualitatively examining recovery from psychosis, the theme 'rebuilding self' incorporated the importance of improving self-esteem. Hopelessness has been widely identified with stigma (Livingston & Boyd, 2010), but this relationship has not been shown to be mediated by self-esteem in previous research. Again, these findings indicate that if service users are presenting with hopelessness and poor levels of personal recovery, assessment of their self-esteem may be helpful.

One of the strengths of the study was its examination of perceived stigma. Interestingly, this study identified that perceived stigma was also associated with the same outcomes and trends as experienced stigma which has not been identified in previous research. This research may support the important idea that a person does not have to have overt experiences of stigma to experience the negative consequences of stigma (Elaine Brohan, Mike Slade, et al., 2010). Perceived stigma was associated with all dependent variables and was mediated by both self-esteem and internalised shame. However, this must be interpreted tentatively as perceived stigma was not examined in a model along with experienced stigma, which may share some or all of its significant variance. This has important clinical implications, in that perceived stigma should be explored with people who experience psychosis to examine its potential impacts.

This study also has a number of limitations. It was a secondary analysis of data collected for a research trial and validation of the SIMS measure (A. Morrison et al., 2016; L. Wood, E. Burke, R. Byrne, G. Enache, et al., 2016) . Therefore, the outcome variables examined were limited to what was included in these original studies. The trial and SIMS studies were designed in partnership with service users who did not feel measures examining symptoms of psychosis were a necessary part of the trial or validation. However, a limitation of the current study was the lack of measurement of experiences of psychosis which would have provided important insight into the psychological impacts of stigma and consequences for psychotic experiences. Another limitation of the study was the cross-sectional design. This design can identify associations between variables but cannot truly identify causation which would require a longitudinal design. Furtermore, a criticism of mediation analysis is that other unmeasured variables may be responsible for change in both mechanisms and outcomes which has not been accounted for. Future research, should attempt to examine any potential confounders and control for those using appropirate analysis (Emsley, Dunn, & White, 2010).

The construct of internalised shame (measured by the internalised shame scale) arguably overlapped with a number of other relevant factors such as self-esteem, social exclusion, and internalised stigma. This was demonstrated by the potential multicolinearity with a number of the other examined factors. The high multicolinearity and small sample size also meant that internalised shame and self-esteem were not examined in the same mediation model, and therefore it cannot be determined how these mediator variables compare. In summary, further research should examine the impacts of stigma, internalised shame and self-esteem on particular aspects of experiences of psychosis such as auditory hallucinations and delusions. The use of other outcome measures should be explored, such

as measure of psychotic symptoms (e.g. Positive and Negative Synrome Scale, Kay et al., 1987) and more specific measure of shame (e.g. Other as Shamer Scale, Goss et al., 1994). Moreover, a larger sample of participants should be included in order to compare all variables in one model.

This study has important clinical implications for future research examining interventions for people who experience psychosis and who are struggling with the impacts of stigma. A number of trials have already assessed the acceptability and feasibility of psychosocial interventions for internalised stigma in people who experience psychosis but have often not improved their primary outcome of internalised stigma, or secondary outcomes such as self-esteem (Fung et al., 2011; Lucksted et al., 2011; Russinova et al., 2014), empowerment and social anxiety. The majority of examined interventions have not used intervention strategies which focus on alleviating internalised shame as part of their intervention. A handful of intervention studies have attempted to target self-esteem to alleviate internalised stigma; M. D. Knight et al. (2006), P. T. Yanos et al. (2011), and E. McCay et al. (2007) all describe an intervention which focused on self-esteem and stigma, and which found positive change in self-esteem following their group interventions. The findings of this study would indicate that internalised shame and low self-esteem are important factors in understanding the impacts of stigma on emotional distress, personal recovery, and disclosure. Therefore future interventions addressing internalised shame and self-esteem in relation to stigma should be piloted and assessed for feasibility and acceptability.

In conclusion, stigma is associated with depression, hopelessness and personal recovery in psychosis. Internalised shame and low self-esteem play an important role in further understanding this relationship.

7. Chapter 7: Study 5 - An integrative cognitive model of internalised stigma in psychosis

This study has been published in Behavioural and Cognitive Psychotherapy:

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7.1. Abstract

Background: Internalised stigma is a significant difficulty for those who experience psychosis but it has never been conceptualised using cognitive theory.

Aims: The aim of this paper is to outline a cognitive model conceptualising internalised stigma in people who experience psychosis.

Method: Previous literature is reviewed, critiqued and synthesised to develop the model. It draws upon previous social cognitive models of internalised stigma and integrates cognitive-behavioural theory and social mentality theory.

Results: This paper identifies key cognitive, behavioural and emotional processes which contribute to the development and maintenance of internalised stigma, whilst also recognising the central importance of cultural context in creating negative stereotypes of psychosis. Moreover, therapeutic strategies to alleviate internalised stigma are identified. A case example is explored and a formulation and brief intervention plan was developed in order to illustrate the model in practice.

Conclusion: An integrative cognitive model is presented which can be used to develop individualised case formulations, which can guide cognitive behavioural interventions targeting internalised stigma in those who experience psychosis. More research is required to examine the efficacy of such interventions. In addition, it is imperative to continue to research interventions which create change in stigma at a societal level.

Key words: Cognitive, psychosis, internalised stigma, social mentality theory.

Ethics statement: The authors have abided by the Ethical Principles of Psychologists and APA code of conduct. Ethical approval was not sought for this paper as it is a theoretical paper which did not gather data from human participants.

Conflicts of interest: The authors have no conflict of interest with respect to this publication.

7.2. Introduction

Stigma is experienced when "individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (pg. 505; Crocket et al., 1998) . Negative public attitudes towards people who experience psychosis continue to prevail despite widely-publicised anti-stigma media campaigns such as Rethink Mental Illness's 'Time to Change' initiative in the UK (C. Henderson & Thornicroft, 2013; TNS BMRB, 2014), which may be due to these campaigns addressing general mental health rather than psychosis specifically. Internalised stigma occurs when an individual becomes aware of negative stereotypes and applies them to oneself, often resulting in emotional distress (P. Corrigan & A. Watson, 2002). The internalised stigma of psychosis is associated with negative personal impacts including increased hopelessness, depression, low self-esteem and self-efficacy, reduced social networks, and reduced engagement with mental health services (P. W. Corrigan et al., 2006; B. G. Link et al., 2001; Livingston & Boyd, 2010).

Internalised stigma is a particularly prevalent issue among people with psychosis; 41.7% of a large European sample reported moderate to high levels of internalised stigma (Elaine Brohan, Rodney Elgie, et al., 2010). As a consequence, the construct of internalised stigma and its theoretical underpinnings have been increasingly scrutinised. To date, it has not been conceptualised from a cognitive-behavioural perspective despite internalised stigma having cognitive and behavioural consequences (Rüsch et al., 2006). The majority of theoretical models have been developed using social cognitive theory, and relate to the broader concept of 'severe mental illness' (SMI), and have therefore lacked specificity. There is a model of social anxiety that incorporates stigma in psychosis (Birchwood et al., 2007), but this was not specific to internalised stigma. We propose a theoretical framework

which conceptualises internalised stigma in psychosis from a cognitive-behavioural perspective.

7.3. Social cognitive theory of stigma

Link and Phelan (2001) outlined one of the original social cognitive conceptualisations of stigma. Drawing upon evolutionary theories of social and natural selection, they explain that people distinguish and label human difference. Dominant cultural beliefs connect the labelled person to undesirable characteristics, and the person is then placed in a distinct category different to us, which allows for emotional distancing and results in status loss. Due to social, economic and political power, the stigmatised individual experiences disapproval, rejection exclusion and discrimination in society. The person develops appraisals that others will reject and devalue them, which consequently causes emotional distress and impacts on their behaviours, causing them to withdraw and avoid social situations (B. G. Link et al., 2004). P. Corrigan and A. Watson (2002) built upon this theory and distinguished between public and self-stigma. Public stigma comprises three components: stereotypes (negative beliefs about a group), prejudice (agreement with the belief and/or negative emotional reaction) and discrimination (negative behavioural response to prejudice). Self-stigma also comprises the same three components but applied to one's self. They further detail that appraisals of stigma can lead to low self-esteem and self-efficacy if the perceived legitimacy of public stigma is high or righteous anger if the perceived legitimacy is low and there is high group identification.

Further refinement by Elaine Brohan, Mike Slade, et al. (2010) focused on personal stigma and identified three distinct categories which form the construct: experienced, perceived and internalised stigma (Elaine Brohan, Mike Slade, et al., 2010). Experienced stigma has been defined as "instances of discrimination ...on the grounds of their perceived

unacceptability or inferiority" (Scrambler & Hopkins, 1986). Perceived stigma is that extent to which the stigmatised person believes that others associate them with the negative stereotypes (B. G. Link, 1987). Internalised stigma, as defined by Corrigan and Watson (2002a), is the agreement with the negative stereotypes and the consequential emotional distress.

One of the main drawbacks of these models of stigma is that they lack clinical applicability and there is insufficient emphasis on the complex relationships between the components of stigma. Moreover, they have been broad and not solely focused on those who experience psychosis. This broadness has restricted the models' specificity to include the complex interaction between stigma and pre-existing experiences of psychosis (Drapalski et al., 2013). This led to more clinically focused models being developed.

Major and O'Brien (2005), further examined by Rusch, Corrigan, Wassel, et al. (2009), developed a stress-coping model of stigma which identified why some individuals internalise stigma as distressing and others do not. This internalisation is dependent on sensitivity to rejection, perceived legitimacy of stereotypes, experiences of discrimination, identification with labelled group and stigma appraisals, which leads to stress (Rusch, Corrigan, Wassel, et al., 2009). This can impact on the behavioural outcomes for the individual, for example, lead to avoidance and withdrawal. Drapalski et al. (2013) and Schrank et al. (2014) proposed and tested two further models of internalised stigma which incorporated the impacts on psychiatric symptoms. Internalised stigma was core to development and maintenance of psychiatric symptoms in both models. These models are the first clinical models of internalised stigma to include the impacts on psychiatric symptoms of psychosis. However, both models have significant limitations, being simplistic and lacking specificity regarding the psychological processes involved in the development and maintenance of internalised stigma.

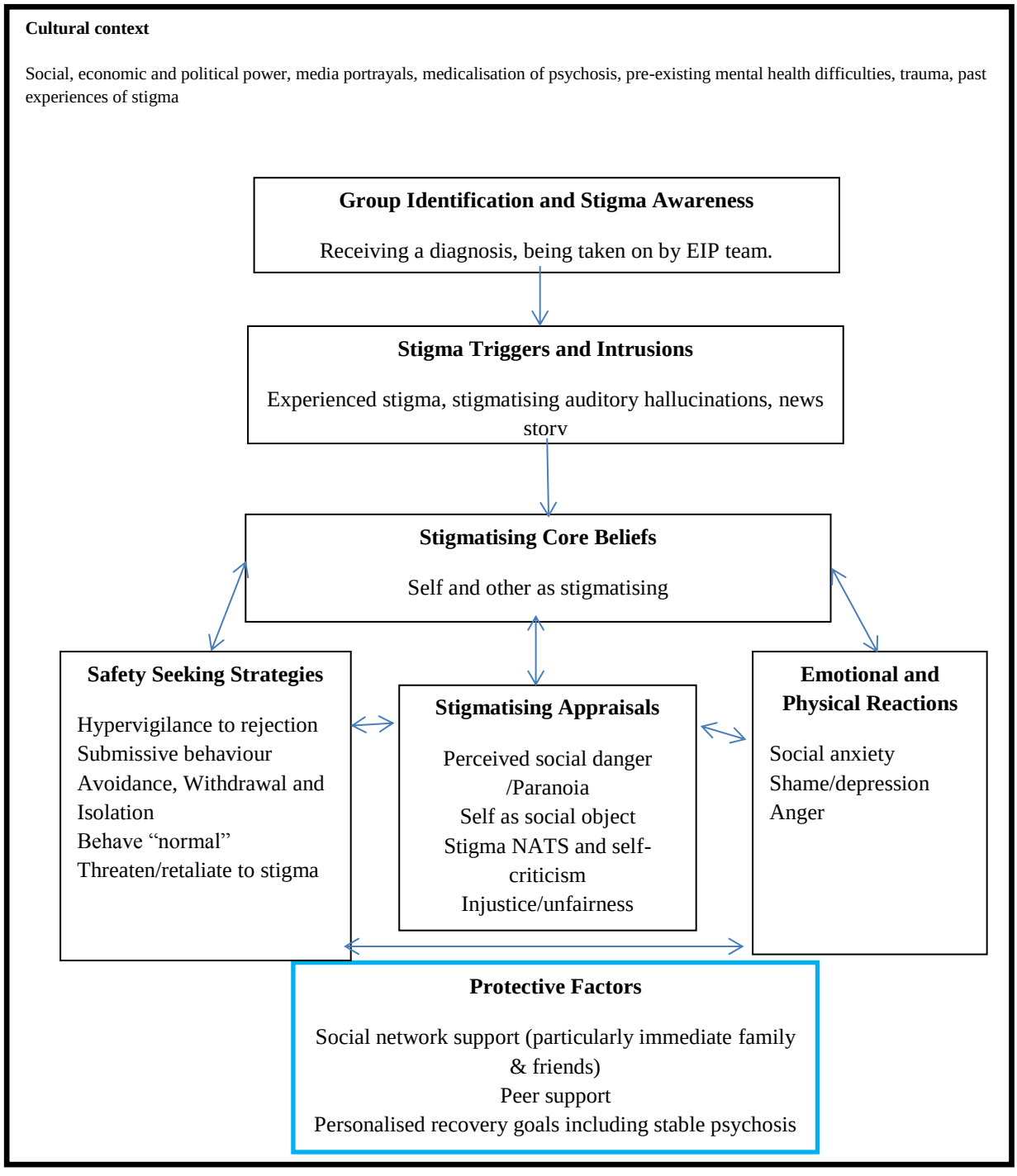
Only one model has examined the role of stigma in maintaining distress in people who experience psychosis using cognitive-behavioural theory (Birchwood et al., 2007); however, this was focused on understanding social anxiety in psychosis, utilising stigma shaming beliefs as one component of the model. This model does not capture the complex emotional reactions to internalised stigma (such as depression, hopelessness, anger), or attempt to explain why only some people experience internalised stigma, and does not draw upon relevant stigma theory, for example, Link & Phelan (2001), and Corrigan & Watson (2002a). Birchwood et al. (2007) suggested that internalised cultural values of mental illness stigma lead the person to develop an other-to-self focus; i.e. worries that he/she will be judged or rejected by others. This leads to a self-focus, which results in the individual becoming hypervigilant towards how they look or perform in social situations (D.M. Clark, 2001). These collectively cause catastrophic shaming beliefs, which either results in anger or anxiety responses. Despite limitations, the theory described by Birchwood et al. (2007) has informed the current proposed model; however, it primarily seeks to explain the development and maintenance of social anxiety in psychosis, rather than internalised stigma.

7.4. A cognitive model of internalised stigma in psychosis

To date, the proposed theoretical models of stigma indicate a role for cognitive and behavioural components, which maintain internalised stigma in SMI (P. Corrigan & A. Watson, 2002; Rusch, Corrigan, Wassel, et al., 2009). Furthermore, these models have also suggested the role of aspects of evolutionary psychology such as loss of social status and learned helplessness (B. Link & Phelan, 2001). However, the psychological models described to date have not simultaneously drawn upon cognitive theory which appears imperative to understanding internalised stigma, nor have they outlined why some people experience internalised stigma and others do not, or described a theoretical model which

could inform therapeutic practice. This paper presents a model which will address these issues by integrating elements of the existing stigma models with social mentality theory (SMT; Gilbert, 2000) and a cognitive model of psychosis (Morrison, 2001) to describe a cognitive model of internalised stigma specifically for people who experience psychosis. This model is shown in figure 10.

Figure 10: A cognitive model of internalised stigma in psychosis



7.4.1. Cultural Content

The cultural context of the stigmatised person is extremely important to consider in the development and maintenance of internalised stigma. In their conceptualisation of stigma, B. Link and Phelan (2001) comment upon social, economic and political power in causing and maintaining stigma, and Green (2009) explains that stigma would not exist without it. Negative media portrayals and the medicalisation of psychosis continue to maintain stigmatising public attitudes towards people who experience psychosis (J. Read & Harre, 2001). Consequently, people with psychosis are associated with the most negative stereotypes such as dangerousness, unpredictability and an inability to recover (Crisp et al., 2005). Moreover the medicalisation of psychosis and the depiction of it as a biological mental illness has been found to perpetuate stigma by reinforcing an "us and them" paradigm (Angermeyer et al., 2011). J. Read and Harre (2001) found that biological and genetic explanations of mental health difficulties were directly related to negative stereotypes (being seen as dangerousness, antisocial and unpredictable) and also with a reluctance to develop relationships. Therefore, an individual with psychosis is likely to develop an awareness of the stigma of psychosis prior to experiencing it themselves.

Finally, it is important to emphasise the importance of pre-existing trauma and mental health difficulties in the cause and maintenance of internalised stigma. It is acknowledged that increased levels of trauma worsen the severity of psychotic symptoms (Shelvin, Houston, Dorahy, & Adamson, 2008). It is postulated that the more severe the experiences of trauma, the more likely it is that the person will experience internalised stigma and become distressed. This is due to the likely increase of sensitivity to threatening experiences such as stigma (Gilbert, 2010). Collectively, this social context perpetuates stigma and can act as a causal and maintenance factor. It shapes the person's pre-existing conceptualisations of psychosis which influence how they interpret their own experiences.

7.4.2. Group identification and stigma awareness

Watson et al. (2007) describe that an integral part of internalising stigma was to (a) identify with the stigmatised group and (b) to believe that this group identification was legitimate, which is also integral to this model. Key factors such as having insight (Hasson-Ohayon et al., 2012), pre-existing low self-esteem or shame (P. W. Corrigan et al., 2006), and pre-existing social identity (P. Yanos, Roe, & Lysaker, 2010) have all been found to contribute to group identification and the consequential development of internalised stigma.

It has been identified that experiencing a first episode of psychosis can result in a fear of stigma, therefore it is likely that group identification can begin at this point (Franz et al., 2010; Iqbal, Birchwood, Chadwick, & Trower, 2000). Furthermore, a recent service user-led study examining the impact of diagnosis found that receiving a diagnosis of psychosis or schizophrenia-spectrum disorder led to feelings of internalised stigma (Pitt, Kilbride, Welford, Nothard, & Morrison, 2009). Participants described that once they had received a diagnosis they felt "labelled" which was a cause of "social exclusion" (p.421). It is likely that an event such as receiving a psychiatric diagnosis which confirms the belongingness to the stigmatised group can trigger this process.

Stigma awareness (Watson et al., 2007), which has also been described as perceived stigma (Elaine Brohan, Mike Slade, et al., 2010) and anticipated stigma (Gerlinger et al., 2013), occurs at this stage and is the belief that others view people with psychosis negatively and associate them with negative stereotypes. Stigma awareness has been found to be directly related to internalised stigma causing experiences such as withdrawal and poor self-efficacy in those who experience psychosis (Kleim et al., 2008). This relationship was also found in a large international study (n=1229) where internalised stigma was predicted by perceived discrimination (Elaine Brohan, Rodney Elgie, et al., 2010).

Our model postulates that group identification and stigma awareness would cause people to evaluate their social roles, supported by SMT (Gilbert, 2010). SMT based within evolutionary psychology theory, outlines a model to understand humans' abilities to detect threats within their social environment (Gilbert, 2010). Social mentalities coordinate our cognition, affect and behaviours in order to undertake our social roles. If we experience significant threat, our social role is devalued and shame is experienced. This is supported by stigma-relevant research; for example, Rusch, Todd, Bodenhausen, Olschewski, and Corrigan (2010) found that perceived legitimacy of stigma was directly associated with automatic shame-related associations in a group of people with mental health problems.

7.4.3. Stigma triggers

'Stigma triggers' are internal and external factors which can activate internalised stigma. The primary external trigger is experienced stigma. The most common experiences of stigma are verbal abuse, physical abuse, loss of contact or rejection, patronising attitudes, disapproval and being judged (Dinos et al., 2004). Within SMT, experienced stigma would be considered a social threat which would trigger the threat system (our emotional system which reacts to threatening situations; Gilbert, 2010) in stigmatised people (Gumley & Schwannauer, 2006).

Some research has illustrated that a stigmatised person can internalise stigma without experiencing stigma if they perceive stigma to be an ongoing threat (Quinn, Williams, & Weisz, 2015). As a consequence, triggers of stigma have been noted to include witnessing a stigmatising event or news story (Elaine Brohan, Mike Slade, et al., 2010). The present authors would also hypothesise that neutral triggers, as identified in the psychosis model (A. P. Morrison, 2001), may also trigger internalised stigma. Similarly, neutral internal bodily sensations may also be interpreted in a catastrophic manner and trigger internalised

stigma, as outlined in other cognitive models of psychosis (A. P. Morrison, 2001) and panic (D.M. Clark, 1986).

Qualitative interviews with service users have identified that auditory hallucinations and intrusive stigma-oriented thoughts or memories can act as triggers of internalised stigma (Wood, Byrne, Enache, & Morrison, 2016). Participants explained that certain auditory hallucinations had stigmatising content, telling them that they were "mad" and "bad". Furthermore, they reported experiencing intrusive thoughts, images or memories related to an incident of experienced stigma. Relatively little is known about the relationship between internal triggers and internalised stigma; the few studies available have examined stigma and psychosis more broadly. For example, P.H. Lysaker, Davis, Warman, Strasburger, and Beattie (2007) examined a small sample (n=36) of people with schizophrenia and found that ongoing positive symptoms significantly predicted internalised stigma(although the specific psychotic symptoms were not identified).

7.4.4. Stigmatising core beliefs

When the individual has (a) identified with the group and perceives stigma as legitimate and (b) experienced a stigma trigger, they will go on to activate stigma based core beliefs. Core beliefs are defined as fundamental, inflexible, absolute, and generalised beliefs that people hold about themselves, others and the world (A. Beck, 1979). Extensive research has been conducted to understand the core beliefs of people who experience psychosis (Fowler et al., 2006; B. Smith et al., 2006). They broadly fall into two categories: beliefs of negative self-evaluation, particularly of being different (Gumley & Schwannauer, 2006), and beliefs that others are hostile, rejecting and untrustworthy (Fowler et al., 2006). Stigma-specific core beliefs have been documented as associated with internalised stigma (Birchwood et al., 2007; Hinshaw, 2007). Most commonly, an individual can internalise the stereotypes and believe that they are dangerous, mad and unpredictable (J. B. Ritsher et

al., 2003), therefore core beliefs regarding the self are likely to incorporate this content. Furthermore, stigma-related core beliefs are also going to reflect existing core beliefs related to experiences of psychosis; for example, beliefs of being different and others being hostile/rejecting are common in psychosis (Fowler et al., 2006). This is unsurprising given the high prevalence of experiences of adversity that are also commonly stigmatised, such as sexual abuse and institutional care (Varese et al., 2012).

7.4.5. Stigma appraisals

Stigma-related appraisals are core to internalised stigma and have been described as intrusive and automatic (Rusch et al., 2010). The stigmatised person is also likely to have a cognitive-attentional bias (A. P. Morrison, 2001), which consequentially leads them to have heightened self-focused attention, attentional bias and ruminative processes (Wells, 1995; Wells & Matthews, 1994) regarding stigma. We hypothesise that there are three subtypes of appraisals which pertain to different emotional responses. The first subtype of appraisal would relate to social anxiety and paranoia and refer to perceived social danger (Michail & Birchwood, 2009, 2013). If socially anxious, the person would process themselves as a social object (detailed monitoring of themselves in social situations) (Birchwood et al., 2007; D.M. Clark, 2001). Secondly, stigma-specific negative automatic thoughts (NATS) and self-criticism are widely documented to be associated with depression (A. Beck, 1979; Gilbert & Procter, 2006), and more recently have been demonstrated in people with psychosis (Shahar et al., 2004; Waite, Knight, & Lee, 2015). Finally, cognitions pertaining to injustice and unfairness are also considered important; for example, Watson et al. (2007) report that when people perceive stigma to be unfair or unwarranted, or they feel disrespected, they will experience righteous anger and frustration.

7.4.6. Emotional and physiological consequences

The subtypes of stigma appraisals are hypothesised to lead to three key emotional responses in relation to stigma. Firstly, it is proposed that appraisals related to social danger and processing the self as a social object will lead to social anxiety. This has been identified in a number of studies with people who experience psychosis (P. Lysaker et al., 2010; Markowitz, 1998). In the qualitative literature, (social) anxiety and fear have also been identified by service users as a response to stigma (Wood, Burke, Byrne, et al., 2015). Birchwood et al. (2007) illustrated that in a sample of people experiencing first episode psychosis that social anxiety was associated with greater shame, that their diagnosis socially marginalised them and resulted in loss of social status.

Secondly, shame and depression are recognised as emotional responses to stigma due to a loss of social rank (Gilbert, 2010). This has also been widely documented in systematic reviews of internalised stigma (Livingston & Boyd, 2010), service user literature (L. Wood, R. Byrne, et al., 2016), and quantitative explorations through path analysis (P. H. Lysaker et al., 2007; Vass et al., 2015; P. Yanos, Roe, Markus, & Lysaker, 2008). Shame and depression have been illustrated to be directly predicted by different forms of stigma but also mediate the relationship between stigma, recovery, positive symptoms on psychosis and recovery (Vass et al., 2015).

Finally, anger has been identified as a response to stigma, although there has been less exploration of its relationships with stigma compared to the other emotional responses. Anger has been described as a positive response to stigma and considered righteous and empowering (Watson et al., 2007). Anger occurs when an individual identifies with the stigmatised group but perceives the stigma to be unjust or unfair (Rusch, Angermeyer, & Corrigan, 2005). This has also been described as important by service users who

experience psychosis in qualitative interviews (Dinos et al., 2004; Wood, Burke, Byrne, et al., 2015).

7.4.7. Safety seeking strategies

Safety seeking behaviours are utilised to prevent a feared catastrophe and are widely documented in cognitive models (D. M. Clark & Wells, 1995; Salkovskis, Clark, Hackmann, Wells, & Gelder, 1999). Within psychosis, safety seeking behaviours are also prevalent and broadly pertain to avoidance and resistance (Tully, Wells, & Morrison, under review). Safety seeking behaviours within internalised stigma in psychosis would serve to protect the individual from feeling stigmatised by others. One of the most significant safety behaviours for internalised stigma is the avoidance of disclosure about experiences of psychosis to all areas of their social network (e.g. friends, family, employers) (Corrigan et al., 2013). Service users have also described having to "act normally" when they are around others by hiding their experiences of psychosis (Pyle & Morrison, 2013). Social avoidance is also an identified coping strategy for stigma by keeping a distance from others and not having relationships in order to protect against rejection. Furthermore, stigmatised people are more likely to avoid mental health services due to concerns regarding stigma (Rusch et al., 2005).

Another potential safety seeking behaviour is heightened awareness and threat monitoring of stigma. It is widely documented that people who experience psychosis and trauma have a heightened threat system due to actual threat experiences (Freeman, Garety, & Kuipers, 2001; A. P. Morrison, 2001; A. P. Morrison et al., 2003). In particular, psychosis is underpinned by interrelational trauma and is thought to be at the core of the development and maintenance of psychosis (Braehler et al., 2013). In a similar vein, experienced and perceived stigma are additional social threats which could increase hypervigilance and attunement to social cues regarding stigma (Birchwood et al., 2007).Additionally, another

safety behaviour identified is submission within relationships. Submissive behaviour is a widely documented safety behaviour with cognitive models of depression (Gilbert & Allan, 1998). From an evolutionary perspective, submissive behaviours are a result of low social rank, i.e. seeing oneself as not good enough in comparison to others, and show themselves in the context of others who are more powerful (Gilbert & Allan, 1998). Within the context of internalised stigma, submission can be understood as protecting the individual from powerful and stigmatising others.

Other types of safety-seeking responses include cognitive strategies which aim to manage the distressing cognitions and emotions as a response of internalised stigma. Such strategies are often described as metacognitive and include tactics such as anticipatory processing, post-event rumination, selective attention to unwanted thoughts and cognitive avoidance or suppression. Such strategies are widely noted in the psychosis literature as an attempt to manage the cognitive and emotional distress (A. P. Morrison, 2001).

