# Self-management and peer support interventions for people with Severe Mental Illness

**Melanie Lean** 

D.Clin.Psy. Thesis (Volume 1), 2017 University College London

# **UCL Doctorate in Clinical Psychology**

# Thesis declaration form

| I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis. |
|--|
| Signature:   |
| Name: Melanie Lean   |
| Date:  |

#### Overview

This thesis investigates the effectiveness of self-management interventions for people with severe mental illness. Part one is a systematic review and meta-analysis of self-management interventions for those with severe mental illness. Part two reports on resilience outcomes in a randomised controlled trial of a peer-delivered self-management program for people recently discharged from crisis care (ISRCTN registration: http://www.isrctn.com/ISRCTN01027104). It also investigates baseline predictors of resilience. Part three, the critical appraisal, examines the concepts of self-management and resilience. It also considers the methodological and conceptual challenges of conducting randomised controlled trials of complex mental health interventions, particularly in populations where outcomes are largely socially determined.

# **Table of Contents**

| Overview  | 3  |
|---|----|
| Acknowledgements  | 7  |
| Part 1- Literature Review   | 8  |
| Abstract  | 9  |
| Introduction  | 10 |
| Methods   | 13 |
| Inclusion Criteria  | 13 |
| Exclusion Criteria  | 15 |
| Search Strategy   | 16 |
| Data Extraction and Quality Assessment  | 17 |
| Statistical Analysis  | 18 |
| Results   | 19 |
| Narrative Synthesis   | 21 |
| Study Characteristics   | 21 |
| Content of Self-Management Interventions: A typology                          | 37 |
| Outcome measures  | 40 |
| Risk of Bias  | 42 |
| Narrative Synthesis Summary   | 43 |
| Quantitative Synthesis  | 43 |
| Quantitative Summary  | 54 |
| Discussion  | 54 |
| Strengths and limitations of the review                                       | 56 |
| Implications for practice   | 58 |
| Research implications   | 59 |
| References  | 60 |
| Part 2 - Empirical Paper  | 72 |
| Abstract  | 73 |
| Introduction  | 74 |
| The current Study and hypotheses  | 78 |
| Results   | 89 |
| Baseline characteristics of participants                                      | 90 |
| Effect of Peer Support self-management intervention on resilience             | 95 |
| Univariate and multivariate analysis of predictors of resilience at 18 months | 95 |

| Discussion  | 99       |
|---|----------|
| Limitations   | 100      |
| Strengths   | 102      |
| Clinical and Research Implications  | 103      |
| References  | 105      |
| Part 3 - Critical Appraisal   | 113      |
| Practical challenges in the conduct of large complex interventions  | 115      |
| Research Design Issues  | 117      |
| Conclusion  | 122      |
| References  | 123      |
| Appendix 1: PRISMA Search strategy  | 126      |
| Appendix 2. Full Risk of Bias Assessment  | 133      |
| Appendix 3. Forest Plots for select outcomes of meta-analysis   | 135      |
| Appendix 4 Funnel Plots for assessment of Publication Bias (of meta-analy 10 or more studies)                             |          |
| Appendix 5. Post-hoc sub-group analysis of TAU only and active control  |          |
| Appendix 6. Ethics Approval   | 148      |
| Appendix 7. 18-month Ethics Approval  | 152      |
| Appendix 8. Patient Information Statement and Informed Consent Form   | 156      |
| Appendix 9. Recovery Workbook   | 167      |
| Appendix 10: Full baseline interview schedule   | 175      |
| Appendix 11. Connor Davidson Resilience Scale (CD-RISC-10)  | 176      |
| Appendix 12. Statement of Joint working   | 177      |
| List of Tables  |          |
| Part 1  |          |
| Table 1. Study population and design  | 22       |
| Table 2. Intervention characteristics organised by proposed types of interven   | tions 29 |
| Table 3. Summary of self-management intervention typologies   | 38       |
| Table 4. Outcomes Measures used in included trials  | 41       |
| Table 5. Analysis of Self-Management Intervention (SM) for people with mental illness compared to control (active or TAU) |          |

# Part 2

| Table 1. Baseline demographic characteristics of participants who completed the resilience outcome measure at 18 months91      |
|--|
| Table 2. Clinical characteristics at baseline of participants who completed the resilience outcome measure at 18 months        |
| Table 3. Baseline measures of participants who completed the resilience outcome measure at 18 months in each study condition93 |
| Table 4. Comparison of baseline characteristics of completers and drop-outs94  |
| Table 5. Association between treatment allocation and drop-outs95  |
| Table 6. Univariate predictors of resilience after 18 months post discharge from CR7 care97                                    |
| Table 7. Multivariate predictors of resilience after 18 months post discharge from CRT care98                                  |
| List of Figures  |
| Part 1   |
| Figure 1. PRISMA flowchart   |
| Figure 2. Cochrane Risk of Bias Summary42  |
| Figure 3. Forest plot of total symptoms at end of treatment46  |
| Figure 4. Forest plot of total symptoms at follow-up46   |
| Figure 5. Forest plot of depression and anxiety symptoms at end of treatment47   |
| Figure 6. Forest plot of depression and anxiety symptoms follow-up47   |
| Figure 7. Forest plot of total self-rated recovery at end of treatment48   |
| Figure 8. Forest plot of total self-rated recovery at follow-up48  |
| Figure 9. Forest Plot of functioning at end of treatment50   |
| Figure 10. Forest plot of functioning at follow-up50   |
| Figure 11. Forest plot of quality of life at end of treatment5   |
| Figure 12. Forest plot of quality of life at follow-up5  |
| Part 2   |
| Figure 1. CONSORT flow diagram82   |
| Figure 2. Scatterplot of resilience (CD-RISC-10) at 18 months and baseline measure   |
| of recovery (QPR)96  |

## **Acknowledgements**

I would like to express an enormous amount of gratitude for all of the wonderful people that have contributed to this study. Especially every person who kindly gave their time to participate in this study, the peer support workers who delivered the intervention, and the CRT staff who work in underfunded services but still took time to help recruit participants in the hope to improve services and the lives of the people they care for.

Special thanks to Dr Miriam Fornells-Ambrojo for her expert guidance, compassion and sense of humour whilst we gestated together: Miriam- an actual human; myself a thesis. A very special thanks to Prof Chris Barker who valiantly stepped up to help deliver this thesis in the final months. It has been a most enriching and containing experience to work with Chris: academically, personally and grammatically.

To Prof Sonia Johnson and Dr Bryn Lloyd-Evans: thank you for another opportunity to work with you both on such a great project and for your input and guidance throughout. To my CORE posse of possums (Kate, Danni, Mikey, Becky, Marina, Jingyi, Siobhan, Puffin, Liberty and Ruimin) a huge thank you! It was a privilege to work with you all and to now call you friends. A special thanks to Dr Louise Marston who was very gracious and generous in her time and patience teaching me random effects multilevel modelling.

To my mum, as always thanks for your support- 14 years on still 'keeping the proteins alive'. Matt, Jolene and Alfred- thanks for the pet therapy and company. Thanks also to Heidi- who has seen me through another thesis and is still the yin to my yang. And finally, to my favourite person, Henry, for always making me laugh and for coming home to hold my hand during this final push.

# **Part 1- Literature Review**

Self-management interventions for people with severe mental illness: a systematic review and meta-analysis

#### Abstract

Aims: Severe mental illness has a considerable and persistent impact on individuals, their families and carers. In addition to standard care, self-management interventions can assist to empower individuals in their recovery by providing the knowledge and skills to enable them to make informed decisions to manage their own care. The present review aimed to evaluate the effectiveness of self-management interventions for adults with Severe Mental Illness (SMI)

**Method:** A systematic review and narrative synthesis (n=32 studies) of randomised controlled trials of self-management interventions was conducted. A meta-analysis (n= 30 studies) of symptomatic, relapse, recovery, functioning and quality of life outcomes was conducted using Revman.

Results: From the narrative synthesis, self-management interventions could be classified into five categories: illness management and compliance; bipolar specific illness management; transition to community from ward; coping oriented; and recovery oriented interventions. From the meta-analysis, self-management interventions conferred benefits in terms of reducing symptoms, improving functioning and quality of life: both at the end of treatment and sustained at follow up. Overall the effect size was small to medium, however a larger effect size was seen for symptoms at follow up. There was no evidence that self-management decreased risk of relapse as objectively measured, but subjective sense of recovery and self-efficacy improved at end of treatment and follow up.

**Conclusion:** The provision of self-management interventions alongside standard care is likely to be a useful strategy in improving outcomes for people with severe mental illness.

#### Introduction

Severe Mental Illness (SMI) is a category of major psychiatric disorders associated with persistently impaired functioning in areas such as work, social relationships and self-care (Färdig, Lewander, Fredriksson, & Melin, 2011), and includes the diagnoses of schizophrenia, schizoaffective disorder, bipolar, and severe depression (DSM–IV, American Psychiatric Association, 2000). The impact of SMI at the individual level is wide, ranging from cognitive impairment, social isolation and stigma to inequalities in healthcare access, poorer physical health and increased mortality (Lawrence & Kisely, 2010). Furthermore, there is a significant health and financial burden often experienced by the families and carers of people with SMI (Yesufu-Udechuku et al., 2015), as well as a substantial cost to mental health services (McCrone, Dhanasiri, Patel, Knapp, & Lawton-Smith, 2008) as services face the challenge of meeting a complex mix of clinical and social need.

Recovery from SMI is often complex and lengthy, and can be understood as both a process and an outcome (Deegan, 1989 cited in Torrey, Rapp, Van Tosh, McNabb, & Ralph, 2005). The clinical recovery outcomes for people with SMI often focus on recurrent relapses and re-admissions, persistence of symptoms (often despite taking medication) and ongoing (sometimes lifelong) contact with mental health services. For individuals, the process can involve recovering their connection with others, their community, and their own sense of meaning, purpose and efficacy (Torrey et al., 2005) to progress in life beyond the challenges posed by mental illness (Noordsy et al., 2002). The estimated rate of recovery from SMI is contested and dependent on a range of factors such as the definition of recovery, outcomes evaluated, length of follow up, and setting (Slade & Longden, 2015). Figures have ranged from 13.5% clinical recovery in a recent systematic review of recovery in schizophrenia (Jääskeläinen et al., 2013) to 46% in a 10-year follow up study of people who presented with a first episode of psychosis (Revier et al., 2015).

Nevertheless, the impact on individuals in terms of social exclusion (from employment and relationships) remains high (Slade & Longden, 2015).

There are a number of effective treatment approaches for those with SMI including psychopharmacotherapy, and psychosocial interventions such as social support, family interventions, psychoeducation, cognitive behaviour therapy for psychosis, supported employment and social skills training (Mueser & McGurk, 2004; Oud et al., 2016). However, in spite of the range of interventions available, relapse is common, and long term sustained recovery is a reality for few. Illness selfmanagement interventions draw on elements of these evidence-based practices to empower individuals by providing the knowledge and skills to enable them to make informed decisions to manage their own care (Mueser & McGurk, 2004), cope with symptoms, and reduce susceptibility to relapse and reliance on services (Mueser et al., 2002). The largest and most comprehensive review of interventions that improve the course of SMI was conducted by Mueser and colleagues in 2002 and identified four crucial elements: (i) providing psychoeducation about mental illness and its treatment; (ii) behavioural tailoring to facilitate medication adherence; (iii) developing a relapse prevention plan; and (iv) teaching coping strategies for persistent symptoms.

The Illness Management and Recovery (IMR) program was developed to integrate these four elements into a single, manualised package that can be delivered to groups or individuals (Mueser et al., 2006). While this specific intervention has been widely delivered across multiple countries and settings, other similar self-management interventions have developed independently, many of which also incorporate the key elements identified by Mueser and colleagues (2002). The result of which is a large body of interventions known as self-management being delivered to those with SMI, but with little in the way of

characterising these interventions in terms of their similarities and differences, or an evaluation of their effectiveness.

Several reviews of self-management interventions have been conducted previously, but have tended to focus on broad, non-specific self-management interventions such as psychoeducation (Lincoln, Wilhelm, & Nestoriuc, 2007; Zhao, Sampson, Xia, & Jayaram Mahesh, 2015) or self-help (Scott, Webb, & Rowse, 2015), or be confined to specific populations (Zou et al., 2013). A comprehensive systematic review and meta-analysis of all studies of self-management interventions (defined as those that include Mueser et. al.'s (2002) key evidence-based components of self-management) has yet to be done. The present review is the first to summarise and synthesise the content of self-management interventions and provide a typology to describe the current state of self-management for SMI. It assesses the effectiveness of self-management in the typical mixed populations of people with SMI found in NHS secondary care settings. It is likely in the current climate of austerity and in the context of increasing service-user choice and empowerment that psychosocial interventions will increasingly rely on equipping individuals to manage their own mental wellbeing. Furthermore, these interventions offer the flexibility to be delivered by peers, in groups, or online. As such it is likely that self-management will increasingly become an important treatment approach for those with severe mental illness and an understanding of its effectiveness is essential.

# Aims

This paper reviews self-management interventions for populations with Severe Mental Illness (SMI) and aims to:

 Provide a narrative synthesis of available self-management interventions in terms of orientation, essential components, and other defining characteristics.

- Review the evidence of the immediate and longer term effectiveness of selfmanagement in relation to the following outcomes:
  - a) Symptomatic recovery
  - b) Relapse prevention
  - c) Reduced need for hospitalisation
  - d) Subjective recovery
  - e) Functioning
  - f) Quality of Life

#### **Methods**

A review protocol was developed following PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & The Prisma Group, 2009) that outlined the research question, inclusion and exclusion criteria, search strategy and analysis plan and was registered at PROSPERO (Ref: CRD42017043048). There was no funding source for this study.

#### **Inclusion Criteria**

Inclusion criteria were developed using the PICO (Participant, Intervention, Comparison, & Outcome) method (Moher et al., 2009):

# **Participants**

Studies were included if participants were adults aged 18 years and over and diagnosed with a Severe Mental Illness (SMI), that is with a clinical diagnosis of schizophrenia spectrum disorders (schizoaffective disorder, delusional disorder and psychosis), bipolar disorder, major depression or studies with mixed populations (including personality disorder) using secondary care mental health services.

Participants at any stage of their illness, that is as part of early intervention, or more chronic/later stages were included in this review.

#### Intervention

Studies were included if they featured the delivery of a "self-management intervention" directly to service users that was designed to educate and equip individuals with the skills to manage symptoms, relapses and overall psychosocial functioning (Mueser, Deavers, Penn, & Cassisi, 2013). Self-management interventions could be delivered in conjunction with treatment as usual. In order to investigate the effectiveness of self-management itself, interventions with a broader focus that included self-management as only one of the intervention components were not included in the current review, unless it was possible to ascertain the unique impact of self-management. To be considered a self-management intervention for the purposes of this systematic review the intervention had to include all of the following three domains identified by Mueser and Colleagues (Mueser et al., 2002) as effective areas of self-management:

- Psychoeducation about mental illness and its treatment (in order to make informed decisions about care)
- Recognition of early warning signs of relapse and development of a relapse prevention plan
- 3. Coping skills for dealing with persistent symptoms

Additionally, the self-management intervention should include a recoveryfocused element such as that defined by Mueser et al. (2013) to set personal goals
based on an individual's own hopes for recovery and learn how to effectively
manage their illness in the context of pursuing those goals.

Strategies for medication management, the fourth domain identified by Mueser and colleagues (2002), was not a necessary domain for a self-management intervention to be included into the current review.

# Comparison

All randomised controlled trials (RCTs) including cluster RCTs and factorial RCTs were considered for inclusion. Quasi randomised studies were excluded.

Studies employing either treatment as usual or active controls were included in this review.

#### Outcome

If studies reported on any of the following outcomes they were included in the metaanalyses

- 1. Symptom-focused outcomes
- Relapse (symptomatic relapse, or service use outcomes (admissions; days in hospital)
- 3. Recovery-focused outcomes (refers to specific measures developed in conjunction with service users, that aim to tap participants' own perceived sense of recovery related to concepts such as overcoming "stuckness", self-empowerment and efficacy, social connectedness, functioning, overall well-being, hope and the pursuit of a meaningful life. Separate analyses looked at outcomes measuring total self-rated recovery and measures looking at individual elements thought to be indicative of recovery such as hope, empowerment and self-efficacy).
- 4. Functioning (global)
- 5. Quality of life

# **Exclusion Criteria**

# Studies were excluded if:

 The intervention had a therapeutic focus beyond that of improving an individual's self-management of their illness (e.g. cognitive remediation, cognitive behavioural therapy, basic life skills or social skills) which prevented evaluating the specific efficacy of the self-management component.

#### 2. The intervention was delivered:

- i) to family members (either as the target recipients of the intervention or in addition to the service user participants).
- ii) as part of, or alongside another intervention e.g. The Life Goals

  Programme when it was part of the multi-component collaborative care

  model, Life Goals Collaborative Care (LG-CC) (Bauer et al., 2006a, 2006b;

  Bauer, Biswas, & Kilbourne, 2009) was excluded on the basis of the

  additional nurse care management component.

# **Search Strategy**

A systematic search for all relevant literature was conducted using a PRISMA (Moher et al., 2009) search strategy of the following databases: Medline, Embase, PsychINFO, DARE and CENTRAL from their inception until November 2016. This was part of a broader search of clinical trials originally conducted in 2012-13 as part of the NICE Schizophrenia Guidelines (National Institute for Health and Care Excellence (NICE), 2014b). The relevant parts of this published search strategy utilised in the current study are included in Appendix 1. Abstracts were screened based on the review protocol and any uncertainties were reviewed by supervisor to reach a consensus. The full text of these papers were reviewed to ensure they met the criteria specified for inclusion in this review. Twenty percent of the full text articles assessed for eligibility (n=63) were blindly assessed to meet inclusion and exclusion criteria by a senior member of the research team. The few cases of disagreement were discussed and consensus reached. Additionally, a hand search of reference lists was conducted.

All abstracts were retrieved and added to Mendeley referencing software (Version 1.16.3).

# **Data Extraction and Quality Assessment**

Data were extracted and reviewed in Microsoft Excel. Raw outcome data extracted from papers published prior to 2012 was kindly provided by the Cochrane Collaboration group from the original search conducted as part of the schizophrenia guidelines development. The relevant studies and outcome data were then extracted according to this current review protocol and checked against the original manuscripts. Characteristics of the study design, the intervention, participants and outcomes for all available data at all provided time points were extracted. Authors were contacted and asked to provide any missing data. Where necessary (i.e. unable to obtain original data from authors), outcomes reported as mean difference were converted to mean and standard deviation using baseline data where available if the number of participants was consistent at both time points. Baseline standard deviation (SD) was used as a conservative estimate of SD for the follow up time point. When analysing symptoms, depression and anxiety scores for some studies were combined to create a composite "Affect" score for anxiety and depression (as per Cochrane Handbook table 7.7a (Higgins & Green, 2011). When a study had three arms either the active intervention arm or active control arm (depending on which met the inclusion/exclusion criteria) was compared to the treatment as usual arm in the analysis. For analyses where the pooling of outcome scales were in differing directions, the mean of the intervention group was swapped with the mean of the control group, which is equivalent to reversing the direction of the scale. For the outcomes of functioning, quality of life and recovery, all scores were multiplied by -1 so the direction of effect was in line with other analyses in this review (i.e. that higher scores indicated a worse outcome).