7.4.8. Protective Factors

A number of protective factors are suggested by the proposed theoretical model, which has been drawn from existing evidence. Firstly, social network support has been outlined. Supportive relationships and secure attachments are important to our well-being and can protect us from social threats such as stigma (Gumley et al., 2010). This is widely documented in the stigma literature (Chronister, Chou, & Lao, 2013), particularly from qualitative explorations of service user perspectives (Pyle & Morrison, 2013). Even when an individual has multiple experiences of stigma, the close social network of family and friends acts as a buffer (Wood, Burke, Byrne, et al., 2015), which has been supported by a recent mediation analysis (Chronister et al., 2013).

The second most commonly cited protective factor against stigma is peer support, for similar reasons as those outlined above. In addition, peer support offers understanding, normalisation and empathy (Russinova et al., 2014). Peer support has been shown to improve self-identity and self-esteem, make the individual feel more valued, and ultimately reduce internalised stigma (Repper, 2013). Qualitative accounts have supported this finding; service users state they appreciate "being around people who are the same", and that it brings "a silent understanding" (L. Wood, R. Byrne, et al., 2016). Interventions for internalised stigma which have included peer support have also shown promising results (Corrigan et al., 2013; Russinova et al., 2014).

Developing personal recovery goals have been identified as an important protective factor. The 'recovery movement' has long emphasised the importance of overcoming stigma as part of the recovery process (Allot, Loganathan, & Fulford, 2002; Pitt et al., 2007). In addition to overcoming stigma, qualitative research has identified that having idiosyncratic goals are important to achieve despite stigma, for example gaining employment, accessing education and developing relationships (Andreasen et al., 2003; L. Wood, R. Byrne, et al., 2016). In addition, having stable experiences of psychosis has been identified as an important protective factor against stigma as experiencing overt symptoms, such as responding to auditory hallucinations, can make you a vulnerable target for experienced stigma (Rusch et al., 2005; L. Wood, R. Byrne, et al., 2016). Finally, and in relation to empowerment and righteous anger, service users have noted that activism, such as open disclosure about personal experiences, or involvement in a service user movement such as the Hearing Voices Network (Corstens, Longden, McCarthy-Jones, Waddingham, & Thomas, 2014) and Mad Pride (Dellar, Curtis, & Leslie, 2003), can be helpful in tackling both internalised and public stigma .

7.5. Case example

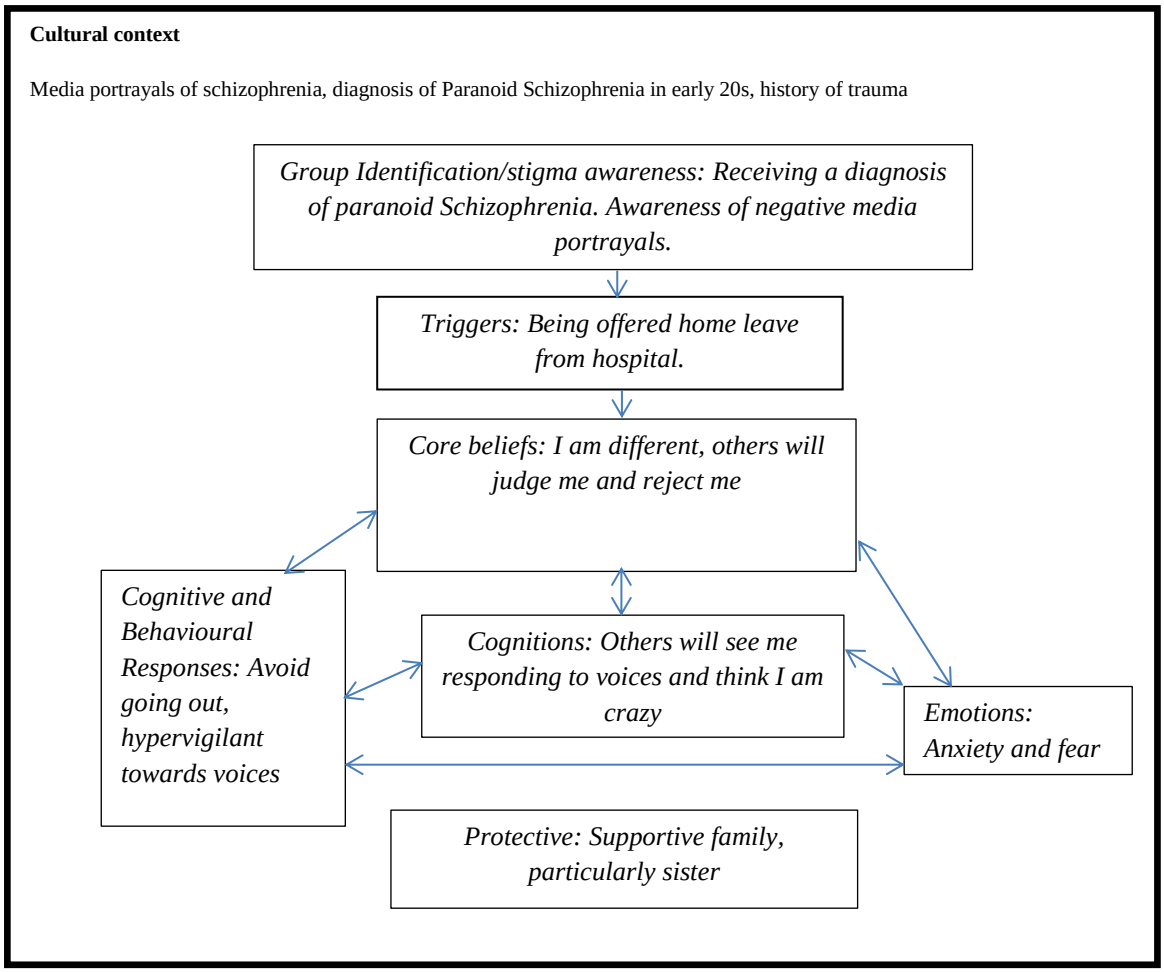
In order to demonstrate the application of this formulation a case formulation is presented with a brief treatment plan.

Mark was a 39 year old, White British, single man with a diagnosis of Paranoid Schizophrenia who had a history of experiencing auditory hallucinations and paranoid beliefs since university in his early twenties. He had recently been admitted into a psychiatric inpatient ward following a relapse of his psychosis. He was in hospital for four months and nearer discharge was becoming more preoccupied with readjusting to his life away from hospital. In particular he was concerned about experiencing stigma and discrimination in social situations. Mark enjoyed going to the local pub to watch football but was reluctant to do so as he was concerned that others will judge him and verbally abuse him when he was out. His experiences of internalised stigma have been included in a formulation outlined in figure 11. Mark identified with the stigmatised group and has done since he received a diagnosis of Paranoid Schizophrenia a few years after his first episode of psychosis. Since this time, he has been concerned about stigma due to the negative media portrayals of "schizophrenics" being "crazy" and "violent". He has experienced verbal discrimination in the past as a result of responding to his voices in public, when passers-by called him "crazy" and a "nutjob". The recent trigger for his current internalised stigma cycle was being offered home leave from hospital. This triggered his core beliefs of being different and that others would be judgemental and rejecting.

In regard to the maintenance cycle of Mark's stigma beliefs, his appraisal was that when going out on leave others will call him "crazy" when he is out in public. This caused him to experience anxiety and fear in relation to the social context and activated his safety seeking behaviours of only going out when he really needed to, masking his voices, and

being hypervigilant towards them. These safety behaviours in turn maintained his cycle of internalised stigma. Mark was keen to break the cycle of internalised stigma and we set up a series of behavioural strategies in order to challenge his belief that he would be called "crazy" when out on leave. Mark's behavioural experiments related to going out with his sister to the local pub as he was less likely to respond to voices when in the company of others and people were less likely to notice if he did as they would assume he was speaking to his sister. Mark became less preoccupied with what others thought of him and he was able to go out with his sister on a number of occasions which reduced his anxiety, and then later was able to go out on his own.

Figure 11 – A formulation of Mark's experiences of internalised stigma



7.6. Clinical Implications

The outlined cognitive model of internalised stigma in psychosis is the first of its kind and has some important clinical implications in supporting service users to overcome internalised stigma. Essentially, it is imperative that future clinical interventions for psychosis target the cognitive and behavioural responses that are affected by stigma. To date, the research examining the efficacy of interventions to reduce internalised stigma has been inconsistent with most trials not finding a significant improvement in their primary outcome (L Wood et al., 2016). In a systematic review of internalised stigma interventions, L Wood et al. (2016) concluded that the inconsistent findings were potentially due to the lack of formulation or conceptualisations of individual participants' internalised stigma difficulties. This present paper outlines a framework to support the development of idiosyncratic formulations of internalised stigma in order to inform clinical interventions. Furthermore, an idiosyncratic formulation would also facilitate personal understanding and normalisation which have been identified as important factors within internalised stigma interventions by service users (L. Wood, E. Burke, R. Byrne, & A. Morrison, 2016).

Specific recommendations for intervention include identification of the different levels of stigma cognitions (core beliefs and stigma appraisals) and identification of safety behaviours, which are both likely to be crucial in optimising the efficacy of intervention. Techniques for modifying cognitions in relation to internalised stigma include psychoeducation, normalisation, behavioural experiments, reducing avoidance and generating alternative explanations of stigma beliefs which have been used in previous internalised stigma cognitive therapy trials (A. Morrison et al., 2016; Uchino et al., 2012). Psychoeducation and normalisation have been highlighted as particularly helpful in

alleviating internalised stigma by service users who experience psychosis (L. Wood, E. Burke, R. Byrne, & A. Morrison, 2016). In the same study, the therapeutic relationship was highlighted as particularly important and a process which modelled a non-stigmatising relationship. As a consequence, it is proposed that a good therapeutic relationship is important in implementing therapy for internalised stigma based on the model proposed here.

Finally, this model demonstrates the importance of the cultural context in causing and maintaining stigma, and that internalised stigma would not exist without it (P. Corrigan & A. Watson, 2002). Therefore a final implication is the continued need to develop interventions which tackle stigma at a societal level through service user activism and public education.

In conclusion, this paper has presented a theoretical model of understanding internalised stigma using cognitive theory and SMT. It is the first model developed which can be used in clinical practice to develop a formulation with a person with experience of internalised stigma related to psychosis. It provides a framework for developing an idiosyncratic formulation and structuring a cognitive therapy intervention. Further randomised controlled trials of cognitive therapy interventions for internalised stigma are required based on this theoretical model. Moreover, future studies should also test the mechanisms of action within the model. For example, examine whether cognitive strategies such as psychoeducation or normalisation reduces internalised stigma through impact on stigma appraisals and core beliefs. However, we also require change in public attitudes at a societal level, since eliminating the negative stereotypes of psychosis would ensure that there are no stigmatising attitudes to internalise.

8. Chapter 8: Study 6 - A brief cognitive therapy intervention for internalised stigma in acute inpatients who experience psychosis: A feasibility randomised controlled trial

This paper has been submitted to Psychiatry Research

Wood, L., Byrne, R., Enache, G., & Morrison, A. (in submission) A brief cognitive therapy intervention for internalised stigma in acute inpatients who experience psychosis: A feasibility randomised controlled trial. *Psychiatry Research.*

8.1. Abstract

Background: Internalised stigma has been identified as a significant problem for people who experience psychosis, therefore, psychological interventions are required. This study aimed to examine the feasibility and acceptability of a brief Cognitive Behavioural Therapy (CBT) intervention for internalised stigma with acute psychiatric inpatients that experience psychosis.

Method: A feasibility randomised controlled trial was conducted, comparing CBT with a psychoeducational (PE) control arm. A total of 30 participants (aged 18-65 with psychosis and currently admitted to a psychiatric hospital) were randomised (using a web service) to one of two conditions. Participants were assessed at baseline, post intervention (one to two weeks) and at follow-up (one month). Both interventions incorporated two hours of sessions over a two week period. The outcomes examined were internalised stigma (primary outcome), stigma, attitudes toward mental health problems, personal recovery, depression and self-esteem.

Results: Recruitment was conducted over a seven month period from five acute psychiatric wards. Forty five potential participants were approached and 30 (66%) consented to take part in the study. Fifteen participants were randomised to CBT and fifteen to PE. Feasibility data demonstrated that both the research process and interventions were feasible and acceptable. Examination of outcomes demonstrated that there was no identified benefit of one intervention type over another. There were no adverse events related to study participation.

Conclusion: This trial was feasible to deliver. A future definitive trial should be conducted within improved methodological rigor.

Trial registration: NCT02853396, Trial funding: None

8.2. Introduction

Stigma is an experience which occurs when an individual "possesses (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context" (pg. 50; Crocker et al., 1998) . Stigma is widely associated with a psychiatric diagnosis and people with such diagnoses are often discriminated against and marginalised (M. C. Angermeyer & H. Matschinger, 2003; Graham Thornicroft, Rose, & Kassam, 2007). People with psychosis are viewed most negatively by the public and seen as dangerous and unpredictable (Angermeyer & Dietrich, 2006). Stigma has been described as having two sub-components: public and internalised stigma (Corrigan & Watson, 2002a). P. W. Corrigan and A. C. Watson (2002) defined public stigma as "the negative reaction that the general population has to people with mental illness", and internalised stigma (self-stigma) as "the prejudice that people with mental illness turn against themselves" (pg. 16).

Internalised stigma is detrimental to the individual as it causes an array of negative cognitive, behavioural, and emotional consequences. Previous research has identified that internalised stigma can cause emotional distress such as anxiety, shame, depression, and hopelessness, in addition to pre-existing mental health problems (Livingston & Boyd, 2010; Schrank et al., 2014). It is also detrimental to an individual's sense of self and can lower self-esteem and self-efficacy, and cause disempowerment (P. W. Corrigan et al., 2006). Moreover, it has been identified to cause delayed access to treatment, self-isolation and lack of disclosure regarding mental distress (Franz et al., 2010). Internalised stigma has been shown to increase both positive and negative symptoms, which further impedes recovery from psychosis (P. H. Lysaker et al., 2007; Schrank et al., 2014). In a large international study, moderate to high levels of internalised stigma were reported by almost half (47%) of the participants with psychosis (Elaine Brohan, Mike Slade, et al., 2010).

Due to the pervasiveness of internalised stigma in those who experience psychosis, a number of interventions have been developed to reduce internalised stigma. Wood et al. (2016) conducted a systematic review and identified 12 studies which had examined the efficacy of psychosocial interventions in reducing internalised stigma with people who experience psychosis. Interventions included psychoeducation (Fung et al., 2011), peer-led interventions (Russinova et al., 2014), forms of CBT (M. D. Knight et al., 2006; Lucksted et al., 2011; A. Morrison et al., 2016; Roe et al., 2014; P. T. Yanos et al., 2011), and disclosure interventions (Corrigan et al., 2013). The systematic review established that psychosocial interventions did not significantly improve internalised stigma post-therapy or at follow-up, but did show benefit on some secondary outcomes post-therapy (self-efficacy and insight). Moreover, the studies were heterogeneous and suffered from methodological bias. None of the interventions included in the review incorporated an individualised formulation based on internalised stigma theory (L Wood et al., 2016). Formulations are essential in underpinning psychological therapies in order to guide the intervention (British Psychological Society, 2011), and have been identified by experts as crucial in delivering cognitive behavioural therapy for psychosis (A. Morrison & Barratt, 2010). The review concluded that further research examining the effects of internalised stigma interventions is required.

To date, all internalised stigma interventions have been conducted with outpatients, and no inpatient stigma focused interventions have been developed for those who experience psychosis. Stigma has been identified as a significant issue for those who experience psychosis and who are admitted to a psychiatric inpatient setting. In a recent qualitative study, L. Wood, R. Byrne, et al. (2016) interviewed 25 psychiatric inpatients with psychosis about their experiences of stigma. They identified that stigma was a concern and this related to all aspects of their hospitalisation including admission (particularly forced

admission), their treatment by staff during admission, and post-discharge within the community. In a large survey-based study, stigma was identified as a risk factor for suicide post discharge (Schromerus et al., 2015). Collectively, this demonstrates that stigma is a significant problem for psychiatric inpatients.

CBT is the first-line recommended intervention for people who experience psychosis at all different stages, including the first episode, acute, and severe and enduring (NICE, 2014). Moreover, CBT has been utilised for internalised stigma and has been demonstrated to be an acceptable therapy for people with psychosis (A. Morrison et al., 2016; L. Wood, E. Burke, R. Byrne, & A. Morrison, 2016). Wood, Byrne, and Morrison (2017) have developed an integrative cognitive model of internalised stigma for psychosis which would be useful in guiding a CBT informed intervention. Therefore, the aim of this study was to examine the feasibility and acceptability of a CBT formulation-based intervention for internalised stigma in psychosis with acute inpatients, to identify whether a definitive trial is possible. CBT was compared to a brief psychoeducational (PE) internalised stigma intervention.

The specific aims of this study were:

1. To assess how many eligible people agreed to participate in the study (recruitment rates, recruitment timeframe, the willingness of clinicians to refer participants, and consent rates).
2. To examine the feasibility of conducting research with acute inpatients with psychosis (willingness of participants to be randomised, dropout rates, service user feedback, time needed to undertake research study).

3. To examine the feasibility and acceptability of the interventions (adherence to treatment, service user feedback, types of change mechanisms used, serious adverse events, examination of primary and secondary outcomes).
4. To examine the acceptability and feasibility of the outcome measures to examine the effects of the interventions.

8.3. Methodology

8.3.1. Study design

A feasibility Randomised Controlled Trial (RCT) was conducted following guidance from Consolidated Standard for Reporting Trials (CONSORT; Boutron et al., 2008; Thabane et al., 2016). The trial was undertaken between June 2016 and March 2017 as part of the first author's PhD. The study was registered on a trial registry before it commenced (clinicaltrials.gov; NCT02853396) and received Health Research Authority (HRA) approval (IRAS ID 187857).

8.3.2. Sample size

To evaluate the feasibility and acceptability of the research process and psychological intervention, a sample of 30 participants was utilised. This is recommended as an appropriate sample size for feasibility trials of clinical interventions (Eldridge et al., 2016).

8.3.3. Sample inclusion and exclusion criteria

Participants were included if they were i) aged 18-65 ii) met criteria for a schizophrenia-spectrum diagnoses (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder or psychotic disorder not otherwise specified; ICD-10), or met criteria for an Early Intervention Service (EIS) to allow for diagnostic uncertainty iii) able to give informed consent and have the capacity to consent iv) receiving care from a clinical inpatient team v) able to complete the study in English, vi) self-reported that stigma was causing them negative emotional consequences. They were excluded if they were i) Non-English speakers (due to translation costs), ii) had an acquired brain injury or substance misuse judged to be the acute cause of the psychotic experiences iii) lacking capacity for informed consent (the researcher worked with the participant to assess whether they

understood the information sheet and study and, therefore, their ability to give informed consent) iv) experiencing severe thought disorder (as defined by the referring clinical staff member).

8.3.4. Recruitment

Potential participants were recruited from five acute psychiatric wards (three male and two female) in North East London Foundation Trust (NELFT) between June 2016 and February 2017. The researcher (LW or GE) attended staff meetings to promote the study. Clinical staff were asked to discuss the study with potential participants, and either the service user or staff member contacted the researchers regarding participation in the project. The researcher met with the participant at the venue and time of their choice and gave the participant the information sheet to read about the study. Written informed consent was taken.

8.3.5. Randomisation and masking

Participants were randomly assigned electronically to either the CBT or PE condition by LW using the computerised system Sealed Envelope (www.sealedenvelope.com) with permuted blocks of four, six and eight. Assessments were not conducted blind due to limited study resources, but self-report measures were employed so participants could complete assessments independently where possible (in an attempt to reduce bias). A small number of assessments were completed with support from the therapist (n=5), as the participants were unable to complete the measures alone and the research assistant was not available.

8.3.6. Experimental Condition

Participants allocated to the experimental condition received a two-hour Cognitive Behavioural Therapy (CBT) intervention session (across one or two sessions) that involved developing a case formulation based on the cognitive model of internalised stigma outlined by Wood et al. (2017) (figure 10). These sessions were undertaken within a two week period. The sessions collaboratively assessed and created a narrative of the participants' experiences of internalised stigma, and developed a personalised internalised stigma formulation. An internalised stigma-related goal was identified and a brief intervention strategy was collaboratively developed in relation to this goal. The range of permissible change mechanisms drew upon strategies outlined by A. Morrison et al. (2003). Intervention strategies included guided discovery, skills development, normalising and belief change strategies, behavioural experiments targeting internalised stigma-relevant appraisals and negative beliefs about self, including public stereotypes of psychosis, and evaluating decisions about whether to disclose.

8.3.7. Control Condition

Participants allocated to the control condition received a two-hour session (across one or two sessions) receiving psychoeducation (PE) material relating to internalised stigma in psychosis (Appendix 30). The aim of the material was to help people understand the impact of stigma and the prevalence of internalised stigma. The intervention was an adapted version of a previously utilised PE stigma intervention (Pyle, 2013). It comprised four modules; psychoeducation about stigma, psychoeducation about psychosis, myth-busting stereotypes and tackling stigma. The resources were taken from a number of sources including the Time to Change website (Time to Change, 2016), and relevant literature (A. Morrison et al., 2003; AP Morrison et al., 2008).

Both interventions were delivered by the same therapist, author LW.

8.3.8. Materials

8.3.8.1. Feasibility outcomes

Feasibility data was collected on a pre-developed sheet which recorded: recruitment rates, recruitment timeframe, willingness of clinicians to refer participants, consent rates, willingness of participants to be randomised, dropout rates, time needed to undertake research study, adherence to treatment, types of change mechanisms used, serious adverse events.

A feedback questionnaire was developed to gain feedback on the therapeutic interventions and the research process. Participants were asked for their thoughts on helpful and unhelpful aspects of the intervention, aspects about the intervention that they would change, positive and negative aspects of participation and whether they have disclosed about their mental health following the intervention.

A demographics sheet was developed to examine patient characteristics such as age, gender, ethnicity, employment status, marital status, education level, diagnosis, current service use, admission status, the length of admission at consent, and length of contact with mental health services.

8.3.8.2. Clinical Outcomes

The Internalised Stigma of Mental Illness Inventory-Shortened (ISMI-S; Boyd et al., 2014) was utilised as a measure of primary outcome. It is a 10-item scale assessing internalised stigma covering five subscales; alienation, stereotype endorsement, perceived

discrimination, stigma resistance and social withdrawal. This measure demonstrates good internal consistency (Cronbach alpha = 0.90) (Boyd et al., 2014). Higher scores indicate higher internalised stigma

The Stigma Scale (SS; King et al., 2007) is a 26 item scale assessing stigma and perceived discrimination. It has three subscales discrimination, disclosure and positive aspects. Only the disclosure and positive subscales were utilised for the purpose of this study (16 items) as they are the two subscales most sensitive to change (Morrison et al., 2016). Both subscales demonstrated good internal consistency (Discrimination =088; Positive Aspects = 0.64) (King et al., 2007). Higher scores demonstrate higher stigma.

The Self-Esteem Rating Scale (SERS; Lecomte et al., 2006) is a 20 item measure of self-esteem. It has two subscales; positive self-esteem and negative self-esteem. The scale has high internal consistency (Cronbach alpha = 0.90; Lecomte et al., 2006). Higher scores indicate higher self-esteem.

The Process of Recovery Questionnaire – short form (QPR; Law et al., 2014) is a user-defined 15-item measure of personal recovery. It has good internal consistency (Cronbach alpha = 0.93; Law et al., 2014). Higher scores indicate improved personal recovery.

The Beck Depression Inventory-Primary Care (BDI-PC; Beck et al., 1997) is a 7 item brief version of the original 21-item BDI questionnaire (A. T. Beck et al., 1996). It demonstrates good internal consistency (Cronbach alpha = 0.86; Beck et al., 1997). Higher scores demonstrate higher levels of depression.

The Attitudes towards Mental Health Problems (AMHP) measure (Gilbert et al., 2007) is a 35-item self-report measure of stigma. For this research, the sub-scales relating to stigma awareness and internalised shame were utilised (15-items). The scale demonstrates high internal consistency (Cronbach alpha = 0.85 and 0.97; Gilbert et al., 2007). Higher scores indicate higher stigma attitudes.

8.3.9. Procedure

Participants were asked to complete all primary and secondary outcome measures (all self-report measures) at baseline, post therapy (one to two weeks) and one-month follow-up post therapy. The assessment took approximately 30 minutes to complete. Participants either completed the measures individually or facilitated by the researcher (GE and LW). At the follow-up assessment, all participants were asked to complete a feedback questionnaire about taking part in the study.

8.3.10. Data collection and Analysis

As this was a feasibility study, the main focus of the analysis was on descriptive statistics of the key indicators of the success of the feasibility trial, including participant recruitment, retention and acceptability. These were reported before the examination of the outcome measures. The feedback questionnaire was analysed using quantitative content analysis (Krippendorff, 2004). Themes were identified, coded, collapsed and examined for frequency of occurrence.

For the examination of the sample demographics and outcome measures, quantitative analysis was undertaken in SPSS (version 23; IBM, 2015). Participant demographic data was initially screened for any differences between groups using between samples t-test and

Mann Whitney U test (dependent on the type of data being examined). Individual questionnaire data where less than 20% was missing was replaced with the mean. Data was checked for normality through examination of skewness and kurtosis (Kim, 2013). Primary analysis was undertaken using intention-to-treat (ITT) analysis and missing data was managed using last observation carried forward (Streiner & Geddes, 2001). Changes in all outcome measures were analysed using Analysis of Covariance (ANCOVA) with summed scores as dependent variables and the baseline value of the relevant outcome measure as a covariate. Post-therapy and follow-up data were analysed separately to utilise all available data.

8.4. Results

8.4.1. Participant demographics

A total of 30 participants consented to take part in this study. Participant demographics can be found for the final recruited sample in Table 17. The two groups did not significantly differ in demographic distribution except for ethnicity, with the PE group comprising predominantly black and ethnic minority participants.

Table 17 – Sample demographics

Category		**Total (n=30)**	**CBT (n=15)**	**PE (n=15)**	**Between group difference**
		Mean (SD)	**Mean (SD)**	**Mean (SD)**	**t (p)**
Age		33.63 (12.86)	32.07 (12.21)	35.58 (13.89)	-1.131 (0.897)
Length of admission at consent (days)		26.20 (19.25)	24.40 (21.48)	28.00 (17.72)	-0.689 (0.491)
Number of admissions		4.03 (4.10)	3.93 (2.34)	4.13 (5.42)	-0.409 (0.688)
Category	**Sub-category**	**N (%)**	**N (%)**	**N (%)**	**Sig**
Gender	Male	23 (76.67)	10 (60.00)	13 (86.67)	0.367
	Female	7 (23.33)	5 (33.33)	2 (13.33)	
Admission Status	Section 2	13 (43.33)	6 (40.00)	6 (40.00)	0.067
	Section 3	7 (23.33)	2 (13.33)	5 (33.33)	
	Section 37	1 (3.33)	0 (0.00)	1 (6.67)	
	Informal	5 (16.67)	4 (26.67)	1 (6.67)	
	Unknown	4 (10.00)	2 (13.33)	2 (6.67)	
Diagnosis	Schizophrenia	18 (60.00)	8 (53.33)	10 (66.67)	0.217
	First Episode	4 (20.00)	2 (13.33)	2 (13.33)	
	Psychosis	2 (6.67)	1 (6.67)	1 (6.67)	
	Schizoaffective	6 (20.00)	4 (26.67)	2 (13.33)	
Ethnicity	White British	6 (20.00)	5 (33.33)	1 (6.67)	0.026*
	Asian	11 (36.67)	5 (33.33)	6(40.00)	
	Black	11 (36.67)	5 (33.33)	6 (40.00)	
	Other	2 (6.67)	0 (0.00)	2 (13.33)	
Employment Status	Full-time	3 (10.00)	1 (6.67)	2 (13.33)	0.174
	Part-time	1 (3.33)	1 (6.67)	0 (0.00)	
	Unemployed	22 (73.33)	13 (86.67)	9 (60.00)	
	Student	2 (6.67)	0 (0.00)	2 (13.33)	
	Other	2(6.67)	0 (0.00)	2 (13.33)	
Marital Status	Single	26 (86.67)	12(80.00)	14 (93.33)	0.512
	Married	2 (6.67)	1 (6.67)	1 (6.67)	
	Separated	1 (3.33)	1 (6.67)	0 (0.00)	
	Other	1 (3.33)	1 (6.67)	0 (0.00)	
Education level	Secondary	6 (20.00)	2 (13.33)	4 (26.67)	0.539
	Further	13 (43.33)	7 (46.67)	6 (40.00)	
	Higher	11 (36.67)	6 (40.00)	5 (33.33)	

*N - Number of participants in group, CBT –Cognitive Behaviour Therapy, PE – Psychoeducation, *- significant at 0.05 level.*

8.4.2. Baseline descriptive statistics

The means and standard deviations across measures can be found in Table 18. The sample demonstrated moderate levels of internalised stigma (ISMI-S), stigma (SS), and negative attitudes toward mental health problems (AMHP) at baseline. Furthermore, the sample demonstrated low levels of depression (BDI-PC), and reasonably high levels of self-esteem (SERS) and personal recovery (QPR).