#### Assessment of Bias

Assessment of bias was performed using the Cochrane Collaboration Risk of Bias Tool (Higgins & Green, 2011). Each study was rated for risk of bias due to sequence generation, allocation concealment, blinding of assessors, selective outcome reporting and incomplete data. The blinding of participants in trials of complex interventions is problematic. As such, it is assumed that blinding of participants was at high risk for all studies. Risk of bias was rated as high (weakening confidence in results), low (unlikely to seriously alter results) or unclear.

#### Publication Bias

Funnel plots will be generated to examine publication bias in analyses with more than 10 studies.

## **Statistical Analysis**

Review Manager Software (Revman 5.2) was used to conduct the metaanalyses. When outcome data was reported for more than one follow-up point, the time point closest to 1-year post intervention was used. Where more than one outcome measure was used to report an outcome in the same study, we included the outcome more commonly reported by other studies in the analysis. On the rare event that a study reported both relapse and readmission data, we included the readmission data in the analysis.

#### Effect Size Calculation

Effect sizes for continuous data were calculated as standardised mean difference, Hedges' g and studies were weighted using inverse variance. For dichotomous outcomes we calculated risk ratios and combined studies using the Mantel-Haenszel method (Higgins & Green, 2011). All outcomes are reported with 95% confidence intervals (CI) using random effects modelling. If reported by studies, intention to treat data was used in the present analysis.

# Heterogeneity

Heterogeneity of studies was assessed through visual inspection of forest plots, the p value of Chi squared test (Q) and calculating the I<sup>2</sup> statistic, which describes the percentage of the variability in effect estimates that is due to heterogeneity rather than chance (Cuijpers, 2016). A p value less than 0.10 and an I<sup>2</sup> exceeding 50% suggests substantial heterogeneity. Quantifying inconsistency across studies in this way allowed us to explore the possible reasons for heterogeneity through sensitivity analysis.

Sensitivity analyses were carried out using the "one-study-removed" method to examine the effect of a specific study on the pooled treatment effect. When a study was identified as substantially contributing to heterogeneity, the potential sources of clinical or methodological heterogeneity were reviewed and compared to the remaining studies to evaluate if their exclusion from the particular meta-analysis was warranted.

#### Results

Of the 6365 potentially relevant citations, 63 papers were retrieved and assessed for inclusion (See figure 1). Of these 14 were excluded because they were not mental health self-management interventions (either they did not meet the three criteria for inclusion, or covered social skills training only); one study was not completed (protocol paper only); and a further 10 papers were outside of the scope of this review (i.e. self-management intervention was delivered as part of a trial of overall collaborative care model, or included family members in the intervention). One paper was included from a reference hand search. Thirty-two randomised controlled trials were therefore included in the narrative synthesis (from 39 full-text articles). Two studies were not included in the meta-analyses (Eckman et al., 1992; Kopelowicz, Wallace, & Zarate, 1998) as they did not report usable outcomes.

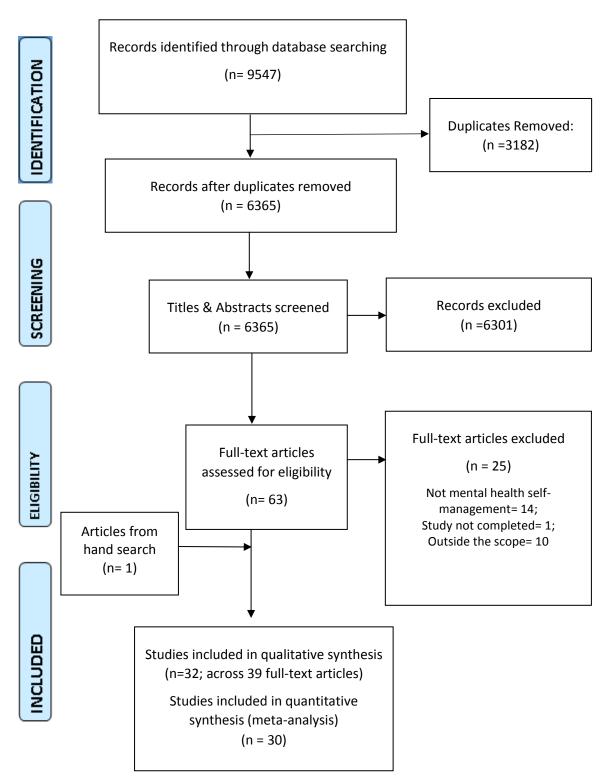


Figure 1. PRISMA flowchart

# **Narrative Synthesis**

# **Study Characteristics**

A detailed breakdown of the characteristics of the studies included in this review can be found in Table 1. Studies are grouped according to control group: treatment as usual or active. A brief outline of key features are provided below.

## **Participants**

Studies included in this review randomised a total of 4961 participants with a median sample size of 106 (range 32 to 555). The majority of studies were conducted in western countries (k=25), with a smaller but significant proportion in Asian and developing countries (k=7). The majority of studies (k=24) included participants that were currently living in the community, with eight studies recruited from inpatient settings.

The mean age was 40 years, suggesting a chronic duration of illness, and 44% of participants were female. In relation to clinical diagnosis, 16 studies included only participants with schizophrenia spectrum disorder and seven included only those with a diagnosis of bipolar disorder. The remaining nine included mixed populations of participants with schizophrenia, psychosis, bipolar, major depressive disorder and personality disorder.

Table 1. Study population and design

|   |         |            | Sampl   | e chara | acteristics           |            |             | Compara   | itor   | Time points <sup>†</sup><br>(in weeks) |              |
|---|---------|------------|---|---------|-----------------------|------------|-------------|---|--|--|--------------|
| Study ID  | Country | Context    | Diagnosis <sup>‡</sup><br>(% of<br>sample)            | Age     | Gender<br>%<br>female | Total<br>N | Active<br>N | Intervention  | Control                                      | Post-<br>treatment                     | Follow<br>up |
| Treatment As usual  |         |            |   |         |                       |            |             |   |  |  |              |
| ATKINSON 1996<br>(Atkinson, Coia,<br>Gilmour, & Harper,<br>1996)                              | UK      | Community  | SZ 100%   | NR      | 37                    | 146        | 73          | Education groups for People with Schizophrenia  | TAU- Wait list control                       | 20                                     | 32           |
| BARBIC 2009<br>(Barbic, Krupa, &<br>Armstrong, 2009)  | CAN     | Community  | SZ 100%   | 45      | 33                    | 33         | 16          | Recovery Workbook   | TAU  | 12                                     | NR           |
| CHIEN 2013<br>(Chien & Lee, 2013)   | НК      | Community  | SZ 100%   | 26      | 45                    | 96         | 48          | Mindfulness-Based<br>Psychoeducation Program<br>(MBPP)  | TAU  | NR                                     | 37;<br>102*  |
| CHIEN 2014<br>(Chien & Thompson,<br>2014)   | НК      | Community  | SZ 100%   | 26      | 43                    | 107        | 36          | Mindfulness-Based Psychoeducation Program (MBPP)  | TAU & Active control (basic psychoeducation) | 25                                     | 52           |
| COOK 2011<br>(Cook et al., 2011;<br>Cook, Copeland, et<br>al., 2012; Jonikas et<br>al., 2013) | US      | Community  | SZ: 21%<br>BP: 38%<br>MDD:<br>25%;<br>Other:<br>15%   | 46      | 66                    | 555        | 276         | Wellness Recovery Action Planning (WRAP)  | TAU  | 14                                     | 40           |
| COOK 2012<br>(Cook, Steigman, et<br>al., 2012; Pickett et<br>al., 2012)                       | US      | Community  | SZ: 21%;<br>BP:40%;<br>MDD:<br>18%;<br>Other:<br>8.6% | 43      | 56                    | 428        | 212         | Building Recovery<br>of Individual Dreams and<br>Goals through Education<br>and Support (BRIDGES) | TAU  | 14                                     | 40           |
| FARDIG 2011<br>(Färdig, Lewander,<br>Melin, Folke, &<br>Fredriksson, 2011)                    | SWE     | Outpatient | SZ 100%   | 40      | 46                    | 41         | 21          | Illness management and Recovery program   | TAU  | 39                                     | 91           |

|   |         |            | Sampl   | e chara | acteristics           |            |             | Compara  | ator           | Time points <sup>†</sup><br>(in weeks) |                |
|---|---------|------------|---|---------|-----------------------|------------|-------------|--|----------------|--|----------------|
| Study ID  | Country | Context    | Diagnosis <sup>‡</sup><br>(% of<br>sample)            | Age     | Gender<br>%<br>female | Total<br>N | Active<br>N | Intervention   | Control        | Post-<br>treatment                     | Follow<br>up   |
| HASSON 2007<br>(Hasson-Ohayon,<br>Roe, & Kravetz,<br>2007)            | ISR     | Inpatient  | SZ: 84%;<br>BP: 3%;<br>P: 3%;<br>Other: 3%            | 35      | 35                    | 210        | 119         | Illness management and Recovery program  | TAU            | 35                                     | NR             |
| LEVITT 2009<br>(Levitt et al., 2009)                                  | US      | Community  | SZ: 32%;<br>BP:12%;<br>P: 6%;<br>MDD:43;<br>Other: 7% | 54      | 37                    | 104        | 54          | Illness management and<br>Recovery program   | TAU: Wait list | 22                                     | 72             |
| LIN 2013<br>(Lin et al., 2013)  | TWN     | Inpatient  | SZ 100%   | 35      | 36                    | 97         | 48          | Adapted IMR  | TAU            | 3                                      | 7              |
| PERRY 1999<br>(Perry, Tarrier,<br>Morriss, Mccarthy, &<br>Limb, 1999) | UK      | Outpatient | BP 100%   | 45      | 68                    | 69         | 34          | Teaching patients with bipolar disorder to identify early symptoms of relapse and obtain treatment | TAU            | NR                                     | 26, 52*,<br>78 |
| SAJATOVIC 2009<br>(Sajatovic et al.,<br>2009)                         | US      | Community  | BP 100%   | 41      | 62                    | 164        | 84          | Life Goals Program   | TAU            | NR                                     | 13; 26;<br>52* |
| SALYERS 2010<br>(Salyers et al., 2010)                                | US      | Community  | P: 55%;<br>BP: 10%;<br>Other:17;<br>missing:<br>18%   | 42      | 46                    | 324        | 183         | Illness management and Recovery program  | TAU            | 52                                     | 104            |

|   |         |            | Sampl                                      | e chara | acteristics           |            |             | Compar   | ator                   | Time points <sup>†</sup><br>(in weeks) |              |
|---|---------|------------|--|---------|-----------------------|------------|-------------|--|------------------------|--|--------------|
| Study ID  | Country | Context    | Diagnosis <sup>‡</sup><br>(% of<br>sample) | Age     | Gender<br>%<br>female | Total<br>N | Active<br>N | Intervention   | Control                | Post-<br>treatment                     | Follow<br>up |
| SHON 2002<br>(Shon & Park, 2002)  | KOR     | Outpatient | SZ: 55%;<br>P: 15%<br>Other:<br>29%        | 33      | 42                    | 40         | 20          | Self-Management education program  | TAU                    | 12                                     | NR           |
| SMITH 2011<br>(Smith et al., 2011)  | UK      | Community  | BP 100%                                    | 44      | 62                    | 50         | 24          | Beating Bipolar  | TAU                    | NR                                     | 43           |
| TODD 2014<br>(Todd, Jones, Hart,<br>& Lobban, 2014;<br>Todd, Solis-Trapala,<br>Jones, & Lobban,<br>2012)                  | UK      | Community  | BP 100%                                    | 43      | 72                    | 122        | 61          | Living with Bipolar (LWB)  | TAU: Wait list control | 13; 26*                                | NR           |
| TORRENT 2013<br>(Torrent et al., 2013)  | ESP     | Outpatient | BP 100%                                    | 40      | Not<br>reported       | 268        | 82          | Psychoeducation + TAU Study had 3 arms (intervention in original study Functional Remediation) | TAU                    | 21                                     | NR           |
| VAN GESTEL-<br>TIMMERMANS 2012<br>(Van Gestel-<br>Timmermans,<br>Brouwers, van<br>Assen, & van<br>Nieuwenhuizen,<br>2012) | NL      | Outpatient | PD: 31%<br>P: 33%;<br>other:<br>36%        | 44      | 66                    | 333        | 168         | "Recovery Is Up to You"  | TAU                    | 13                                     | 26           |

|   |         |            | Sampl                                      | Compara | Time points <sup>†</sup><br>(in weeks) |            |             |  |   |                    |              |
|---|---------|------------|--|---------|--|------------|-------------|--|---|--------------------|--------------|
| Study ID                                    | Country | Context    | Diagnosis <sup>‡</sup><br>(% of<br>sample) | Age     | Gender<br>%<br>female                  | Total<br>N | Active<br>N | Intervention   | Control   | Post-<br>treatment | Follow<br>up |
| VREELAND 2006<br>(Vreeland et al.,<br>2006) | US      | Outpatient | SZ 100%                                    | NR      | 55                                     | 71         | 40          | Team Solutions   | TAU   | 24                 | NR           |
| ZHOU 2014<br>(Zhou, Zhang, & Gu,<br>2014)   | CHN     | Community  | SZ 100%                                    | 35      | 47                                     | 201        | 103         | Modules of the UCLA<br>Social & Independent<br>Living Skills Program             | TAU   | 26                 | 130          |
| Active Control                              |         |            |  |         |  |            |             |  |   |                    |              |
| ANZAI 2002<br>(Anzai et al., 2002)          | JPN     | Inpatient  | SZ 100%                                    | 47      | 25                                     | 32         | 16          | Social and Independent<br>Living Skills Program-<br>Community Re-entry<br>Module | Active -<br>Conventional<br>occupational<br>rehabilitation<br>program | 9                  | 52           |
| CHAN 2007<br>(Chan, Lee, & Chan,<br>2007)   | СН      | Inpatient  | SZ 100%                                    | 36      | 0                                      | 81         | 44          | Transforming Relapse and Instilling Prosperity (TRIP)                            | Active - traditional ward occupational therapy (WOT) programme        | NR                 | 54           |
| COLOM 2003<br>(Colom et al., 2003,<br>2009) | ESP     | Outpatient | BP 100%                                    | NR      | 63                                     | 120        | 60          | Psychoeducation + TAU  | Active:<br>Unstructured<br>support group                              | 21                 | 104*;<br>260 |

|  |         |            | Sampl   | e chara | acteristics           |            |             | Compara  | tor  | Time points <sup>†</sup><br>(in weeks) |              |
|--|---------|------------|---|---------|-----------------------|------------|-------------|--|--|--|--------------|
| Study ID   | Country | Context    | Diagnosis <sup>‡</sup><br>(% of<br>sample)        | Age     | Gender<br>%<br>female | Total<br>N | Active<br>N | Intervention   | Control  | Post-<br>treatment                     | Follow<br>up |
| COOK 2013<br>(Cook et al., 2013a)  | USA     | Community  | SZ: 26%;<br>BP 31%;<br>MDD:27%<br>; Other:<br>16% | 46      | 50                    | 143        | 72          | Wellness Recovery Action Planning (WRAP)   | Active: Choosing<br>Wellness: Healthy<br>Eating Curriculum<br>9x2.5hr sessions | 9                                      | 35           |
| ECKMAN 1992<br>(Eckman et al.,<br>1992)  | US      | Outpatient | SZ 100%   | 40      | 0                     | 41         | 20          | Social and Independent<br>Living Skills Program-<br>Medication and Symptom<br>Self-management modules                | Active: Supportive<br>Group<br>Psychotherapy                                   | 26                                     | 78           |
| KOPELOWICZ 1998<br>(Kopelowicz et al.,<br>1998; Mackain,<br>Smith, Wallace, &<br>Kopelowicz, 1998) | US      | Inpatient  | SZ 100%   | 35      | 29                    | 59         | 28          | Community re-entry program   | Active:<br>Occupational<br>therapy<br>group                                    | NR                                     | 5            |
| PROUDFOOT 2012<br>(Proudfoot et al.,<br>2007, 2012)  | AUS     | Outpatient | BP 100%   | NR      | 70                    | 419        | 139         | Online Bipolar Education<br>Program (BEP) + email<br>support from expert<br>patients known as Informed<br>Supporters | Active: Online<br>Bipolar Education<br>Program (BEP)                           | NR                                     | 26           |
| SALYERS 2014<br>(Salyers et al., 2014)   | USA     | Community  | SZ: 100%  | 48      | 20                    | 118        | 60          | IMR  | Active:<br>unstructured<br>problem solving<br>group                            | 39                                     | 78           |
| SCHAUB 2016<br>(Schaub et al., 2016)   | DEU     | Inpatient  | SZ: 96%;<br>P:4%                                  | 34      | 47                    | 196        | 100         | Group-based Coping<br>Oriented Program (COP)   | Active: Supportive group treatment   | 8                                      | 52*;<br>104  |

|   |         |            | Sampl                                      | e chara | Compar                | Time points <sup>†</sup><br>(in weeks) |                 |  |                                       |                    |                     |
|---|---------|------------|--|---------|-----------------------|--|-----------------|--|---------------------------------------|--------------------|---------------------|
| Study ID                                    | Country | Context    | Diagnosis <sup>‡</sup><br>(% of<br>sample) | Age     | Gender<br>%<br>female | Total<br>N                             | Active<br>N     | Intervention   | Control                               | Post-<br>treatment | Follow<br>up        |
| WIRSHING 2006<br>(Wirshing et al.,<br>2006) | US      | Inpatient  | SZ 100%                                    | 46      | 2                     | 94                                     | Not<br>reported | Modified Community Re-<br>Entry Program<br>(CREP)                                | Active: Illness<br>Education Class    | NR                 | 53                  |
| XIANG 2006<br>(Xiang et al., 2006)          | CHN     | Outpatient | SZ 100%                                    | 39      | 51                    | 96                                     | 48              | Social and Independent<br>Living Skills Program-<br>Community re-entry<br>module | Active: Supportive counselling        | 8                  | 33                  |
| XIANG 2007<br>(Xiang et al., 2007)          | CHN     | Inpatient  | SZ 100%                                    | 39      | 53                    | 103                                    | 53              | Social and Independent<br>Living Skills Program-<br>Community re-entry<br>module | Active: Group psychoeducation program | 4                  | 26; 56*;<br>78; 108 |

<sup>\*</sup>Time point used in meta-analysis. + Time point of data collection in weeks post randomisation. NR: Not Reported; TAU Treatment as Usual

<sup>‡</sup>Abbreviations: SZ: schizophrenia or schizoaffective disorder; BP: bipolar disorder; P: psychosis; MDD: major depressive disorder; PD: personality disorder.

#### Interventions

The characteristics of the self-management interventions included in this review, along with a description of each intervention are summarised in table two.

The studies are organised according to the typology of self-management interventions proposed in this review and are outlined in more detail on the following pages.

In all 32 studies, self-management interventions were provided in addition to treatment as usual. While the content and scope of the self-management interventions included in this review was largely dictated by the inclusion and exclusion criteria, there were several areas of variation across studies. In particular, the duration of interventions ranged broadly from 1 to 43 weeks (median duration 12 weeks). Likewise face to face/group contact time also ranged widely from 4 to 96 hours (median 23 hours). Most interventions were delivered in a group format, and facilitated by clinicians (k=22) or peer (k=5). The remaining studies were delivered to participants individually, either as an online, computer based intervention (k=2), by a clinician (k=1) or by peer (k=1). Finally, one study used a combination of group and individual sessions facilitated by clinician. All interventions were delivered from a manualised protocol of some form, however the depth, detail and fidelity of the intervention to the manual was not always reported in detail.

#### Controls

Self-management interventions were compared to treatment as usual in 18 studies, waiting list control conditions in 2 studies and the remaining 12 had active control conditions such as group counselling, occupational therapy or psychoeducation (Please see table 2 below).

Table 2. Intervention characteristics organised by proposed types of interventions

| Study ID  | Format    | Facilitator | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description   |
|---|-----------|-------------|---------------|-------------------|----------------------------|----------------------------|---|
| Illness Mana  | gement ar | nd Complia  | nce Interv    | entions           |                            |                            |   |
| ATKINSON<br>1996<br>(Atkinson et<br>al., 1996)                  | Group     | Clinician   | 20            | 20                | 1.5                        | 30                         | Education group Sessions alternated between an information session (short presentation and discussion) followed by a problem-solving session. Patients were given a manual outlining the content of the sessions, which included: The meaning of schizophrenia to the individual, Current understandings and treatment for schizophrenia, identifying early signs of relapse and problem solving around managing relapse, symptoms, medication & side effects. Problem solving around relationships with friends and family, teaching social skills and stress management, and rehabilitation and linking in to community resources.                                |
| CHAN 2007<br>(Chan et al.,<br>2007)                             | Group     | Clinician   | 10            | 2                 | 0.8                        | 8                          | Transforming Relapse and Instilling Prosperity (TRIP)  Utilizes strategies from IMR however is not a direct derivative of the program. TRIP is an intensive, ward-based illness management program aims to decrease treatment non-compliance and improve patient's insight and health through didactic teaching of information about their illness and open discussion of adaptive life and coping skills. Sessions cover two categories i) illness orientated (mental health, medication management, relapse prevention planning, symptom management) and ii) health orientated (emotion management, rehabilitation resources, healthy living, stress management). |
| FARDIG 2011<br>(Färdig,<br>Lewander,<br>Melin, et al.,<br>2011) | Group     | Clinician   | 40            | 40                | 1                          | 40                         | Illness Management and Recovery (IMR) Program Is a clinician led, curriculum based program for service users with SMI. Teaches evidence-based techniques for improving illness self-management: psychoeducation, cognitive-behavioural approaches to medication adherence, relapse prevention, social skills training (e.g., to enhance social support), coping skills training (e.g., for persistent symptoms). Overall aim is to help clients learn about mental illnesses and strategies for treatment; decrease symptoms; reduce relapses and rehospitalisation; and make progress toward goals and toward recovery.  |
| HASSON<br>2007<br>(Hasson-<br>Ohayon et<br>al., 2007)           | Group     | Clinician   | 35            | 35                | 1                          | 35                         | Illness Management and Recovery (IMR) Program Follows the standardized curriculum-based approach of IMR. Educational handouts that are a central part of the Illness Management and Recovery program were translated into Hebrew and adapted for use in Israel.   |

| Study ID                                       | Format                  | Facilitator         | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description   |
|--|-------------------------|---------------------|---------------|-------------------|----------------------------|----------------------------|---|
| LEVITT<br>2009<br>(Levitt et al.,<br>2009)     | Group                   | Clinician           | 40            | 20                | 1                          | 40                         | Illness Management and Recovery (IMR) Program The standard IMR program was delivered to those living in supportive housing.   |
| LIN<br>2013<br>(Lin et al.,<br>2013)           | Group                   | Clinician           | 6             | 3                 | 1.5                        | 9                          | Adapted Illness Management and Recovery (IMR) Program  Adapted IMR to fit in-patient acute care setting with the primary focus on symptom and medication management, while maintaining a recovery perspective. The adapted IMR program was based on three abbreviated modules from the original IMR program: Practical Facts about Schizophrenia, Using medication Effectively, and Coping with Problems and Persistent Symptoms. The IMR sessions usually started during the third week of hospitalization. Individuals who were discharged from the hospital before completing the adapted IMR program were invited to continue with the same IMR group until they had completed it. Brief essays about recovery written by individuals who had completed the adapted IMR program were also included. |
| SALYERS<br>2010<br>(Salyers et<br>al., 2010)   | Individual<br>and group | Clinician +<br>Peer | - 43          | 43                | 1                          | 43                         | Illness Management and Recovery (IMR) Program This study assessed the effectiveness of IMR when delivered to those receiving Assertive Community Treatment.   |
| SALYERS<br>2014<br>(Salyers et<br>al., 2014)   | Group                   | Clinician           | 39            | 39                | 1                          | 39                         | Illness Management and Recovery (IMR) Program Standard program  |
| SHON<br>2002<br>(Shon &<br>Park, 2002)         | Group                   | Clinician           | 12            | 12                | 1                          | 12                         | Medication and Symptom Management Education program Sessions covered the following key areas: six sessions covered introduction of the psychiatric disorders; recognising symptoms and a variety of coping strategies, 3 sessions reinforcing knowledge concerning medication use and side effects, and 3 sessions covering relapse warning symptoms and coping skills and prevention strategies. Utilised a range of teaching, video vignettes, and small group discussions.   |
| VREELAND<br>2006<br>(Vreeland et<br>al., 2006) | Group                   | Clinician           | 96            | 24                | 1                          | 96                         | <b>Team Solutions Program</b> Group based intervention consisting of three, eight-week modules covering the following topics and workbooks: i) Understanding Your Illness and Recovering From Schizophrenia; ii) Understanding Your Treatment and Getting the Best Results From Your Medication; and iii) Helping Yourself Prevent Relapse and Avoiding Crisis Situations. This program was developed by pharmaceutical company Elli Lily.  |

| Study ID  | Format       | Facilitator | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description  |
|---|--------------|-------------|---------------|-------------------|----------------------------|----------------------------|--|
| Bipolar Spec                                      | ific IIIness | s Managem   | ent           |                   |                            |                            |  |
| COLOM<br>2003<br>(Colom et<br>al., 2003,<br>2009) | Group        | Clinician   | 21            | 21                | 1.5                        | 32                         | Manual de Psicoeducacion en Tastornos Bipolares Aims to prevent recurrences and reduce time spent ill. Addresses four main issues: illness awareness, treatment compliance, early detection of prodromal symptoms and recurrences and life style regularity through talk on topic of session, exercise related to topic and active discussion.   |
| TORRENT<br>2013<br>(Torrent et<br>al., 2013)      | Group        | Clinician   | 21            | 21                | 1.5                        | 31.5                       | Psychoeducation based on Manual de Psicoeducacion en Tastornos Bipolares This psychoeducation intervention (based on Colom, 2003) aimed to prevent recurrences of bipolar illness by improving four main issues: illness awareness, treatment adherence, early detection of prodromal symptoms of relapse, and lifestyle regularity. Note: study has three arms- Functional remediation, psychoeducation and treatment as usual. Functional remediation arm was not included in this analysis as it does not meet inclusion criteria.  |
| SAJATOVIC<br>2009<br>(Sajatovic et<br>al., 2009)  | Group        | Clinician   | 6             | 6                 | 1.25                       | 7.5                        | Life Goals Program The Life Goals Program (LGP) is a manualised, structured group psychotherapy program for individuals with bipolar disorder. It is based on behavioural principles from social learning and self-regulation theories and focuses on systematic education and individualized application of problem solving in the context of mental disorder to promote illness self-management. LGP is organized in two phases which cover illness education, management, and problem solving. Phase I is the core psychoeducational intervention. The optional phase II group sessions address goal setting and problem solving in an unstructured format. |
| SMITH<br>2011<br>(Smith et al.,<br>2011)          | Individual   | Computer    | 8.5           | 17                | NR                         | N/A                        | Beating Bipolar  The key areas covered in the package are: (i) the accurate diagnosis of bipolar disorder; (ii) the causes of bipolar disorder; (iii) the role of medication; (iv) the role of lifestyle changes; (v) relapse prevention and early intervention; (vi) psychological approaches; (vii) gender-specific considerations, and (viii) advice for family and carers. Online modules were required to be completed in sequential order and throughout the trial there was an opportunity for participants in the intervention group to discuss the content of the material with each other within a secure, moderated discussion forum.               |

| Study ID  | Format     | Facilitator                   | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description  |
|---|------------|-------------------------------|---------------|-------------------|----------------------------|----------------------------|--|
| TODD 2014<br>(Todd et al.,<br>2014, 2012)                 | Individual | Computer                      | 10            | 26                | NR                         | N/A                        | Living with Bipolar (LWB)  LWB is an online interactive recovery informed self-management intervention, broadly based on the principles of Cognitive Behavioural Therapy and psychoeducation. The intervention aims to help people to: increase their knowledge, self-esteem and self-efficacy around managing bipolar in order to pursue personally meaningful recovery goals. Ten interactive modules were developed: (1) Recovery & Me;(2) Bipolar &Me (3) Self-management &Me (4) Medication & Me; (5) Getting to Know Your Mood Swings; (6) Staying well with Bipolar; (7) Depression & Me; (8) Hypomania & Me; (9) Talking about my diagnosis; and (10) Crisis &Me. Worksheets were used to enhance learning and personalise the content, and could be down-loaded or printed out. Case studies and worked examples, written by service users were used extensively to reduce perceived isolation through shared experience. A mood checking tool was available for participants to help them identify major changes in their mood. Participants receive information about the most appropriate modules, given their mood symptoms. In line with the recovery agenda participants were given access to all aspects of the intervention and encouraged to use it as and when they felt appropriate. |
| PROUDFOOT<br>2012<br>(Proudfoot et<br>al., 2007,<br>2012) | Individual | Computer<br>and Peer<br>email | 8             | 8                 | 0.5                        | 4                          | Online Bipolar Education Program (BEP) + Informed Supporters (email support from expert patients)  The online psychoeducation program consisted of topics covering causes of bipolar disorder, diagnosis, medications, psychological treatments, omega-3 for bipolar disorder, wellbeing plans, and the importance of support networks. It was supplemented by email based coaching and support from 'Informed Supporters' (i.e. peers) to answer specific questions or to provide examples of how to apply the education material to their everyday lives. Emails focused on effective self-management across three domains: medical, emotional and role management, and were linked to the content of the online psychoeducation program. Questions of a clinical nature were referred to suitable clinicians.   |
| PERRY<br>1999<br>(Perry et al.,<br>1999)                  | Individual | Clinician                     | 11.97         | 9                 | 0.75                       | 9                          | Teaching patients with bipolar disorder to identify early symptoms of relapse and obtain treatment  Treatment occurred in two stages: collaboratively exploring previous relapses and training the patient to systematically identify the idiosyncratic nature and timing of their prodromal symptoms of manic or depressive relapse. Diaries were kept to distinguish symptoms associated with normal mood variation from prodromes. Once prodromes had been recognised by the patient, an action plan was created and rehearsed (such as ways to seek early treatment from a professional). The full relapse plan of warning and action stage prodromal symptoms for manic and depressive relapse with the plan for seeking treatment was recorded on a card in laminated plastic, which was carried by the patient.   |

| Study ID  | Format | Facilitator | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description  |
|---|--------|-------------|---------------|-------------------|----------------------------|----------------------------|--|
| Transition to   | Commun | ity from Wa | ard           |                   |                            |                            |  |
| ANZAI<br>2002<br>(Anzai et al.,<br>2002)  | Group  | Clinician   | 18            | 9                 | 1                          | 18                         | Social and Independent Living Skills (SILS) - Community Re-entry Module  The Community Re-entry Module consists of sessions on medication management, warning signs of relapse and how to develop and implement an emergency plan to deal with relapse, how to find and secure housing and continuing psychiatric care in the community, and how to reduce stress and promote coping after discharge. The conventional program emphasizes arts and crafts, reality-orientation groups, and work assignments in the hospital.   |
| ECKMAN<br>1992<br>(Eckman et<br>al., 1992)  | Group  | Clinician   | 52            | 26                | 1.5                        | 78                         | SILS- Medication and Symptom management modules Utilised two modules from the UCLA Social and Independent Living Skills Program. Medication and Symptom Self-management modules  |
| KOPELO-<br>WICZ<br>1998<br>(Kopelowicz<br>et al., 1998;<br>Mackain et<br>al., 1998) | Group  | Clinician   | 8             | 1                 | 0.75                       | 6                          | SILS - Community re-entry program  Based on the UCLA Social and Independent Living Skills Modules and modified for use in the rapid-turnover, "crisis" operations of a typical acute psychiatric inpatient facility. Sessions focused on preparing participants for discharge through teaching knowledge and skills to understand their disorders and the medications that control it, to develop an aftercare treatment plan by identifying problems, specifying remedial and maintenance services, and linking with service providers, teaching skills to avoid illicit drugs, cope with stress, organize a daily schedule, and make and keep appointments with service providers. |
| ZHOU<br>2014<br>(Zhou et al.,<br>2014)  | Group  | Clinician   | 26            | 26                | 2                          | 52                         | SILS- Medication and Symptom management modules  The Medication Management and Symptom Management Modules of UCLA program were delivered.  Additionally, at the end of the intervention, participants were given a self-management check-list journal (which monitored medication adherence, sleep, side effects, residual symptoms and signs of relapse) and the main caregiver was asked to provide guidance on the process. Participants in the intervention group attended monthly self-management group meetings (for 24 months) where community mental health workers checked and evaluated their journals.  |
| WIRSHING<br>2006<br>(Wirshing et<br>al., 2006)                                      | Group  | Clinician   | 8             | 1                 | 1                          | 8                          | Modified Community Re-Entry Program (CREP) Based on the UCLA Community re-entry modules modified to be administered during brief hospitalizations to address the immediate needs of a patient who is transitioning back into the community.  |

| Study ID  | Format     | Facilitator | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description  |
|---|------------|-------------|---------------|-------------------|----------------------------|----------------------------|--|
| XIANG<br>2006<br>(Xiang et al.,<br>2006)  | Group      | Clinician   | 16            | 8                 | 1                          | 16                         | SILS- Community Re-entry Module Chinese version of the community re-entry module.  |
| XIANG<br>2007<br>(Xiang et al.,<br>2007)  | Group      | Clinician   | 16            | 4                 | 1                          | 16                         | SILS- Community Re-entry Module Chinese version of the community re-entry module   |
| Recovery Or   | iented Sel | f-Managem   | ent           |                   |                            |                            |  |
| BARBIC<br>2009<br>(Barbic et al.,<br>2009)  | Group      | Peer        | 12            | 12                | 2                          | 24                         | The Modified Recovery Workbook program  Training uses combination of teaching, group discussion and practical exercises, complemented by a workbook for use between sessions. Uses an educational process to increase awareness of recovery, increase knowledge and control of the illness, increase awareness of the importance and nature of stress, enhance personal meaning and sense of potential, build personal support, and develop goals and plans of action. *Note: does not include strategies for medication management  |
| COOK 2013<br>(Cook et al.,<br>2013a)  | Group      | Peer        | 9             | 9                 | 2.5                        | 22.5                       | Wellness Recovery Action Planning (WRAP) Group sessions consisted of lectures, individual and group exercises, personal sharing and role modelling, and voluntary homework to practice using and refining one's WRAP plan between groups. The content of each session is described fully elsewhere (Cook, Copeland, Jonikas et al., 2012), and consisted of: (a) the key concepts of WRAP and recovery, (b) personalized strategies to maintain well-being, (c) daily maintenance plans with simple and affordable tools to foster daily wellness, (d) advance planning to proactively respond to self-defined symptom triggers, (e) early warning signs that a crisis is impending and advance planning for additional support during these times, (f) advance crisis planning to identify preferred treatments and supporters when in acute phases of the illness, and (g) post crisis planning to resume daily activities and revise one's WRAP plan if needed. |
| COOK 2011<br>(Cook et al.,<br>2011; Cook,<br>Copeland, et<br>al., 2012;<br>Jonikas et<br>al., 2013) | Group      | Peer        | 8             | 8                 | 2.5                        | 20                         | Wellness Recovery Action Planning (WRAP) Behavioural health illness self-management intervention where participants create an individualized plan to achieve and maintain recovery by learning to utilize wellness maintenance strategies, identify and manage symptoms and crisis triggers, and cope with psychiatric crises during and following their occurrence. Instructional techniques promote peer modelling and support by using personal examples from peer facilitators' and students' lives to illustrate key concepts of self-management and recovery.  |

| Study ID   | Format      | Facilitator | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description   |
|--|-------------|-------------|---------------|-------------------|----------------------------|----------------------------|---|
| COOK 2012<br>(Cook,<br>Steigman, et<br>al., 2012;<br>Pickett et al.,<br>2012)        | Group       | Peer        | 8             | 8                 | 2.5                        | 20                         | Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES) Course topics included recovery principles and stages; structured problem-solving and communication skills training; strategies for building interpersonal and community support systems; brain biology and psychiatric medications; diagnoses and related symptom complexes; traditional and non-traditional treatments for SMI; and relapse prevention and coping skills.  |
| VAN GESTEL-<br>TIMMERMAN<br>S<br>2012<br>(Van Gestel-<br>Timmermans<br>et al., 2012) | Group       | Peer        | 12            | 12                | 2                          | 24                         | "Recovery Is Up to You" Course  Trained peer instructors (at an advanced state of their recovery process) were employed to facilitate this group intervention, with discussion and skills practice. Participants used a standardized workbook that covered recovery-related themes: the meaning of recovery to participants, personal experiences of recovery, personal desires for the future, making choices, goal setting, participation in society, roles in daily life, personal values, how to get social support, abilities and personal resources, and empowerment and assertiveness. Important elements of the course were the presence of role models, psychoeducation and illness management, learning from other's experiences, social support, and homework assignments. |
| Coping Orien   | nted Self-I | Managemen   | nt            |                   |                            |                            |   |
| CHIEN<br>2013<br>(Chien &<br>Lee, 2013)  | Group       | Clinician   | 12            | 24                | 2                          | 24                         | Mindfulness-Based Psychoeducation Program (MBPP)  The program is a psychoeducational program that addresses patients' awareness and knowledge of schizophrenia and builds skills for illness management. (a) phase 1: orientation and engagement, empowerment and focused awareness of experiences, bodily sensations/thoughts and guided awareness exercises and homework practices; (b) phase 2: education about schizophrenia care, intentionally exploring and dealing with difficulties regarding symptoms and problem-solving practices; and (c) phase 3: behavioural rehearsals of relapse prevention strategies, accessible community support resources and future plans.   |
| CHIEN<br>2014<br>(Chien &<br>Thompson,<br>2014)                                      | Group       | Clinician   | 12            | 24                | 2                          | 24                         | Mindfulness-Based Psychoeducation Program (MBPP) As described above in Chien, 2013  |

| Study ID                                   | Format | Facilitator | #<br>sessions | Duration<br>(wks) | Session<br>Length<br>(hrs) | Dose<br>(hrs) <sup>†</sup> | Intervention Name & Description  |
|--|--------|-------------|---------------|-------------------|----------------------------|----------------------------|--|
| SCHAUB<br>2016<br>(Schaub et<br>al., 2016) | Group  | Clinician   | 12            | 7                 | 1.25                       | 15                         | Group-based Coping Oriented Program (COP)  COP seeks to improve understanding of the illness and its treatment, to teach coping strategies for specific stressors and symptoms, to activate the use of internal and external resources, and to enhance self-confidence and hope. COP combines elements of illness management with cognitive behavioural therapy for psychosis. Includes psychoeducation, cognitive-behavioural teaching principles (e.g. cognitive restructuring, role playing, problem solving). Thus, the program was intended to foster the development of a lifestyle that enhances positive activities and health. COP focused on topics of greatest concern to patients, such as symptom-management (e.g., coping with anxiety and positive symptoms), managing stress (stress-management including mindfulness and problem solving), building up rewarding activities, time management, social skills (e.g., dealing with relatives, getting to know people), reintegration into the workplace, and providing information about outpatient services. In early groups, participants identified specific distressing symptoms for which coping strategies were selected and taught. |