Table 18 – Baseline outcome data

	Whole sample (n=30)	**CBT (n=15)**	**PE (n=15)**
	Mean (SD)	**Mean (SD)**	**Mean (SD)**
ISMI	23.75 (5.82)	24.07 (5.03)	23.43 (6.70)
SS	35.64(9.18)	36.38 (6.64)	34.93 (11.40)
QPR	42.47 (12.37)	43.00 (15.14)	41.93 (9.34)
BDI-PC	5.03 (3.92)	5.149 (3.84)	4.93 (4.13)
SERS	102.59 (19.83)	99.07 (18.45)	105.87 (21.13)
AMHP	17.00 (8.89)	17.42 (6.03)	16.57 (11.29)

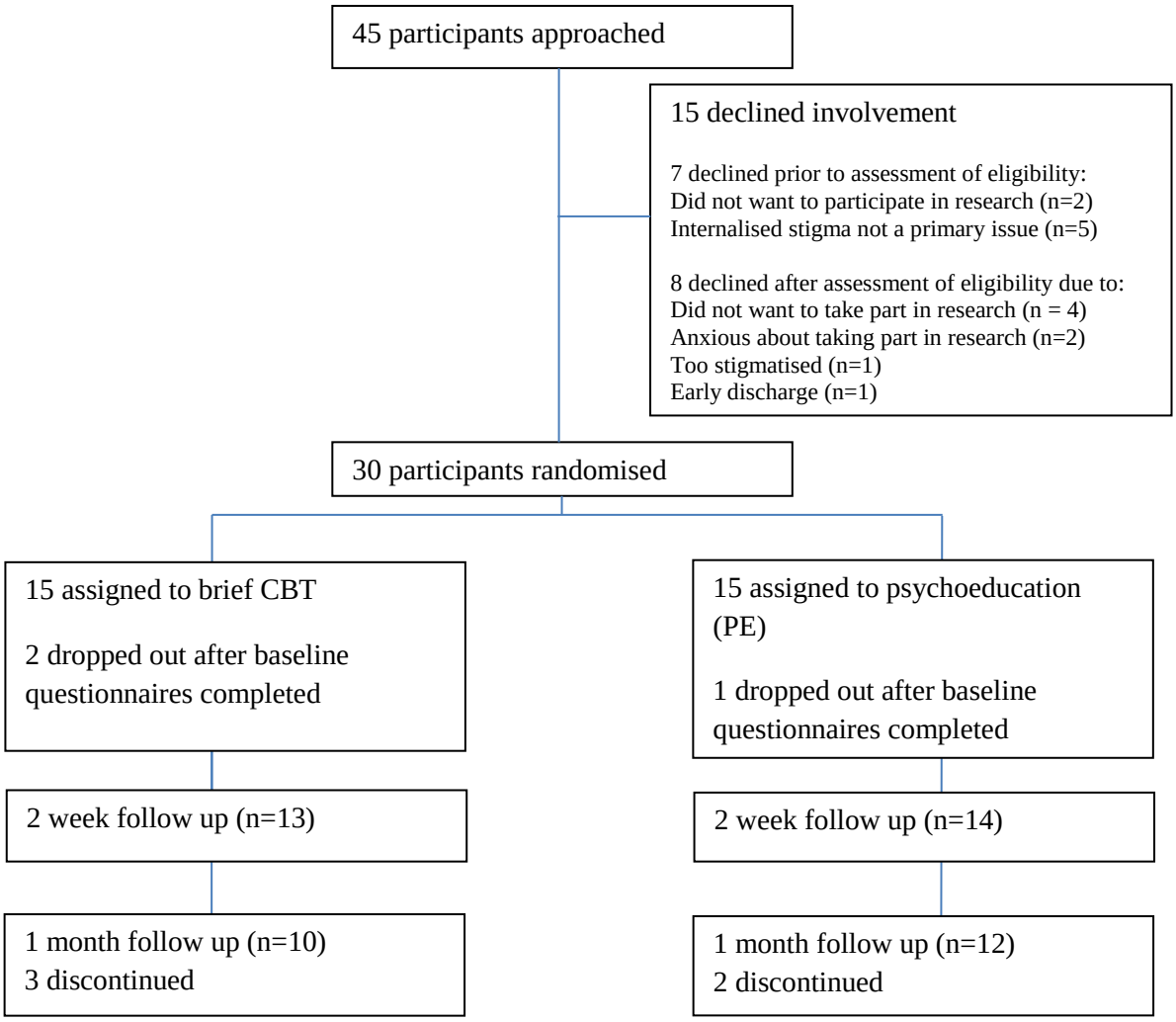
ISMI – Internalised Stigma of Mental Illness Inventory, SS – Stigma Scale, QPR – Process of Recovery Questionnaire, BDI-PC – Beck Depression Inventory Primary Care, SERS – Self-Esteem Rating Scale, AMHP – Attitudes towards Mental Health Problems, SD – Standard Deviation, CBT – Cognitive Behaviour Therapy, PE – Psychoeducation.

8.4.3. Feasibility of the research process

A consort diagram outlining recruitment can be seen in figure 12 (Boutron et al., 2008). All clinical staff approached to help with recruitment provided potential participants for the study indicating a willingness to support recruitment. Recruitment was completed within eight months which is comparable to other similar successful trials (Morrison et al., 2016). A total of 45 participants were approached for this study. A final total of 30 (66.67%) of

the participants approached consented to take part in the study demonstrating that recruitment was feasible as the recruitment target was met. All 30 participants were randomised; 15 to the CBT arm and 15 to the PE arm. All participants (100%) recruited in the study consented to being randomised. The study achieved its aim of retaining participants for the end of treatment (90%) and neared desired retention level at follow-up (73%). All participants who were lost to follow-up had been discharged from the hospital.

Figure 12 – CONSORT diagram of participant flow



8.4.4. Participant feedback on the research process

A total of 19 of 22 (86%) participants completed the feedback questionnaire and responded to the questions regarding their experience of the research process. 14 (74%) participants reported no problems with the research process and reported no distress arising from taking part in the study, 2 (11%) reported that the questionnaires were difficult (the ISMI and SS in particular), and 2 (11%) remarked that the disruptive ward environment made taking part in the research difficult, and 1 (5%) participant reported that there was too much information to take in (PE arm).

8.4.5. Feasibility and acceptability of the interventions

Engagement with both interventions appeared reasonable. Of those who began the CBT intervention (n=13), 11 (85%) participants completed the allocated therapy sessions (one participant was very drowsy and was not able to complete the second session, and the other had deteriorated in their mental state). 3 (23%) chose to have one two-hour session, and 10 (77%) chose to have two one-hour sessions. The intervention lasted the full allocated two hours for all participants. The change mechanisms utilised within the CBT intervention varied: 4 (36%) participants received psychoeducation material, 3 (27%) completed behavioural experiments regarding challenging stigma, 1 (9%) received normalising stories of stigma, 1 (9%) received material on the rights of employees in the workplace with mental health, 1 (9%) completed disclosure strategies taken from (Corrigan et al., 2013), and 1 (9%) explored the impact of diagnosis.

Regarding the PE intervention, 14 participants began the intervention with 11 (78%) participants completing the full intervention, all choosing to have one session (100%). One participant (7%) was discharged before the intervention could be undertaken, and 2

changed their mind following randomisation (14%) and did not complete the intervention. The psychoeducation was on average 30 minutes shorter than the CBT intervention which was based on the time to go through the PE intervention material (with time for the participants to reflect and discuss ideas which were raised).

Examination of the feedback questionnaire also demonstrated that both interventions were acceptable to participants. In regard to the CBT condition participants, 9 of 12 participants (75%) who undertook the intervention completed the feedback questionnaire. The feedback reported that the most helpful element of the CBT intervention was: that it was informative (33%), that it was normalising (11%), being able to disclose about stigma experiences (33%), and being able to talk to someone who was non-judgmental and empathic (22%). The only unhelpful elements of the intervention were: the noisy ward environment (22%), and that the sessions were too short (11%). The remainder of participants reported that nothing was unhelpful (67%). Seven (78%) participants reported that following the intervention, they were more able to disclose about their mental health experiences.

In regard to the PE group, 10 of 12 participants (83%) who undertook the intervention completed the feedback questionnaire. The most helpful element of the PE intervention were increased understanding (60%), being able to disclose experiences (20%), being given resources (10%), and one did not find anything beneficial (10%). In regard to unhelpful elements, two participants (20%) reported that the information was too complex; the rest of participants (80%) did not report anything unhelpful about the intervention. Two participants (20%) reported that they were more able to disclose following the intervention.

One adverse event was recorded during the trial which was in the CBT group. The participant attempted suicide following being discharged from the hospital, but this was not considered to be related to participation in the trial.

8.4.6. Examination of primary and secondary outcomes

Table 19 displays the results for the outcome measures post therapy (one to two weeks) and at follow-up (one month). The primary outcome (ISMI-S) demonstrated that there were no significant differences between CBT and PE at the end of treatment and at follow-up on any statistical indicators. In regard to the secondary outcomes, no significant differences between CBT and PE were found for the SS, BDI-PC and AMHP at end of therapy and at follow-up. The F-statistic and related p-values demonstrated significance favouring the PE intervention on the QPR and SERS at end of therapy, but the Cohen's d statistic (and confidence intervals) demonstrated a non-significant difference between interventions on these outcomes. No significant differences were identified on any outcomes at follow-up.

Table 19 – Descriptive statistics, ANCOVA results, effect sizes (Cohen's d) for post therapy (two weeks) and follow-up (one month) data

Measure	Post-therapy (two weeks)		Follow-up (one month)		Post-therapy					Follow-up				
	Mean (SD)		Mean (SD)		Mean (SD)					Mean (SD)				
	CBT	*PE*	*CBT*	*PE*	*F*	*P*	*D*	*LCI*	*HCI*	*F*	*P*	*d*	*LCI*	*HCI*
ISMI-S	23.92 (3.89)	22.86 (5.33)	23.57 (2.68)	21.78 (5.27)	0.306	0.585	-0.238	-1.903	1.427	1.313	0.263	-0.442	-1.934	1.050
SS	34.33 (7.49)	31.00 (8.26)	33.40 (7.60)	30.36 (9.27)	0.479	0.756	-0.439	-3.251	2.374	1.254	0.273	-0.373	-3.339	2.593
QPR	43.73 (12.66)	45.93 (13.34)	40.87 (16.63)	43.27 (10.39)	3.466	0.046	0.175	-4.319	4.669	0.866	0.360	0.179	-4.613	4.971
BDI-PC	4.93 (4.96)	3.87(2.95)	5.07 (5.77)	3.60 (2.94)	0.682	0.416	-0.270	-1.681	1.141	1.411	0.246	-0.330	-1.9913	1.253
SERS	97.67 (19.45)	103.33 (22.20)	96.20 (25.40)	101.87 (22.99)	11.901	0.035	0.281	-6.934	7.496	0.010	0.922	0.242	-8.132	8.617
AMHP	20.07 (8.91)	14.98 (10.41)	15.53 (5.82)	15.20 (11.54)	4.628	0.052	-0.543	-3.893	2.806	0.866	0.360	-0.037	-3.197	3.122

AMHP – Attitude towards Mental Health Problems, BDI-PC – Beck Depression Inventory for Primary Care, CBT- Cognitive Behaviour Therapy, D-Cohen's D, F – F-value, HCI – Higher Confidence Interval, ISMI-S- Internalised Stigma of Mental Illness Scale-Short, LCI – Lower Confidence Interval, P-P-value, PE – Psychoeducation, QPR – Process of Recovery Questionnaire, SD – Standard Deviation, SERS – Self-Esteem Rating Scale, SS – Stigma Scale.

8.5. Discussion

To the authors' knowledge, this is the first individual CBT-informed intervention for internalised stigma to be examined for feasibility and acceptability with acute psychiatric inpatients that experience psychosis. The study identified that recruitment was feasible as there was an adequate pool of eligible participants to recruit from, recruitment was conducted in a reasonable timeframe, and recruitment targets were met. The research process was also feasible and acceptable as all participants were willing to be randomised, dropout rates were minimal, and service user feedback was positive. Both internalised stigma interventions (CBT and PE) were identified as feasible and acceptable for inpatients that experience psychosis. Both interventions did not demonstrate any impact on primary or secondary outcomes, although the p-values demonstrated that the PE intervention significantly improved personal recovery and self-esteem (although this was not supported by the effect size and confidence intervals).

This study demonstrated that conducting an RCT of brief psychological interventions within an inpatient setting was generally feasible. However, follow-ups following discharge were more challenging, with all participants lost to follow-up being those who were discharged from the inpatient unit. Furthermore, the brief interventions were conducted within the psychiatric inpatient environment where individual patients are receiving intensive treatments of medical interventions, alongside access to other therapeutic interventions (occupational and psychological therapies). Therefore, there were multiple confounding factors influencing outcome measures, and reliably measuring the effect of the intervention was a challenge.

The trial sample included an over representation of black and ethnic minority (BME) participants. Research has demonstrated that black males have higher than average rates of admission to a psychiatric inpatient ward and are more likely to be admitted for longer

(Care Quality Commission, 2010), which is reflected in this sample. Moreover, relevant qualitative stigma research also demonstrates that BME members are also more likely to experience multiple-stigmas (e.g. racism) which make their stigma experiences more complex (Pyle & Morrison, 2013). This may demonstrate that future inpatient stigma interventions may need to be adapted for this population.

This study, where possible, attempted to uphold methodological rigour as recommended by CONSORT (Boutron et al., 2008; Thabane et al., 2016) but was constrained by the limited resources available for this study. This study attempted to ensure rigor by publishing a pre-defined study protocol and being registered on a trial registry, having an active control group, using self-report measures, using independent randomisation procedures (using a web-based specialist randomisation service), and following reporting guidance of feasibility trials outlined by CONSORT (Boutron et al., 2008; Thabane et al., 2016). However, there were several methodological limitations that may have led to methodological bias within this study.

Although this was not a primary aim of the study, one of the main limitations was the small sample size which is underpowered to detect small or moderate effects on outcome. Both groups were relatively small in size (n=15) and, therefore, no definitive conclusion can be drawn regarding the statistical outcome. The p-values suggested that the PE intervention was superior to CBT in improving recovery and self-esteem, but the effect sizes and confidence intervals suggested this was not the case. Thabane et al. (2016) recommend not reporting p-values as feasibility trials are not powered to statistically examine outcomes, and therefore can be misleading. However, p-values were reported as this was described in the pre-defined published protocol. Therefore, this study has not drawn any conclusions regarding the effects of the interventions based on the reported p-values.

Another limitation was the trial was not being conducted blind due to limited resources. Lack of blinding can lead to significant methodological bias which can limit trial findings (J.P.T Higgins et al., 2011). For example, Pildal et al. (2007) identified that lack of blinding was associated with exaggerated estimates of intervention effects.

Limitations regarding the interventions themselves were also identified. Firstly, this study did not allow for a detailed assessment of the participant's experiences of stigma before undertaking the therapy interventions. This meant that either part of the intervention time was spent conducting an assessment (CBT arm) and less time was available for formulation and intervention, or that little was known about the participants' stigma experiences (PE arm). This study would have benefitted from having an assessment of an individual's experience of personal stigma through the use of a measure such as the SIMS which would have addressed this limitation.

Regarding the interventions, another difficulty was the varied length of the CBT and PE interventions. The CBT intervention lasted longer than the structured PE intervention by approximately 30 minutes (25%). This lost time may have impacted on the effectiveness of the PE intervention given that the interventions were so brief. Further research should attempt to address this by ensuring interventions are equally matched in length. In addition, the CBT and PE arguably overlapped in content. A number of the CBT participants had psychoeducation as their change mechanism, and the PE intervention was based on psychoeducation material taken from CBT resources (AP Morrison et al., 2008). An active control was used due in order to supply data on the relative efficacy and tolerability of the CBT intervention. However, future research should either consider the use of treatment as usual or ensure that an active control has no overlapping content.

Due to the intensive medical treatment, some participants were drowsy and struggled with their memory and concentration which can result from heavy psychiatric medication use (Moncrieff, Cohen, & Mason, 2009). This may have impacted on the effectiveness of the intervention. There was also a risk of contamination due to both interventions being delivered by the same therapist. As this was a small feasibility trial with limited resources, this was unavoidable but future research should use independent therapists for each study arm.

Some limitations arose due to the chosen outcome measures. Firstly, there was no measure of psychotic symptoms, which was the result of the service user involvement in the trial design. This did not allow for examination of the effectiveness of the intervention on psychotic symptoms, despite the evidence base demonstrating that there is a reciprocal relationship between internalised stigma and psychotic symptoms (Schrank et al., 2014).

The use of self-report measures for examining the outcome of the study was a further constraint. Self-report measures have some limitations including difficulties in engaging participants, an inconsistent and fluctuating ability to motivate participants, primary and recency effects, over-reporting of experiences, and the questionable credibility of participants' self-reporting (Paulhus & Vazire, 2007). Furthermore, the primary outcome measure has been demonstrated to have flawed reliability and validity (Elaine Brohan, Mike Slade, et al., 2010). The decision to include only self-report measures was partly as an attempt to uphold blindness where possible, but also due to their ability to elicit data quickly from participants, which was deemed important given the short timeframe between assessment time points. However, given the described problems with drowsiness, memory and concentration it was likely that the data collected from the self-report measures was less reliable. A clinician-administered semi-structured interview measure, such as the SIMS (L. Wood, E. Burke, R. Byrne, G. Enache, et al., 2016), was not utilised due to

concerns regarding participant burden and the short timescale of the project (the SIMS measures stigma experience across a one month period). Nevertheless, further research within an inpatient setting should include a combination of self-report and interviewer-rated measures.

A final limitation was the use of the 'last observation carried forward' ITT method to account for missing data within the study (Streiner & Geddes, 2001). This method has been criticised for ignoring the trajectory of change, and other more complex ITT methods have been developed as a result (for example, multiple imputation methods) (White et al., 2011). However, such complex methods were considered unnecessarily complex for a small feasibility trial.

A number of clinical implications arose from the trial. Firstly, the feasibility data demonstrated that participants are willing to take part in a study examining and intervening in internalised stigma which suggests that it is a problem for acute inpatients. Assessment of internalised stigma is not routinely conducted within an acute inpatient environment but may be important to inform patient care. Moreover, a number of participants in both conditions reported benefitting from developing their understanding of stigma, having a safe space to discuss issues pertaining to stigma, and talking with a non-judgemental practitioner were important components of the intervention. This demonstrates that having stigma-based educational information within the ward setting which can be discussed with non-judgmental and empathic staff members may be beneficial. A number of implications arose regarding the delivery of psychological interventions within an acute inpatient setting. Due to the hectic nature of inpatient settings and high use of medication, flexibility in the time, date and duration of sessions was particularly important in facilitating participants' engagement in the interventions. Moreover, written therapeutic material was important for participants to keep so they could remember what was discussed.

As there is such a paucity of research examining stigma within the inpatient setting, this study recommends that a programme of research examining the effectiveness of stigma interventions within the acute inpatient setting should be conducted. Firstly a large definitive RCT of CBT and PE for internalised stigma with acute inpatients with psychosis should be conducted. Moreover the examination of feasibility and acceptability of established peer-led stigma interventions such as Honest, Open Proud (HOP; Corrigan et al., 2013) and photovoice (Russinova et al., 2014) should be conducted within the acute inpatient setting.

In conclusion, a brief CBT or PE intervention for internalised stigma with acute inpatients that experience psychosis appears feasible and acceptable within the constraints of methodological limitations. A larger methodologically rigorous definitive RCT would need to be conducted to determine effectiveness.

9. Chapter 9: Discussion

This chapter will draw together and summarise the main findings from the six studies outlined within this thesis. The chapter will begin by outlining the key aims of the thesis and how they were met, and describe key findings. The chapter will outline the broader themes arising from the results across all studies. The strengths and limitations of the overall thesis will be explored. The clinical implications and implications for the research evidence base will be outlined. Final conclusions will then be drawn.

9.1. Summary of thesis aims

The broad aim of this thesis was to explore and examine methods of assessment, formulation and therapeutic support for those experiencing psychosis and personal stigma. A particular focus was with the acute psychiatric inpatient population who have experiences of psychosis. To achieve this, six key aims were developed, and are outlined below in order to set the scene for this discussion chapter.

9.1.1. Aim 1 (Study 1): To conduct a systematic narrative review of psychosocial interventions for internalised stigma in psychosis.

In order to meet this aim, systematic narrative synthesis and meta-analysis methodologies were utilised to conduct a review of psychosocial interventions of internalised stigma in psychosis. Study 1 addressed this aim and was titled "Psychosocial interventions for internalised stigma in people with a schizophrenia-spectrum diagnosis: a systematic narrative synthesis and meta-analysis" (Chapter 3). The review identified 12 relevant studies, which had examined a variety of internalised stigma interventions with people who experience psychosis. The review identified a variety of interventions with a number being either CBT (Knight et al., 2006; Morrison et al., 2016) or informed by CBT (Narrative

Enhancement Cognitive Therapy, Yanos et al., 2011; Ending Self-Stigma, Luckstead et al., 2011; Health Self-Concept, McCay et al., 2011), psychoeducation based interventions (Link et al., 2002; Fung et al., 2011; Uchino et al., 2012), peer-led interventions (Corrigan et al., 2013; Russinova et al., 2014), and one study had utilised sociodrama (Sousa et al., 2012). All interventions were group based except one (Morrison et al., 2016), and were heterogeneous. The most commonly used intervention methods were psychoeducation, normalising, thought challenging, peer connection and social skills training.

The meta-analysis failed to find a significant effect on the primary outcome (internalised stigma) but found significant effects for two secondary outcomes, self-efficacy and insight. Moreover, the review identified that there was no consistency in outcomes measured across the studies or in use of specific outcome measures, apart from the Internalised Stigma of Mental Illness (ISMI) inventory (J.B. Ritsher & Phelan, 2004), which was utilised by the majority of studies. In particular, none of the stigma measures identified within the review met relevant reliability and validity criteria (Elaine Brohan, Mike Slade, et al., 2010), therefore identifying the need to develop a psychometrically robust measure of stigma for people who experience psychosis.

The review identified that there was a need to conduct more rigorously designed research trials to examine the efficacy of internalised stigma interventions, as most studies included in the review were moderate to high risk of bias. Moreover, there appeared to be a need to examine further the efficacy of internalised stigma interventions specifically for people who experience psychosis. Some studies have demonstrated that individuals who experience psychosis have the highest levels of internalised stigma with increased avoidance and social distance from others, than those with other psychiatric diagnoses

(Karidi et al., 2015; Oliveria et al., 2015). Consequently, participants with psychosis within individual studies may not have benefitted as much from a group intervention with others who do not have the same psychiatric diagnosis.

To summarise, the current evidence base of internalised stigma interventions for psychosis is low quality, heterogeneous and at risk of methodological bias. However, the review demonstrated that there are some benefits of internalised stigma interventions in improving self-efficacy and insight. Furthermore, the review outlined the need for the development of a reliable and valid outcome measure of personal stigma from psychosis, and for larger scale randomised controlled trials to be conducted examining the efficacy of psychosocial interventions for internalised stigma in people who experience psychosis.

9.1.2. Aim 2 (Study 2): To develop a reliable and valid semi-structured interview measure of internalised stigma for people who experience psychosis.

As identified in the review in Study 1, and concluded within Brohan et al's (2010) review, there are no reliable and valid measures available to examine the personal stigma experiences of people with psychosis. Therefore, the aim of Study 2 was to develop a reliable and valid measure of personal stigma for people who experience psychosis. Aim 2 was addressed by the study titled "Semi-structured Interview Measure of Stigma (SIMS) in psychosis: Assessment of psychometric properties". A semi-structured interview measure of stigma in psychosis was developed in consultation with service users and examined for its psychometric properties. The SIMS measure was demonstrated to be a reliable and valid measure of personal stigma for people who experience psychosis. To the author's knowledge, this is the first measure of personal stigma developed specifically for people who experience psychosis.

One of the strengths of the SIMS was that it was developed as a semi-structured interview measure. As outlined in their review of available stigma measures, Elaine Brohan, Mike Slade, et al. (2010) identified that all available measures were self-report measures. Semi-structured interview measures have a number of benefits over self-report measures such as the interviewer being able to clarify any interviewee questions, having the flexibility to be led by the experiences of the interviewee, improved participant engagement, and being better placed to discuss sensitive issues (Phellas et al., 2011). Although it was not empirically tested, the author postulates that the SIMS may be more engaging for service users than previous stigma measures which have all been self-report outcome measures. However, this would need to be formally examined in further empirical research in order to definitively determine if this was the case.

The other main benefit of the SIMS was its specificity for people with psychosis. It was demonstrated to have better sensitivity to change and validity than other stigma measures utilised within Study 2, which arguably could be due to the examination of psychosis experiences. The SIMS included a subscale examining the impacts of stigma on experiences of psychosis, which has not been included in previous measures of personal stigma. Previous research has demonstrated that stigma experiences can impact on symptoms of psychosis (Caveleti et al., 2014; Schrank et al., 2014). Therefore this is a critical component of personal stigma experiences.

Another benefits of the SIMS over established self-report measures (such as the ISMI) is that the SIMS also examined psychological components of personal stigma (Elaine Brohan, Mike Slade, et al., 2010). It had specific subscales which examined the cognitive, behavioural and emotional impacts of stigma, which can perpetuate personal stigma. The

detailed understanding of such components are necessary when undertaking therapies such as CBT (A. Beck, 1979), and therefore the SIMS can gather relevant clinical information, which may inform the development of a psychological formulation and intervention plan.

Study 2 had some limitations including a test-retest reliability and sensitivity to change time point longer than recommended, and a moderate sample size for the examination of reliability and validity. However, despite this, the SIMS was demonstrated to be a reliable and valid measure of personal stigma in psychosis.

9.1.3. Aim 3 (Study 3): To examine and understand the subjective experiences of stigma for acute inpatients that also experience psychosis.

Due to the paucity of literature examining the subjective experiences of stigma from psychosis with an acute inpatient population, the aim of Study 3 was to examine the personal experiences of stigma from psychosis from an acute inpatient perspective. This was achieved using qualitative methodology, specifically thematic analysis (TA), to examine participant subjective experiences. This was achieved by Study 3 "Acute inpatients' experiences of stigma from psychosis: A qualitative exploration". Three superordinate themes were identified within this study, 'stigmatising social environment and networks', 'stigmatised person with psychosis' and 'stigma interactions'. These are briefly outlined below.

The theme stigmatising social environment identified the all-encompassing nature of stigma and its penetrative effect across all aspects of a person's social network. This supports previous qualitative literature which examined stigma experiences in a community sample (Wood, Burke, Byrne, et al., 2015). Particular subordinate themes

identified within this category identified the negative labels held about psychosis, the public's discriminatory behaviour, and the identification of multiple social stigmas. In regards to inpatient experiences, the dominant use of the medical model within the inpatient setting, as well as the stigma of being hospitalised and sectioned was identified. This theme identified that being in hospital can generate personal stigma for individuals with psychosis with staff treatment being a particular source of stigma. As identified in previous research, a biogenetic understanding of mental health is associated with increased stigmatising beliefs (J. Read & Harre, 2001). Therefore the dominant medical model within the inpatient setting is likely to increase stigmatising beliefs and behaviours towards inpatients with psychosis. This highlights that stigma interventions, both staff and patient focused, may be beneficial in reducing stigma within the inpatient setting.