NR – Not reported; N/A – Not Applicable

# Description of intervention, with assumption that meets 4 criteria (\*with exception of Barbic).

<sup>†</sup> Total intervention contact time

## Content of Self-Management Interventions: A typology

In an attempt to develop a typology of self-management interventions a detailed table outlining the format, facilitation and duration of the studies, along with the content of each intervention was created (Table 2). From this the common elements (largely dictated by the review's inclusion criteria and previous reviews of self-management (Mueser et al., 2002) as well as distinguishing features of each intervention) were synthesised into 4 broad categories of self-management interventions displayed in Table 3.

Illness Management and Compliance based Interventions

Ten studies (Table 2) were categorised as providing an intervention for schizophrenia or mixed populations that focused primarily on illness recovery, meaning that the skills taught focused on the illness itself and strategies aimed at symptom reduction through psychoeducation, relapse prevention planning and medication management. These interventions tended to be more problem or "deficit focused" (Priebe, Omer, Giacco, & Slade, 2014) in contrast to those categorised as recovery oriented programs. The majority of studies in this category utilised the Illness management and Recovery based intervention (McGuire et al., 2014), or an adapted version of this program. An additional seven interventions in this category were developed specifically for the self-management of bipolar disorder. These interventions focused on strategies such as in-depth analyses of previous episodes to enable participants to track early signs and symptoms of relapse (Janney, Bauer, & Kilbourne, 2014), which were incorporated into relapse plans, and an emphasis on establishing lifestyle regularity as a way for individuals to manage their illness (Murray et al., 2011).

Table 3. Summary of self-management intervention typologies

| Proposed Intervention                   |                      |                       | Components<br>on criteria |                          | Other defining characteristics |                   |                         |             |  |
|---|----------------------|-----------------------|---------------------------|--------------------------|--------------------------------|-------------------|-------------------------|-------------|--|
| Types                                   | Psycho-<br>education | Relapse<br>Prevention | Coping skills             | Medication<br>Management | Personal<br>Recovery Goals     | Peer<br>Delivered | Lifestyle<br>Regulation | Mindfulness |  |
| 1.1 Illness management & compliance     | <b>√</b> √           | <b>√</b> √            | ✓                         | <b>√</b> √               | ✓                              | *                 | -                       | -           |  |
| 1.2 Bipolar specific illness management | <b>/ /</b>           | <b>√</b> √            | ✓                         | <b>/</b> /               | ✓                              | *                 | <b>√</b> √              | -           |  |
| 2. Transition to community from ward    | <b>√</b> ✓           | <b>√</b> √            | ✓                         | <b>√</b> ✓               | -                              | -                 | -                       | -           |  |
| 3. Coping oriented                      | ✓                    | ✓                     | <b>√</b> √                | ✓                        | ✓                              | -                 | -                       | ✓           |  |
| 4. Recovery oriented                    | ✓                    | <b>√</b> √            | ✓                         | ✓                        | <b>√</b> √                     | <b>√</b> ✓        | -                       | -           |  |

Note: ✓ ✓ Indicates predominant focus of intervention types.

<sup>✓</sup> Indicates component is present but not the primary focus of this type of intervention

<sup>\*</sup> Only one study in category utilised peer facilitation (Proudfoot et al., 2012; Salyers et al., 2010)

Interventions were predominantly clinician facilitated, with the exception of two studies which employed peer support in addition to a clinician facilitator (Salyers et al., 2010) or online delivery (Proudfoot et al., 2012). Interestingly this category of self-management intervention was the only one to include online delivery of interventions for self-management of bipolar (Proudfoot et al., 2012; Smith et al., 2011; Todd et al., 2014).

# Transition to community from the ward

Seven studies included in the qualitative synthesis targeted transition from the ward into the community. All studies of this type trialled modules from the UCLA Social and Independent Living Skills (SILS) Program. This is a highly structured behavioural skills training intervention which aims to help individuals reintegrate and live in the community at the highest level of functioning possible. The UCLA SILS is one of the oldest self-management interventions designed to teach the skills to actively seek and obtain one's own comprehensive community care (Liberman et al., 1998). As such the main focus is on teaching skills to manage symptoms and medication adherence, and building basic skills needed for the transition to the community such as how to make and keep appointments and how to foster collaboration between service providers and users (Mackain et al., 1998).

#### Coping oriented interventions

In addition to covering the core self-management criteria, three studies classified into this category, had content which focused on teaching additional coping skills for persistent symptoms and stressors. Two studies incorporated mindfulness training as an additional skill to manage persistent symptoms by increasing participants' awareness of, and relationship to, unwanted thoughts, sensations and negative feelings (Chien & Thompson, 2014). This is the smallest category amongst the typologies however it warranted a separate and distinct category due to the unique content of these programs. This category also featured more recent studies compared to the other categories and the addition of cognitive

approaches and third wave CBT may be a response to the increasing evidence base for use of these therapies with service users with severe mental illness.

## Recovery Oriented Interventions

Five papers were categorised as this type of self-management intervention due to the prominent personal recovery orientation. Interventions in this category adopted a focus on personal recovery, as opposed to illness recovery, and wellness as defined by the individual (Cook et al., 2013), rather than just symptom control through adherence to medication or strict learning of behavioural strategies (Sterling, Von Esenwein, Tucker, Fricks, & Druss, 2010). Instead a sense of meaning, potential and competency was fostered in participants alongside imparting knowledge and increasing self-awareness to help manage their condition (Cook et al., 2012). Recovery focused interventions were exclusively peer delivered and group format. This social aspect to recovery oriented interventions is thought to be critical in modelling self-efficacy (Sterling et al., 2010) and empowering individuals to change health behaviours (Pickett et al., 2012).

## **Outcome measures**

Table 4 outlines the continuous measures used in studies, categorised by outcome type. Dichotomous data were also reported. All outcome measures used across the studies were reported to be well-validated and reliable instruments.

Symptom outcomes were reported on measures ranging from self-rated (The Internal State Scale (ISS) to those rated by caregivers (PECC) and those requiring a clinical interview (PANSS and BPRS). In the majority of studies, relapse was measured as an admission to hospital, however a small minority of trials established relapse in participants when a score was above cut-off point on a scale (e.g. Structured Clinical Interview (SCID) (however only admission data was used in the present analysis). Measures of Quality of life were self-rated whereas functioning

tended to be clinician rated. Measures of recovery which focused on personal recovery as opposed to clinical recovery were exclusively self-rated.

**Table 4. Outcomes Measures used in included trials** 

| Outcome                  | Measure   |  |  |  |  |  |  |  |
|--------------------------|---|--|--|--|--|--|--|--|
| Total Symptoms           | Positive and Negative Syndrome Scale (PANSS) Brief Psychiatric Rating Scale (BPRS) Psychosis Evaluation Tool for Common Use by Caregivers (PECC) Internal State Scale (ISS)   |  |  |  |  |  |  |  |
| Depression &<br>Anxiety  | Brief Symptom Inventory (BSI)- Depression Psychosis Evaluation Tool for Common Use by Caregivers (PECC)- Depression- anxiety Brief Psychiatric Rating Scale (BPRS)- Depression- anxiety Goldberg Anxiety and Depression Scale (GADS)- Depression Hamilton Depression Rating Scale (HAM-D) Montgomery and Asberg Depression Rating Scale (MADRS) Psychological General Well-Being Scale (PGWB)- Anxiety Global Assessment of Functioning–Disability Scale (GAF-DIS) Structured Clinical Interview (SCID) (DSM-III-R)- Depression |  |  |  |  |  |  |  |
| Functioning              | REHAB scale; Social Functioning Scale (SFS); Specific Level of Functioning scale (SLOF); Global Assessment of Functioning (GAF); Social Adaptation Self-Evaluation Scale (SASS); Social Disability Screening Schedule (SDSS); Social Functioning Interview; Work and Social Adjustment Scale (WSAS); Global Assessment Scale (GAS)  |  |  |  |  |  |  |  |
| Quality of Life<br>(QoL) | Quality of Life Scale (QOLS); Quality of Life Index; Quality of Life Scale- Abbreviated (QLS-A); Quality of Life Scale (QLS); Quality of Life in BD scale (Brief version) (QoL.BD-Brief); Manchester Short Assessment of Quality of Life; Psychological General Well-Being Scale (PGWB); WHO Quality of Life - BREF: Environmental  |  |  |  |  |  |  |  |
| Recovery                 | Overall: Recovery Assessment Scale (RAS); Illness Management and Recovery Scales (IMRS); Recovery Attitudes Questionnaire (RAQ); Bipolar Recovery Questionnaire (BRQ); Empowerment Scale; Dutch Empowerment Scale; International Association of Psychosocial Rehabilitation Services (IAPSRS Toolkit); Herth Hope Index; Coping Efficacy Scale; Self- Efficacy Measure; Self-Efficacy for Managing Chronic Disease Scale, Brief Version (SEMCD); Mental Health Confidence Scale (MHCS)  |  |  |  |  |  |  |  |

#### Risk of Bias

The risk of bias summary is shown in Figure 2 and the risk of bias rating for each individual study can be found in Appendix 2. Using the Cochrane Risk of Bias Tool (Higgins & Green, 2011) sequence generation was not sufficiently described in nine studies. Concealment of the allocation sequence was not sufficiently described in 19 studies and high risk of bias in three studies. Blinding of participants and personnel is generally considered to be high in complex interventions of this nature. As such, all studies except for one (Proudfoot et al., 2012) were rated with a high risk of bias. This study (Proudfoot et al., 2012) was rated as low risk for this criterion because the intervention was delivered entirely online, featured an active control, and outcomes were self-rated, so participants and researchers were not aware of their allocation. Lack of blinding of assessors created a high risk of bias in three studies, and in two studies it was unclear if assessors were blind. Six studies were at high risk of bias for missing data (i.e. attrition bias) and four were unclear. Eight studies created a high risk of bias for selective outcome reporting by not clearly reporting all outcomes measured, and 17 were unclear. The "other bias" category refers to whether any studies were discontinued due to adverse events or problems with the study design or acceptability of the intervention. All studies included in this analysis were completed as planned and hence were rated as a low risk of bias.

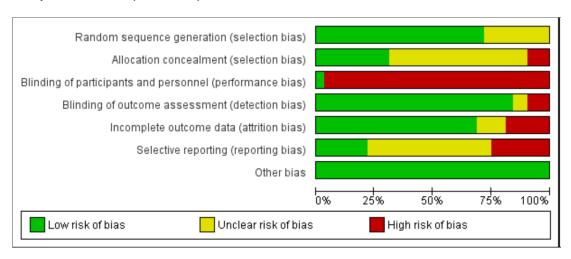


Figure 2. Cochrane Risk of Bias Summary

## **Narrative Synthesis Summary**

Overall self-management interventions shared similarities, in part dictated by the inclusion criteria of this review. Despite this, the narrative synthesis identified key differences in the focus and orientation between programs which allowed for the development of a typology of self-management interventions. Interventions categorised as Illness management and Compliance programs tended to focus on clinical recovery and adherence to medication as a necessary aspect to this. Nested within this category was the Bipolar Illness management interventions which had an additional focus on lifestyle regulation. Bipolar illness management interventions were the only type to utilise online delivery. It is not clear why this has proliferated in this specific population but not been adopted for use more generally with those with severe mental illness. One type of self-management intervention focused on transition into the community. Interventions categorised in the recovery and coping oriented interventions, tended to be those more recently developed, and their approach could be understood as a response to the outstanding need of those with SMI in providing additional ways to cope with persistent symptoms.

In sum, there was a wide variation in the duration, session length and dose (contact time) across interventions, and the majority were delivered in the community, although a smaller subset were delivered in inpatient settings (with the focus on transition to the community). The majority of interventions were predominantly delivered in a group format with only a small minority being peer facilitated.

#### **Quantitative Synthesis**

Data were analysed at two time points: at the end of the treatment intervention (that is, immediately, or within two weeks of the end of treatment) and at follow up (summary of results in Table 5 and forest plots in appendix 3). The median follow-up length was 38 weeks (range 4 to 104 weeks) post-treatment; 52 weeks (range 7 to 130 weeks) post randomisation.

Table 5. Analysis of Self-Management Intervention (SM) for people with severe mental illness compared to control (active or TAU)

|          |  | Time of data     | Triala | als Participants<br>SM/control<br>k) (n) | Estimate | Summary of estimate [95% CI] | Ζ, ρ                               | Favours<br>SM/<br>control | Heterogeneity             |                 |
|----------|--|------------------|--------|--|----------|------------------------------|------------------------------------|---------------------------|---------------------------|-----------------|
|          | Outcome  | collection       | (k)    |  |          |                              |                                    |                           | Q test                    | l²<br>(%)       |
| Symptoms | (1) Total Symptoms   | End of treatment | 12     | 591/553                                  | SMD      | -0.33 [-0.50, -0.16]         | $3.75, p = .0002^*$                | Favours<br>SM             | Q = 21.53, p = .03        | 49 <sup>†</sup> |
|          |  | Follow-up        | 10     | 496/475                                  | SMD      | -0.81 [-1.18, -0.44]         | 4.32, <i>p</i> <.0001 <sup>*</sup> | Favours<br>SM             | Q =66.49, p<.001          | 86 <sup>†</sup> |
|          | Affective Symptoms<br>(Depression/Anxiety)                               | End of treatment | 4      | 161/145                                  | SMD      | -0.34 [-0.62, -0.06]         | $2.41, p = .02^*$                  | Favours<br>SM             | Q = 4.35, p=.23           | 31              |
|          |  | Follow-up        | 6      | 475/489                                  | SMD      | -0.19 [-0.33, -0.04]         | $2.43, p = .02^*$                  | Favours<br>SM             | Q = 5.91, p= .31          | 15              |
| Relapse  | (2) <b>Mean</b> number of relapses (of symptoms or hospitalised)         | End of treatment | 2      | 80/75                                    | SMD      | 0.03 [-0.32, 0.38]           | 0.18, <i>p</i> = .86               | -                         | Q = 1.21, p = .27         | 18              |
|          |  | Follow-up        | 3      | 121/116                                  | SMD      | -0.37 [-0.88, 0.14]          | 1.43, <i>p</i> = .15               | -                         | Q = 7.54, p = .02         | 73 <sup>†</sup> |
|          | <b>Total</b> number of participants who relapsed during the study period | End of treatment | 1      | 60/60                                    | RR       | 0.64 [0.44, 0.94]            | 2.3, $p = .02^*$                   | Favours<br>SM             | N/A                       | N/A             |
|          |  | Follow-up        | 9      | 372/386                                  | RR       | 0.84 [0.59, 1.19]            | 0.99, <i>p</i> = .32               | -                         | Q = 11.09, p = .20        | 28              |
|          | <b>Length</b> of hospitalisation throughout treatment / follow-up        | End of treatment | 2      | 80/75                                    | SMD      | -0.44 [-1.34, 0.46]          | 0.96, <i>p</i> = .34               | -                         | Q = 7.65, <i>p</i> <.001  | 87 <sup>†</sup> |
|          |  | Follow-up        | 4      | 170/189                                  | SMD      | -0.65 [-1.52, 0.21]          | 1.48, <i>p</i> = .14               | -                         | Q = 45.32, <i>p</i> <.001 | 93 <sup>†</sup> |

| -           |                          | Time of data 1<br>collection | Triala        | Participants<br>SM/control<br>(n) | Estimate | Summary of estimate [95% CI] | Z, p                                | Favours<br>SM/<br>control | Heterogeneity             |                 |
|-------------|--------------------------|------------------------------|---------------|-----------------------------------|----------|------------------------------|-------------------------------------|---------------------------|---------------------------|-----------------|
|             | Outcome                  |                              | Trials<br>(k) |                                   |          |                              |                                     |                           | Q test                    | l²<br>(%)       |
|             | (3) Recovery - Total     | End of treatment             | 7             | 339/293                           | SMD      | -0.46 [-0.75, -0.18]         | $3.16, p = .002^*$                  | Favours<br>SM             | Q = 16.87, p = .01        | 64 <sup>†</sup> |
|             |                          | Follow-up                    | 5             | 477/479                           | SMD      | -0.24 [-0.36, -0.11]         | 3.62, <i>p</i> = .0003 <sup>*</sup> | Favours<br>SM             | Q = 3.98, p = .41         | 0               |
|             | Recovery - Empowerment   | End of treatment             | 3             | 187/159                           | SMD      | -1.44 [-2.97, 0.08]          | 1.86, <i>p</i> = .06                | -                         | Q = 44.89, <i>p</i> <.001 | 96 <sup>†</sup> |
| very        |                          | Follow-up                    | 2             | 278/260                           | SMD      | -0.25 [-0.43, -0.07]         | $2.68, p = .007^*$                  | Favours<br>SM             | Q = 1.13, p = .29         | 12              |
| Recovery    | Recovery- Hope           | End of treatment             | 1             | 132/118                           | SMD      | -0.24 [-0.49, 0.01]          | 1.88, <i>p</i> = .06                | -                         | N/A                       | N/A             |
|             |                          | Follow-up                    | 3             | 487/480                           | SMD      | -0.24 [-0.46, -0.02]         | $2.16, p = .03^*$                   | Favours<br>SM             | Q = 5.74, p = .06         | 65 <sup>†</sup> |
|             | Recovery - Self-Efficacy | End of treatment             | 4             | 322/279                           | SMD      | -0.38 [-0.62, -0.15]         | 3.18, <i>p</i> = .0001*             | Favours<br>SM             | Q = 5.41, p= .14          | 45              |
|             |                          | Follow-up                    | 1             | 121/100                           | SMD      | -0.34 [-0.61, -0.07]         | $2.50, p = .01^*$                   | Favours<br>SM             | N/A                       | N/A             |
| Functioning | (4) Eunctioning          | End of treatment             | 10            | 563/550                           | SMD      | -0.39 [-0.69, -0.09]         | $2.56, p = .01^*$                   | Favours<br>SM             | Q = 53.05, <i>p</i> <.001 | 83 <sup>†</sup> |
| Functi      | (4) Functioning          | Follow-up                    | 11            | 625/631                           | SMD      | -0.55 [-0.92, -0.17]         | $2.87, p = .004^*$                  | Favours<br>SM             | Q = 99.11, <i>p</i> <.001 | 90 <sup>†</sup> |
| GoL         | (5) Quality of Life      | End of treatment             | 8             | 398/377                           | SMD      | -0.21 [-0.36, -0.07]         | 2.95, p = .003 <sup>*</sup>         | Favours<br>SM             | Q = 5.5, p = .60          | 0               |
|             |                          | Follow-up                    | 7             | 491/489                           | SMD      | -0.26 [-0.39, -0.13]         | 4.05, <i>p</i> <.0001 <sup>*</sup>  | Favours<br>SM             | Q = 2.84, p = .83         | 0               |