The second theme identified was 'stigmatised person with psychosis' which identified the internal experiences such as stigmatising thoughts, behavioural changes and relationship withdrawal, emotional distress, inferiority and low self-esteem. This theme reflected global and stable personal experiences of stigma (i.e. experiences which did not occur exclusively within the inpatient setting), and were long-standing. This superordinate theme arguably reflects the internalised stigma component identified within the literature (Corrigan and Watson, 2002a), and includes a number of important cognitive, behavioural and emotional elements. This also supported the findings from previous quantitative and qualitative research which has demonstrated similar personal impacts resulting from stigma (P. W. Corrigan et al., 2006; P. Lysaker et al., 2010; Pyle & Morrison, 2013; Schulze & Angermeyer, 2003).

Finally, the third theme identified was 'stigma interactions' which described relational and interactional factors which perpetuate stigma. These included lack of understanding about psychosis, lack of communication/disclosure about psychosis and loss of social contact. Again, these have been demonstrated widely in the relevant quantitative and qualitative stigma literature (Corrigan & Rao, 2013).

A limitation of this study was the use of the SIMS measure as an interview tool to collect the qualitative data from participants. The SIMS was developed as an outcome measure, informed by a cognitive framework, and therefore is not designed to ask open, explorative questions which are best-practice for qualitative research (Flick, 2014). Themes identified within this study arguably mirror the question structure within the SIMS measure, whereas more open questions may have yielded different results. Arguably, the SIMS led to a top-down approach to questioning (i.e. being led by a pre-defined framework), rather than truly being a bottom-up, participant led approach. As discussed in chapter 2, framework analysis is a systematic approach to qualitative analysis which can be used deductively and is informed by a pre-existing theory (Gale et al., 2013). Therefore, given the use of the SIMS as a method of data collection for Study 3, framework analysis was arguably a more appropriate method of analysis for Study 3.

Relatedly, the author aimed to take an inductive position in data analysis in the hope that the analysis was data-led rather than being driven by a pre-existing theory. However, given that the SIMS is an outcome measure informed by a cognitive framework, the questions arguably led to a deductive method of data gathering. This presents a conflicting position that could have impacted on the quality of the data analysis process. The cognitive framework is also evident within the interpretation of participant data (for

example, interpreting worries as a ruminative process) and the author acknowledges that she may have inadvertently had this framework in mind when conducting data analysis.

A further limitation to Study 3 was that the themes were assumed to be resulting from mental illness stigma but they may have also related to other experiences, for example, other forms of stigma and discrimination such as unemployment. The TA analysis took a semantic approach to theme identification therefore any participant content was assumed to be related to mental illness stigma. For example a participant reported that medication was offered too quickly, and due to the nature of analysis this was interpreted to be a form stigma whereas in other research contexts this may not have been the case.

In summary, the themes identified in Study 3 demonstrate that the stigma experienced by inpatients does not significantly differ from those within the community. However, it was also identified that there are specific stigma experiences which occur during a hospital admission such as the treatment by staff on the wards, and disclosure regarding being admitted to an inpatient psychiatric unit. Therefore, this study has identified the need to support inpatients with the stigma faced by an inpatient admission.

9.1.4. Aim 4 (Study 4): To examine the relationship between stigma (experienced and perceived) and psychological factors (self-esteem, internal shame, recovery, depression and hopelessness), and to explore the role of self-esteem and internal shame as potential mediators.

Due to the lack of quantitative examination of psychological factors associated with stigma, the aim was to explore the possible relationships between stigma and psychological factors and explore the role of internal shame and self-esteem as potential mediators. This

was achieved by Study 4, titled "The impact of stigma on emotional distress and recovery from psychosis: the mediatory role of internalised shame and self-esteem", a secondary analysis of data collected for Study 2. This study identified that both experienced and perceived stigma were significantly associated with all psychological factors (internalised shame, self-esteem, depression, personal recovery, and hopelessness). Further, internalised shame and self-esteem were also identified as mediators between stigma (experienced and perceived), and emotional distress (depression, hopelessness) and personal recovery respectively.

Study 4 identified internalised shame and self-esteem to be mediators between stigma (experienced and perceived) and psychological factors (depression, hopelessness, and personal recovery). Internalised shame had not been identified as a mediator between stigma and emotional distress and personal recovery in previous research in people who experience psychosis. Therefore, this research demonstrates that internalised shame is an important component in understanding the personal impacts of stigma. Self-esteem was also identified as a mediator which supports previous research (Vass et al., 2015). The findings suggest that targeting internalised shame and self-esteem within interventions for personal stigma may be helpful. A number of interventions have directly targeted self-esteem (M. D. Knight et al., 2006; E. McCay et al., 2007; P. T. Yanos et al., 2011) but none have focused on internalised shame. This would suggest that stigma interventions which focus on internalised shame should be piloted for feasibility and acceptability.

Study 4 identified that perceived stigma was also associated with all psychological factors (depression, self-esteem, shame, personal recovery and hopelessness). This demonstrates that the anticipation or worry about stigma is significantly associated with emotional

distress and personal recovery. To the author's knowledge, this has not been identified in previous research with psychosis. This study tentatively suggests that psychological interventions should also focus on perceived stigma to reduce the psychological consequences of stigma.

In summary, Study 4 demonstrated that stigma (experienced and perceived) was significantly associated with a number of psychological consequences (internalised shame, low self-esteem, depression, hopelessness and poor personal recovery). Moreover, internalised shame and low self-esteem mediated the relationship between stigma and the other psychological factors.

9.1.5. Aim 5 (Study 5): To develop a cognitive model of internalised stigma in psychosis using clinically relevant theory.

As outlined in the introduction, the available theories regarding stigma do not present a model which explains experiences of internalised stigma using cognitive theory, despite the majority of psychological interventions being underpinned by this theory. Therefore, the aim of Study 5 was to develop an integrative cognitive model of internalised stigma in psychosis which also incorporated the cultural context. This study was titled "An integrative cognitive model of internalised stigma in psychosis". To the author's knowledge, this study has described the first cognitive model of internalised stigma for psychosis. The model drew upon SMT and CBT theory in its development (Gilbert, 2010; Morrison, 2001). The model was able to identify potential cognitions, behaviours, and emotional reactions which may perpetuate internalised stigma in psychosis. Moreover, it also incorporated public stigma and the social context of the individual which contribute to and maintain internalised stigma.

A strength of the model was that it drew upon a number of sources to generate a clinically applicable model of internalised stigma for psychosis, as recommended when developing theoretical models (Clark, 2004). These sources included; service user qualitative literature (Wood, Burke, Byrne, et al., 2015; L. Wood, R. Byrne, et al., 2016), established stigma models (P. Corrigan & A. Watson, 2002; B. Link & Phelan, 2001), relevant cognitive theory (Gilbert, 2010; A. P. Morrison, 2001), and relevant quantitative research examining mechanisms of stigma (Hasson-Ohayon et al., 2012; Vass et al., 2015).

Researchers have outlined the importance of testing theoretical models for accuracy by conducting experimental studies that manipulate hypothesised variables, to identify whether they impact upon the broader construct that they are contributing to (D.M. Clark, 2004). Clark (2004) outlined that experimental studies can often uncover helpful therapeutic change mechanisms which can inform therapeutic practice. As this was not conducted, this model was not able to distinctively state what change mechanisms would improve internalised stigma. Therefore, further research should conduct experimental studies which manipulate the hypothesised mechanisms which contribute to internalised stigma.

Despite the lack of experimental examination, this model still has some important clinical implications. Firstly, this model demonstrates that targeting cognitive and behavioural responses in relation to internalised stigma is important within clinical practice. To date, available interventions have drawn upon cognitive interventions to tackle internalised stigma in SMI. However there have been inconclusive findings (L Wood et al., 2016). Arguably this may be due to the lack of cognitive formulation underpinning the

intervention which would allow for specificity in relation to cognitions and safety behaviours. Moreover, this model is suggestive that some CBT change mechanisms may be helpful in alleviating internalised stigma. These include; psychoeducation, normalisation, shame-based strategies, behavioural experiments, reducing avoidance, to name a few (A. Morrison et al., 2016; L. Wood, E. Burke, R. Byrne, & A. Morrison, 2016). Importantly, the model outlines the importance of continuing to alleviate public stigma present in an individual's cultural context and offers a framework of how to do this.

9.1.6. Aim 6 (Study 6): To examine the feasibility and acceptability of an internalised stigma intervention for inpatients that experience psychosis.

Finally, based on recommendations from Study 1 and personal accounts from Study 3, a psychological stigma intervention for acute inpatients with psychosis was examined for feasibility and acceptability. A psychosocial internalised stigma intervention had not been examined for efficacy in this sample previously despite stigma being a prevalent issue. This aim was achieved through Study 6 titled "A brief cognitive therapy intervention for internalised stigma in acute inpatients who experience psychosis: A feasibility randomised controlled trial". Study 6 demonstrated that conducting a feasibility RCT in the acute inpatient setting with people who experience psychosis was feasible and acceptable. This was demonstrated through recruitment rates, consent rates, the willingness of clinician's to refer participants, willingness of participants to be randomised, the research being conducted in a reasonable timeframe, and positive participant feedback. Furthermore, both internalised stigma interventions (CBT and PE) were also demonstrated to be feasible and acceptable in the acute inpatient setting. This was indicated by treatment adherence, dropout rates, and participant feedback. The statistical results demonstrated that neither intervention was more effective than the other.

A strength of the study was the attempt to follow CONSORT guidance for the design and reporting of feasibility studies (Thabane et al., 2016). Study 6 achieved a number of their recommendations such as: publishing a pre-defined protocol, being registered on a trial registry, having an active control group, using randomisation procedures, and adhering to study reporting guidance. However, largely due to limited study resources, Study 6 suffered a number of methodological limitations which increased bias and limited the reliability of findings. These methodological limitations included: lack of assessor blindness, a small sample size not powered to statistically examine the efficacy of interventions, the use of only self-report measures, and last observation carried forward ITT analysis. However, arguably, these would not have impacted upon the feasibility data presented in this study. A final confounder which may have impacted on the feasibility data was the author being embedded within the psychiatric hospital where the trial took place. This arguably improved feasibility data (such as dropout rates) as the author was freely available and had the flexibility to conduct follow-ups when required. However, the author believes this to be a benefit and potentially makes the trial more reflective of the inpatient clinical environment.

This trial potentially suggests that further experimental studies are required to examine and manipulate the specific hypothesised variables or maintaining factors in order to identify the important targets for change in CBT. It is not known what the key cognitive and behavioural maintenance factors are for internalised stigma in psychosis and therefore CBT cannot be utilised effectively until these are identified. Future research needs to examine and identify such factors in order to develop CBT for this presenting difficulty.

The study demonstrated that stigma is a concern for people with psychosis in the psychiatric acute inpatient setting, and that they were willing to participate in a study which offered an internalised stigma intervention. It was important that the interventions

offered were flexible and were adapted for the inpatient setting (e.g. brief, had material resources, and incorporated the impact of the inpatient environment within the intervention). As there is such little research conducted in the psychiatric acute inpatient setting regarding stigma, there is a need for a large programme of research to be conducted examining the efficacy of internalised stigma interventions. A large definitive RCT should be conducted examining the efficacy of CBT and PE in the psychiatric acute inpatient setting.

9.2. Integration of themes across studies

This section will comment upon the broader themes which have been identified across multiple study papers. It will synthesise the discussions from individual papers to form more generalisable conclusions.

9.2.1. The importance of clinically assessing personal stigma in people who experience psychosis

An important theme which was identified across all studies was the importance of thoroughly assessing experiences of personal stigma with people who experience psychosis. Personal stigma is a complex and idiosyncratic experience which requires a detailed understanding to intervene appropriately. Study 1 identified that a detailed assessment was not present before undertaking interventions aiming to alleviate internalised stigma. Furthermore, Study 1 identified that all available assessment outcome measures of personal stigma were self-report and no clinically relevant interview-based assessment measure was available, which limited the reliability, validity and clinical applicability of available measures. Study 2 demonstrated that a semi-structured interview

measure with clinical applicability had superior reliability and validity compared to other available measures. Study 6 included a brief assessment of stigma within the CBT arm of the study, and not in the PE arm. An assessment was imperative to applying a CBT model and formulating personal stigma experiences. The lack of a formal assessment of stigma prior to intervention is a limitation of this study. In both arms of Study 6, participants appreciated the opportunity to discuss stigma and their related experiences. Collectively, this demonstrates that a thorough and engaging assessment of personal stigma is essential to inform therapeutic intervention, as well as to collect reliable and valid outcome data.

9.2.2. The importance of formulating psychological processes in understanding the development and maintenance of internalised stigma

This thesis suggests that a stigma-based collaborative formulation is essential to inform internalised stigma interventions. Study 1 demonstrated that formulations were not included within the majority of internalised stigma interventions and that this may have limited the efficacy of the therapeutic interventions. The synthesis of literature into a cognitive model (Study 5) outlined the psychological factors and processes which could inform a psychological formulation and demonstrated how they cause and maintain stigma. Studies 3 and 4 were able to identify such psychological factors. Study 3 identified the theme 'stigmatised person with psychosis' which included detail on an array of cognitive, behavioural and emotional factors which resulted from stigma. Study 4 presented a quantitative examination of the impacts of stigma on psychological factors and identified that stigma is significantly associated with internalised shame, low self-esteem, depression, hopelessness and poorer personal recovery.

Collectively, this thesis has identified that there are key psychological factors which need to be integrated into a formulation of internalised stigma which include internal and

external triggers, stigma related cognitions (core beliefs, NATS, self-criticism, paranoid thoughts, processing self as a social object), stigma safety behaviours (avoidance of situations, social functions and people, unwillingness to disclose about mental health problems, helplessness/defeatist behaviours), and consequential emotions (shame, depression, hopelessness, low self-esteem, (social) anxiety. These psychological factors should be considered when formulating people's ongoing experiences of internalised stigma.

9.2.3. The negative impacts of internalised stigma and the need for effective interventions

Another theme spanning across multiple studies was the need to continue to develop effective interventions for internalised stigma. Study 1 demonstrated that there are a number of psychosocial interventions available for internalised stigma but available studies are small and heterogeneous and further research is required. Moreover, Study 3 demonstrated that stigma was a pervasive issue across acute psychiatric inpatients' social networks which had detrimental impacts on the stigmatised person, and this is not being addressed through stigma interventions. Study 6 demonstrated that a brief internalised stigma intervention was feasible and acceptable to service users with psychosis in an acute psychiatric unit. Together, these studies demonstrated that there is a requirement to further develop interventions (public and personal) in order to continue tackling the stigma associated with experiences of psychosis. The types of interventions which may be helpful are discussed in clinical implications (section 9.4).

9.2.4. The prevalence of personal stigma in acute inpatients with psychosis

Another theme across a number of the thesis studies was that personal stigma is a significant issue for people with psychosis who are admitted to a psychiatric inpatient ward. Participants were recruited from a psychiatric inpatient ward for studies 2, 3, 4 and 6 and therefore contributed to the findings of these respective studies. In particular, Study 3, which explored the subjective experiences of stigma from the perspective of psychiatric inpatients with psychosis, identified that stigma was prevalent and related to their experience of hospital admission. Furthermore, Study 6 identified that an inpatient based brief stigma intervention was acceptable and feasible in those currently admitted to a psychiatric ward.

Although the research with psychiatric inpatients is limited, it has demonstrated that stigma is a potential risk factor. As outlined in the introduction, only one previous study had been conducted examining personal stigma in acute inpatients with psychosis which demonstrated that stigma and fear of disclosure regarding an inpatient admission was a concern to participants (McCarthy et al., 1995). Moreover, research has demonstrated that stigma is a significant risk factor for suicide (Pompili et al., 2003). Suicide is one of the main factors contributing to a service users admission to the ward (Royal College of Psychiatrists, 2015), and a significant risk for service users during admission and post-discharge (Schromerus et al., 2015). Therefore, this thesis research supports the findings of these previous research studies. This finding has important clinical implications and recommendations for future research which will be explored further in sections 9.4 and 9.5.

9.3. Critical examination of thesis methodology and data analysis

This section will aim to offer a critical analysis of key methodological issues across the thesis studies. This will include examination of both strengths and limitations of the thesis. It is hoped that transparent critical examination of the thesis methodology will

allow realistic implications and conclusions to be drawn based on the findings of this thesis.

9.3.1. "Bottom-up" research

One of the strengths of the research was that it was derived from the author's experience of clinical practice within a psychiatric inpatient setting, and previous clinical work with people who experience psychosis. Traditionally research is conducted from a "top down" approach with researchers introducing pre-developed clinical practices, often developed away from the real-life clinical setting, and asking clinicians to implement them in their routine clinical practice (Blevins, Farmer, Edlund, Sullivan, & Kirchner, 2010). However, it is recommended that clinicians and academic researchers collaborate in order to develop clinically meaningful research projects (Margison et al., 2000). This research was partly conducted from the "bottom-up" and responded to clinical needs identified within the author's clinical service. Therefore, the design of this thesis was reactive to the immediate clinical needs of psychiatric inpatients and utilised rigorous research methodology to examine this. This had a number of benefits including; researching a psychiatric inpatient population which has been traditionally neglected in stigma research, development of a valid brief internalised stigma intervention which reflected the service context (short admissions), and dissemination to local services.

9.3.2. Sampling

The studies benefitted from including a diverse participant sample representative of gender, ethnicity and culture due to participants being recruited from two sites in Manchester and London respectively. In particular, Black and Minority Ethnic (BME) groups were represented within this sample. Furthermore, the sample was reflective of the psychosis population due to participants being from a number of different services

including; Early Intervention in psychosis Services (EIS), Community Mental Health Teams (CMHTs) and psychiatric inpatient wards. Consequently, the sample was inclusive of first episode, severe and enduring and acute populations along the continuum of psychosis experiences. This means that findings from all studies are more likely to be generalisable to the wider psychosis population.

One limitation in relation to the sample was the confounding factors which influenced the participation of the acute inpatients. A number of participants were drowsy, sedated and demonstrated some thought disorder, which impacted on their concentration. Therefore the completion of the self-report questionnaires, engagement in the semi-structured qualitative interviews, and collaborative engagement in the brief therapeutic intervention was questionable. This reduces the reliability and validity of the findings of the individual studies. However, the benefits outweighed the costs as it allowed the perspectives of this relatively under-researched population to be included in this thesis.

Appropriate sample sizes were recruited for Study 3 (qualitative exploration of personal stigma experiences with acute inpatients with psychosis), and Study 6 (feasibility trial of an internalised stigma intervention). Study 3 recruited 25 participants and met sample requirements for thematic analysis. This sample size is in line with recommendations for thematic analysis outlined by Fugard and Potts (2015) who have described sample size recommendations based on; predicted theme prevalence, participants required in order to identify the least common themes, and sample power. Based on their calculations the required sample size for Study 3 would be 18 – 25 (based on a population theme prevalence of 15 – 20%, 2 desired theme instances of least common theme, and power of 80%). Study 6 also met sample size requirements for clinical feasibility studies (Eldridge et al., 2016). A general rule of thumb is that as minimum of 30 participants are required for feasibility studies. This allowed for the examination of key parameters within the trial,

such as consent rates, drop-outs and examination of outcome measures (Lancaster et al., 2004).

One of the limitations of the sample was the modest sample size utilised for studies 2 (validation of the SIMS), and 4 (examination of relationships between stigma and psychological variables). The analysis utilised for these studies typically requires larger sample sizes. Study 2 conducted a factor analysis which often requires three to ten participants per variable indicating that the sample size could be between 30 – 100 (Nunnally & Bernstein, 1994). Mundfrom, Shaw, and Lu Ke (2009) recommend a sample size of N= 75 – 130 for a factor analysis in order to identify excellent agreement (kappa =0.98). Both recommendations demonstrate that the sample size is within the recommended size but in the lower range. When smaller sample sizes are used in factor analysis, less precise estimates of factor loadings are given, and the factor structure is less stable, therefore findings within study 2 (validation of the SIMS) need to be interpreted with caution (MacCallum, Widaman, Zhang, & Hong, 1999). The sample size was demonstrated to be adequate to conduct the necessary correlation and ICC analysis (Walter, Eliasziw, & Donner, 1998). In regard to the sample size required for mediation analysis, Fritz and MacKinnon (2007) recommended for bias-corrected bootstrapping techniques a sample size of N=71 to identify a moderate effect size and a sample size of N=462 for a small effect size, demonstrating that the mediation sample would not be able to detect any small effect sizes.

One further limitation was the secondary use of the study sample from the RESPECT study (Morrison et al., 2016) to examine test retest reliability (4-month time point) and sensitivity to change analysis (7-month time point) for the psychometric examination of the SIMS. Participants were either randomised to a CBT intervention (n=14) or treatment as usual (n=15) and therefore half of participants received an intervention. This would have

impacted participants' self-report scores on all measures, and the overall psychometric evaluation of the SIMS.

9.3.3. Use of self-report measures

This thesis utilised direct self-report measures for the purposes of studies 2 (validation of the SIMS), 4 (examination of relationships between stigma and psychological variables), and 6 (feasibility trial of an internalised stigma intervention), in order to collect all quantitative data. Self-report measures are usually completed individually by the participant and require the rating statements or questions regarding a given construct on a likert scale (numerical or categorical). Self-report measures have a number of advantages such as; facilitating quick data collection, collection of relatively rich information about a given construct, being psychometrically robust, and easy interpretability (Aiken, 2002; Paulhus & Vazire, 2007). These benefits were the reasons they were utilised for the purposes of this thesis. However, self-report also have a number of flaws including difficulties in engaging participants, an inconsistent and fluctuating ability to motivate participants, primary and recency effects, over reporting of experiences, and the questionable credibility of participants self-reporting (Paulhus & Vazire, 2007). This was a particular concern for the acute psychiatric inpatient participants who were heavily medicated and, at times, struggled to concentrate. The limitations of noteworthy individual self-report measure utilised within this thesis will be explored further below.

The Internalised Stigma of Mental Illness Inventory (ISMI; Ritscher & Phelan, 2004) and the ISMI short scale (ISMI-S; Boyd et al., 2014) were utilised as the primary measure of internalised stigma in all quantitative studies. It is the most widely used measure of internalised stigma and has been utilised in a variety of cross-sectional and intervention studies (Lucksted et al., 2011; A. Morrison et al., 2016; J.B. Ritsher & Phelan, 2004). It

has been determined the most reliable and valid available measure of internalised stigma available (Brohan et al., 2010). However, it also had a number of limitations in relation to this thesis. Firstly, it did not meet all of the reliability and validity criteria outlined by Brohan et al., (2010), and demonstrated floor and ceiling effects. Moreover, it was developed in a sample with SMI and therefore not specific to people with psychosis. It has not been examined for its psychometric properties exclusively within this population. The SURG also fed back that the measure itself was stigmatising due to the stereotyped based statements it incorporates (e.g. "I can't contribute anything to society because I have a mental illness"). In addition, the wording of this measure was changed to state 'mental health problem' rather than "mental illness" as recommended by the SURG, which may have impacted on its reliability and validity. Arguably, changing the stigmatising language may have removed the stigma the questionnaire was trying to measure. This demonstrates that the ISMI/ISMI-S has a number of limitations which may have impacted on the reliability and validity of data collected by this measure.

The Stigma Scale (SS; King et al., 2007) was utilised as a measure of personal stigma as it examines experience of discrimination, disclosure and positive aspects of stigma. Similarly to the ISMI, the SS was demonstrated to meet the majority of reliability and validity criteria but failed to meet the floor and ceiling effects criteria (Brohan et al., 2010). Moreover, the SS has been criticised for not being sensitive to change, particularly the discrimination subscale (Morrison et al., 2016) due to some items asking about general experiences rather than current experiences (e.g. I have been discriminated against by police because of my mental health problems). Therefore, its use as a measure to facilitate psychometric examination (Study 2) and identify a change in outcomes within a feasibility trial (Study 6) is limited.

The Internalised Shame Scale (ISS; Cook, 1987) was utilised in studies 2 and 4 as a measure of internalised shame. To the author's knowledge, this is the only available measure of internalised shame which demonstrates reasonable reliability and validity. However, this measure was developed thirty years ago, and since this time, the evidence base and clinical understandings of internalised shame has grown exponentially (Gilbert, 2010). Arguably, the ISS has conceptualised internalised shame differently to how it is currently understood within the relevant clinical literature. Internalised shame has been defined as a "self-directed attention, feelings and evaluations of self as inadequate, flawed or bad", which is embedded within our threat focused sub-component of our emotional system (pg. 354; Gilbert & Proctor, 2006) . Therefore a measure of internalised shame should particularly focus on the cognitive and emotional consequences of shame, including self-devaluation and self-criticism. The items on the ISS arguably captures aspects which are reflective of low self-esteem, and external shame ("thoughts and feelings that others view the self negatively with feelings of anger or contempt and/or that the self is seen as having characteristics that make one unattractive thus rejectable and vulnerable to attacks from others" pg. 354; Gilbert & Proctor, 2006) rather than internalised shame and therefore is not reliability examining the correct construct. This contributed to the decision to not include in Study 6.

9.3.4. Lack of assessment of psychotic symptoms

As described in the methodology chapter, a measure of psychotic symptoms was not included in this thesis due to feedback from the SURG. They stated that inclusion of a measure of psychotic symptoms would give a conflicting message to participants about stigma. However, the author believes that a lack of inclusion of a psychotic symptom measure has limited the thesis in a number of ways. Study 2 (validation of the SIMS)

would have benefitted from the examination of psychotic symptoms alongside the SIMS as stigma is theoretically hypothesised to have a reciprocal relationship with psychotic symptoms (Schrank et al., 2014), and therefore would be an important factor in the examination of validity. For the same reason, Study 4 (examination of relationships between stigma and psychological variables) would have further benefitted from having a measure of psychotic symptoms in order to examine its relationship with stigma (experienced and perceived). This may have led to some important clinical implications for people who are experiencing high levels of internalised stigma alongside difficult psychotic symptoms. Furthermore, the feasibility trial of an internalised stigma intervention (Study 6) would have been improved if a measure of psychotic symptoms was included. Psychotic symptom measures are usually utilised as a primary outcome measure in the majority of psychological intervention trials in psychosis and used to indicate the efficacy of interventions (Hutton, Wood, Taylor, Irving, & Morrison, 2013; Wykes, Steel, Everitt, & Tarrier, 2008). As this study did not utilise a measure of psychotic symptoms, its efficacy in relation to this outcome cannot be determined, and its inclusion in relevant systematic reviews is limited.

The lack of the examination of psychotic symptoms, as well as changes to the ISMI measure, were a result of SURG consultation. Both of these changes arguably impacted upon the reliability and validity of the thesis research. As outlined, service user involvement is best practice for all research studies (National Involvement Partnership, 2014), and was invaluable in developing key aspects of this thesis research. However, it is also important to ensure that service user involvement does not compromise the aims of the research being conducted.

9.3.5. Lack of experimental examination of the proposed theoretical model of stigma

One of the limitations of this thesis was the absence of the experimental studies which aimed to examine and manipulate the cognitive process outlined in the cognitive model (Study 5) prior to conducting a feasibility trial, as recommended by Clark (2004). Clark (2004) recommended that hypothesised cognitive processes in an outlined theoretical model should be manipulated through a number of experimental studies in order to determine whether they predict symptom change as hypothesised. Therefore this thesis would have benefitted from manipulating key variables such as stigma based cognitions, internalised shame, low self-esteem and specific safety behaviours. In retrospect, this PhD should have included an experimental study which manipulated the psychological variables identified in Study 4 in order to examine whether the variables are maintenance factors in internalised stigma. For example, key hypothesised change mechanisms such as psychoeducation and normalisation could be administered targeting stigma cognitions to see if this impacts on self-reported internalised stigma and related psychological factors. Further experimental studies should be conducted to examine the maintenance factors of internalised stigma.

9.3.6. The conceptual problem of examining "stigma"

One of the main limitations of this thesis was the examination of the construct of stigma itself. As outlined in the introduction, there are many conceptualisations of stigma, and it can be understood in many different ways (P. Corrigan & A. Watson, 2002; B. Link & Phelan, 2001). The author was concerned for a number of studies that the participants did not always fully understand the concept of stigma. This was problematic for a number of reasons, as firstly a number of the studies required for the participant to decide whether stigma was a concern for them. This assumed a prior understanding of stigma which was

not always the case for all participants. Despite the participants' understanding of stigma being explored prior to consent being taken, a number of participants entered the study with limited understanding of stigma. Therefore the sample included participants for which stigma was not an issue. Consequently, study data was affected. For example, in Study 3 (the qualitative exploration of stigma with acute inpatients) participants took part in the study when they did not necessarily identify themselves as having experiences of personal stigma. Further research should explore participant's understanding of stigma prior to them undertaking any research which will be affected by a lack of understanding regarding stigma. The process of helping participants understand stigma should be developed in collaboration with a SURG.

One of the broader limitations to this thesis is that it took an individualised stance to researching stigma. As Corrigan (2016) has recently stated "there is one unintended lesson worth learning in terms of tackling self-stigma. Self-stigma [can be approached] as "the person's problem", rather than a problem of a society that breeds public stigma, prejudice and discrimination" (pg. 71). Although this thesis has acknowledged the role of society throughout this thesis as a significant factor and target for change in regard to stigma, it has nevertheless prioritised internalised stigma which has a danger of locating the problem within the individual. This is especially problematic for studies 5 and 6 which have used cognitive approaches to understand and intervene within the experience of internalised stigma. CBT is already widely criticised of placing the problem within the individual (Moloney, 2004), which is especially pertinent when considering a social issue such as stigma. Sayce (1998) argues that the concept of stigma attaches the problem to the individual rather than those who are behaving discriminatory towards the stigmatised person. Although the author believes that the personal impact of stigma are important to understand and respond to, it is imperative that this is done clearly within a societal context and does not locate the problem within the individual.

9.3.7. Lack of Bonferroni Corrections in study 2 and 4

One of the limitations of studies 2 and 4 was the lack of Bonferroni corrections used to adjust for multiple statistical comparisons. The Bonferroni correction corrects for false positives (Type 1 errors) when multiple comparisons are being conducted on the same dataset (Haynes, 2013). The Bonferroni correction is calculated by dividing α by the number of statistical tests conducted on the data. Therefore, the reader of studies 2 and 4 is able to calculate Bonferroni correction using the available data.

9.4. Clinical Implications

This section will focus on the broad clinical implications identified across the six individual research papers.

9.4.1. The assessment of personal stigma in psychosis

The development of the SIMS measure (Study 2) has demonstrated the importance of conducting a clinical assessment, or incorporating questions as a subcomponent of an assessment, that examines experiences of personal stigma in psychosis. The SIMS was demonstrated to be a reliable and valid measure of personal stigma, which examined the psychological consequences of stigma, including experiences of psychosis. These were identified as important components in understanding the lived experiences of personal stigma. This demonstrates the importance of asking about personal stigma experiences in routine clinical practice. The items from the SIMS suggest that asking about experiences of stigma, perceived stigma and internalised stigma (impacts on self-esteem, relationships, emotions, behaviours, experiences of psychosis, relationships with services, recovery and positive aspects) would be of particular importance. Furthermore, personal stigma experiences can result in emotional distress and worsen experiences of psychosis, and therefore understanding these factors can be imperative to developing a clinical

formulation and intervention plan. The act of disclosing experiences of stigma has been widely demonstrated to have therapeutic benefit for individuals who feel stigmatised (Corrigan & Rao, 2013). It has been demonstrated that the process of being able to be open and honest about personal mental health and stigma experiences can reduce the internalised stigma experienced (Corrigan et al., 2013).

9.4.2. Assessing and intervening with personal stigma with acute inpatients experiencing psychosis

This thesis also identifies the importance of assessing stigma with psychiatric inpatients that experience psychosis. The qualitative exploration (Study 3) and feasibility study (Study 6) both identified that stigma was a difficulty for those included in the study. In the qualitative study, participants identified stigma being a concern for them both during the hospital admission and post-discharge. It was reported that some participants found the process of admission (particularly forced admission/sectioning), certain staff treatment, and some operational procedures stigmatising within the ward environment. This demonstrates the importance of examining any potential stigma experiences with inpatients through a clinical assessment in order to support them with personal stigma. This may need to be examined a different stages of the admission depending on the type of stigma (i.e. from admission, during the stay or post-discharge). Psychological interventions, such as those described in the feasibility study (Study 6) may then be offered to support those experiencing personal stigma.

Furthermore, incorporating the management of stigma into the discharge care plans of psychiatric inpatients may be particularly important. A number of participants in Study 3 identified stigma from their social network and community as particularly concerning for them and it contributed to their concern about stigma post-discharge. It is widely

acknowledged that service users are at highest risk of suicide within one month of discharge from psychiatric hospital (Meehan et al., 2006), and that stigma can contribute to this risk (Pompili et al., 2003). In another recent study, lack of social acceptance was also found to be associated with higher suicide rates (Schromerus et al., 2015). Therefore, this demonstrates the importance of having a full understanding of personal stigma prior to discharge in order to offer service users the most appropriate support to manage this stigma.

In addition, the findings identify the need to develop staff training to increase awareness of the role of stigma within an inpatient setting. A staff intervention which addressed staffs' stigmatising beliefs could be beneficial in improving the personal stigma experienced by psychiatric inpatients with psychosis. A recent study outlined that a staff intervention which challenged the dominant medical model perspective found among staff in the inpatient environment could reduce stigmatising attitudes (Kvaale et al., 2013). Therefore, a training intervention which promoted a psychosocial model of understanding and conceptualising mental health difficulties could reduce stigmatising staff attitudes and consequential discriminatory behaviour (S. C. Hayes, Bissett, Roget, Padilla, & Kohlenberg, 2004).

9.4.3. Formulating personal stigma with people who experience psychosis

In cases where internalised stigma has been identified as a primary presenting problem within a therapeutic context, findings from this thesis would recommend the development of a specific formulation to inform goal development and therapeutic intervention. A psychologically-informed formulation provides a detailed understanding of a person's presenting difficulties incorporating key predisposing, precipitating, perpetuating and protective factors (Johnstone & Dallos, 2013). Formulation has been identified as an

essential process in order facilitate an effective CBT intervention for people with psychosis (Van der Gaag, Valmaggia, & Smit, 2014). In a recent Delphi study examining the opinions of CBT experts, formulation was identified as an essential component of CBT for psychosis (A. Morrison & Barratt, 2010). Moreover, the experts identified that it was essential that the formulation was collaborative, highlighted clients' strengths, be used to inform a treatment plan, be parsimonious, identify relapse factors, and used to set targets for interventions. Service users have also identified the importance of incorporating formulation in CBT for psychosis. In a qualitative systematic review of service user experiences of CBT for psychosis, Wood, Burke, and Morrison (2015) identified the use of formulation to facilitate normalisation, collaboration, and understanding as important to service users within the CBT for psychosis process.

This evidence highlights the importance of using formulations to underpin therapeutic work for internalised stigma. A stigma-specific formulation (as outlined in Study 5) would meet the requirements outlined above in regard to formulation for CBT for psychosis. An internalised stigma formulation would allow for the identification, validation, and normalisation of stigma and discrimination experiences which have contributed to the development of internalised stigma. In a recent qualitative study which examined service user's perspective of a CBT-based stigma intervention, they identified that normalising, development of personal knowledge about stigma, and being understood were important components of the intervention (L. Wood, E. Burke, R. Byrne, & A. Morrison, 2016). Arguably, this demonstrates the important role of a tailored formulation for internalised stigma in psychosis. Furthermore, as outlined in Study 6, a formulation facilitated the identification of more idiosyncratic change mechanisms in order to respond to the individual needs of service users. The goal of the therapy varied from wanting to develop personal understanding of stigma, to managing social anxiety, and wanting to feel more

able to disclose to others about their mental health experiences. Therefore, formulation allows for a more person-centred approach to therapeutic intervention.

9.4.4. Applying CBT to internalised stigma in psychosis

The systematic review (Study 1) and feasibility study (Study 6) both demonstrated that CBT has the potential to be used as a therapeutic intervention to support people experiencing internalised stigma and psychosis. As outlined, CBT is the first line recommended psychological intervention for people who experience psychosis at all stages of the continuum (first episode, severe and enduring and acute presentations) (NICE, 2014). A number of systematic reviews have demonstrated that CBT is an effective intervention for psychosis (small to moderate effects), and demonstrated that it can improve target symptoms, positive symptoms, negative symptoms, functioning, mood and social anxiety (Mehl, Werner, & Lincoln, 2015; Wykes et al., 2008). Therefore it can be effectively utilised to target a variety of difficulties in people with experiences of psychosis.

The systematic review of psychosocial interventions for internalised stigma (Study 1) demonstrated that CBT change mechanisms were incorporated into the majority of the psychosocial interventions (Fung et al., 2011; M. D. Knight et al., 2006; Lucksted et al., 2011; E. McCay et al., 2007; A. Morrison et al., 2016; Uchino et al., 2012; P. T. Yanos et al., 2011), demonstrating the applicability of CBT to internalised stigma in psychosis. In particular, psychoeducation, thought challenging and normalisation were the most frequently utilised change mechanisms by included studies. These mechanisms aim to challenge the negative public stereotypes that may have been internalised and applied to oneself. This may suggest that challenging negative stereotypes is an important aim of the

CBT intervention and that these strategies may be most useful when implementing a CBT informed psychological intervention for internalised stigma.

In regard to the feasibility study (Study 6), it was demonstrated that the CBT intervention was a feasible and acceptable intervention for internalised stigma within a psychiatric inpatient setting. Moreover it described further change mechanisms which may be helpful in alleviating internalised stigma including: psychoeducation, behavioural experiments to challenge stigma, disclosure strategies, normalisation, and exploring the impact of diagnosis. This further supports that CBT can be applied to internalised stigma experiences for people with experiences of psychosis.

9.4.5. Public stigma interventions for psychosis

Although this research has focused on personal stigma experiences, the theoretical research (P. Corrigan & A. Watson, 2002) demonstrates that personal stigma would not exist without public stigma. This was highlighted by the theme 'stigmatising social networks' in the qualitative paper (Study 3), and by the social and cultural context component of the internalised stigma model (Study 5). Therefore, an important clinical implication is the need to continue tackling stigma at a public level. As identified, public stigma can be present in a number of different public groups such as healthcare professionals (mental and physical), the police force, school children, and in the wider public domain (Yang & Link, 2015). Public stigma interventions have been demonstrated to reduce stigmatising attitudes in such groups using strategies such as education and social contact (Corrigan et al., 2012). Furthermore, national level government based media campaigns which have aimed to improve public knowledge through education and personal stories have demonstrated reduced stigmatising public attitudes (C. Henderson & Thornicroft, 2013).

Clinical psychologists have a responsibility to tackle social issues that impact on the mental well-being of service users within clinical services (McGrath & Griffin, 2015). Therefore, an important clinical implication would be for clinical psychologists to consider the wider social context of personal stigma, particularly internalised stigma, and consider what interventions may be best placed to tackle such experiences. Public stigma interventions could be both small interventions as well as larger scale more formalised interventions. Clinical psychologists may be best placed to consider public stigma interventions for health care professionals in their Multi-Disciplinary Teams (MDT) and partner services.

In regard to more informal interventions, clinical psychologists are often embedded within MDTs and are best placed to model non-stigmatising psychosocial perspectives towards mental health which can impact team conceptualisations on a more subtle basis. For example, within clinical meetings, they can question, reflect upon and challenge the often dominant medical approach underpinning mental health services. Moreover, they are skilled to offer more formal staff training, consultation, and take a leadership role in relation to challenging stigma (British Psychological Society, 2010a). Larger scale interventions could include formal staff training on stigma (its conceptualisation, and detrimental impacts) and strategies to reduce stigma, contact interventions (led by, or in collaboration with service users sharing their experiences of stigma and discrimination), and provide alternatives to the biogenetic conceptualisations of mental distress.

9.5. Future Research

Recommendations for future research have been outlined within individual studies. Therefore, this section will focus on expanding on these recommendations where necessary

as well as identify the future research recommendations identified across the six thesis papers.

9.5.1. Definitive randomised controlled trial of CBT for internalised stigma for people with psychosis

The systematic review of psychosocial interventions (Study 1) and feasibility study (Study 6) both concluded that there needs to be definite large-scale randomised controlled trial (RCT) of a CBT for internalised stigma in psychosis intervention. Study 1 identified that the majority of trials examining internalised stigma interventions has been at moderate to high risk of methodological bias (J.P.T Higgins et al., 2011), of small size and at risk of small study effects (IntHoult et al., 2015), and not met the requirements outlined by the Consolidated Standards of Reporting Trials (CONSORT) statement (Boutron et al., 2008) . Furthermore, both Study 6 and another pilot trial in a community sample (A. Morrison et al., 2016) identified that a CBT intervention for internalised stigma was feasible and acceptable to service users but both were small trials (n=30 and n=29 respectively). Therefore, an adequately powered definitive RCT is required to make recommendations regarding CBT and its efficacy for alleviating internalised stigma in psychosis.

9.5.2. Conducting experimental studies to support the theoretical model of internalised stigma

As previously described, it is recommended that precipitating and perpetuating factors are examined experimentally in order to determine their role within a given theoretical model (Clark, 2004). This thesis did not experimentally examine the predisposing precipitating or perpetuating factors of internalised stigma in people with psychosis. As outlined in the introduction, there has been relatively little examination of the factors which contributed to the development (and maintenance) of internalised stigma. In further research, it would

beneficial to do both more exploratory work in regard to qualitative interviews with service users to examine why internalised stigma occurs, and to do quantitative experimental studies to examine and manipulate potential factors which contribute to the internalisation of stigma. Experimental studies should also be conducted to examine maintenance factors such as key stigma cognitions, safety behaviours, and emotional factors to identify their role.

9.5.3. Applications of other therapeutic approaches to internalised stigma

CBT has been proposed by this thesis as a potentially useful therapeutic approach to alleviating internalised stigma with psychosis due to its effective utility with people who experience psychosis (NICE, 2014). However, further research should also examine the potential usefulness of other therapies which have an evidence base in psychosis.

One approach which may be beneficial for internalised stigma in psychosis is Compassion Focused Therapy (CFT; Gilbert, 2010; Gumley et al., 2010). CFT is a third wave psychological therapy that aims to reduce shame and self-criticism, which has developed as a result of relational abuse experience (e.g. bullying, sexual abuse, attachment trauma), through the cultivation of compassion and mindfulness (Gilbert, 2009). CFT is underpinned by Social Mentality Theory (SMT) which outlines that when we experience multiple relational abuse or threat experiences our threat emotion system becomes sensitised which increases the likelihood of experiencing distressing emotions such as shame, anxiety, depression, guilt, and disgust (Gilbert, 2010). As outlined in Study 5, experienced and perceived stigma are arguably forms of relational abuse and threat, and therefore are likely to trigger off of the threat emotion system causing distress. Therefore CFT may be well placed as a psychological intervention to alleviate internalised stigma. A small number of exploratory studies have demonstrated that CFT may be effective in

people with psychosis (Braehler et al., 2013; Laithwaite et al., 2009; Mayhew & Gilbert, 2008), and theoretical models have also been proposed (Birchwood et al., 2007; Gumley et al., 2010). Further research should explore the application of CFT for internalised stigma in psychosis.

A further therapeutic approach which may have benefit for internalised stigma in psychosis is Family Intervention (FI; Garety et al., 2008) . FI is also a recommended psychological intervention for people who experience psychosis (NICE, 2014). FI was developed following extensive research demonstrating the role of the family in significantly influencing the course and outcome of psychosis. Research has demonstrated that factors such as high expressed emotion, criticism, and over-involvement contribute to the development and maintenance of psychosis (Giron et al., 2014). Moreover, family support can improve the prognosis of psychosis and facilitate the recovery process (Norman et al., 2005). Therefore, FI was developed to support service users and their families in maintaining relationships and managing experiences of psychosis. FI has demonstrated small to moderate effects in reducing relapse rates and rehospitalisation indicating that it is a helpful intervention for people experiencing psychosis (Bird et al., 2010).

A new form of family-based intervention called Open Dialogue (Seikkula et al., 2003) has been developed for service users and their families for psychosis and is becoming increasingly used across the UK (Razzaque & Stockmann, 2016). Open Dialogue works with the individual's social network and aims to generate family dialogue, offer psychological continuity, and tolerate uncertainty, in order to generate a collaborative social network focus (Seikkula et al., 2006). It also has a small evidence base demonstrating positive outcomes for people with psychosis (Aaltonen, Seikkula, & Lehtinen, 2011; Seikkula et al., 2006). The stigma literature demonstrates that immediate family and social network can either be a significant source of stigma or a protective factor

against public stigma (De Sousa, Marques, Curral, & Queiros, 2012; Phelan, Bromet, & Link, 1999). Therefore further research should examine the role of FI and Open Dialogue in alleviating stigma (both stigma beliefs of the family and internalised stigma) with people who experience psychosis.

Peer-led or supported interventions may also be applicable in alleviating internalised stigma in psychosis. Peer supported or led interventions have been described as interventions which are led for people with mental health difficulties by people who also have lived experience (Lloyd-Evans et al., 2014). To date, two peer-led interventions have been developed for internalised stigma and have individually demonstrated some benefits for people who experience psychosis, but were both small trials (Rusch et al., 2014; Russinova et al., 2014). In a recent systematic review of peer-supported interventions for people with SMI (n=18 studies), Lloyd-Evans et al. (2014) identified little evidence for the benefits of peer support in reducing symptoms, hospitalisation or satisfaction with services. However studies were small, diverse and at high risk of bias. They concluded that further high-quality research trials were needed to definitively examine the efficacy of peer supported interventions for people with SMI. This thesis would support this conclusion with a recommendation that further large methodologically rigorous RCTs are conducted to examine the efficacy of peer-supported interventions for internalised stigma in psychosis.

9.5.4. Interventions which reduce public stigma

This thesis has demonstrated that internalised stigma is an ongoing problem affecting participants across all research studies. As stated, internalised stigma would not exist without the presence of public stigma (P. Corrigan & A. Watson, 2002), and this indicates that further research needs to continue developing and testing public stigma interventions for SMI and psychosis. The introduction outlined that a number of public stigma

interventions have been developed (Corrigan et al., 2012), including larger scale public campaigns (C. Henderson & Thornicroft, 2013) but public stigmatising attitudes continue to prevail. This thesis has suggested, informed by relevant research literature, that the medically focused messages of stigma campaigns may be limiting the efficacy of public stigma interventions to reduce negative attitudes (Lincoln, Arens, Berger, & Rief, 2008). Therefore, future research should examine the efficacy of public stigma interventions which are underpinned by psychosocial models of mental health.

9.5.5. Development of the evidence base of psychiatric inpatient stigma research

It is evident from the review of the literature within this thesis that there is minimal research which has been conducted within the acute psychiatic inpatient setting. This thesis has demonstrated that stigma is a concern for people who experience psychosis in the inpatient setting (Study 3), and that an intervention for people with acute psychosis is feasible and acceptable (Study 6). Moreover, previous research has demonstrated that inpatients worry about disclosing hospital admission (McCarthy et al., 1995), and that stigma is a risk factor in suicidality post discharge from hospital (Pompili et al., 2003; Schromerus et al., 2015). Therefore, an extensive programme of research needs to be conducted to examine the role of stigma associated with acute psychotic experiences and inpatient admissions.

Firstly, the role of stigma in contributing to an inpatient admission is unclear. In a large cross-sectional study (n=4859), Pompili et al. (2003) demonstrated that stigma was a significant contributing factor to suicide and it is likely that those being admitted to wards are going to be experiencing personal stigma. However, the relationship between suicidality, stigma and acute inpatient admission would need to be explored in further research. Qualitative should be undertaken to understand the subjective experience of stigma about different aspects of the hospital admission, as only two qualitative studies

directly examining stigma (Study 3) have been conducted (McCarthy et al., 1995). It would be imperative to understand subjective experiences of stigma in relation to; psychiatric hospital admission, staff treatment, peer relationships, and discharge. In addition, quantitative experimental studies examining the relationship between variables such as personal stigma, psychotic symptoms, inpatient experience and treatment alliance, suicidality (and other related factors such as hopelessness, and self-harm), depression, would be imperative in understanding the associations.

One final area of further research within the inpatient setting would be research examining the role of stigma within organisational practices and staff attitudes (a form of public stigma) towards psychiatric inpatients with psychosis. As described, the psychiatric inpatient setting is highly dependent on the medical treatment of mental health problems (Royal College of Psychiatrists, 2015), which has been found to be associated with an increase in stigmatising beliefs (Walker & Read, 2002). Therefore, qualitative and quantitative exploration of the attitudes of psychiatric inpatient staff, managers, and policy makers would facilitate the widescale examination of stigmatising attitudes. Moreover, further research should develop, implement and evaluate training packages, underpinned by a psychosocial framework, which aim to reduce the stigmatising staff attitudes in an inpatient setting (Walters, Hogg, & Gillmore, 2016).

9.6. Conclusions

In conclusion, this thesis has demonstrated that internalised stigma is a significantly difficulty for those with psychosis, with a particular focus on those who are psychiatric inpatients. It has been demonstrated that reliable and valid assessment, formulation and therapeutic responses to personal stigma are essential in helping service users manage these experiences. Further research needs to continue to develop the evidence base of

stigma research in inpatient settings, and continue to develop therapeutic responses to internalised stigma in people who experience psychosis.

10. References

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11. Appendices

Appendix 1 – Participant information sheet for studies 2, 3 and 4

1.

Validation of a service user informed measure of stigma in psychosis: exploration in inpatients and outpatients

INFORMATION FOR PARTICIPANTS

You are invited to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have. We'd suggest this should take about 10 minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

Principal Investigators

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What is the purpose of the study?

This study is being conducted as part of the researcher's PhD in clinical psychology.

Research has indicated that people who experience psychosis can be treated differently by others and experience stigma (e.g. negative stereotypes and discrimination). Experiencing stigma can be extremely upsetting and distressing for the individual. A person who experiences psychosis may believe in the negative stereotypes and they may experience negative consequences such as feelings of shame, fear and guilt. We know from research that some people with experiences of psychosis can have difficulties because they internalise stigma which is additional to any difficulties caused by psychosis itself. Research is needed to investigate the usefulness of an interview measure which aims to understand people's experiences of stigma in psychosis. To date, there are no such measures developed from a service user perspective. This study will examine the reliability and validity of an interview measure of stigma. It will also explore whether experiences of stigma are different for inpatients and outpatients.

Why have I been given this information?

We are looking for people who are willing to discuss experiences of stigma in relation to their psychosis. This is because we want to know whether a measure of stigma is reliable and valid for people who experience psychosis.

Volunteers should be experiencing psychosis (such as hearing distressing voices or holding unusual beliefs) and have persistent difficulties. We are asking people who are aged 18 - 65, who identify themselves as experiencing psychosis, and are either under an inpatient or outpatient NHS mental health service.

Do I have to take part?

No. As entry to the study is entirely voluntary, it is up to you to decide whether or not to take part. You should not feel under any pressure to make the decision. If you do decide to take part, you will be asked to sign a consent form. Even after signing this form you will still be free to withdraw at any time and without giving a reason. This will not affect any care you may receive in the future.

What will happen to me if I take part?

You will be invited to meet with researchers at a convenient location for you to discuss the study in more detail. Here the researcher will explain the exact nature of the research, explaining the reasons for conducting this study and answer any questions you may have. You will have at least 24 hours to think about taking part in the study. If you are interested in taking part you will be asked to sign a consent form. The researcher will then arrange to meet you for a one off assessment meeting to conduct the interview measure about your experiences of stigma and complete 6 questionnaires to measure different areas which are related to self-stigma. This meeting should not take more than 1½ hours.

What will I have to do?

You will have to complete the following assessment measures/questionnaires:

Personal information (demographics) sheet – we will ask you some personal details so we know who is taking part, e.g. age, gender, ethnicity, diagnosis.

Semi-structured Interview of Stigma (SIMS) – this is the measure we are testing for reliability and validity. It is an interview asking you about your experiences of stigma. It will take about 30-45 minutes to complete.

Internalised Stigma Scale – this looks at your experiences of internalised stigma. i.e. how much you believe in the negative beliefs associated with psychosis.

Kings Stigma Scale – this looks at your experience of stigma and how you manage it.

Self-Esteem Scale – this asks you about your self-esteem, i.e. how you feel about yourself.

Beck Hopelessness Scale – this will ask you about levels of hopelessness.

Beck Depression Inventory – this will ask you about experiences of depression.

Process of Recovery Questionnaire – this will ask you about your recovery journey.

Will taking part in the study cost me anything?

No. The study will only involve your time.

Who will know I am participating in the study?

Other people involved in your care such as your Consultant Psychiatrist, Care Coordinator and GP (if consented) will be informed.

Will my information be kept confidential and anonymous?

All the information you give will be strictly confidential. However there are two exceptions to this. Study data and material may be looked at by individuals from the University of Manchester, from regulatory authorities or from North East London Foundation Trust, for monitoring and auditing purposes, and this may well include access to personal information. Also, if during the course of the interviews, you express an intention to harm yourself or others. In such circumstances the necessary party would be informed. The results and any published findings will also be anonymous; your name will not be quoted.

All questionnaires will be stored in a locked filing cabinet; questionnaires will be stored in a cabinet separate to personal identifiable data. All electronic data will be stored on a password protected and encrypted computer which only the researcher will have access to. All data and personal information from this study will be kept for eight years after the study has finished so the study can be written up for publication in a research journal as recommended by the Data Protection Act (1988).

What are the advantages and disadvantages of taking part?

Taking part in this research will help the development of a new service-user informed measure of stigma in psychosis. You may find it an enjoyable experience being involved in such work.

It is possible that talking about your personal experiences may result in some distress. The person interviewing you will be sensitive to this as they have experience working with people who experience distressing emotions. You will have the opportunity to discuss any concerns at the end of the interview and you are free to withdraw from the process at any point.

What happens if something goes wrong?

The study does not have any 'medical' interventions. You will only be asked to rate some set questions. There is no 'right and wrong' to this, the study is about finding out the things that are important to you. As such there is nothing about the study that should impact on your current health.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093or by email to research.complaints@manchester.ac.uk

Independent Advice

If you would like independent advice about taking part in research please contact:

Patient Advice and Liaison Service (PALS), North East London Foundation Trust, Trust Headquarters, Goodmayes Hospital, Barley Lane, Ilford, IG3 8XJ. Tel: 0300 555 1200.

What do I need to do now?

If you would like to take part, please contact the researcher, Dr Lisa Wood (contact details on 1st page) or speak to your key worker.

Appendix 2 – Participant information sheet for Study 6

A pilot of a brief CBT formulation focused intervention for internalised stigma with acute inpatients that experience psychosis

INFORMATION FOR PARTICIPANTS

This information sheet is to let you know about a research study that you may be eligible to take part in. Before you decide, it is important that you understand why the research is being done and what it would involve for you. The researcher will go through the information sheet with you and answer any questions you have. This should take about 10 minutes. You can also talk to others about the study if you wish, and please ask us if there is anything that is not clear.

This study has been reviewed by an NHS ethics committee to ensure that the rights, safety, dignity and well-being of everyone that takes part in this study are protected.

Principal Investigators

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Dr Rory Byrne – Post-Doctoral User Researcher, Psychosis Research Unit, Greater Manchester West NHS Foundation Trust, Rico House, M25 9WS, Email: rory.byrne@gmw.nhs.uk

What is the purpose of the study?

This study is being conducted as part of the researcher's PhD in clinical psychology.

Research has shown that people who experience psychosis can be treated differently by others and even suffer verbal abuse and bullying because they experience mental health difficulties. This kind of mistreatment is often referred to as stigma. These experiences can understandably be upsetting and can make people feel ashamed, scared and guilty. This is on top of any distress caused by psychosis itself. This can be worse for people during a stay in a mental health ward due to concerns about going back home into their community. We want to test whether it's helpful to offer people in this situation a brief

talking therapy. So far, there are no talking therapies like this available so new research is needed.

Why have I been given this information?

This research study is looking for people who are willing to talk about experiences of stigma related to psychosis, and to complete a brief talking therapy which aims to help with the problem of stigma. People taking part in the study will have recent experience of psychosis (for example, hearing voices other people don't, or fearing others will harm them), and of stigma (for example, feeling others treat them differently because of psychosis). People taking part should also be aged 18 - 65, and be receiving care from an inpatient NHS mental health service.

Do I have to take part?

No. Taking part in this research study is voluntary therefore it is up to you to decide whether or not to take part. You should not feel under any pressure to take part. If you do decide to take part, you will be asked to sign a consent form. Even after signing this form you will still be free to withdraw at any time and without giving a reason. This will not affect any care you may receive in the future.