<sup>\*</sup>Statistically significant finding (p<0.05); †Indicates high heterogeneity: I² exceeds 50% and/or P value less than 0.10; Note: Random-effects model used

## **Symptoms**

The effect of self-management on psychiatric symptoms was analysed by 12 studies reporting outcome data on measures of total symptoms for 1144 participants. At the end of treatment there was a small but significant benefit of self-management over control for total symptoms (SMD: -0.33, 95% CI [-0.50, -0.16]). Heterogeneity for this outcome was moderate (I<sup>2</sup>=49%).

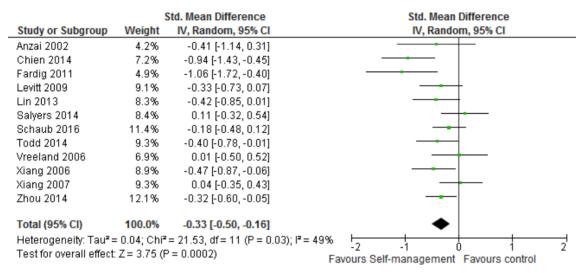


Figure 3. Forest plot of total symptoms at end of treatment

At follow up, 10 studies, with 971 participants showed a marked effect of self-management on total symptoms (SMD= -0.81; -1.18 to -0.44), however this must be considered with caution due to the considerable heterogeneity (I<sup>2</sup>= 86%) displayed across the studies.

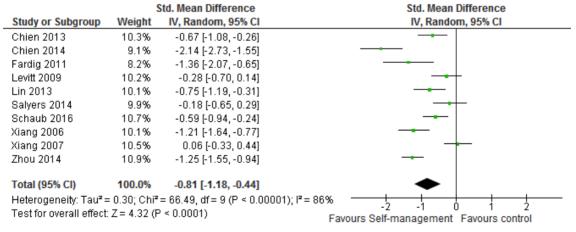


Figure 4. Forest plot of total symptoms at follow-up

No significant effect was found for self-management when looking at positive or negative symptoms subscales separately (please see forest plots Appendix 3).

When looking at symptoms of depression and anxiety, four studies with 306 participants favoured self-management both at end of treatment (SMD= -0.34; 95% CI [-0.62 to -0.06]) and follow up (SMD= -0.19; 95% CI [-0.33 to -0.04]). Heterogeneity (I²) was low, 31% and 15% respectively.

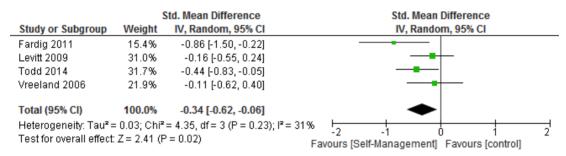


Figure 5. Forest plot of depression and anxiety symptoms at end of treatment

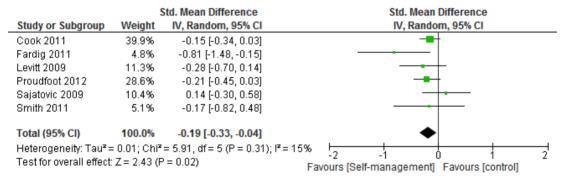


Figure 6. Forest plot of depression and anxiety symptoms follow-up

## Relapse

Overall, self-management interventions did not have a significant effect on the rate of relapse or length of hospitalisation across the studies at both end of treatment and follow up. There was only one study, a Bipolar specific intervention (Colom et al., 2003) with 60 participants that reported a significant effect of self-management on relapse reduction and hospitalisation at the end of treatment when compared to an

active control consisting of an unstructured support group (RR= 0.64; 95% CI [0.44 to 0.94]). Forest plots for relapse can be found in appendix 3.

# Self-rated recovery

Seven studies (n=632) assessed participants overall self-rated recovery at end of treatment, and five studies (n=956) at follow up.

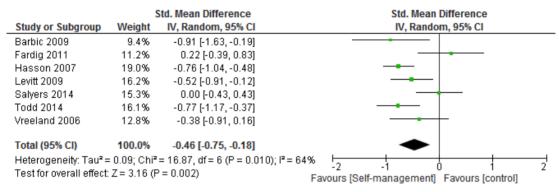


Figure 7. Forest plot of total self-rated recovery at end of treatment

Self-management was favoured over control at both time points with a small to medium significant effect size (SMD: -0.46; -0.75 to -0.18] immediately following treatment, and a smaller but still significant effect at follow up (SMD= -0.24; -0.36 to -0.11). Heterogeneity at end of treatment was moderate ( $I^2$ = 64%), and at follow up was very low ( $I^2$ = 0%).

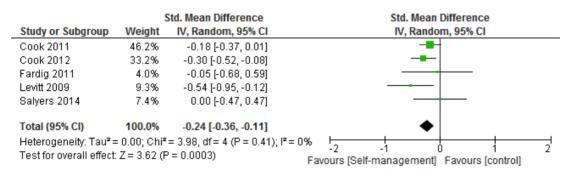


Figure 8. Forest plot of total self-rated recovery at follow-up

## **Empowerment**

At the end of treatment, three studies (n=250) reported on the recovery based outcome of empowerment. They produced a non-significant SMD of -1.44 (95% CI [-2.97, 0.08]; z= 1.86, p= .06). Heterogeneity was considerable ( $I^2$ = 96%). At follow up two studies (n= 221) reported on empowerment. The effect size of difference between groups was small but significant (SMD= -0.25; -0.43, -0.07). Heterogeneity was low ( $I^2$ = 12%).

#### Hope

At end of treatment, only one study (n=250) reported on the recovery outcome of Hope, which produced a non-significant SMD of -0.24 [-0.49, 0.01], z=1.88, p=.06. At follow up three studies with 967 participants showed a small but significant effect favouring self-management over control (SMD= -0.24; [-0.46, -0.02]). Heterogeneity across these studies was substantial ( $I^2=65\%$ ).

# Self-Efficacy

Four studies (n= 601) reported on self-efficacy at end of treatment with a significant SMD -0.38 (95% CI [-0.62, -0.15], z= 3.18, p< 0.001) favouring self-management. Heterogeneity was moderate ( $I^2$ = 45%). Only one study provided data for self-efficacy at follow up, which also favoured self-management (SMD-0.34 [-0.61, -0.07], z= 2.5, p=.01).

Forest plots for the recovery outcomes of empowerment, hope and selfefficacy can be found in Appendix 3.

#### **Functioning**

Ten studies with 1113 participants provided evidence of a small but significant benefit of self-management (SMD= -0.39; -0.69 to -0.09) compared to control on functioning of participants immediately following the end of the intervention.

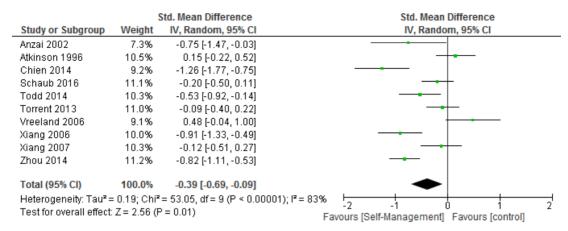


Figure 9. Forest Plot of functioning at end of treatment

At follow up (k= 11, n= 1256) this increased to a medium sized effect of self-management on social and functional disability (SMD= -0.55, -0.92 to -0.17). Heterogeneity was substantial for this outcome at both time points,  $I^2$ = 83% and 90% respectively.

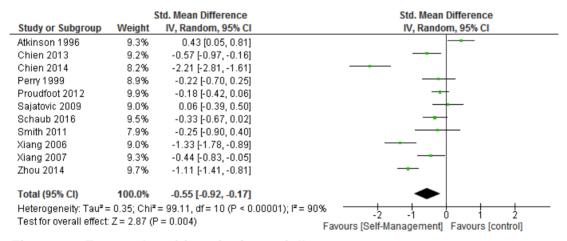


Figure 10. Forest plot of functioning at follow-up

#### Quality of Life

Immediately following the end of the intervention, evidence from eight studies with 775 participants showed a small but significant effect of self-management on participant's self-rated quality of life (SMD= -0.21; -0.36 to -0.07) which was

maintained at follow up (k=7, n=980) (SMD= -0.26, -0.39 to -0.13). Heterogeneity for both of these analyses was low ( $I^2=0\%$ ).

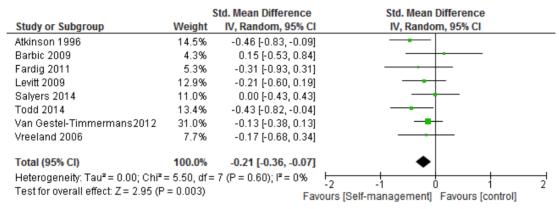


Figure 11. Forest plot of quality of life at end of treatment

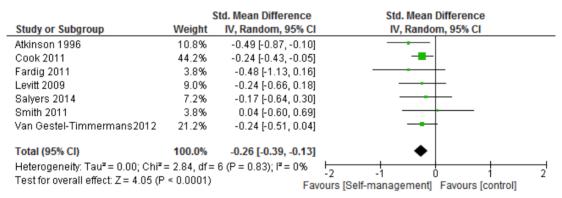


Figure 12. Forest plot of quality of life at follow-up

Heterogeneity and Sensitivity Analyses

Nine of the twenty meta-analyses had high levels of heterogeneity as assessed by an I<sup>2</sup> greater than 50% and/or a significant X<sup>2</sup> test. Of these, eight analyses had more than 3 studies and hence were amenable to the one- study-removed method (Higgins & Green, 2011) to explore sources of statistical heterogeneity. The impact of removing one study sequentially on each meta-analysis is reported below, along with an evaluation of potential clinical or methodological heterogeneity that may warrant removal of that study from the analyses.

## **Symptoms**

For total symptoms at end of treatment, removal of Chien and Thompson (2014) reduced heterogeneity substantially (I² = 32%). The effect size and 95% CI were -0.27 [-0.42, -0.12] (k=11), favouring self-management, as was the case when this study was included. This study differed on two important characteristics that may have contributed to heterogeneity. This study specifically recruited participants with a short duration of illness (less than five years) and excluded those with comorbid mental illness. Consequently the study population (which had a mean illness duration of 2.6 years) may not be representative of those with long-term or chronic schizophrenia (Chien & Thompson, 2014). Furthermore the intervention in this study was uniquely distinct as it utilised mindfulness based approaches to coping with and managing persistent symptoms. Although Chien & Thompson (2014) differed on these characteristics, the overall quality of the study appeared good, with a low risk of bias, and as such does not warrant removal.

At follow up heterogeneity was particularly high, however systematic removal of studies did not produce a significant reduction in heterogeneity for this outcome.

## Relapse

For relapse at follow up, removal of Salyers et al. (2014) reduced heterogeneity substantially (I² = 0%). The effect size and 95% CI were -0.61 [-0.92, -0.30] (k= 2), now favouring self-management. The heterogeneity may have been a product of this study having an active control for which they found no significant difference between self-management and the active control, which is in contrast to the remaining two studies in this analysis (Chien & Lee, 2013; Chien & Thompson, 2014) which did find a significant effect for the intervention (compared to treatment as usual). These two studies also tested the same intervention (mindfulness based self-management) in similar populations (those with a duration of illness less than 5 years). So while the effectiveness of this particular self-management intervention on

mean number of relapses may be apparent, the author advises exercising caution to extend this effect on relapse to all self-management interventions.

For length of hospitalisation, heterogeneity was high at both end of treatment and follow up, however there were only two studies at end of treatment so heterogeneity could not be investigated here. At follow up, systematic removal of each study did not impact on heterogeneity which remained high.

## Self-rated recovery

Similarly, for the total recovery outcome at end of treatment, heterogeneity was high and could not be reduced with the systematic removal of each study. For empowerment at end of treatment, removal of Barbic et al., (2009) reduced  $I^2 = 75\%$ , SMD= -0.09; 95%CI [-0.65, 0.47]. For the recovery related outcome of hope at follow up, the removal of Van Gestel-Timmermans, Brouwers, van Assen, & van Nieuwenhuizen (2012) reduced heterogeneity substantially ( $I^2 = 0\%$ ). The effect size and 95% CI were -0.13 [-0.28, 0.01] now favouring control. All three studies were recovery based self-management interventions, delivered by peer facilitators, and were of similar duration and dose. There was no clear rationale justifying the removal of this study.

#### **Functioning**

Again, for the functioning outcome at both end of treatment and follow up, heterogeneity was high and remained high after the systematic removal of each study.

In sum, although high heterogeneity was identified in a range of metaanalyses, evaluation of clinical and methodological characteristics resulted in the decision to not remove any of the included studies.

#### Publication Bias

Funnel plots were created for the four meta-analyses that had more than 10 studies (Appendix 4). The small number of studies and small number of participants in the studies, meant that it was difficult to discern any evident publication bias.

## **Quantitative Summary**

In summary, self-management interventions were effective in reducing symptoms, improving functioning and quality of life by the end of treatment and this was sustained at follow up. Overall the effect size was small to medium, however a larger effect size was seen for symptoms at follow up. There was no evidence that self-management improved risk of relapse as objectively measured, but subjective sense of recovery and self-efficacy significantly improved at end of treatment and follow up.

#### **Discussion**

This is the first comprehensive systematic review and meta-analysis evaluating self-management interventions for people with severe mental illness. The reviewed evidence suggests that self-management does confer benefits across a broad range of outcomes. Specifically, self-management does have a positive impact on overall symptoms, and symptoms of depression and anxiety, both at end of treatment, and at 1-year follow-up. The effect size for self-management on total symptoms is similar to those found in recent meta-analyses of cognitive behavioural therapy for psychosis (CBTp): pooled effect size -0.33 [95%CI: -0.47 to -0.19] (Jauhar et al., 2014) and 0.40 [95%CI [0.252, 0.58] (Wykes, Steel, Everitt, & Tarrier, 2008). Since the clinical population and outcome measures used in the present review are notably more heterogeneous than those in the CBTp reviews, direct comparisons should not be made. However, the CBTp reviews does provide a close

approximation of the typical effect sizes that can be achieved in large-scale, complex interventions in clinical populations towards the more severe end of the spectrum. At longer term follow up (approx. 1 year post intervention) self-management had a large effect (SMD=-0.81; 95%CI [-1.18,-0.44]). Due to the high heterogeneity however, it is probably more conservative to consider the lower end of the confidence interval as indicative of the likely effect size.

Despite the positive effect on symptoms, this did not translate into significant reductions in rates of relapse or length of hospitalisation for self-management interventions. This was in contrast to previous meta-analyses of self-management interventions for those with schizophrenia (Zou et.al., 2013) who found a significant impact on relapse and readmission. This lack of impact on relapse was also in contrast to reviews of other interventions, including family intervention for psychosis which showed a significant reduction in risk of relapse (up to 12 months) and admissions (during treatment) and CBTp which significantly reduced the rate of hospitalisations (up to 18 months) following the end of treatment compared to people receiving standard care alone (National Institute for Health and Clinical Excellence, 2009). Although it must be noted that only a small portion of studies, 5 of the 31 RCTS in the CBTp review measured readmission.

One way self-management attempts to address relapse prevention is through building social support and resilience to stress (Mueser et al., 2013). The role of the social environment in the development and persistence of psychotic disorder has been well established (Bebbington, 2015). It is possible that the follow up length in this review was not long enough for individuals to re-establish both their sense of self efficacy in relation to managing their illness, but also to navigating their social environment. What this review seems to suggest is that the strategies contained in self-management interventions are valuable in helping individuals manage residual symptoms and difficulties but is not sufficient to prevent relapses.

However, self-management did demonstrate a significant medium sized effect on global functioning, and a small but significant effect on quality life at both end of treatment and 1-year follow-up. Furthermore, self-management seems to confer a small benefit specifically to outcomes valued by consumers (Slade & Longden, 2015), that is outcomes related to personal recovery, and individual's sense of empowerment, hope and self-efficacy. While the small effect on overall recovery and self-efficacy was seen at both end of treatment and follow up, the effect on the recovery concepts of empowerment and hope were significant at follow up only. Again it could be that individuals require an experience of their self as efficacious over time to establish a sense of empowerment and hope in relation to their ability to self-manage their illness. Interestingly despite the move towards personal as opposed to clinical recovery only a third of studies reported on these outcomes.