What will happen to me if I take part?

You can meet a researcher for this study at a convenient location for you to discuss the study in more detail. The researcher will talk through the study in detail with you, explaining the reasons for running this study and answering any questions you may have. You will have at least 24 hours to think about taking part in the study. If you are interested in taking part you will be asked to sign a consent form.

If you take part we will ask you to meet for an initial assessment to complete a number of questionnaires, with an additional two hours of talking therapy to look at the problems of stigma. We would then ask you to meet for a further two assessment sessions after therapy. There are more details about this below.

What will I have to do?

You will take part in some assessment sessions and a brief taking therapy explained more below:

Assessment sessions

You will be asked to complete three assessments with a researcher. One assessment will take place before the therapy, one immediately after the therapy, and another one month later. The last assessment may be at your home address if you are no longer in hospital then. You will be asked to complete some questionnaires for each assessment session (which take about 30-40 minutes) about your experiences of stigma and the impact this has had on your self-esteem, mood, and recovery. In the final session you will also be asked for feedback about taking part in the study.

Therapy for stigma

For the therapy, you will be randomly selected to receive one of two types of therapy (which last for two hours across one or two sessions):

1 - Information giving: This therapy aims to help people understand their experiences of psychosis and stigma better. This therapy will involve discussing facts and figures about stigma and psychosis, identifying famous people who have psychosis, looking at recovery stories from others who have experienced psychosis, and understanding other people's experiences of stigma.

2 - Cognitive Behavioural Therapy (CBT): CBT is a talking therapy which has been shown to help with a wide range of physical and emotional difficulties. It helps people by looking at how they think and act in certain situations, and changing the way they think or act to help them feel better. The aim of therapy in this case is to talk about your personal experiences of psychosis and stigma. You will be supported to share your story and discuss how stigma has affected you. Together with the therapist, you will hopefully reach an understanding of how stigma has affected you, and look at ways of coping that we hope improve your experiences.

The therapy is brief and will be completed by the end of the research study.

Will taking part in the study cost me anything?

No. The study will only involve your time.

Who will know I am participating in the study?

Other people involved in your care such as your Consultant Psychiatrist, Care Coordinator and GP (if consented) will be informed.

Will my information be kept confidential and anonymous?

All the information you give will be strictly confidential so it will not be shared with anyone else. However there are two reasons why this confidentiality may be broken. Study documents may be looked at by individuals from the University of Manchester, from North East London Foundation Trust, or other authorities for monitoring and auditing purposes, and this may well include access to personal information. Also, if during the course of the study, there were concerns about your safety or the safety of others, a member of your clinical team would have to be told.

The results of this research study and any published versions will also be anonymous; your name will not be quoted. You can ask to receive a copy of the results of the study but we do not usually provide individual results.

All questionnaires will be stored in a locked filing cabinet. Questionnaires will also be kept separate to any documents with personal information on them (such as your name). All electronic data (such as answers to questionnaires typed into a computer file) will be stored on a password protected computer which only the researcher will have access to. All data and personal information from this study will be kept for eight years after the study

has finished so the study can be written up for publication in a research journal as recommended by the Data Protection Act (1988).

What are the advantages and disadvantages of taking part?

Taking part in this research will help us to develop a new talking therapy for stigma related to psychosis. You may find it an enjoyable experience being involved in such work. You will be given £5 as a token of appreciation for each assessment you complete. You will receive up to £15 for your time in the study.

It is possible that talking about your personal experiences could sometimes lead to feeling upset. The researchers will be sensitive to your needs as they have experience working with people with upsetting or distressing emotions. You will have the opportunity to talk about any concerns you have at the end of the interview and you are free to withdraw from the research study at any point.

What happens if something goes wrong?

This project does not have any medical interventions such as asking to take a new medication. You will only be asked to complete questionnaires with the researcher and to take part in a brief talking therapy. There is no 'right and wrong' to this, the study is about finding out the things that are important to you. As such there is nothing about the study that should impact on your current health.

It is necessary for us to point out that if you were to feel that taking part in this research project caused you upset or harm, there are unfortunately no special compensation arrangements. However if you were harmed due to someone's negligence (for example, if the researcher did not do their job as they should), then you may have grounds for a legal action, but you may have to pay for this.

Minor Complaints

If you take part in this project and later have a minor complaint then please contact Dr Lisa Wood on 0300 555 1076.

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response to your minor complaint from the researcher then please contact the Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by **telephoning 0161 275 2674 or 275 2046.**

Independent Advice

If you would like independent advice about taking part in research please contact:

Patient Advice and Liaison Service (PALS), North East London Foundation Trust, Trust Headquarters, Goodmayes Hospital, Barley Lane, Ilford, IG3 8XJ. Tel: 0300 555 1200.

What do I need to do now?

If you would like to take part, please contact the researcher, Dr Lisa Wood (contact details on first page) or please speak to your key worker.

Appendix 3 – Consent form for studies 2, 3 and 4

CONSENT FORM

Participant Identification Number for this study: …….

Title of Project:

Validation of a service user informed measure of stigma in psychosis: exploration in inpatients and outpatients

Name of Researcher: Lisa Wood

Name of Participant: **Please initial box**

1. I confirm I have read and understand the participant information sheet (PIS) dated 01.10.14.(version 1) for the above study, have been given a copy to keep and have had the opportunity to ask questions. ☐

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

3. I agree to take part in the research study which will involve one assessment with the researcher ☐

4. I consent to my service-user interview of stigma (SIMS) being audio recorded (optional) ☐

5. I consent to anonymised direct quotations from my interview to be used in write up and publications (optional) ☐

6. I consent to being contacted about the results of the study (optional). ☐

7. I consent to my GP being informed about my participation in this research study (optional) ☐

8. I consent to a copy of this consent form being kept with my medical notes (optional) ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 copy for participant; 1 for researcher; 1 to be kept with medical notes

Appendix 4 – Consent form for Study 6

CONSENT FORM

Participant Identification Number for this study: …….

Title of Project:

A pilot of a brief CBT intervention for internalised stigma with acute inpatients that experience psychosis

Name of Researcher:

Name of Participant: **Please initial box**

1. I confirm I have read and understand the participant information sheet (PIS) dated 29.05.16.(version 2), for the above study, have been given a copy to keep and have had the opportunity to ask questions. ☐

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

3. I consent to taking part in the research study which will involves a brief stigma intervention and monitoring assessments. ☐

4. I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

5. . I consent to being contacted about the results of the study (optional). ☐

6. I consent to my GP being informed about my participation in this research study (optional) ☐

   I consent to a copy of this consent form being kept with my medical notes (optional) ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 copy for participant; 1 for researcher; 1 to be kept with medical notes

Appendix 5 – Ethical approval for studies 2, 3 and 4

NHS
Health Research Authority

NRES Committee London - Camberwell St Giles
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 3421391

13 January 2015

Dr Lisa Wood
North East London Foundation Trust
Goodmayes Hospital
Barley Lane
IG3 8XJ

Dear Dr Wood

Study title:	**Validation of a service user informed measure of stigma in psychosis: exploration in inpatients and outpatients**
REC reference:	**14/LO/2164**
IRAS project ID:	**166557**

Thank you for your letter of 5th January 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this 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 the REC Manager, Miss Elizabeth Hearn, nrescommittee.london-camberwellstgiles@nhs.net. 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.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System 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 approvals 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 NRES. 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).

NHS
Health Research Authority

Ethical review of research sites

NHS sites

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

Non-NHS sites

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Participant Leaflet]	1	01 October 2014
Covering letter on headed paper [Cover letter]	1	01 October 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		31 October 2014
GP/consultant information sheets or letters	1	01 October 2014
Interview schedules or topic guides for participants [SIMS]	2	
IRAS Checklist XML [Checklist_18112014]		18 November 2014
IRAS Checklist XML [Checklist_05012015]		05 January 2015
Letter from sponsor		31 October 2014
Non-validated questionnaire [Demographics Sheet]		01 October 2014
Participant consent form	1	01 October 2014
Participant consent form		
Participant information sheet (PIS)	1	01 October 2014
Participant information sheet (PIS)		
REC Application Form [REC_Form_18112014]		18 November 2014
Referee's report or other scientific critique report [Report from Dr Oliver Mason]		17 October 2014
Research protocol or project proposal	1	01 October 2014
Summary CV for Chief Investigator (CI) [Lisa Wood]		
Summary CV for student [Rory Byrne]		
Summary CV for supervisor (student research) [Anthony Morrison]		
Validated questionnaire [Beck Depression Inventory (BDI)]		
Validated questionnaire [Beck Hopelessness Scale (BHS)]		
Validated questionnaire [Internalised Stigma of Mental Illness (ISMI) scale]		
Validated questionnaire [King Stigma Scale (KSS)]		
Validated questionnaire [Process of Recovery Questionnaire (QPR)]		
Validated questionnaire [Self-Esteem Rating Scale (SERS)]		

NHS
Health Research Authority

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

HRA Training

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

14/LO/2164	Please quote this number on all correspondence

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

Yours sincerely

pp Richard

Mr John Richardson
Chair

Appendix 6 – R&D approval for studies 2, 3, and 4

North East London NHS
NHS Foundation Trust

Research and Development Office
North East London NHS Foundation Trust,
1st Floor Maggie Lilley Suite,
Goodmayes Hospital,
Barley Lane,
Goodmayes,
Essex, IG3 8XJ

Date: 14 January 2015

Dear Lisa Wood,

Re: R&D ref no 2359 – Validation of a service user informed measure of stigma in psychosis: exploration in inpatients and outpatients

I am pleased to inform you that the above named study has been granted approval and indemnity by Professor Martin Orrell, Director of Research and Development North East London NHS Foundation Trust. You must act in accordance with the North East London NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework. Should any untoward events occur, it is **essential** that you contact your Trust supervisor and the Research and Development Office immediately. If patients or staff are involved in an incident, you should also contact the Governance and Assurance department, in Goodmayes Hospital, and complete the Incident and Reporting Form, namely the IR1 form.

This approval is valid until 30 September 2016. You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee, if your project is extended or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

Yours sincerely,

Sandeep Toot

Research and Development Manager, North East London NHS Foundation Trust

Appendix 7 – University of Manchester Sponsorship for studies 2, 3, and 4

The University of Manchester

Faculty of Medical & Human Sciences
The University of Manchester
Oxford Road
Manchester M13 9PT

www.manchester.ac.uk

Friday, 31 October 2014

To whom it may concern

This is to confirm that, where appropriate, insurance policies held by the University of Manchester will cover the research project entitled **Validation of a service user informed measure of stigma in psychosis: exploration in inpatients and outpatients** which we have been informed is being conducted by **Dr Lisa Wood** under the supervision of **Professor Tony Morrison.**

The University has insurance available in respect of research involving human subjects that provides cover for legal liabilities arising from its actions or those of its staff or supervised students. The University also has insurance available that provides compensation for non-negligent harm to research subjects occasioned in circumstances that are under the control of the University.

Provision of this insurance cover in respect of a specific project may be subject to the acceptance of the project by the University's insurers and is conditional upon the project receiving approval from an appropriate ethics committee.

Signed on behalf of the University of Manchester,

Lynne MacRae

Lynne MacRae Dated: **31.10.2014**
Research Practice Coordinator
Faculty of Medical & Human Sciences

Appendix 8 – Ethical approval for Study 6

NHS
Health Research Authority

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

Telephone: 020 71048008

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

06 June 2016

Dr Lisa Wood
Turner Ward
Goodmayes Hospital
Barley Lane
IG3 8XJ

Dear Dr Wood

Study title:	**A pilot of a brief CBT formulation focused intervention for internalised stigma with acute inpatients that experience psychosis**
REC reference:	**16/NW/0332**
IRAS project ID:	**187857**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

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

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

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

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

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

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

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

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

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

Registration of Clinical Trials

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

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

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

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

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

Ethical review of research sites

NHS sites

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

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

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

Document	*Version*	*Date*
Copies of advertisement materials for research participants	1	01 October 2014
Covering letter on headed paper		
Covering letter on headed paper [AMENDED cover letter]	2	29 May 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
GP/consultant information sheets or letters	1	08 February 2016
Letter from sponsor		
Non-validated questionnaire [Demographics sheet]	1	01 October 2014
Non-validated questionnaire [Feedback Questionnaire]	1	08 February 2016
Other [Rory CV]		
Other [LW.RB A mental health awareness programme]		
Participant consent form	1	08 February 2016
Participant information sheet (PIS) [AMENDED PIS]	2	29 May 2016
REC Application Form [REC_Form_12042016]		12 April 2016
Referee's report or other scientific critique report		
Research protocol or project proposal	1	08 February 2016
Summary CV for Chief Investigator (CI)		
Summary CV for student		
Summary CV for supervisor (student research)		
Validated questionnaire [QPRS Process of Recovery Questionnaire]		
Validated questionnaire [Internalised Stigma of Mental Illness Inventory]		
Validated questionnaire [Attitudes towards mental health problems]		
Validated questionnaire [Beck Depression Inventory]		
Validated questionnaire [King Stigma Scale]		
Validated questionnaire [Self-esteem scale]		

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

User Feedback

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

HRA Training

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

16/NW/0332	Please quote this number on all correspondence

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

Yours sincerely

pp.

Mrs Julie Brake
Chair

Email:nrescommittee.northwest-liverpoolcentral@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ms Lynne Macrae*
Ms Fiona Horton, North East London Foundation Trust

Appendix 9 - Health Research Authority Approval for Study 6

NHS
Health Research Authority

Dr Lisa Wood
Turner Ward
Goodmayes Hospital
Barley Lane
IG3 8XJ

Email: hra.approval@nhs.net

04 August 2016

Dear

Letter of HRA Approval

Study title:	**A pilot of a brief CBT formulation focused intervention for internalised stigma with acute inpatients that experience psychosis**
IRAS project ID:	**187857**
REC reference:	**16/NW/0332**
Sponsor	**University of Manchester**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

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

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

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

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

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

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

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

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

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

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

Scope

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

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

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

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

Your IRAS project ID is **187857**. Please quote this on all correspondence.

Yours sincerely

Alex Thorpe
Senior Assessor

Email: hra.approval@nhs.net

Appendix 10 - R&D approval for Study 6

NELFT NHS
NHS Foundation Trust

Research and Development Office
North East London NHS Foundation Trust,
1st Floor Maggie Lilley Suite,
Goodmayes Hospital,
Barley Lane,
Goodmayes,
Essex, IG3 8XJ

22 June 2016

Dear Lisa Wood,

RE: A pilot of a brief CBT formulation focused intervention for internalised stigma with acute inpatients that experience psychosis

R&D Ref: 187857

I am pleased to inform you that the above named study has been granted approval and indemnity by North East London NHS Foundation Trust. You must act in accordance with the North East London NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework. Should any untoward events occur, it is **essential** that you contact your Trust supervisor and the Research and Development Office immediately. If patients or staff are involved in an incident, you should also contact the Governance and Assurance department, in Goodmayes Hospital, and complete the Incident and Reporting Form, namely the IR1 form.

You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

Yours sincerely,

Sandeep Toot

Research and Development Manager, North East London NHS Foundation Trust.

Appendix 11 - University of Manchester sponsorship form for Study 6

The University of Manchester

Faculty of Medical & Human Sciences
The University of Manchester
Oxford Road
Manchester M13 9PT

www.manchester.ac.uk

20 March 2016

To whom it may concern

Sponsor Reference: 16113

Role of the Research Sponsor under the Research Governance Framework for Health & Social Care and the Medicines for Human Use (Clinical Trials) Regulations 2004 (SI2004/1031)

I hereby confirm that the University of Manchester would be prepared to accept the role of research sponsor as currently defined in the *Research Governance Framework for Health & Social Care Version 2 (DoH 2005)* and the *Medicines for Human Use (Clinical Trials) Regulations 2004 (SI2004/1031)*, in relation to the study:

A pilot of a brief CBT formulation-focused intervention for internalised stigma with acute inpatients that experience psychosis

I have been informed that this study will be led by **Professor Tony Morrison** of The University of Manchester.

Sponsorship is subject to the following conditions:

1) The lead investigator for the study must be an employee of the University of Manchester. For student research the academic supervisor is considered to be the lead investigator.
2) An appropriate contract must be agreed between the University and the funding body.
3) The research must be reviewed and approved by appropriate ethics, NHS and regulatory bodies and registered in accordance with University insurance requirements.

To enable the sponsor to meet their responsibilities as listed in section 3.8 of the Research Governance Framework, Chief Investigators are asked to adhere to the responsibilities as outlined in section 3.6 of the Framework (available at: https://www.gov.uk/government/publications). In line with this requirement **Professor Tony Morrison** must ensure that all involved in the research project understand and discharge their responsibilities in accordance with the agreed protocol and any relevant management, ethical and regulatory approvals.

Chief Investigators are also reminded that they must register NHS REC approval with The University of Manchester Research Ethics Office.

If you have any queries about sponsorship of this project then please address them to Professor Nalin Thakker, Associate Vice President for Research Integrity, The University of Manchester, Christie Building, Oxford Road, Manchester M13 9PL, or email research-governance@manchester.ac.uk

Yours Faithfully,

Lynne MacRae

Lynne MacRae Dated: **20.03.2016**
Research Practice Coordinator
Faculty of Medical & Human Sciences

Appendix 12 – Systematic review protocol for study 1

UNIVERSITY of York
Centre for Reviews and Dissemination

PROSPERO International prospective register of systematic reviews

A systematic review of self-stigma interventions for people who experience psychosis

Lisa Wood, Anthony Morrison, Rory Byrne

Citation
Lisa Wood, Anthony Morrison, Rory Byrne. A systematic review of self-stigma interventions for people who experience psychosis. PROSPERO 2014:CRD42014015161 Available from http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42014015161

Review question(s)
Are internalised stigma interventions associated with improvements of internalised stigma for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual? (PRIMARY OUTCOME)

Are internalised stigma interventions associated with improvements of overall symptoms in psychosis for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in negative symptoms for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in positive symptoms for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in self-esteem for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in depression for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in hopelessness for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in shame for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in anxiety for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements recovery for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Are internalised stigma interventions associated with improvements in quality of life for people with schizophrenia-spectrum diagnoses, when compared to treatment as usual?

Searches
To examine the evidence base, a comprehensive search will be conducted using Cochrane Central Register of Controlled Trials (CENTRAL), Current controlled trials Ltd, PsycINFO, EMBASE and MEDLINE in order to identify relevant studies across both psychology and psychiatry.

Search terms will include Schizo* OR psychosis OR psychotic OR Delusion* OR Voices OR Hallucinat* OR Mental Illness AND Stigma AND Intervention OR Therapy OR CBT OR Trial.

Types of study to be included
Due to the paucity of studies in this area, uncontrolled and non-randomised studies will be included. Studies will be included if they report baseline, end of treatment and/or follow-up data.

Condition or domain being studied
Schizophrenia-spectrum disorder, including first-episode psychosis.

Participants/ population
Inclusion: People with schizophrenia-spectrum disorder diagnosis (as diagnosed using any recognised diagnostic criteria).

Exclusion: People with learning disabilities or primary diagnosis of substance/alcohol misuse.

Intervention(s), exposure(s)
Psychological interventions which aim to target internalised stigma.

Comparator(s)/ control
Treatment as Usual (TAU), waiting list control, plus other psychosocial treatments.

Outcome(s)

Primary outcomes

The primary outcome is a significant reduction in IS at the end of treatment and at follow-up. Studies must provide outcome data on a valid and reliable measure of stigma.

Secondary outcomes

The following secondary outcome measures will be assessed, change in overall symptoms in psychosis, positive symptoms, negative symptoms, self-esteem, depression, hopelessness, shame, anxiety, recovery, and quality of life.

Data extraction, (selection and coding)
Data will be extracted by the researcher from identified studies into pre-defined tables with disagreements discussed in supervision. Study characteristics such as type of intervention, group or one-to one, duration of treatment, session number, control condition, number of arms of study, diagnosis types, demographics (age, gender, ethnicity), consent rates, dropout rates, average length of sessions, percentage of participants who had the full amount of sessions, length of sessions, data from each assessment time point (e.g. baseline, post therapy, follow-up points) were collected. Analysis of any available relapse, rehospitalisation and adverse events (which have been reported to the ethics committee) will be conducted on available data.

Risk of bias (quality) assessment
A detailed examination of the quality of the studies will be undertaken using the Grades Recommendation, Assessment, Development, and Evaluation (GRADE) tool, and bias with the Cochrane risk of bias tool (Higgins & Green, 2011). Assessment of quality will be important in assisting the interpretation of results given the use of uncontrolled and non-randomised studies. Quality assessments will be carried about the researcher and discussed in detail in supervision.

Strategy for data synthesis
The initial aim will be to conduct a meta-analysis with identified studies. However, if not enough studies are identified for meta-analysis to be conducted a narrative synthesis will be conducted with available data (Popay et al., 2006).

Analysis of subgroups or subsets
If there are enough studies, comparison between CBT and other psychosocial treatments will be made.

Dissemination plans
Peer reviewed publications, conferences, seminars, workshops

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Organisational affiliation of the review
None

Review team
Dr Lisa Wood, North East London Foundation Trust
Professor Anthony Morrison, Greater Manchester West NHS Foundation Trust
Dr Rory Byrne, Greater Manchester West NHS Foundation Trust

Anticipated or actual start date
01 December 2014

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31 March 2015

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None

Conflicts of interest
None known

Language
English

Country
England

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
Humans; Psychotic Disorders

Appendix 13 – Study leaflet for studies 2, 3 and 4

Who are we looking for?

People who:

- Volunteers should be experiencing psychosis (such as hearing distressing voices or holding unusual beliefs) and have persistent difficulties.

-Are between 18-65 years

-Under a NHS mental health inpatient or outpatient service (e.g. acute ward, CMHT, CRT, crisis team).

Who cannot take part?

For ethical reasons we cannot accept people who:

- Cannot give informed consent
- Cannot communicate in English
- Have an organic cause of the experiences of psychosis

What can we do for service-users who do want to take part?

- You will have the opportunity to talk about your experiences.
- You will have the chance to help other service-users by contributing to research that will help clinical practise
-You will receive feedback about the study and its outcomes
-We will come and complete the tasks with you wherever you feel comfortable

If you have any other questions about the study or think you might want to take part, please contact:

Lisa Wood

Tel:

Please note:

If put your name down to participate but change your mind at a later date, you are under no obligation to continue to participate

Participant Information

A service user measure of stigma in psychosis: exploration in inpatients and outpatients

Dr Lisa Wood – Clinical Psychologist

Professor Tony Morrison – Clinical Psychologist Supervisor

Dr Rory Byrne – Researcher and supervisor

Background

People who experience psychosis are one of the most stigmatised groups out of all those with mental health diagnoses.

Stigma has been shown to have negative impacts on people who experience psychosis because stigma beliefs can be internalised and then people feel bad about themselves. Research has shown that stigma can make people experience difficult emotions such as shame, guilt and fear.

Stigma can also have a number of other impacts, such as stopping people from accessing the help they need, worsening experiences of psychosis and preventing recovery.

Due to all these impacts, it is very important to understand people's experience of stigma in relation to their psychosis. However, at the moment, there are no reliable ways of understanding the experience of stigma in relation to people's experiences of psychosis from a service user perspective. This project aims to examine an interview measure of stigma for its reliability and validity.

Outline of project

This project will asking people to complete an interview measure about their experiences of stigma in relation to their psychosis. In addition, we will also need people to complete some other measures to compare it to. Overall, we will be asking you questions about:

-*Experience of stigma*: Feeling judged because of your mental health experiences.

- *Self-esteem*: How you feel about yourself.

-*Hopelessness*: how hopeful or hopeless you feel about your future.

-*Depression*: if you feel low in mood or depressed.

-*Recovery*: where you think you are in your recovery journey at the moment.

-*Shame*: your experiences of shame.

What do we need from service-users?

We need people who have experiences of psychosis and who are willing to discuss their experiences of stigma. We will ask people to take part in a one off meeting with the researcher.

We need the people to:
- Take part in an assessment session (lasting approximately 60-90 minutes) where people need to fill out seven measures/questionnaires and a personal information sheet.

-You will be given a participant information sheet and a consent form to sign before taking part.

-You will be given the opportunity to ask any questions you like before, during and after taking part in the research study.

-You are free to withdraw at any point and this will not impact on your clinical care.

Appendix 14 – Study leaflet for Study 6

Who are we looking for?

People who:

- Volunteers should be experiencing psychosis (such as hearing distressing voices or holding unusual beliefs) and have persistent difficulties.

-Are between 18-65 years

-Under a NHS mental health inpatient or outpatient service (e.g. acute ward, CMHT, CRT, crisis team).

Who cannot take part?

For ethical reasons we cannot accept people who:

- Cannot give informed consent
- Cannot communicate in English
- Have an organic cause of the experiences of psychosis

What can we do for service-users who do want to take part?

- You will have the opportunity to talk about your experiences.
- You will have the chance to help other service-users by contributing to research that will help clinical practise
-You will receive feedback about the study and its outcomes
-We will come and complete the tasks with you wherever you feel comfortable.
You will get £5 for each assessment session you complete.

If you have any other questions about the study or think you might want to take part, please contact:

<u>Please note:</u>
If put your name down to participate but change your mind at a later date, you are under no obligation to continue to participate.

Participant Information

MANCHESTER 1824
The University of Manchester

NELFT NHS
NHS Foundation Trust

A brief intervention for internalised stigma in psychosis for acute inpatients

Dr Lisa Wood – Clinical Psychologist

Professor Tony Morrison – Clinical Psychologist Supervisor

Dr Rory Byrne – Researcher and supervisor

Background

People who experience psychosis are one of the most stigmatised groups out of all those with mental health diagnoses.

Stigma has been shown to have negative impacts on people who experience psychosis because stigma beliefs can be internalised and then people feel bad about themselves. Research has shown that stigma can make people experience difficult emotions such as shame, guilt and fear.

Stigma can also have a number of other impacts, such as stopping people from accessing the help they need, worsening experiences of psychosis and preventing recovery.

Due to all these impacts, we want to try and develop and offer a brief intervention for people who experience psychosis who are also acute inpatients. A stigma intervention has never been developed for them previously.

This project aims to examine the helpfulness of a stigma intervention for acute inpatients that experience psychosis.

Outline of project

This project will involve people undertaking a stigma intervention. You will be randomised to either an intervention which will develop a personal understanding of your stigma experiences OR to an intervention where you learn about stigma. Both interventions will involve:

1. Discussing your experiences of stigma with a clinical psychologist.

2. Learning more about how stigma impacts on people who experience psychosis.

In order to see if the intervention has helped we will also need you to complete three monitoring assessments to see how the intervention has impacted on your wellbeing.

What do we need from service-users?

We need people who have experiences of psychosis and who are willing to discuss their experiences of stigma.

We need the people to:

- Take part in three monitoring assessment sessions (lasting approximately 30 minutes) where people need to fill out seven measures/questionnaires and a personal information sheet. These will occur before the intervention, immediately after and one month follow-up.

-You will complete a stigma intervention lasting two hours over one or two sessions.

-You will be given the opportunity to ask any questions you like before, during and after taking part in the research study.

-You are free to withdraw at any point and this will not impact on your clinical care.

Appendix 15 - Semi-Structured Interview Measure of Stigma (SIMS) in psychosis

A semi structured interview measure to examine people's experience of stigma in psychosis

Information for interviewees

About the Interview

In this interview we will be asking you about your experiences of stigma in relation to your experiences of psychosis. The interview aims to explore what stigma means to you, what experiences of stigma you may have had and the impact it may have had on your day to day life.

The interview with be conducted with a researcher who understands about the role of stigma and the impacts it can have. They will be sensitive to the difficulties you may have faced as a result of stigma and want to understand your experiences in more detail. The interview will last around 30 – 45 minutes.

We understand that this interview may bring up experiences that are distressing so please take time to consider what you want to discuss with the interviewer. You are free to discuss as much as you feel able to. There are no right or wrong answers; we would just like to find out more about your experiences. It is helpful for us to know as much as we can about your experiences of stigma so we can develop a better understanding of stigma in psychosis to help develop mental health services in the future.

Thank you for agreeing to take part in this interview. If you have any questions before taking part please contact the interviewer:

Name:

Contact address:

Contact Number:

Introduction

Thank you for agreeing to complete this semi-structured interview measure. This measure aims to find out about people's experiences of stigma and the impacts it has had on their well-being and day to day lives.