Methodological Limitations of Primary studies

While all studies included in this review were randomised controlled trials and of fair quality, there was variation in the reporting of sequence generation, allocation concealment and, as is common in complex interventions, blinding of participants and personnel was not always consistent. The greatest cause for concern was the selective reporting of outcomes which was noted or not clearly reported in over half of the studies reviewed. Furthermore, the small number of studies and small number of participants in the studies, meant that it was difficult to discern any evident publication bias. These limitations must be considered alongside the findings presented in this review to avoid an overestimate of the benefit of self-management.

## Strengths and limitations of the review

This review gives a broad indication of the effectiveness and potential value of self-management interventions for people with severe mental illness. A strength of this review is the generalisability of the findings to current practice. For instance, it

included a diagnostically heterogeneous sample of people with SMI, representative of those presenting in secondary care mental health services, and included samples from a wider range of countries and cultures.

As with any review of this nature, there are methodological limitations that must be considered. Heterogeneity was found to be high across many of the meta-analyses, and while a certain amount of heterogeneity is inevitable, we have tried to mitigate this through the use of random effects modelling (Higgins & Green, 2011). Additionally, heterogeneity of the outcome measures included in each meta-analysis (particularly the self-rated recovery outcomes) means caution should be exercised in the interpretation of these findings. A further potential limitation is from the risk of bias quality assessment of the studies included in this review. Interestingly, readmission rates and service use outcomes were infrequently measured by studies. This could be a useful outcome to include for future studies of self-management.

The choice to pool together comparisons of self-management against TAU or against active controls in the same analyses could be criticised in that they ask quite different questions. A post-hoc sub group analysis of TAU only and active control only studies was conducted (see forest plots in Appendix 5). No differential pattern of outcomes between the different comparators was found. Arguably, TAU varies hugely among the included studies, and all of the active controls are treatments which might be available from a multi-disciplinary community mental health team. Thus, irrespective of whether TAU and active controls are combined or not, the analysis is evaluating the addition of self-management to highly varied care.

In an attempt to present data in a simple format, it was classified into two time points: end of treatment and 1-year follow-up. While the follow up time point used in this review is intended to indicate the presence of a more enduring effect of self-management this may not necessarily be the case. This is because not all studies

followed up their participants for a full year, and also the time point of data collection is measured in weeks post randomisation, not weeks post treatment. Accordingly, the variation in intervention length across studies means that for some studies the 1-year follow-up time point may in fact be only 6 months post intervention.

A final limitation in conducting this review was the lack of consensus of how to define the concept known as self-management. While this review has to some extent attempted to characterise the types of interventions, it unfortunately cannot indicate how specific components of these interventions may have been effective. The interventions reviewed here are complex, and while they employ overlapping techniques, are also likely to vary in their modes of action and their subsequent effect on outcomes. In particular, the two studies by Chien and colleagues (2013; 2014) that included mindfulness were a departure from the other self-management approaches in this review; however, it is important to include studies testing additional methods of managing persistent symptoms within the self-management context. It could be beneficial to include more mindfulness aspects in future self-management interventions. In spite of a wide range of self-management interventions and some heterogeneity across studies, results appear generally in favour of self-management.

#### Implications for practice

While self-management for this population has been previously recommended at a guideline level (National Institute for Health and Care Excellence (NICE), 2014a) (National Institute for Health and Care Excellence (NICE), 2014b), it remains to be implemented at a service level. On the basis of this review teaching self-management is likely to be a useful strategy and due to its group format, may even be a cost-effective approach compared to other currently available interventions for this population. It may also provide a first good step in socialising patients to a

collaborative way of working that may result in better engagement throughout and into subsequent treatment. Providing self-management as a standard part of care, in addition to current treatment as usual, could help empower people with severe mental illness to feel equipped with the skills, strategies, plans and knowledge to effectively live with their illness.

## **Research implications**

In terms of future research, it would be important to work to understand the mechanisms of effect and critical components of self-management programmes – which are multi-faceted, complex interventions. Additionally, further conceptual work to establish an optimal typology for self-management interventions is necessary. This could involve the further development and validation of the typology proposed in this review.

## References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4th ed., text rev.)*. http://doi.org/10.1176/appi.books.9780890423349
- Anzai, N., Yoneda, S., Kumagai, N., Nakamura, Y., Ikebuchi, E., & Liberman, R. P. (2002). Training persons with Schizophrenia in illness self-management: a randomized controlled trial in Japan. *Psychiatric Services (Washington, D.C.)*, 53(5), 545–547. http://doi.org/10.1176/appi.ps.53.5.545
- Atkinson, J. M., Coia, D. A., Gilmour, W. H., & Harper, J. P. (1996). The impact of education groups for people with schizophrenia on social functioning and quality of life. *The British Journal of Psychiatry*, *168*(2), 199–204. http://doi.org/10.1192/bjp.168.2.199
- Barbic, S., Krupa, T., & Armstrong, I. (2009). A randomized controlled trial of the effectiveness of a modified recovery workbook program: preliminary findings. 

  Psychiatric Services (Washington, D.C.), 60(4), 491–497.

  http://doi.org/10.1176/appi.ps.60.4.491
- Bauer, M. S., Biswas, K., & Kilbourne, A. M. (2009). Enhancing multiyear guideline concordance for bipolar disorder through collaborative care. *American Journal of Psychiatry*, *166*(11), 1244–1250. http://doi.org/10.1176/appi.ajp.2009.09030342
- Bauer, M. S., McBride, L., Williford, W. O., Glick, H., Kinosian, B., Altshuler, L., ...

  Sajatovic, M. (2006a). Collaborative care for bipolar disorder: part I. Intervention and implementation in a randomized effectiveness trial. *Psychiatric Services*(Washington, D.C.), 57(7), 927–36. http://doi.org/10.1176/appi.ps.57.7.927
- Bauer, M. S., McBride, L., Williford, W. O., Glick, H., Kinosian, B., Altshuler, L., ...

  Sajatovic, M. (2006b). Collaborative care for bipolar disorder: Part II. Impact on clinical outcome, function, and costs. *Psychiatric Services (Washington, D.C.)*,

- 57(7), 937–945. http://doi.org/10.1176/appi.ps.57.7.937
- Bebbington, P. (2015). Unravelling psychosis: psychosocial epidemiology, mechanism, and meaning. *Shanghai Archives of Psychiatry*, *27*(2), 70–81. http://doi.org/10.11919/j.issn.1002-0829.215027
- Chan, S. H.-W., Lee, S. W.-K., & Chan, I. W.-M. (2007). TRIP: a psycho-educational programme in Hong Kong for people with schizophrenia. *Occupational Therapy International*, *14*(2), 86–98. http://doi.org/10.1002/oti.226
- Chien, W. T., & Lee, I. Y. M. (2013). The mindfulness-based psychoeducation program for chinese patients with schizophrenia. *Psychiatric Services*. http://doi.org/http://dx.doi.org/10.1176/appi.ps.002092012
- Chien, W. T., & Thompson, D. R. (2014). Effects of a mindfulness-based psychoeducation programme for Chinese patients with Schizophrenia: 2-year follow-up. *The British Journal of Psychiatry*. http://doi.org/10.1192/bjp.bp.113.134635
- Colom, F., Vieta, E., Martinez-Aran, A., Reinares, M., Goikolea, J. M., Benabarre, A., ... Corominas, J. (2003). A randomized trial on the efficacy of group psychoeducation in the prophylaxis of recurrences in bipolar patients whose disease is in remission. *Archives of General Psychiatry*, 60(4), 402–7. http://doi.org/10.1001/archpsyc.60.4.402
- Colom, F., Vieta, E., Sánchez-Moreno, J., Palomino-Otiniano, R., Reinares, M., Goikolea, J. M., ... Martínez-Arán, A. (2009). Group psychoeducation for stabilised bipolar disorders: 5-Year outcome of a randomised clinical trial. *British Journal of Psychiatry*, 194(3), 260–265. http://doi.org/10.1192/bjp.bp.107.040485
- Cook, J. A., Copeland, M. E., Floyd, C. B., Jonikas, J. A., Hamilton, M. M., Razzano,

- L. A., ... Boyd, S. (2012). A Randomized Controlled Trial of Effects of Wellness Recovery Action Planning on Depression, Anxiety, and Recovery. *Psychiatric Services*, *63*(6), 541–7. http://doi.org/10.1176/appi.ps.201100125
- Cook, J. A., Copeland, M. E., Jonikas, J. A., Hamilton, M. M., Razzano, L. A., Grey,
  D. D., ... Boyd, S. (2011). Results of a randomized controlled trial of mental illness self-management using wellness recovery action planning. *Schizophrenia Bulletin*, 38(4), 881–891. http://doi.org/10.1093/schbul/sbr012
- Cook, J. A., Jonikas, J. A., Hamilton, M. M., Goldrick, V., Steigman, P. J., Grey, D.
   D., ... Copeland, M. E. (2013a). Impact of Wellness Recovery Action Planning on service utilization and need in a randomized controlled trial. *Psychiatric Rehabilitation Journal*. http://doi.org/10.1037/prj0000028
- Cook, J. A., Jonikas, J. A., Hamilton, M. M., Goldrick, V., Steigman, P. J., Grey, D.
  D., ... Copeland, M. E. (2013b). Impact of Wellness Recovery Action Planning on service utilization and need in a randomized controlled trial. *Psychiatric Rehabilitation Journal*. http://doi.org/10.1037/prj0000028
- Cook, J. A., Steigman, P., Pickett, S., Diehl, S., Fox, A., Shipley, P., ... Burke-Miller, J. K. (2012). Randomized controlled trial of peer-led recovery education using Building Recovery of Individual Dreams and Goals through Education and Support (BRIDGES). Schizophrenia Research, 136(1–3), 36–42. http://doi.org/10.1016/j.schres.2011.10.016
- Cuijpers, P. (2016). *Meta-analyses in mental health research: A practical guide*.

  Amsterdam: Vrije Universiteit Amsterdam.
- Eckman, T., Wirshing, W., Marder, S., Liberman, R., Johnston-Cronk, M., Zimmerman, K., & Mintz, J. (1992). Techniques for training schizophrenic patients in illness self-management: A controlled trial. *American Journal of Psychiatry*.

- Färdig, R., Lewander, T., Fredriksson, A., & Melin, L. (2011). Evaluation of the Illness Management and Recovery Scale in schizophrenia and schizoaffective disorder. Schizophrenia Research, 132(2–3), 157–164. http://doi.org/10.1016/j.schres.2011.07.001
- Färdig, R., Lewander, T., Melin, L., Folke, F., & Fredriksson, A. (2011). A randomized controlled trial of the illness management and recovery program for persons with schizophrenia. *Psychiatric Services (Washington, D.C.)*, *62*(6), 606–612. http://doi.org/10.1176/appi.ps.62.6.606
- Hasson-Ohayon, I., Roe, D., & Kravetz, S. (2007). A randomized controlled trial of the effectiveness of the illness management and recovery program. *Psychiatric Services*, 58(11), 1461–1466. http://doi.org/10.1176/appi.ps.58.11.1461
- Higgins, J., & Green, S. (Eds.). (2011). Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. The Cochrane Collaboration. Retrieved from http://handbook.cochrane.org.
- Jääskeläinen, E., Juola, P., Hirvonen, N., McGrath, J. J., Saha, S., Isohanni, M., ... Miettunen, J. (2013). A systematic review and meta-analysis of recovery in schizophrenia. *Schizophrenia Bulletin*, *39*(6), 1296–1306. http://doi.org/10.1093/schbul/sbs130
- Janney, C. A., Bauer, M. S., & Kilbourne, A. M. (2014). Self-management and bipolar disorder-a clinician's guide to the literature 2011-2014. *Current Psychiatry Reports*, *16*(9), 485. http://doi.org/10.1007/s11920-014-0485-5
- Jauhar, S., McKenna, P. J., Radua, J., Fung, E., Salvador, R., & Laws, K. R. (2014).
  Cognitive-behavioural therapy for the symptoms of schizophrenia: Systematic review and meta-analysis with examination of potential bias. *British Journal of Psychiatry*, 204(1), 20–29. http://doi.org/10.1192/bjp.bp.112.116285

- Jonikas, J. A., Grey, D. D., Copeland, M. E., Razzano, L. A., Hamilton, M. M., Floyd, C. B., ... Cook, J. A. (2013). Improving propensity for patient self-advocacy through wellness recovery action planning: Results of a randomized controlled trial. *Community Mental Health Journal*, 49(3), 260–269. http://doi.org/10.1007/s10597-011-9475-9
- Kopelowicz, a, Wallace, C. J., & Zarate, R. (1998). Teaching psychiatric inpatients to re-enter the community: a brief method of improving the continuity of care. *Psychiatric Services (Washington, D.C.)*, 49(10), 1313–1316.
- Lawrence, D., & Kisely, S. (2010). Inequalities in healthcare provision for people with severe mental illness. *Journal of Psychopharmacology (Oxford, England)*, *24*(4 Suppl), 61–8. http://doi.org/10.1177/1359786810382058
- Levitt, A. J., Mueser, K. T., Degenova, J., Lorenzo, J., Bradford-Watt, D., Barbosa, A., ... Chernick, M. (2009). Randomized controlled trial of illness management and recovery in multiple-unit supportive housing. *Psychiatric Services*(Washington, D.C.), 60(12), 1629–36. http://doi.org/10.1176/appi.ps.60.12.1629
- Liberman, R. P., Wallace, C. J., Blackwell, G., Kopelowicz, A., Vaccaro, J. V., & Mintz, J. (1998). Skills training versus psychosocial occupational therapy for persons with persistent schizophrenia. *American Journal of Psychiatry*, *155*(8), 1087–1091. http://doi.org/10.1176/ajp.155.8.1087
- Lin, E. C.-L., Chin Hong, C., Wen-Chuan, S., Mei-Feng, L., Shujen, S., Mueser, K. T., ... Hong-Song, W. (2013). A randomized controlled trial of an adapted Illness Management and Recovery program for people with Schizophrenia awaiting discharge from a psychiatric hospital. *Psychiatric Rehabilitation Journal*, 36(4), 243–249. http://doi.org/10.1037/prj0000013
- Lincoln, T. M., Wilhelm, K., & Nestoriuc, Y. (2007). Effectiveness of psychoeducation for relapse, symptoms, knowledge, adherence and functioning in psychotic

- disorders: A meta-analysis. *Schizophrenia Research*, *96*(1–3), 232–245. http://doi.org/10.1016/j.schres.2007.07.022
- Mackain, S. joy, Smith, T. E., Wallace, C. W., & Kopelowicz, A. (1998). Evaluation of a community re-entry program. *International Review of Psychiatry*, *10*(1), 76–83. http://doi.org/10.1080/09540269875159
- McCrone, P., Dhanasiri, S., Patel, A., Knapp, M., & Lawton-Smith, S. (2008). Paying the price: the cost of mental health care in England to 2026. *The British Journal of Psychiatry: The Journal of Mental Science*, *184*, 386–92. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/15123501%5Cnhttp://www.library.nhs.uk/H ealthManagement/ViewResource.aspx?resID=290410
- McGuire, A. B., Kukla, M., Green, A., Gilbride, D., Mueser, K. T., & Salyers, M. P. (2014). Illness Management and Recovery: A Review of the Literature.

  \*Psychiatric Services, 65(2), 171–179. http://doi.org/10.1176/appi.ps.201200274
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The Prisma Group. (2009).
  Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The
  PRISMA Statement (Reprinted from Annals of Internal Medicine). *Physical Therapy*, 89(9), 873–880. http://doi.org/10.1371/journal.pmed.1000097
- Mueser, K. T., Corrigan, P. W., Hilton, D. W., Tanzman, B., Schaub, A., Gingerich, S., ... Herz, M. I. (2002). Illness Management and Recovery: a review of the research. *Psychiatric Services*, *53*(10), 1272–1284. http://doi.org/10.1176/appi.ps.53.10.1272
- Mueser, K. T., Deavers, F., Penn, D. L., & Cassisi, J. E. (2013). Psychosocial treatments for schizophrenia (pp. 465–497). 4139 El Camino Way, P.O. Box 10139, Palo Alto CA 94306, United States: Annual Reviews Inc. http://doi.org/http://dx.doi.org/10.1146/annurev-clinpsy-050212-185620

- Mueser, K. T., & McGurk, S. R. (2004). Schizophrenia. *Lancet*, *363*(9426), 2063–2072. http://doi.org/10.1016/S0140-6736(04)16458-1
- Mueser, K. T., Meyer, P. S., Penn, D. L., Clancy, R., Clancy, D. M., & Salyers, M. P. (2006). The illness management and recovery program: Rationale, development, and preliminary findings. *Schizophrenia Bulletin*, 32(SUPPL.1). http://doi.org/10.1093/schbul/sbl022
- Murray, G., Suto, M., Hole, R., Hale, S., Amari, E., & Michalak, E. E. (2011). Self-management strategies used by "high functioning" individuals with Bipolar Disorder: from research to clinical practice. *Clinical Psychology and Psychotherapy*, 18(18), 95–109. http://doi.org/10.1002/cpp
- National Institute for Health and Care Excellence (NICE). (2014a). Bipolar disorder: assessment and management. Clinical guideline 185. Retrieved from https://www.nice.org.uk/guidance/%0Acg185
- National Institute for Health and Care Excellence (NICE). (2014b). *Psychosis and schizophrenia in adults: prevention and management*. Retrieved from nice.org.uk/guidance/cg178
- National Institute for Health and Clinical Excellence. (2009). Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care (update), (82), London: Nice. http://doi.org/10.1093/schbul/sbp021
- Noordsy, D., Torrey, W., Mueser, K., Mead, S., O'Keefe, C., & Fox, L. (2002).

  Recovery from severe mental illness: an interpersonal and functional outcome definition. *International Review of Psychiatry*, *14*(4), 318–326.

  http://doi.org/10.1080/0954026021000016969
- Oud, M., Mayo-Wilson, E., Braidwood, R., Schulte, P., Jones, S. H., Morriss, R., ...

- Kendall, T. (2016). Psychological interventions for adults with bipolar disorder: Systematic review and meta-analysis. *British Journal of Psychiatry*, *208*(3), 213–222. http://doi.org/10.1192/bjp.bp.114.157123
- Perry, A., Tarrier, N., Morriss, R., Mccarthy, E., & Limb, K. (1999). Randomised controlled trial of efficacy of teaching patients with bipolar disorder to identify early symptoms of relapse and obtain treatment. *BMJ*, *318*(January), 149–153.
- Pickett, S. A., Diehl, S. M., Steigman, P. J., Prater, J. D., Fox, A., Shipley, P., ...