There are eleven sections in total which broadly cover what stigma means to you, experiences of stigma, impacts of stigma on how you feel and what you do and impacts of stigma on relationships. When answering the question, please think about your experiences and thoughts from **the past month**.

It will take approximately 30 – 45 minutes to complete. If there are any questions that are too difficult to answer please let me know.

The interview is concerned with the experiences of stigma associated with experiences of psychosis.

Do you want me to use the word 'psychosis' when we talk about your experiences, or is there a different term that you would use to describe your experiences?

1. Understanding of stigma

What is your understanding of stigma?
What does it mean to you?

If person is not sure, read *the definition from the Oxford Dictionary: 'a mark of disgrace associated with a particular circumstance, quality, or person'* ***and/or use*** *'a prejudice based on negative stereotyping' (Corrigan & Penn, 1999).*

2. <u>Perceived stigma</u> (abnormality, dangerous/violent, permanence/untreatable, unpredictable, incapable)

How do you think a person with _____/ experiences of psychosis is viewed by society?

↓

Are they viewed differently from others? In what ways?

↓

What specific characteristics are associated with _____/ the diagnosis?

↓

Do you think the public view you in a similar way?

↓

How much do you think about this? (Every day / week / month?)

↓

How long for? (Hours / minutes / seconds)

↓

Does thinking/worrying about this upset you? Can you rate it out of 10? (10=most upset can imagine)

↓

Have you been thinking about this more or less over the **past month** or is it about the same?

3. <u>Experienced Stigma</u> (assault, verbal abuse, ridicule, treated as inferior, discredited, discrimination, avoidance)

Have you had any direct experiences of stigma?

↓

Have you ever been discriminated against / been treated differently to others because of _____/ you have experiences of psychosis?

↓

Can you tell me about this? **What** happened? **Who** was involved? **When** did it happen?

↓

How bad was that experience? Could you rate it out of 10? (10=worst/most upsetting can imagine)

↓

What other experiences of stigma / discrimination have you had?

↓

Have you had anything like this happen in the **past month**?

4. <u>Self-esteem</u> (inferiority, low confidence, self-criticism, sense of not belonging)

How does public stigma / your experiences of stigma/discrimination make you feel about yourself?

↓

Has it changed the way you think or feel about yourself? How do you view yourself now?

↓

How much do you think about this? (Every day / week / month?)

↓

Do you think stigma has a negative impact on your self-esteem?

↓

How much do you think that stigma is responsible for your low self-esteem? Can you rate it (10= total responsible for low self-esteem. No other reason)

↓

How have things been in the **past month**? (Worse / better / same)

5. <u>Emotional responses</u> (depression, anxiety, anger, guilt, shame)

How does stigma make you feel? Do you experience any difficult emotions as a result of stigma?

↓

Have there been times when you have felt _____? Can you rate it out of 10 (10= worst can imagine)

↓

How often do you feel that way? (Daily/weekly/monthly)

↓

How long does it last? (Continuous / hours / minutes?) Are you able to distract yourself from this feeling?

↓

How much do you think that stigma has impacted upon your _____? Can you rate it out of 10 (10=totally responsible for _____)?

↓

How have things been in the **past month**? (Worse / better / same)

6. <u>Safety behaviours/Avoidance</u> (Lack of disclosure, self-isolation, avoidance, alcohol/drug use)

Do you think stigma has impacted upon your daily life? How so?

↓

Does it stop you from doing things? What kind of things?

↓

Are there particular places / situations / people you might avoid because of stigma?

↓

How often in the past week / month do you do/avoid this?

↓

How much do you think that stigma is responsible for _____ on a scale of 0 – 10 (10=totally responsible for _____)?

↓

Do you avoid discussing your _____/ experiences of psychosis with others?

↓

Who have you told about your difficulties?

↓

Do you ever do things like drink or use drugs to cope with stigma?

↓

How have things been in the **past month**? (Worse / better / same)

7. <u>Impacts on relationships</u> (Avoidance, rejection, discrimination, no understanding, shame brought to family)

Do you think that your experiences of stigma have affected your relationships with others?

↓

What relationships have been affected? Friends / family / work / society?

↓

How have your relationships changed? Do people treat you differently? Do you see these people as much?

↓

How much do you think that stigma has impacted upon your relationships on a scale of 0 – 10 (10=stigma totally responsible for change)?

↓

How have things been in the **past month**? (Worse / better / same)

8. **<u>Impacts on psychosis (positive symptoms)</u>** (voices, visions, paranoia, unusual beliefs)

Have your experiences of stigma impacted on your _____/ experiences of psychosis?

↓

Has it made your _____ worse? In what ways?

↓

Does it affect the frequency? (Duration / Distress / Conviction)

↓

If voices: Loudness? Location?

↓

How much do you think that stigma has impacted upon your _____ on a scale of 0 – 10 (10 being worst)?

↓

How have things been in the **past month**? (Worse / better / same)

9. **<u>Impacts on Treatment and accessing services</u>** (Help-seeking, telling others about treatment, treatment access e.g. psychological therapy, relationships with professionals, taking medication)

Can you think of times where your treatment has been affected by stigma? How so?

↓

How does it make you feel about your treatment?

↓

Has stigma affected you accessing mental health services? Did you perhaps delay looking for treatment through fear of stigma?

↓

Has it affected your relationships with mental health professionals /services?

↓

How much do you think that stigma has impacted upon your accessing/your relationship with mental health services on a scale of 0 – 10 (10 being worst)?

↓

How have things been in the **past month**? (Worse / better / same)

10. <u>Positive impacts of stigma</u> (understanding, compassion, personal strength, improved self-esteem, improved relationships)

Has stigma had any positive impacts on your day to day life? How so?

↓

Has it had positive impacts on your mood?

↓

Has it had positive impacts on how you feel about yourself?

↓

Has it make you do things differently?

↓

Has it had positive impacts on your relationships?

↓

Have you noticed any improvements in _____?

↓

How have things been in the **past month**? (Worse / better / same)

11. <u>Recovery</u> Personal qualities (acceptance, hope, learning, understanding), Behaviours (quality of life, accessing education, joining groups, disclosure), Support from others (peers, family, partner)

What are your hopes for the future / recovery? What are your recovery goals?

↓

Do you think experiences of stigma have impacted on your recovery? In what way / what aspects?

↓

How much do you think that stigma has impacted upon your recovery on a scale? Can you rate it out of 10? (10 = stigma has made my recovery impossible)

<u>To be asked to inpatients only (not to be scored):</u>

Have you experienced any stigma or discrimination whilst on the ward? If yes, what has happened?
How do you think nursing staff perceive/view you/patients on the ward?

How has this impacted upon you? Emotions? Behaviours? Psychosis? Relationships with staff? Recovery?

SCORING THE SEMI-STRUCTURED INTERVIEW MEASURE of STIGMA (SIMS)

This is a scale for measuring people's experiences of stigma related to their experiences of psychosis. This measure was developed from a systematic review of qualitative studies examining stigma in psychosis through interviews or focus groups. The scale contains eleven subscales (ten of which are scored) examining different dimensions of stigma.

Items

1. Understanding of stigma
2. Perceived stigma
3. Experienced stigma
   Internalised stigma
4. Self-esteem
5. Emotional change
6. Safety behaviours/Avoidance
7. Relationships
8. Impacts on experiences of psychosis
9. Treatments
10. Positive affects
11. Subjective recovery

This scale is based on the three categories of stigma identified in the literature; perceived stigma, experienced stigma and internalised stigma (Brohan et al, 2010). Each scale is rated on a five point Likert scale (0-4) where 0 broadly indicates no experience/impact on the given area and 4 indicates a severe/large impact on the given area. All items are rated on the interviewee's experiences **in the past month**.

The interviewer first has to consider whether the item is present, by examining its definition. If the item is absent it is scored 0. If it is present, the severity must then be scored. When measuring the severity of the impact on each scale it is important to take into account the frequency, duration, amount of distress, intensity of distress, and impacts on day to day functioning. If you are unsure between two items, please score modestly and choose the lower score.

With all items, please score based on information given by interviewee, if an interviewee is not sure or doesn't know then you cannot score them on this item.

Each item comes with specific questions to elicit specific information about the item to facilitate scoring. The domains described in each question can be used as prompts for further questioning.

Each item asks the interviewee to rate the severity of their experience on a likert scale of 0-10 (10 being worst), use this score to help guide your scoring:

Scoring guidance:

0. **Not present:** Experiences or impacts of stigma are not present.

1. **Minimal:** questionable or subtle experiences or impacts of stigma, likely to be rated 1-2 by the interviewee on the Likert scale.
2. **Mild:** is indicative of experience or impacts of stigma whose presence is clearly established but not pronounced and interferes little in day to day functioning. Likely to be rated 3-5 by the interviewee on the Likert scale.
3. **Moderate:** characterises experiences/impacts of stigma, thought representing a serious problem, either occurs only occasionally or intrudes on daily life only to a moderate extent. Likely to be rated 6-8 by the interviewee on the Likert scale.
4. **Severe:** represents experiences/impacts of stigma which is present very frequently, proves highly disruptive to one's life and often calls for direct supervision. Likely to be rated 9-10 by the interviewee on the Likert scale.

Perceived stigma

Perceived stigma has been defined by LeBel (2008) as '*a) what an individual thinks most people believe about the stigmatised group in general b) how the individual thinks society views him/her personally as a member of the stigmatised group'*. This subscale is aiming to examine both of these dimensions when measuring perceived stigma so it is extremely important to ask interviewee's about **their views of stigma associated with psychosis and whether they think people think that about themselves**. It is important to take both into consideration when scoring interviewee's perceived stigma.

It is important to not measure the impacts that perceived stigma is having on the person within this subscale as this is measured under internalised stigma.

Experienced stigma

Experienced stigma has been defined by Van Brakel et al (2006) as *'experience of actual discrimination and/or participation restrictions on the part of the person affected'.* This subscale is aiming to examine experiences of overt discrimination or prejudice that the interviewee has faced because of stigma attached to their experiences of psychosis. **It is extremely important to consider the severity of the experiences when scoring this scale.** For example, being over protected/infantilised should not be considered on the same level as physical abuse or violence.

It is important that the impacts of experienced stigma are not measured here (e.g. emotional responses, behaviours etc) as these are considered within the internalised stigma scales.

Internalised stigma

Internalised stigma has been defined by Corrigan and Watson (2002) as '*the product of internalisation of shame, blame, hopelessness, guilt and fear of discrimination associated with mental illness'.* The systematic review of the literature revealed a number of dimensions of internalised stigma which this scale has encompassed as individual subscales. Internalised stigma is the measuring

the impacts of perceived and/or experienced stigma on the interviewee in a variety of domains. Therefore it is extremely important to consider the severity of the impacts of perceived and/or experienced stigma in the different domains.

References

Corrigan, PW & Watson, A.C. (2002) The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9:35-53.

LeBel, T. (2008) Perceptions of and responses to stigma. *Sociology Compass*, 2:409-432.

Van Brakel, WH, Anderson, AM, Mutatkar, RK, Bakirtzief Z, Nicholls, PG, & Raju MS (2006) The Participation Scale: measuring a key concept in public health. *Disability and Rehabilitation*, 28:193-203.

1. **<u>Understanding of stigma</u>**
   NOT SCORED

2. **<u>Perceived stigma</u>**
   Domains: Abnormal, dangerous/violent, permanence/untreatable, unpredictable (lack of willpower), incapable (incapable of relationships, parenting, work, child-like, cognitively impaired, not able to have a fulfilling life, perceived as dirty, blamed for own psychosis).

0

Doesn't perceive any stigma to be associated to psychosis and does not believe that he/she is perceived differently by society.

1

Perceives stigma to be associated with one or two of the domains but does not believe that he/she is perceived differently by society.

2

Perceives stigma to be associated with one or two of the domains and does believe that he/she is perceived differently by society **or** perceived stigma to be associated with three or four of the domains but does not believe that he/she is perceived differently by society.

3

Perceives stigma to be associated with three of the domains and does believe that he/she is perceived differently by society.

4

Perceives stigma to be associated with four or more of the domains and does believe that he/she is perceived differently by society.

3. Experienced stigma

Domains:

- **Social groups:** Friends, family, community groups (e.g. police, health professionals) Vocational groups (work colleagues, education) peers.
- **Forms of stigma:** Verbal abuse (ridiculed), physical abuse, treated as inferior (patronised, over-protected/infantilised, discredited), acts of discrimination (unfairly treated, loss of opportunities), being avoided.

0

No experiences of stigma, does not believe that he/she is treated differently by society.

1

He/she has experienced stigma from one of the social groups and/or one form of stigma

2

He/she has experienced stigma from two of the social groups and/or two forms of stigma.

3

He/she has experienced stigma from three of the social groups and/or three forms of stigma.

4

He/she has experienced stigma from four or more of the social groups and/or four or more forms of stigma.

4. <u>Self-esteem</u>

Domains: Inferior (inadequacy, incapability, disempowerment), low confidence (disappointed in self), different/not belonging, self-attacking/critical, internalizing of stereotypes (outlined in question 2).

0

No experiences of stigma, does not believe that he/she is treated differently by society.

1

He/she has experienced stigma from one of the social groups and/or one form of stigma

2

He/she has experienced stigma from two of the social groups and/or two forms of stigma.

3

He/she has experienced stigma from three of the social groups and/or three forms of stigma.

4

He/she has experienced stigma from four or more of the social groups and/or four or more forms of stigma.

5. <u>Emotional responses</u>

Domains: Anger, anxiety (social anxiety, fear) depression, guilt, shame (embarrassment)

0

No negative impacts on emotions. Does not apply.

1

He/she has experience in one or two of the domains and/or there are minimal impacts.

2

He/she has experience in one or two of the domains and there are mild impacts.

3

He/she has experience of three domains and/or there are moderate impacts.

4

He/she has experience of four or more of the domains and/or there are severe impacts.

6. Safety behaviours / Avoidance

Domains: Lack of disclosure about mental health problems (secrecy, denial), self-isolation (avoidance of people), avoidance of situations (avoidance of places), alcohol/drug use.

0

No evidence of avoidance. Does not apply.

1

Stigma has impacted on one or two domains and/or there are minimal impacts on behaviours.

2

Stigma has impacted on one or two domains and there are mild impacts on behaviours.

3

Stigma has impacted on three domains and/or there are moderate impacts on behaviours.

4

Stigma has impacted on four domains and/or there is severe impact behaviours. Almost full social isolation.

7. Impacts on relationships

Domains: Impacts of relationships with family, friends, partner, children, parents, work colleagues.

Types of impacts: Avoidance from others (people avoid you, don't ask how you are, rejection), treat you differently (don't trust you, people fear you), don't understand you (don't understand your experiences), shame brought to family.

0

No impacts on relationships. Does not apply.

1

Stigma has impacted one or two domains and/or there are minimal impacts on relationships.

2

Stigma has impacted one or two domains and there are mild impacts on relationships.

3

Stigma has impacted on three domains and/or there are moderate impacts on relationships.

4

Stigma has impacted on four domains and/or there are severe impacts on relationships.

8. <u>Impacts on psychosis (positive symptoms)</u>

Domains: voices, visual hallucinations, persecutory delusions, paranoia, other delusions.

0

No impacts on experiences of psychosis. Does not apply.

1

Stigma has impacted one or two domains and/or there are minimal impacts on psychosis.

2

Stigma has impacted one or two domains and there are mild impacts on psychosis.

3

Stigma has impacted on three domains and/or there are moderate impacts on psychosis.

4

Stigma has impacted on four or more domains and/or there are severe impacts on psychosis

9. <u>Impacts on treatment and accessing services</u>

Domains: telling others about treatment, treatment access (accessing psychological therapies/mental health services), relationships with services (relationships with professionals), taking medication.

0

No impacts on treatment / accessing services. Does not apply.

1

Stigma has impacted one or two domains and/or there are minimal impacts on treatment and accessing services.

2

Stigma has impacted one or two domains and there are mild impacts on treatment and accessing services.

3

Stigma has impacted on three domains and/or there are moderate impacts on treatment and accessing services.

4

Stigma has impacted on four domains and/or there are severe impacts on treatment and accessing services.

10. Positive impacts of stigma

Domains: compassion (understanding), personal strength (empowerment, resilience, fighting against stigma), improved self-esteem (improving social rank), improvements in relationships with friends/family/peers, positive emotions.

0

No positive impacts on stigma. Does not apply.

1

Stigma has had a positive impact one domain and/or there are minimal positive effects.

2

Stigma has had a positive impact on one or two domains and there are mild positive effects.

3

Stigma has had a positive impact on three domains and/or there are moderate positive effects.

4

Stigma has had a positive impact on four or more domains and/or there are large positive effects.

11. Recovery

Domains:

- **Personal qualities:** acceptance of self, acknowledging that recovery is a continuous battle, hope for the future, learning from experience, having understanding for self and others.
- **Behaviours:** Quality of life, gaining employment, accessing education, joining social groups, being mobile, being able to discuss problems
- **Support from others:** Peer support, understanding from others, family support, sympathy and empathy from others.

0

No impacts on recovery from psychosis. Does not apply.

1

Stigma has impacted one or two domains and/or there are minimal impacts on recovery.

2

Stigma has impacted one or two domains and there are mild impacts on recovery.

3

Stigma has impacted on three domains and/or there are moderate impacts on recovery.

4

Stigma has impacted on four or more domains and/or there are severe impacts on recovery.

Appendix 16 – Internalised Stigma of Mental Illness Inventory (ISMI)

We are going to use the term 'mental health problems' in the rest of this questionnaire, but please think of whatever you feel is the best term for your experiences.

For each question, please mark whether strongly disagree (1), disagree (2), agree (3) or strongly agree (4).

	Strongly disagree	Disagree	Agree	Strongly agree
1. I feel out of place in the world because I have mental health problems	1	2	3	4
2. Having mental health problems has spoiled my life	1	2	3	4
3. People without mental health problems could not possibly understand me	1	2	3	4
4. I am embarrassed or ashamed that I have mental health problems	1	2	3	4
5. I am disappointed in myself for having mental health problems	1	2	3	4
6. I feel inferior to others who don't have mental health problems	1	2	3	4
7. Stereotypes about people with mental health problems apply to me	1	2	3	4
8. People can tell that I have mental health problems by the way I look	1	2	3	4
9. People with mental health problems tend to be violent	1	2	3	4
10. Because I have mental health problems, I need others to make most decisions for me	1	2	3	4
11. People with mental health problems cannot live a good, rewarding life	1	2	3	4
12. People with mental health problems shouldn't get married	1	2	3	4
13. I can't contribute anything to society because I have mental health problems	1	2	3	4
14. People discriminate against me because I have mental health problems	1	2	3	4
15. Others think that I can't achieve much in life because I have mental health problems	1	2	3	4
16. People ignore me or take me less seriously just because I have mental health problems	1	2	3	4
17. People often patronize me, or treat me like a child, just because I have mental health problems	1	2	3	4
18. Nobody would be interested in getting close to me because I have mental health problems	1	2	3	4
19. I don't talk about myself much because I don't want to burden others with my mental health problems	1	2	3	4
20. I don't socialize as much as I used to because my mental health problems might make me look or behave "weird"	1	2	3	4
21. Negative stereotypes about mental health problems keep me isolated from the "normal" world	1	2	3	4
22. I stay away from social situations in order to protect my family or friends from embarrassment	1	2	3	4
23. Being around people who don't have mental health problems makes me feel out of place or inadequate	1	2	3	4
24. I avoid getting close to people who don't have mental health problems to avoid rejection	1	2	3	4
25. I feel comfortable being seen in public with someone whom it is obvious has mental health problems	1	2	3	4
26. In general, I am able to live my life the way I want to	1	2	3	4
27. I can have a good, fulfilling life, despite my mental health problems	1	2	3	4
28. People with mental health problems make important contributions to society	1	2	3	4
29. Living with mental health problems has made me a tough survivor	1	2	3	4

Appendix 17 - Internalised Stigma of Mental Illness Inventory – Short Form (ISMI-S)

ID:_____

Internalized Stigma of Mental Illness Inventory – 10-item Version (ISMI-10)

We are going to use the term "mental illness" in the rest of this questionnaire, but please think of it as whatever you feel is the best term for it. For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

	Strongly disagree	Disagree	Agree	Strongly agree
1. Mentally ill people tend to be violent.	1	2	3	4
2. People with mental illness make important contributions to society.	1	2	3	4
3. I don't socialize as much as I used to because my mental illness might make me look or behave "weird."	1	2	3	4
4. Having a mental illness has spoiled my life.	1	2	3	4
5. I stay away from social situations in order to protect my family or friends from embarrassment.	1	2	3	4
6. People without mental illness could not possibly understand me.	1	2	3	4
7. People ignore me or take me less seriously just because I have a mental illness.	1	2	3	4
8. I can't contribute anything to society because I have a mental illness.	1	2	3	4
9. I can have a good, fulfilling life, despite my mental illness.	1	2	3	4
10. Others think that I can't achieve much in life because I have a mental illness.	1	2	3	4

Appendix 18 – Stigma Scale (SS)

Stigma Scale – Short form

You will find below a list of sentences. For each one of them, you need to check off the answer that best suits you by ticking the box next to the statement.

Answer all the questions without exception. Don't spend too much time thinking about the answer, as it is your first impression that is important.

		Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
1	Having had mental health problems has made me a more understanding person	☐	☐	☐	☐	☐
2	I do not feel bad about having had mental health problems	☐	☐	☐	☐	☐
3	I worry about telling people I receive psychological treatment	☐	☐	☐	☐	☐
4	Some people with mental health problems are dangerous	☐	☐	☐	☐	☐
5	People have been understanding of my mental health problems	☐	☐	☐	☐	☐
6	My mental health problems have made me more accepting of other people	☐	☐	☐	☐	☐
7	I am scared of how other people will react if they find out about my mental health problems	☐	☐	☐	☐	☐
8	I would have had better chances in life if I had not had mental health problems	☐	☐	☐	☐	☐
9	I do not mind people in my neighbourhood knowing I have had mental health problems	☐	☐	☐	☐	☐
10	I would say I have had mental health problems if I was applying for a job	☐	☐	☐	☐	☐
11	I worry about telling people that I take medicines/tablets for mental health problems	☐	☐	☐	☐	☐
12	Having had mental health problems has made me a stronger person	☐	☐	☐	☐	☐
13	I do not feel embarrassed because of my mental health problems	☐	☐	☐	☐	☐
14	I avoid telling people about my mental health problems	☐	☐	☐	☐	☐
15	I feel the need to hide my mental health problems from my friends	☐	☐	☐	☐	☐
16	I find it hard telling people I have mental health problems	☐	☐	☐	☐	☐

Thank you for completing this questionnaire

Appendix 19 – Beck Depression Inventory Primary Care (BDI-PC)

BDI-Primary Care

ID_____
Date:_____

This questionnaire consists of groups of statements. Please read each group of statements carefully, then pick out the **one statement** in each group which best describes the way you have been feeling during the **past 2 weeks, including today!** Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle the statement which has the largest number.

---

1 **0** I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2 **0** I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3 **0** I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4 **0** I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can't get any pleasure from the things I used to enjoy.

5 **0** I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

6 **0** I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

7 **0** I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

Appendix 20– Beck Hopelessness Scale (BHS)

Beck Hopelessness Scale

ID number ☐☐☐☐ Assessor ☐☐

Date ☐☐ ☐☐ ☐☐☐☐

Statement	True	False
1. I look forward to the future with hope and enthusiasm	T	F
2. I might as well give up because there is nothing I can do about making things better for myself.	T	F
3. When things are going badly, I am helped by knowing that they can't stay this way forever.	T	F
4. I can't imagine what my life would be like in ten years.	T	F
5. I have enough time to accomplish the things I want to do.	T	F
6. In the future, I expect to succeed in what concerns me most.	T	F
7. My future seems dark to me.	T	F
8. I happen to be particularly lucky, and I expect to get more of the good things in life than the average person.	T	F
9. I just can't get the breaks, and there's no reason I will in the future.	T	F
10. My past experiences have prepared me well for the future.	T	F
11. All I can see ahead of me is unpleasantness rather than pleasantness.	T	F
12. I don't expect to get what I really want.	T	F
13. When I look ahead to the future, I expect that I will be happier than I am now.	T	F
14. Things just don't work out the way I want them to.	T	F
15. I have great faith in the future.	T	F
16. I never get what I want, so it's foolish to want anything.	T	F
17. It's very unlikely that I will get any real satisfaction in the future.	T	F
18. The future seems vague and uncertain to me.	T	F
19. I can look forward to more good times than bad.	T	F
20. There's no use in really trying to get anything I want because I probably won't get it.	T	F

Appendix 21 – Self-Esteem Rating Scale (SERS)

SELF ESTEEM RATING SCALE – Short form (Lecomte et al, 2006)

This questionnaire is designed to measure how you feel about yourself. It is not a test, so there are no right or wrong answers. Please answer each item as carefully and accurately as you can be using the following scale. Please place a number in the box next to the item.

1 = Never
2 = Rarely
3 = A little of the time
4 = Some of the time
5 = A good part of the time
6 = Most of the time
7 = Always

	1. I feel that others do things much better than I do.*
	2. I feel confident in my ability to deal with people.
	3. I feel that I am likely to fail at things I do.*
	4. I feel that people really like to talk with me.
	5. I feel that I am a very competent person.
	6. When I am with other people, I feel that they are glad I am with them.
	7. I feel that I make a good impression on others.
	8. I feel confident that I can begin new relationships if I want to.
	9. I feel ashamed about myself.*
	10. I feel inferior to other people.*
	11. I feel that my friends find me interesting.
	12. I feel that I have a good sense of humour.
	13. I get angry at myself over the way I am.*
	14. My friends value me a lot.
	15. I am afraid I will appear stupid to others.*
	16. I wish I could just disappear when I am around other people.*
	17. I feel that if I could be more like other people then I would feel better about myself.*
	18. I feel that I get pushed around more than others.*
	19. I feel that people have a good time when they are with me.
	20. I wish that I were someone else.*

Appendix 22 – Process of Recovery Questionnaire (QPR)

ID:_____

We developed this questionnaire in order to understand more about the process of recovery; what's helpful and what's not so helpful.
Everyone is different and there will be differences for everyone. The items on this questionnaire were developed through a process of interviewing service users about their recovery journeys. We hope that by filing in this questionnaire you will help us find out information that is important to you and your own recovery. Not all factors will be important to you, since everyone is different. This questionnaire is not intended to be used to impose anything against your wishes.

If you would like to fill in the questionnaire, please take a moment to consider and sum up how things stand for you at the present time, in particular over the last 7 days, with regards to your mental health and recovery. Please respond to the following statements by putting a tick in the box which best describes your experience.

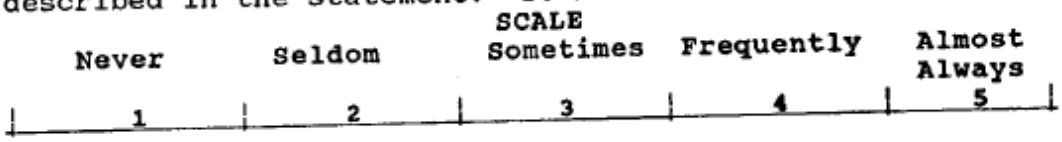
	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
1. I feel better about myself					
2. I feel able to take chances in life					
3. I am able to develop positive relationships with other people					
4. I feel part of society rather than isolated					
5. I am able to assert myself					
6. I feel that my life has a purpose					
7. My experiences have changed me for the better					
8. I have been able to come to terms with things that have happened to me in the past and move on with my life					
9. I am basically strongly motivated to get better					
1(I can recognise the positive things I have done					
1: I am able to understand myself better					
1: I can take charge of my life					
1: I can actively engage with life					
1- I can take control of aspects of my life					
1! I can find the time to do the things I enjoy					

Thank you for completing this questionnaire

Appendix 23 – Internalised Shame Scale (ISS)

DIRECTIONS: Below is a list of statements describing feelings or experiences that you may have had from time to time or that are familiar to you because you have had these feelings and experiences for a long time. Most of these statements describe feelings and experiences that are generally painful or negative in some way. Some people will seldom or never have had many of these feelings. Everyone has had some of these feelings at some time, but if you find that these statements describe the way you feel a good deal of the time, it can be painful just reading them. Try to be as honest as you can in responding.

Read each statement carefully and circle the number to the left of the item that indicates the frequency with which you find yourself feeling or experiencing what is described in the statement. DO NOT OMIT AN ITEM.



SCALE						
1	2	3	4	5	1.	I feel like I am never quite good enough.
1	2	3	4	5	2.	I feel somehow left out.
1	2	3	4	5	3.	I think that people look down on me.
1	2	3	4	5	4.	All in all, I am inclined to feel that I am a success.
1	2	3	4	5	5.	I scold myself and put myself down.
1	2	3	4	5	6.	I feel insecure about others opinions of me.
1	2	3	4	5	7.	Compared to other people, I feel like I, somehow, never measure up.
1	2	3	4	5	8.	I see myself as being very small and insignificant.
1	2	3	4	5	9.	I feel I have much to be proud of.
1	2	3	4	5	10.	I feel intensely inadequate and full of self doubt.

1	2	3	4	5	11.	I feel as if I am somehow defective as a person, like there is something wrong with me.
1	2	3	4	5	12.	When I compare myself to others, I am not as important.
1	2	3	4	5	13.	I have an overpowering fear that my faults will be revealed in front of others.
1	2	3	4	5	14.	I feel I have a number of good qualities.
1	2	3	4	5	15.	I see myself striving for perfection only to continually fall short.
1	2	3	4	5	16.	I think others are able to see my defects.
1	2	3	4	5	17.	I could beat myself over the head with a club when I make a mistake.
1	2	3	4	5	18.	On the whole, I am satisfied with myself.
1	2	3	4	5	19.	I would like to shrink away when I make a mistake.
1	2	3	4	5	20.	I replay painful events over and over in my mind until I am overwhelmed.
1	2	3	4	5	21.	I feel I am a person of worth, at least on an equal plane with others.
1	2	3	4	5	22.	At times I feel like I will break into a thousand pieces.
1	2	3	4	5	23.	I feel as if I have lost control over my body functions and my feelings.
1	2	3	4	5	24.	Sometimes I feel no bigger than a pea.
1	2	3	4	5	25.	At times, I feel so exposed that I wish the earth would open up and swallow me.

1	2	3	4	5	26.	I have this painful gap within me that I have not been able to fill.
1	2	3	4	5	27.	I feel empty and unfulfilled.
1	2	3	4	5	28.	I take a positive attitude toward myself.
1	2	3	4	5	29.	My loneliness is more like emptiness.
1	2	3	4	5	30.	I always feel like there is something missing.

Appendix 24 – Attitudes towards Mental Health Problems Questionnaire (AMHP)

		Strongly disagree	Disagree	Agree	Strongly Agree
1	I think my community would look down on me	0	1	2	3
2	I think my community would see me as inferior	0	1	2	3
3	I think my community would see me as inadequate	0	1	2	3
4	I think my community would see me as weak	0	1	2	3
5	I think my community would as not measuring up to their standards	0	1	2	3
6	I think my family would look down on me	0	1	2	3
7	I think my family would see me as inferior	0	1	2	3
8	I think my family would see me as inadequate	0	1	2	3
9	I think my family would see me as weak	0	1	2	3
10	I think my family would as not measuring up to their standards	0	1	2	3
11	I would see myself as inferior	0	1	2	3
12	I would see myself as inadequate	0	1	2	3
13	I would blame myself for my problems	0	1	2	3
14	I would see myself as a weak person	0	1	2	3
15	I would see myself as a failure	0	1	2	3

Appendix 25– Demographics sheet

MANCHESTER 1824
The University of Manchester

Demographics Sheet

Participant No		Gender	☐ Male ☐ Female
Date of Birth	_ _/ _ _/ _ _ _ _	Age	
Schooling	☐ Primary ☐ Secondary ☐ Further ☐ Higher	**Age left full time education**	
Employment Status	☐ F/T ☐ P/T ☐ Disabled ☐ Student ☐ Unemployed ☐ Home worker ☐ Retired ☐ Voluntary		
Marital Status	☐ Single ☐ Married ☐ Common law ☐ Separated ☐ Divorced ☐Widowed		
Ethnicity			

Asian/Asian British ☐Bangladeshi ☐Indian ☐Pakistani ☐Any other Asian background Black/Black British ☐African ☐Caribbean ☐Any other Black background	Mixed ☐White & Asian ☐White and Black African ☐White and Black Caribbean ☐Any other mixed background White ☐British ☐Irish ☐ Any other White background	Other ☐Chinese ☐Any other ethnic group Specify_____ ____
Religious Beliefs		
☐ Buddhism ☐ Christianity ☐ Islam	☐ Sikhism ☐ Hinduism ☐ Judaism	☐ Atheism ☐Jainism ☐ Other, _____

The following to be filled out from participant:			
First contact with MHS	_ _/ _ _/ _ _ _ _	**First issues with psychosis**	_ _/ _ _/ _ _ _ _
Number of Hospital Admissions		**Date of admission:**	
Service Type	☐ EI ☐ CMHT ☐ AO ☐ IP ☐ Other _____		
Primary Diagnosis (if any)	☐ Schizophrenia ☐ Acute and transient psychotic disorder ☐ Schizoaffective disorder ☐ Persistent delusional disorder ☐ Other Specify code _____		
Experiences of psychosis	☐ Paranoia ☐ Voices ☐ Unusual beliefs/delusions ☐ visual hallucinations Please specify experiences: _____ _____ _____		

Appendix 26 - Feedback questionnaire

NELFT NHS
NHS Foundation Trust

ID:_____

1. Please could you tell me about your experience of the stigma intervention.

   (a) What parts did you find helpful?

   (b) What parts did you find unhelpful?

   (c) How would you improve the intervention?

2. Please could you tell me about your experience of taking part in the research study.

(a) Where there any aspects that you found difficult?

(b) How would you improve the process?

3: How many people have you discussed your mental health with since you have left hospital?

4.Have you felt more able to discuss your mental health difficulties with others?

5.If, yes, how has this changed?

Appendix 27 – Feasibility data collection sheet

Stigma study feasibility data

Study start/end date:	Start:	End:

Date	Ward	Number of patients reported by staff as eligible (only those who have psychosis experiences)
Recruitment start/end date:	Start:	End:

Researcher Introduced to potential participant by staff (initial)	Approached (Y/N)	Consented/Declined (C/D)	Reason

Participant number:	
Date approached:	
Date consented into study:	
Baseline:	Date: Yes/No Reason: Number of times approached:
Post therapy:	Date: Yes/No Reason: Number of times approached:
Follow-up	Date: Yes/No Reason: Number of times approached:
Feedback questionnaire completed:	Yes/No Reason:
Condition:	
Therapy change mechanism:	
Number of sessions completed including time:	
Therapy notes including therapy interfering issues:	
Serious adverse event (please detail):	Yes/No

Appendix 28 – Feasibility study published protocol

ClinicalTrials.gov

A Study of a Cognitive Behaviour Therapy for Internalised Stigma Intervention for Inpatients With Psychosis

This study is currently recruiting participants. (see Contacts and Locations)

Verified August 2016 by University of Manchester

Tracking Information	
First Received Date ICMJE	July 29, 2016
Last Updated Date	August 3, 2016
Start Date ICMJE	July 2016
Estimated Primary Completion Date	February 2017 (Final data collection date for primary outcome measure)
Current Primary Outcome Measures ICMJE **(submitted: August 1, 2016)**	Internalised stigma of mental illness scale [Time Frame: 10 minutes]
Original Primary Outcome Measures ICMJE	*Same as current*
Change History	Complete list of historical versions of study NCT02853396 on ClinicalTrials.gov Archive Site
Current Secondary Outcome Measures ICMJE **(submitted: August 1, 2016)**	• Process of Recovery Questionnaire [Time Frame: 5 minutes] • Beck Depression Inventory [Time Frame: 5 minutes] • Beck Hopelessness Scale [Time Frame: 5 mins] • Self-Esteem Rating scale [Time Frame: 5 mins] • Attitudes towards mental health scale [Time Frame: 5 mins]
Original Secondary Outcome Measures ICMJE	*Same as current*
Current Other Outcome Measures ICMJE	*Not Provided*
Original Other Outcome Measures ICMJE	*Not Provided*
Descriptive Information	
Brief Title ICMJE	A Study of an Cognitive Behaviour Therapy for Internalised Stigma Intervention for Inpatients With Psychosis

Official Title [ICMJE]	A Pilot of a Brief Cognitive Behaviour Therapy Formulation Focused Intervention for Internalised Stigma With Acute Inpatients That Experience Psychosis
Brief Summary	Stigma is a significant concern for those who experience psychosis. People with psychosis are the most stigmatised group of all mental health difficulties. There is a lack of research examining the effectiveness of psychological therapies for people who experience psychosis who are also experiencing negative impacts of stigma. To date, all studies examining stigma therapies have been conducted with outpatients and no support have been developed for inpatients. The aim of this study to conduct a pilot randomised controlled trial of a brief therapy (based on cognitive behavioural therapy)to help participants cope with stigma. It will be compared to a educational control intervention. Both therapies will last approximately two hours and be conducted in one or two sessions by the principal investigator (clinical psychologist). Participants will be given a number of questionnaires assessing a number of outcomes such as impacts of stigma, depression, recovery, and self-esteem. Participants will be assessed on these measure prior to the therapy, post therapy and at follow-up.
Detailed Description	A single-blind randomised controlled pilot trial will be conducted comparing a Cognitive Behaviour Therapy formulation driven internalised stigma intervention (experimental group) against a psychoeducational control intervention (control group). It will follow recommendations outlined by the Medical Research Council's framework for the development and evaluation of complex interventions. This will allow for the medication of the intervention if necessary in order to examine what type of intervention is best suited to the inpatient environment. Aim: To examine the efficacy of a formulation driven intervention for internalised stigma in psychosis with acute inpatients. The intervention will be compared to a brief psychoeducational internalised stigma intervention. Description of therapies: Experimental Condition The experimental condition will receive a two hour intervention session (across one or two sessions) which will be based on a Cognitive Behaviour therapy formulation. These sessions will be undertaken within a two week period. The sessions will collaboratively assess and create a narrative of the participants' experiences of stigma, and develop a personalised stigma formulation. A stigma-related goal will be identified and a brief intervention will be collaboratively developed to tackle this goal. The intervention formulation and change mechanisms will draw upon strategies for people who experience psychosis. Intervention strategies may include guided discovery, skills development, normalising and belief change strategies, including behavioural experiments targeting stigma-relevant appraisals and negative beliefs about self including public stereotypes of psychosis, and supporting decisions about whether to disclose. Control Condition The control condition will receive a two hour session receiving psychoeducation and normalising material relating to stigma in psychosis. The aim of the material is normalise experiences of psychosis and stigma. Information

	includes prevalence rates of psychosis, experiences of stigma and discrimination commonly reported by those who experience psychosis. Both interventions will be delivered by the same therapist.
Study Type ICMJE	Interventional
Study Phase	*Not Provided*
Study Design ICMJE	Allocation: Randomized Intervention Model: Parallel Assignment Masking: Single Blind (Outcomes Assessor) Primary Purpose: Treatment
Condition ICMJE	• Cognitive Behaviour Therapy for Internalised Stigma • Psychoeducation
Intervention ICMJE	• Other: Cognitive Behaviour Therapy • Other: Psychoeducation
Study Arms	• Experimental: Cognitive behavioural therapy Cognitive behaviour therapy Intervention: Other: Cognitive Behaviour Therapy • Active Comparator: Psychoeducation psychoeducation Intervention: Other: Psychoeducation
Publications *	*Not Provided*

*** Includes publications given by the data provider as well as publications identified by ClinicalTrials.gov Identifier (NCT Number) in Medline.**

Recruitment Information	
Recruitment Status ICMJE	Recruiting
Estimated Enrollment ICMJE	30
Estimated Completion Date	September 2017
Estimated Primary Completion Date	February 2017 (Final data collection date for primary outcome measure)
Eligibility Criteria ICMJE	Inclusion Criteria: Aged 18-65 Who meet criteria for a schizophrenia-spectrum diagnoses (schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder or psychotic disorder not otherwise specified; ICD-10) Able to give in-formed consent and have capacity to consent

	Receiving care from a clinical in-patient team Able to complete the interview in English Self-report being concerned about stigma Exclusion Criteria: Non-English speakers (due to translation costs) An acquired brain injury or substance misuse judged to be the acute cause of the psychotic experiences Lacking capacity for informed consent (the applicant will work with the participant to assess whether they understand the information sheet and study and therefore their ability to give informed consent) Experiencing severe thought disorder
Sex/Gender	Sexes Eligible for Study: All
Ages	18 Years to 65 Years (Adult)
Accepts Healthy Volunteers	No
Contacts ICMJE	
Listed Location Countries ICMJE	United Kingdom
Removed Location Countries	
Administrative Information	
NCT Number ICMJE	NCT02853396
Other Study ID Numbers ICMJE	16/NW/0332
Has Data Monitoring Committee	No
U.S. FDA-regulated Product	*Not Provided*
Plan to Share Data	*Not Provided*
IPD Description	*Not Provided*
Responsible Party	Lisa Wood, University of Manchester
Study Sponsor ICMJE	Lisa Wood
Collaborators ICMJE	*Not Provided*
Investigators ICMJE	*Not Provided*
Information Provided By	University of Manchester
Verification Date	August 2016

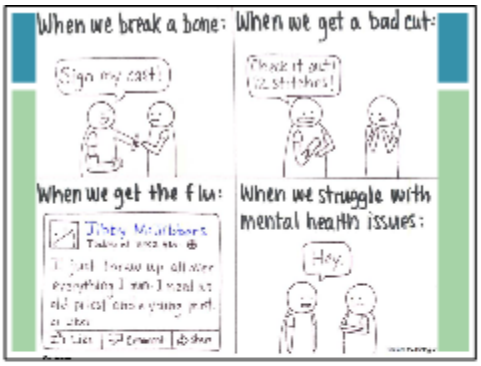
Appendix 29- Excluded studies at full text

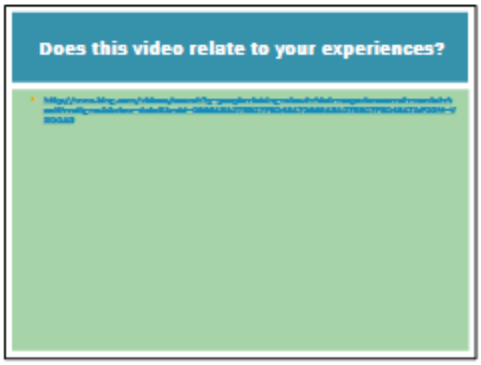
- Shimostsu, S., Horikawa, N., Emura, R., Ishikawa, S., Nagao, A., Ogata, A., Hiejima, S., Hosomi, J. (2014) Effectiveness of group cognitive-behavioural therapy in reducing self-stigma in Japanese Psychiatric Patients. Asian Journal of Psychiatry, 10, 39 – 44
  Reason for exclusion: Not examining intervention with people diagnosed with a schizophrenia-spectrum diagnosis
- Brown, S. (2010) Implementing a brief hallucination simulation as a mental illness stigma reduction strategy. Community Mental Health Journal, 46, 500 – 504
  Reason for exclusion: Not examining intervention with people diagnosed with a schizophrenia-spectrum diagnosis
- Michaels, P., Corrigan, P.W., Buchholz, B., Brown, J., Arthur, T., Netter, C., MacDonald-Wilson, K. (2014) Changing stigma through a consumer-based stigma reduction program. Community Mental Health Journal, 50, 395-401.
  Reason for exclusion: Intervention was implemented with those who have severe mental illness and did not report diagnosis. Corresponding author contacted (13/12/2014) via email to ask if they were able to give diagnosis data. Author reported that this data was not collected and therefore publication does not meet criteria of ≥50% people who have a schizophreniform diagnosis.
- Luoma, J.B., & Kohlenberg, B.S. (2011) Slow and Steady Wins the Race: A Randomized Clinical Trial of Acceptance and Commitment Therapy Targeting Shame in Substance Use Disorders. *Journal of Consulting and Clinical Psychology*. 80, 1, 43-53.
  Reason for exclusion: Not examining intervention with people diagnosed with a schizophrenia-spectrum diagnosis
- Sibitz, I., Provaznikova, K., Lipp, M., & Lakeman, R. (2013) The impact of recovery-oriented day clinical treatment on internalized stigma: Preliminary report. Psychiatry Research. 326-332.
  Reason for exclusion: Intervention did not primarily focus on reducing internalised stigma.
- Morrison, A.P., Birchwood, M., Pyle, M., Flach, C., Stewart, S., Byrne, R., Patterson, P., Jones, P.B., Fowler, D., Gumley, A.I., French, P. (2013) Impact of cognitive therapy on internalised stigma in people with at-risk mental states. British Journal of Psychiatry. 203, 140 – 145
  Reason for exclusion: Intervention did not primarily focus on reducing internalised stigma.
- Aho-Mustonen, K., Tiihonen, J., Repo-Tihonen, Ryynanen, P., Miettinen, R., Raty, H. (2011) Group psychoeducation for long-term offender patients with schizophrenia: An exploratory randomised controlled trial. Criminal Behaviour and Mental Health. 21, 163-176.
  Reason for exclusion: Intervention did not primarily focus on reducing internalised stigma.
- Shin, S., Lukens, E. (2002) Effects of psychoeducation for Korean Americans with chronic mental illness. Psychiatric Services. 53 (9), 1125 – 1131.
  Reason for exclusion: Intervention did not primarily focus on reducing internalised stigma.
- MacInnes, D.L., & Lewis, M. (2008) The evaluation of a short group programme to reduce self-stigma in people with serious and enduring mental health problems. *Journal of Psychiatric & Mental Health Nursing*, 15, 59 – 65

Reason for exclusion: Author was contacted via email on three occasions but no response received. Therefore we were unable to ascertain whether ≥50% of participants had a schizophreniform diagnosis.

- Lucksted, A (ongoing) Ending Self Stigma: Randomized Trail to Reduce Internalized Stigma among People with SMI
  Reason for exclusion: Trial not yet complete.

Appendix 30– Psychoeducation intervention





Discussion: Stigma in the inpatient setting

- Worries about being discharged and stigma?
- Experiencing stigma on the ward?
- Stigma of being admitted to hospital?
- Stigma leading to inpatient admission?

What can help with personal stigma?

- Understanding what mental health and psychosis is (part 1)
- Developing personal recovery goals (part 2)
- Understanding what the misunderstandings of psychosis are (part 3)
- Learn how to tackle stigma (part 4)

Part 1. General Mental Health Information

What is Mental Health?

- Mental health is just one part of our general health and wellbeing.
- Mental health doesn't always stay the same, it can change depending on life **circumstances**.
- We all have mental health needs.

Mental Health Problems

- The term "mental health problem" refers to a range of **problems that affect a persons ability to get on with life**.
- When someone is experiencing a mental health problem, changes may occur to the persons:
  - Thoughts
  - Feelings
  - Behaviours
  - Physical wellbeing

There are so many mental health terms, what do they all mean?

- Mental health problems may be different for different people
- To understand and help with these difficulties, problems that are very similar are grouped together into types of problems and given a name or a diagnosis.

Some examples of diagnosed mental health problems are….

- Depression
- Eating disorders
- Psychosis
- Post-Traumatic Stress Disorder (PTSD)
- Anxiety

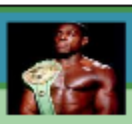
How common are mental health problems?

- Mental health problems are more common than people think.
- **1 in 4** British people will experience some form of a mental health problem in their life.
- It is estimated that approximately **450 million people world wide have a mental health problem.**

Question:

Which of the following famous people do you think have experienced a mental health problem?


Kurt Cobain, Musician?


Frank Bruno, Boxer?


Ruby Wax, Presenter?


Johnny Depp, Actor?


Anthony Hopkins, Actor?


Princess Diana

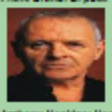
Answer: **All of them** have reported experiencing a mental health problem.


Kurt Cobain: Depression


Frank Bruno: Bi polar


Ruby Wax: Depression


Johnny Depp: Depression


Anthony Hopkins: Has reported having voices


Princess Diana: Depression and eating disorder

- Are there any other celebrities that you know of who have experienced mental health problems?

Part 2.

Psychosis, or –
What word do you use to describe your experiences?

What is Psychosis?

- Psychosis is a word used to described a number of experiences including:
  - **Hearing voices**, sometimes referred to as hallucinations.
  - **Seeing things other people can not**, sometimes referred to as hallucinations.
  - **Unusual beliefs** that are not shared by others, sometimes referred to as delusions
- Sometimes the word schizophrenia is used to refer to psychosis, though this is just one form of psychosis.

How common are these experiences?

- Around **3** out of every **100** people will experience a psychotic episode. That's around **7,500** people developing a first episode of psychosis **each year**.
- **100,000** people receive help **every year** in Britain for psychosis.
- Psychosis is more **common than insulin dependent diabetes**.

To put this in context…

The seating capacity of the Olympic Stadium (Stratford) is **80,000** people.

That means we would need the whole stadium to seat everyone for psychosis, each year in Britain

Hearing Voices

Discussion: Have you ever heard a voice?

1) Have you heard someone talking to you when no one was there?
2) Have you heard mumbling?
3) Have you heard any unexplained noises?

Hearing voices

- Hearing voices could be experienced by anyone.
- **10-25%** of the general population have had such experiences at least once.
- Studies with **college students** who do not have mental health problems, have found that the experience of **hearing voices is common** (37-39%).

How many people in Britain have heard a voice at some time?

- A recent study found that 16% of the population have heard voices. That would suggest that about **10 million** people in Britain have heard voices at some time.
- That's the same number as the population of Belgium in 2005!

Video of hearing voices

https://www.youtube.com/watch?v=VRql4IxuXAw

Personal Beliefs (that others don't hold)

What are personal beliefs that others don't hold?

- **Paranoia**; e.g. having thoughts that others are watching you or going to harm you in some way
- **Feeling controlled**; e.g. thoughts that something is controlling your actions and urges
- Feeling that other people can hear your thoughts out loud, like they are being broadcast on a radio
- Believing that there are special meanings for you in the media, that it is talking about you in some way

Discussion: Have you ever held beliefs that others don't hold?

- Have you ever held beliefs that others did not agree with?
- Have you ever felt paranoid or that others were trying to harm you?
- Have you ever felt that others were trying to control you?
- Have you ever thought there was special meaning in things that was especially directed towards you?

How common are these types of beliefs?

- Research has suggested that the following percentage of British adults expressed beliefs in various unscientific phenomena:
  - 50% of people believe that thoughts can be transferred between people.
  - 25% believe in reincarnation.
  - 25% believe in horoscopes.
  - 21% believe in the devil.

Feeling Paranoid

Discussion: Have you ever felt paranoid?

- Have you ever felt paranoid or worried about your safety?

Paranoia: an example of an unusual belief

- Paranoia/ suspicion is the belief that other people or things wish to do you harm. It could also be about feeling disliked/manipulated.
- Often, society encourages us to be suspicious of others:
  - Newspapers have stories of crimes.
  - There are many conspiracy theories on the internet.
  - There are CCTV cameras across towns to monitor violence.
  - Governments warn us to keep a look out for terrorists.
- People who develop psychosis may start out with common suspicious beliefs that over time become exaggerated.

What does research tells us about paranoid thoughts.

- Research shows that it is very **common to feel like someone is out to get you** or harm you in some way.
- The definitions of paranoia can vary. One study indicated that
  - 93% of the population believed that, at some point they had been talked about behind their back.
  - 80% of people had often felt that strangers were looking at them critically.

One research study demonstrated that about **25% of people with no history of mental health problems had thoughts that someone wanted to harm them**. That's about 15 million people in the UK, almost double the amount of people living in London (8.5 million)!

How many people have paranoid thoughts each week in the UK?

- 30 – 40% of the population thought once a week that negative comments about them were being put around.
- **That's 18 – 24 million people in the UK per week**
- 10 -30% of the population thought once a week that they were possibly under threat. That threat tended to be mild rather than severe.
- **That's 6 – 18 million people in the UK per week**

Paranoia & Psychosis

People with psychosis may experience more extreme forms of the paranoid beliefs discussed in this presentation. This simply means that:

- they may believe their paranoid thoughts more strongly, they may have them more frequently
- they may be more troubled by them or the thoughts may have more unusual content than those reported by the general population.

As discussed later paranoia can be a normal reaction to very stressful live events!

VIDEO OF PARANOIA AND PERSONAL BELIEFS THAT OTHERS DON'T HOLD

- https://www.youtube.com/watch?v=0-FYNNq4uMI
- https://www.youtube.com/watch?v=GXt9hPzHHi4
- (start from 2.05 – 2.40)

Part 3. Challenging the stereotypes of psychosis

There are many misunderstandings about psychosis.

We will review three of the main ones...

Misunderstanding 1: Psychosis is a brain disease.

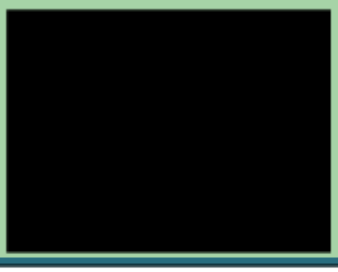
Lets consider whether there is evidence to support this

What Causes Psychosis?

- We don't know exactly yet.
- It is thought psychosis may occur when stress and vulnerability interact.
- Types of stress include:
  - Difficult life events
  - Difficult relationships
  - Trauma

- Types of vulnerability include:
  - Social (poverty/ living in a city)
  - Biological (such as genetics).
  - Psychological factors (worries about self and others).

Psychosocial Understandings of Psychosis: Video of Rory



Fact:

- Physical aspects of our body or brain only seems to accounts for a small part of why people have experiences of psychosis.
- Our life experiences and the social situations we are born into explain a much bigger part.

Misunderstanding 2: People with psychosis are dangerous

Lets consider whether there is evidence to support this

- **Fact:** The most reliable predictors of violence are:
  - Being male
  - Alcohol and drug use

- **FACT: Only a small proportion of all violent crimes are committed by people** who experience **psychosis.**
- The proportion of violent crimes in society committed by people who experience psychosis is less than 10%.
- **That means that over 90% of all violent crimes being committed are by people who don't experience psychosis.**

- The vast majority of people who are violent do not suffer from mental health difficulties
- Sadly, people who experience psychosis are more likely to be victims than commit crimes (Appleby, et al., 2001)

Misunderstanding 3: You can not recover from psychosis

Lets consider whether there is any evidence to support this

FACT: Recovery from psychosis is possible and more common than people think. Lets consider what the word recovery means and examine some evidence in relation to recovery from psychosis....

What is Recovery?

1. **Rebuilding life** (improved quality of life, doing things like studying, working, volunteering, going out and seeing friends and family)
2. **Rebuilding self** (motivation, self esteem, understanding distressing experiences)
3. **Hope for a better future** (feeling included in society, personal change, challenging others' beliefs about recovery from mental health problems).

What evidence is there that people recover from psychosis?

- One study found that, **one-half to two-thirds of people with experience of psychosis,** continued with important aspects of life such as friendships, work, and taking care of themselves did not worsen
- The same study also found that **68% did not show any signs or symptoms of psychosis at a 20 – 25 year follow up** from when they first presented to a mental health service.

What factors can help recovery from psychosis?

- We know that the **earlier** someone gets help for psychosis the **more likely** they are to make a **recovery** and at a faster rate.
- One study demonstrated that **just over half** of the people seen by specialist psychosis teams made a full or partial **recovery within 2** years.
- Other factors such as a **supportive network** of family and friends can help someone recover.
- **Reducing the stigma** of psychosis is an important factor in helping recovery.

Making sense of your own experiences of psychosis

- https://www.youtube.com/watch?v=DjD8_mW7CUc

Part 4.
How to cope with stigma

Initiatives to reduce stigma

- Time to Change
- http://www.time-to-change.org.uk/

Initiatives to reduce stigma

- Only us: No 'them and us' - Only Us. Whatever our mental health label, 4/4 of us are human beings.
- https://twitter.com/onlyuscampaign

Some important things to remember!

1. **Anyone** of us could **experience a mental health problem**.
2. **Mental health problems are very common. Psychosis is more common than people think** and psychotic-like experiences occur in the general population.
3. Psychosis occurs as a **normal reaction to difficult life events. Many people can recover from psychosis.**
4. **Understanding, support and acceptance** are the key to helping people feel better.

What can you do to fight stigma?

- Join Time to Change Campaign @timetochange
- Only Us Campaign: get a smiley badge @onlyuscampaign
- Sharing stories and disclosure
- Any other ideas?