  Cook, J. A. (2012). Consumer empowerment and self-advocacy outcomes in a randomized study of peer-led education. *Community Mental Health Journal*, 48(4), 420–430. http://doi.org/10.1007/s10597-012-9507-0
- Priebe, S., Omer, S., Giacco, D., & Slade, M. (2014). Resource-oriented therapeutic models in psychiatry: Conceptual review. *British Journal of Psychiatry*, *204*(4), 256–261. http://doi.org/10.1192/bjp.bp.113.135038
- Proudfoot, J., Parker, G., Hyett, M., Manicavasagar, V., Smith, M., Grdovic, S., & Greenfield, L. (2007). Web-based bipolar disorder program. *Australian and New Zealand Journal of Psychiatry*, *41*, 903–909.
- Proudfoot, J., Parker, G., Manicavasagar, V., Hadzi-Pavlovic, D., Whitton, A., Nicholas, J., ... Burckhardt, R. (2012). Effects of adjunctive peer support on perceptions of illness control and understanding in an online psychoeducation program for bipolar disorder: A randomised controlled trial. *Journal of Affective Disorders*, *142*(1–3), 98–105. http://doi.org/10.1016/j.jad.2012.04.007
- Revier, C. J., Reininghaus, U., Dutta, R., Fearon, P., Murray, R. M., Doody, G. A., ... Jones, P. B. (2015). Ten-year outcomes of First-Episode Psychoses in the MRC ÆSOP-10 Study. *The Journal of Nervous and Mental Disease*, *203*(5), 379–86. http://doi.org/10.1097/NMD.000000000000000000

- Sajatovic, M., Davies, M. A., Ganocy, S. J., Bauer, M. S., Cassidy, K. A., Hays, R.
  W., ... Calabrese, J. R. (2009). A comparison of the life goals program and treatment as usual for individuals with bipolar disorder. *Psychiatric Services* (Washington, D.C.), 60(9), 1182–9. http://doi.org/10.1176/appi.ps.60.9.1182
- Salyers, M. P., McGuire, A. B., Kukla, M., Fukui, S., Lysaker, P. H., & Mueser, K. T. (2014). A randomized controlled trial of illness management and recovery with an active control group. *Psychiatric Services (Washington, D.C.)*. http://doi.org/10.1176/appi.ps.201300354
- Salyers, M. P., McGuire, A. B., Rollins, A. L., Bond, G. R., Mueser, K. T., & MacY, V. R. (2010). Integrating assertive community treatment and illness management and recovery for consumers with severe mental illness. *Community Mental Health Journal*, *46*(4), 319–329. http://doi.org/10.1007/s10597-009-9284-6
- Schaub, A., Mueser, K. T., von Werder, T., Engel, R., Moller, H. J., & Falkai, P. (2016). A randomized controlled trial of group Coping-Oriented Therapy vs Supportive Therapy in Schizophrenia: results of a 2-year follow-up. Schizophrenia Bulletin, 42 Suppl 1, S71-80. http://doi.org/http://dx.doi.org/10.1093/schbul/sbw032
- Scott, A. J., Webb, T. L., & Rowse, G. (2015). Self-help interventions for psychosis: A meta-analysis. Clinical Psychology Review, 39, 96–112.
  http://doi.org/http://dx.doi.org/10.1016/j.cpr.2015.05.002
- Shon, K.-H., & Park, S.-S. (2002). Medication and symptom management education program for the rehabilitation of psychiatric patients in Korea: The effects of promoting schedule on self-efficacy theory. *Yonsei Medical Journal*, *43*(5), 579–589.
- Slade, M., & Longden, E. (2015). The empirical evidence about mental health and recovery: how likely, how long, what helps?, (July), 1–33.

- Smith, D. J., Griffiths, E., Poole, R., di Florio, A., Barnes, E., Kelly, M. J., ... Simpson, S. (2011). Beating Bipolar: Exploratory trial of a novel internet-based psychoeducational treatment for bipolar disorder. *Bipolar Disorders*, *13*(5–6), 571–577. http://doi.org/10.1111/j.1399-5618.2011.00949.x
- Sterling, E. W., Von Esenwein, S. A., Tucker, S., Fricks, L., & Druss, B. G. (2010).

  Integrating wellness, recovery, and self-management for mental health
  consumers. *Community Mental Health Journal*, *46*(2), 130–138.

  http://doi.org/10.1007/s10597-009-9276-6
- Todd, N. J., Jones, S. H., Hart, A., & Lobban, F. A. (2014). A web-based self-management intervention for Bipolar Disorder "living with bipolar": a feasibility randomised controlled trial. *Journal of Affective Disorders*. http://doi.org/10.1016/j.jad.2014.07.027
- Todd, N. J., Solis-Trapala, I., Jones, S. H., & Lobban, F. A. (2012). An online randomised controlled trial to assess the feasibility, acceptability and potential effectiveness of "Living with Bipolar": A web-based self-management intervention for Bipolar Disorder. Trial design and protocol. *Contemporary Clinical Trials*, 33(4), 679–688. http://doi.org/10.1016/j.cct.2012.02.011
- Torrent, C., Bonnin, M., Ph, D., Martínez-arán, A., Ph, D., Valle, J., ... Ph, D. (2013).

  Efficacy of Functional Remediation in Bipolar Disorder: A Multicenter

  Randomized Controlled Study, (August), 852–859.

  http://doi.org/10.1016/j.psychres.2010.06.020
- Torrey, W., Rapp, C., Van Tosh, L., McNabb, C., & Ralph, R. (2005). Recovery principles and Evidence Based Practice: essential ingredients of service improvement. *Community Mental Health Journal*, *41*(1), 91–100.

- Van Gestel-Timmermans, H., Brouwers, E. P. M., van Assen, M. a. L. M., & van Nieuwenhuizen, C. (2012). Effects of a Peer-Run Course on Recovery From Serious Mental Illness: A Randomized Controlled Trial. *Psychiatric Services*, 63(1), 54–60. http://doi.org/10.1176/appi.ps.201000450
- Vreeland, B., Minsky, S., Yanos, P. T., Menza, M., Gara, M., Kim, E., ... Allen, L. (2006). Efficacy of the team solutions program for educating patients about illness management and treatment. *Psychiatric Services (Washington, D.C.)*, 57(6), 822–8. http://doi.org/10.1176/appi.ps.57.6.822
- Wirshing, D. A., Guzik, L. H., Zorick, T. S., Pierre, J. M., Resnick, S. A., Goldstein, D., & Wirshing, W. C. (2006). Community re-entry program training module for schizophrenic inpatients improves treatment outcomes. *Schizophrenia Research*, 87(1–3), 338–339. http://doi.org/10.1016/j.schres.2006.06.030
- Wykes, T., Steel, C., Everitt, B., & Tarrier, N. (2008). Cognitive behavior therapy for schizophrenia: Effect sizes, clinical models, and methodological rigor. Schizophrenia Bulletin, 34(3), 523–537. http://doi.org/10.1093/schbul/sbm114
- Xiang, Y. T., Weng, Y. Z., Li, W. Y., Gao, L., Chen, G. L., Xie, L., ... Ungvari, G. S. (2006). Training patients with schizophrenia with the community re-entry module: A controlled study. *Social Psychiatry and Psychiatric Epidemiology*, *41*(6), 464–469. http://doi.org/10.1007/s00127-006-0050-6
- Xiang, Y. T., Weng, Y. Z., Li, W. Y., Gao, L., Chen, G. L., Xie, L., ... Ungvari, G. S.
  (2007). Efficacy of the community re-entry module for patients with schizophrenia in Beijing, China: Outcome at 2-year follow-up. *British Journal of Psychiatry*, 190(JAN.), 49–56. http://doi.org/10.1192/bjp.bp.106.023697
- Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., ... Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-

- analysis. *British Journal of Psychiatry*, 206(4), 268–274. http://doi.org/10.1192/bjp.bp.114.147561
- Zhao, S., Sampson, S., Xia, J., & Jayaram Mahesh, B. Psychoeducation (brief) for people with serious mental illness, Cochrane Database of Systematic Reviews (2015). John Wiley & Sons, Ltd. http://doi.org/10.1002/14651858.CD010823.pub2
- Zhou, B., Zhang, P., & Gu, Y. (2014). Effectiveness of self-management training in community residents with chronic schizophrenia: a single-blind randomized controlled trial in Shanghai, China. *Shanghai Jingshen Yixue*, *26*(2), 81–87. http://doi.org/http://dx.doi.org/10.3969/j.issn.1002-0829.2014.02.004
- Zou, H., Li, Z., Nolan, M. T., Arthur, D., Wang, H., & Hu, L. (2013). Self-management education interventions for persons with schizophrenia: a meta-analysis.

  International Journal of Mental Health Nursing. Retrieved from http://onlinelibrary.wiley.com/o/cochrane/cldare/articles/DARE-12013027496/frame.html

# Part 2 - Empirical Paper

Resilience following a crisis for people with severe mental illness: a randomised controlled trial of a peer-provided self-management intervention.

### **Abstract**

Aims: Following mental health crisis there is frequently a lack of continuity of care, which is thought to contribute to relapse, and impact on recovery. This study seeks to determine if provision of a peer supported self-management intervention following a crisis has an effect on resilience at 18 months. It also seeks to determine if any baseline characteristics of participants are predictors of resilience at 18 months.

Methods: In total 441 participants were recruited from Crisis Resolution Teams

(CRT) across six National Health Service (NHS) Trusts. They were randomised to a 10-week peer supported self-management intervention utilising a recovery workbook, or a control group consisting of the recovery workbook only. At 18-months post-randomisation, follow-up data was collected for 250 participants. The effectiveness of peer support was assessed by comparing the intervention arm to the active control. Random effects multilevel modelling with clustering at the peer support level was used for the predictors of resilience analysis.

**Results:** There was no effect of peer support on resilience at 18 months post-randomisation. Two variables were found to be predictive of a resilient outcome: Social Outcomes Index (SIX) and the Questionnaire about the Process of Recovery (QPR), however the amount of change elicited is unlikely to be clinically meaningful in terms of improvement in sense of recovery, social functioning or general well-being.

**Conclusions:** The lack of effect in terms of the peer support intervention or in identifying predictors of resilience may be related to the complex and interrelated factors that have a cumulative, and ongoing, impact on the development of resilience.

### Introduction

Crisis Resolution Teams (CRTs) provide rapid assessment and treatment of mental health crises in the community as an alternative to acute inpatient admission (Department of Health, 2001). Published evidence has been predominantly positive and suggest that CRTs: reduce inpatient admissions (Glover, Arts, & Babu, 2014; Jethwa, Galappathie, & Hewson, 2007; Johnson, Nolan, Hoult, et al., 2005; Johnson, Nolan, Pilling, et al., 2005; Keown, Tacchi, Niemiec, & Hughes, 2007); lower healthcare costs (McCrone, Johnson, Nolan, Pilling, Sandor, Hoult, McKenzie, Thompson, et al., 2009; McCrone, Johnson, Nolan, Pilling, Sandor, Hoult, McKenzie, White, et al., 2009) and have been found to increase service user satisfaction with acute care (Johnson, Nolan, Hoult, et al., 2005; Johnson, Nolan, Pilling, et al., 2005).

However, areas of dissatisfaction have also been reported by service users. Particular concerns have been raised in relation to the lack of continuity of care between services following a crisis (Clark, Khattak, & Nahal, 2008; National Audit Office, 2007). CRT care is often experienced by service users as ending suddenly, with little in the way of advice or education provided on after-care strategies to minimise future crises (Hopkins & Niemiec, 2007). This perceived lack of continuity is evident in figures which indicate that a high proportion of service users return to acute care within a year of a period of CRT care ending (Johnson, Nolan, Pilling, et al., 2005).

One option to assist in the transition from intensive crisis care to care in the community is through the delivery of self-management programs, in particular, peer-supported self-management programs. There is currently evidence for the effectiveness of self-management programs in helping mental health service users to develop the skills and strategies to manage their own mental health through psychoeducation, developing coping skills to manage persisting symptoms, learning to identify early warning signs of crisis and developing ways to respond to crises and

other difficulties (Barbic, Krupa, & Armstrong, 2009; Cook et al., 2009; Mueser & Gingerich, 2011). Evidence also indicates that the delivery of peer support following a mental health crisis; that is support provided by people who have themselves experienced mental ill health, alongside existing mental health service support can improve outcomes for people (Bowers et al., 2006).

Peer support is becoming increasingly popular in the UK and abroad, and there is substantial evidence for the benefits that it may provide to service users. Studies have found that peer support can empower service users to think and behave in new ways (Davidson et al., 1999); provide a frame to make sense of their experiences (Repper & Carter, 2011); improve social skills and functioning resulting in an increased social network (Ochocka, Nelson, Janzen, & Trainor, 2006).

Additionally, peer support workers are able to forge effective and stable alliances with this typically difficult to engage client group (Davidson, Chinman, Sells, & Rowe, 2006).

A unique aspect of the peer support relationship is that of reciprocity. This refers to the opportunity to receive and give support, which is reported to be highly valued by service users. It also represents a shift in the dynamic and power balance typically encountered in mental health services (Ochocka et al., 2006). Since peers tend to be further along their road to recovery they may instil hope (Davidson, Chinman, Sells, & Rowe, 2006), provide opportunities for upward social comparison (Wood, 1989) and growth through vicarious learning and the expectation of success via exposure to a positive role model (Simoni, Franks, Lehavot, & Yard, 2013). This tangible possibility of recovery shared through experiential knowledge (Borkman, 1976) is something that healthcare professionals and their "professional knowledge" may be less able to provide.

The theoretical underpinnings to account for peer support's efficacy require further development (Simoni et al., 2013) to the extent that peer support has been

described "as a method in search of a theory" (Turner &Shepherd, 1999, cited in Simoni et al., 2013). Some proposed theories include social support theory, social cognitive theory and empowerment theory (Simoni et al., 2013). These theories can account for peer support mode of action through the development of an individual's resources to engage in adaptive coping and problem solving (social support theory, Cohen & Wills, 1985); increased self-efficacy through vicarious or observational learning (Bandura, 1989); and empowerment created through continuity and relatedness in connection to others (empowerment theory, Kieffer, 1984). Furthermore, support from a similarly situated other may foster self-development, decision making skills, and a sense of community.

The proposed modes of action of peer support have considerable overlap with the proposed factors that are thought to contribute to resilience. While resilience itself has no single agreed definition (Deegan, 2005), it has been conceptualized as both a trait and a process (Luthar, Cicchetti, & Becker, 2007; Windle, Bennett, & Noyes, 2011). The most widely agreed definition accepts resilience as a dynamic process of positive adaptation to adversity (Luthar et al., 2007) or "bouncing back". The key element to the development of resilience is in the experience of adversity and subsequent adjustment. As such those having recently suffered a crisis could be well positioned to benefit from an intervention and support that might target resilience. Additionally, peer support workers who themselves have overcome adversity and recovered (suggesting the development of resilience), may be best placed to share their knowledge gained through their experiences. Furthermore, investigating resilience in those with severe mental illness (SMI) could be particularly relevant given the variation in recovery trajectories between individuals, which may in part be accounted for by differences in resilience.

Much of the research on resilience to date has focused on resilient trajectories in relation to children and developmental psychopathology (for an

overview see Luthar, Sawyer, & Brown, 2006). There has been little research into the role of resilience in the course of severe mental illness (Georgiades, Farquharson, & Ellett, 2015; Torgalsbøen, 2012). However, there is preliminary evidence that lower levels of resilience are associated with higher levels of persecutory delusions in those with early psychosis (Georgiades et al., 2015). It is reasonable to assume, although the research has not yet been conducted, that higher levels of resilience would be associated with improved recovery outcomes. Additionally, since resilience involves behaviours, thoughts and actions that can be learned and developed (American Psychological Association, 2015) it potentially could be improved through working with a peer support worker to develop self-management skills.

Resilience varies over the life course- it can be learnt and improved as well as eroded by difficult life circumstances (Mental Health Strategic Partnership, 2013). Building resilience has been linked to relationships, social connectedness and positive social support (Ozbay et al., 2007), as well as neighbourhood social capital and environmental factors (Rutten et al., 2013). These are particularly relevant for people with SMI, a notably socially isolated group, disproportionally affected by poverty and deprivation (Marmot, 2010). A focus on resilience is an inherently strengths-based approach (Rapp, 1998 in Deegan, 2005) a contrast to the deficit-based model of mental health services. The potential to target resilience through peer support and self-management interventions may provide additional means through which coping and adapting can be developed as well as foster empowerment and hope for service users to make a difference in their recovery (Mental Health Strategic Partnership, 2013).

The employment of peer support workers to deliver self-management interventions to service users is becoming increasingly common within NHS services, further backed by the recent NICE guidelines (2014) recommendations for the care of individuals with psychosis and schizophrenia (NICE, 2014) These guidelines

acknowledge the paucity of evidence for peer support and request high quality research on peer support programmes. Accordingly, the 2014 NICE guidelines research recommendations call for research specifically focusing on the clinical and cost effectiveness of peer support interventions in people with psychosis and schizophrenia (NICE, 2014). However, to date, there have been no evaluations of peer-provided, self-management interventions specifically for people leaving CRT care. Furthermore, the benefits of peer provided service are yet to be reliably demonstrated to be more effective than current service provision (Lloyd-Evans et al., 2014).

## The current Study and hypotheses

The CORE (Crisis resolution team Optimisation and RElapse prevention) study was a five-year programme of research funded by the National Institute for Health Research (NIHR). The study, conducted within NHS crisis resolution teams, aimed to optimise team functioning, prevent relapse and enhance recovery. One stream of this research programme involved the development and testing of a peer-delivered self-management intervention that aims to bridge the gap between crisis and continuing care. A multi-site randomised controlled trial (RCT) commenced in March 2014. It tested whether a peer-provided, self-management programme and recovery workbook compared to a control group receiving the recovery booklet only, could reduce relapse and promote recovery for people leaving Crisis Resolution Team care.

In 2015 this study received further funding to collect follow-up data at 18-months post-randomisation. It was argued that the original data collection point at four months post-randomisation may have been too soon post-crisis to capture any significant improvement in symptoms or self-rated recovery. In particular, recovery for participants with difficulties towards the more severe end of the spectrum, typical of

those receiving treatment from Crisis Resolutions teams, is likely to occur over a longer time course, due to both the inherent complexity and the variability in the clinical course of severe mental illness (Liberman & Kopelowicz, 2005). It was hypothesized that collection of data at 18-months could demonstrate any sustained effect of peer support on symptoms and self-rated recovery. In addition, it would add valuable follow up data for this population group in general, where longer-term outcome data is often lacking (Castelein, Bruggeman, Davidson, & Van Der Gaag, 2015).

The present study assesses one potential aspect of recovery, resilience, a measure of which was added to this project at the 18-month follow-up time point. Specifically, this study investigated the effect of peer support following discharge from crisis resolution team treatment on resilience. The main research questions were:

- 1. Did the peer support group differ from the control group (Recovery workbook only) on a measure of resilience at 18 months?
- 2. What baseline variables predicted resilience at 18 months?

It was hypothesised that participants in the peer support (treatment) group would be more likely to show improvements on resilience at the 18-month follow-up time point than those in the control group.

## Method

The findings reported here are drawn from a large cluster Randomised

Controlled Trial (RCT) (ISRCTN registration: http://www.isrctn.com/ISRCTN

01027104) that aimed to test whether a peer-provided, self-management programme
and recovery workbook could reduce relapse and promoted recovery for people
leaving Crisis Resolution Team care. The present study used the outcome data from
selected baseline and 18-month follow-up measures. The study had two arms: the

intervention arm consisted of a peer supported self-management intervention utilising a recovery workbook, and the control arm consisted of the recovery workbook only.

## Setting

Participants were recruited from Crisis Resolution Teams (CRT) in six

National Health Service (NHS) Trusts covering inner city, mixed urban and rural

areas. Peer support sessions and data collection took place in a location convenient
to the participant, such as their home, an appropriate public space or NHS premises.

Risk assessments for these sessions were made by clinical CRT staff who knew the
participant. If risk was identified, then meetings took place on NHS premises only. A
buddy check-in system was used to ensure researcher safety during home visits.

#### Recruitment

A total of 441 participants were recruited to the main CORE study (http://www.isrctn.com/ISRCTN01027104). A CONSORT diagram (Figure 1) depicts the process of recruitment and follow up of participants through the trial. Of these 441 participants, 250 completed follow up interviews at 18 months post randomisation. To be recruited into the study, participants had to have:

- a) Be over 18 years of age
- b) been on the caseload of a participating CRT for at least one week
- c) had capacity to give written informed consent to the study
- d) been discharged from crisis care within the past month

#### Exclusion criteria were:

- a) People who in the view of the clinical team presented such high risk to others, that it would be unsafe for peer support workers to meet with them even in a mental health service setting.
- b) People who were discharged to addresses outside the catchment area.

c) People who could not understand the intervention when delivered in English.

In order to achieve a study sample that was broadly representative of Crisis Resolution Team service users, a recruitment threshold was set that stipulated that at least 50% of participants must have a diagnosis of schizophrenia, other psychosis, or bipolar disorder. Within this stipulation, participation in the study was offered to all eligible service users in participating Crisis Resolution Teams until the recruitment target for each service was reached.

#### Ethical Considerations

Ethical approval was granted by the North-East Research Ethics Committee on 19 July 2012 (Ref: 12/LO/0988; Appendix 6). Subsequent approval for the present 18-month follow-up substantial amendment was granted on 18 December 2015 (see Appendix 7). All participants were provided with a written information sheet and the opportunity to discuss with a study staff member (Appendix 8). It was reiterated that participation was entirely voluntary. Participants provided written informed consent at each time point of data collection.

#### Sample Size

Due to the design of this study, an achieved power calculation was conducted retrospectively. G\*Power (Version 3.1.5) statistical software (Faul, Erdfelder, Lang, & Buchner, 2007) was used to calculate the level of power achieved given the final sample size in this study, that is 125 participants in each arm of the study.

Accordingly, the sample in this study would have a 99% power to detect a medium effect size of d= 0.5, and 76% power to achieve a small effect size of d= 0.3 at a p<0.05 level of significance.

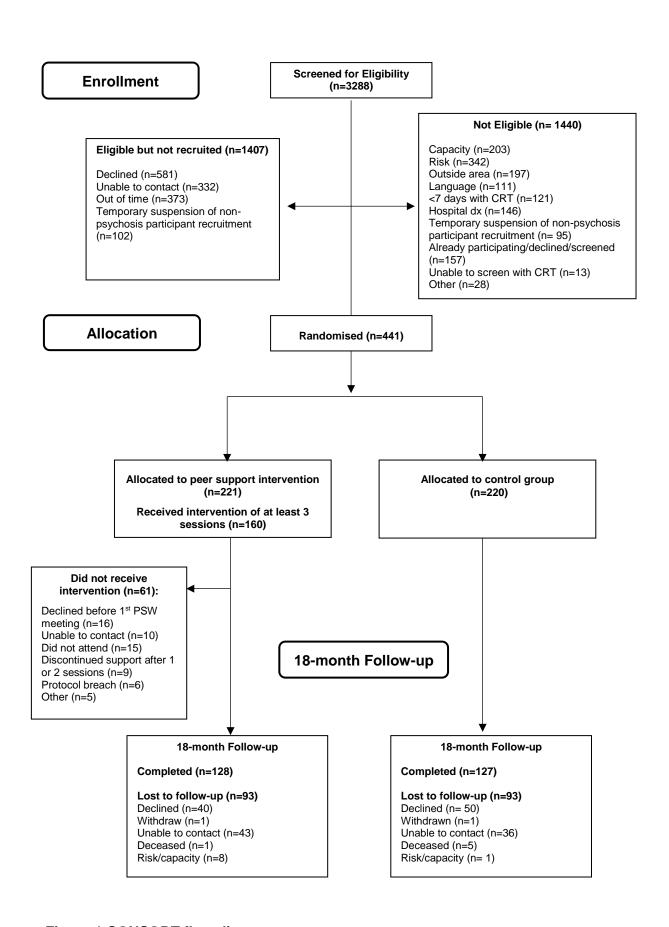


Figure 1 CONSORT flow diagram

# Description of intervention

Participants allocated to the intervention arm of the study received up to ten sessions of tailored self-management guidance delivered by a peer support worker. The intervention included both structured and unstructured elements delivered to participants through a self-management workbook. The workbook (Appendix 9) covered the following:

- Identifying and setting individual personal recovery goals
- Help to create plans to re-establish support networks and functioning in the community following a crisis
- Space to reflect on and use recent experience of crisis to identify early
   warning signs and develop an action plan to manage and even avoid relapse
- Planning strategies and coping resources to maintain wellbeing following a crisis

The self-management workbook was adapted from recovery resources compiled by Dr Rachel Perkins and colleagues at South West London and St Georges NHS Foundation Trust (Perkins & Rinaldi, 2007) and further informed by self-management resources such as the Wellness Recovery Action Plan (Cook et al., 2009) and relapse prevention interventions (Birchwood, Spencer, & McGovern, 2000).

The peer provision in the intervention arm was designed to help guide participants to think about and plan for their recovery using the workbook as a framework. The peer support worker was trained to offer empathetic listening, and also aimed to instil hope through appropriate sharing of skills and coping strategies acquired through their own recovery journey. Peer support meetings took place weekly on a one-to-one basis, as arranged between the participant and the peer support worker. The entire programme of peer support was delivered within the first

three months of participants leaving CRT care. Peer supporters were not matched to participants, though participants could opt to see a peer support worker of the same gender if they wished.

## Peer Support Workers

Peer support workers, people who themselves had experienced mental health problems and used mental health services, were employed to deliver the intervention. They were trained in the use of the workbook and how to support participants in using it, as well as safety, confidentiality, appropriate self-disclosure, roles and boundaries, engagement and listening skills and cultural sensitivity. Regular group supervision was provided for the peer support workers facilitated by CRT and clinicians.

## Control Group

Participants in the control group were offered a copy of the study selfmanagement workbook but no additional guidance on how to use it and no meetings with a peer support worker.

Participants in both arms of the study continued to access treatment as usual, including medication.

### Randomisation

Once written consent was obtained and baseline measures completed, participants were randomly allocated to intervention or control groups using a computerised randomisation system (Sealed Envelope Ltd) to block randomise participants into treatment and control groups, stratified by site. Senior study staff conducted randomisation and informed participants and the CRT about which treatment group they had been allocated to. Due to the nature of the intervention the

study was single blind. While it was not possible to blind participants to whether they were allocated to the treatment or control group, every effort was made to ensure study researchers collecting outcome data were blind to participants' allocation status. For instance, researchers sought to minimise unblinding by prompting participants not to disclose which trial group they were in, both when setting up interviews and during the interview itself.

## Measures

Demographics: A structured interview was conducted with each participant where descriptive information about the person's social and demographic characteristics: age, gender, ethnicity, accommodation and living situation, employment status, educational attainment, past service use and GP contacts over the previous three months were collected. Details regarding service use were collected from patient records. The full baseline interview schedule can be found in Appendix 10.

The primary outcome variable was measured using the *Connor Davidson Resilience Scale (CD-RISC-10;* Connor & Davidson, 2003: Appendix 11), a self-rated scale developed for clinical practice to measure resilience and stress coping ability. The 10-item version used in the present study (score range 0-40) comprises items 1, 4, 6, 7, 8, 11, 14, 16, 17, and 19 from the original scale, and was developed on the basis of factor analysis. Sample items were "I am able to adapt when changes occur" and "I try to see the humorous side of things when I am faced with problems". Respondents were asked to rate each statement with reference to the previous month, understanding that if a particular situation had not arisen in this time, then the response should be determined by how the person thinks they would have reacted. Items were rated on a five-point scale, ranging from 0 = "not true at all" to 4= "true nearly all the time". Scoring is based on summing all items. Higher scores reflect greater resilience. The scale yielded good psychometric properties

(internal consistency, convergent and discriminant validity, and construct validity (Connor & Davidson, 2003); and in a US general community sample (n=764), the mean CD-RISC-10 score was 31.8 (SD=5.47) (Davidson & Connor, 2015). In the present study the scale had good reliability:  $\alpha$ =0.90.

The Questionnaire about the Process of Recovery (QPR; Neil et al., 2009: Appendix 10) is a 22-item measure of self-rated recovery developed in conjunction with service users. The questionnaire contains a range of declarative statements relating to their mental health and recovery such as "I am able to assert myself"; "I am able to develop positive relationships with other people"; and "I can weigh up the pros and cons of psychiatric treatment". Respondents were asked to sum up how things stand for them in relation to the statements over the last 7 days on a 5 point Likert scale from 0= "disagree strongly" to 4= "agree strongly". Total scores range 0 to 88 with higher scores indicative of greater levels of recovery. The QPR is reliable, valid and strongly associated with general psychological wellbeing, quality of life and empowerment all of which are crucial in recovery from psychosis (Neil et al., 2009).

The *Illness Management and Recovery Scale- patient version* (IMR; Mueser & Gingerich, 2005: Appendix 10) is a 15-item measure of outcomes targeted by the Illness Management and Recovery Program (a self-management program). Each item addresses a different aspect of an individual's illness, its management, and personal recovery and includes items such as "How much do your symptoms get in the way of doing things that you would like to or need to do" and "in a normal week, how many times do you talk to someone outside of your family (like a friend, coworker, classmate, roommate etc.)". Participants are asked to respond on a 5 point Likert scale (scored 1-5), with response anchors varying depending on the item. Higher scores indicate greater levels of recovery. It has sound psychometric properties, however predictive validity of the scales is yet to be assessed (Mueser & Gingerich, 2005).

The *Brief Psychiatric Rating Scale (BPRS*; Overall & Gorham, 1962:

Appendix 10) is a 24-item measure of psychiatric symptoms rated by the interviewer based on the participant's responses to a structured interview schedule. The tool consists of 18 symptom constructs such as "somatic concern", "emotional withdrawal", "unusual thought content" and "blunted affect" that are rated by the researcher on a scale from one (not present) to seven (extremely severe). Higher scores indicate a higher level of psychopathology. The scale has good psychometric properties in terms of reliability and validity (Overall & Gorham, 1962).

The *Social Outcomes Index* (SIX; Priebe, Watzke, Hansson, & Burns, 2008: Appendix 10) is a four-item objective measure of respondents' social circumstances regarding employment, accommodation, living situation and social contact.

Participants are requested to respond in relation to their current circumstances to four items such as "are you currently employed?" and "Have you met with a friend in the last week?". The response anchors vary depending on the item, for example for the employment item possible responses are 0= "none"; 1= "voluntary/ protected/ sheltered work"; 2= "regular employment"; whereas friendship responses were 0= "No"; 1= "yes". The resulting score of SIX ranges from 0 to 6, with a higher score indicating a higher level of social capital and outcomes. The SIX does not measure a construct, instead the SIX score combines objective responses to very different items, thus the total score can be considered a global reflection of social outcomes (Priebe et al., 2008).

The *UCLA Loneliness Scale* (ULS-8; Hays & DiMatteo, 1987: Appendix 10) is an eight-item measure of perceived loneliness. Items include: "How often do you feel that there is no one you can turn to?" and "How often do you feel people are around you but not with you?". Respondents are asked to indicate their response on a four-point scale ranging from 1= "never" to 4= "always". A higher score indicates a greater level of perceived loneliness. The scale is highly reliable in terms of internal

consistency and test-retest reliability and has demonstrated good convergent and construct validity (Hays & DiMatteo, 1987).

The Health and Lifestyles Survey Social Capital Questionnaire (HLSSC; Health Education Authority, 1995: Appendix 10) is a six-item measure of neighbourhood social capital. Respondents are asked to respond to questions regarding their neighbourhood such as "is it a place where you feel personally safe?" and "is it a place where neighbours look after each other?". Response options are 1= "yes", -1= "no" or 0= "don't know". A higher score indicates better neighbourhood social capital. Information on psychometric properties is not available, however the scale forms part of a large national survey (Health Education Authority, 1995).

The *Lubben Social Network Scale: Short Version* (LSNS-6; Lubben et al., 2006: Appendix 10) is a six item self-report measure of social engagement with family and friends. Items are split into domains of family (e.g. "How many relatives do you feel close to such that you could call on them for help?") and friends (e.g. "how many friends do you feel at ease with that you could talk about private matters). Responses are rated on a scale 0= "none" to 5= "nine or more". Total scores range from 0 to 30, individual scoring below 12 are considered to be socially isolated. Higher scores indicate higher levels of social engagement with their social network. The scale demonstrated high levels of internal consistency, stable factor structures, and high correlations with criterion variables when across several populations (Lubben et al., 2006).

#### Data Collection

Study measures were completed at baseline, and at the follow-up interview four and eighteen months after the baseline interview, once the peer supported, self-management programme had been completed. The measure of resilience (the

Connor Davidson Resilience Scale (CD-RISC-10) was completed at the 18-month follow-up interview only. All study measures were completed with participants as a structured interview. Participants were offered a £20 gift of cash as an acknowledgment of their time and contribution to the study.

#### Researcher Role

This study was part of a programme of research conducted within a large research team. My contribution to the work involved adding to the follow-up research design with the addition of the resilience measure to the study protocol, along with obtaining substantial amendments to the existing ethics approval. During data collection, I worked in a coordinator role overseeing progress of recruitment and data collection, providing consultation in relation to ways to streamline and increase recruitment. I also contributed to recruitment by contacting "difficult to reach" participants outside of business hours (i.e. in the early evening) to catch participants who may work during the day. All other aspects of the research were distinct and independent.

## Results

At follow up, data was collected from 255 participants, with 250 having usable data for this study. Baseline characteristics of the patients in each group (peer support versus control) were summarised using descriptive statistics. Histograms of the distribution of the outcome variables were inspected visually. All were sufficiently close to normal distribution to justify using parametric statistics. Chi-square or t-tests, as appropriate, were used to check for differences between groups. An alpha level of .05 was used for all statistical tests.

To assess the effectiveness of the peer support self-management intervention on resilience, the intervention arm was compared to the active control arm using a two-sample t-test with equal variances. Random effects multilevel

modelling with clustering by the peer supporter was used for the predictors of resilience analysis. Multilevel modelling was necessary because the participants were naturally nested within groups - by treatment arm; severity of mental health (psychosis or not); NHS trust; and peer support worker- which violates the assumption of independence, required for ordinary least square regression and which would otherwise overstate the statistical significance (Nezlek, 2008). For the dependent variable resilience (CD-RISC-10), at least 7 of the 10 items needed to be completed in order to consider the scale usable. For missing answers, the mean of all completed answers was used to impute the score.

# **Baseline characteristics of participants**

As outlined in Table 1, the mean age of the 250 participants was 40 years (range 18 to 75) and 60% (n=149) were female. The majority (63%; n= 156) were white British or from another white ethnic background, while the remaining 37% (n= 93) were of black, Asian or mixed ethnicity. A small minority of participants were married or cohabiting (26%; n= 64), with the remaining 74% (n=186) being single, separated or divorced. In terms of educational attainment, 55% (n= 136) had a school level education or below and 45% (n= 113) had a post school qualification such as a Higher National Diploma (HND), degree or postgraduate qualification.

In terms of baseline demographics there was no difference between participants randomised to receive the peer support intervention and those that were allocated to the control group (Table 1).

In relation to clinical features (Table 2), the majority of participants had diagnoses of schizophrenia, psychosis or bipolar affective disorder, followed closely by depressive and anxiety disorders. Fifteen percent of participants (n= 37) had a diagnosis of personality disorder. In terms of service use, 36% (n=91) had never

had an admission to a psychiatric hospital. Of the 64% (n= 158) of participants who had had an admission once or more over their lifetime, 38% (n=96) had been compulsorily detained.

Table 1. Baseline demographic characteristics of participants who completed the resilience outcome measure at 18 months

| Variable                           | Total <sup>a</sup><br>N=250 | Peer Support <sup>b</sup><br>N= 125 | Control <sup>b</sup><br>N= 125 | Statistical<br>Test (df) | р    |
|------------------------------------|-----------------------------|-------------------------------------|--------------------------------|--------------------------|------|
| Age M(SD)                          | 40.0(12.3)                  | 39.9 (12.6)                         | 40.12(12.1)                    | t(248) = 0.13            | 0.90 |
| Gender                             |                             |                                     |                                |                          |      |
| Male<br>Female                     | 101 (40)<br>149 (60)        | 54 (43)<br>71 (57)                  | 47 (38)<br>78 (62)             | $\chi^2(1) = 0.81$       | 0.37 |
| Ethnicity                          |                             |                                     |                                |                          |      |
| White British                      | 130 (52)                    | 59 (47)                             | 71 (57)                        | $\chi^2(4) = 3.06$       | 0.55 |
| White other<br>Black/Black British | 26 (11)<br>53 (21)          | 15 (12)<br>28 (23)                  | 11 (9)<br>25 (20)              |                          |      |
| Asian/Asian British                | 24 (10)                     | 13 (10)                             | 11 (9)                         |                          |      |
| Mixed                              | 16 (6)                      | 10 (8)                              | 6 (5)                          |                          |      |
| Marital Status                     |                             |                                     |                                |                          |      |
| Married or cohabiting              | 64 (26)                     | 31 (25)                             | 33 (26)                        | $\chi^2(3) = 4.58$       | 0.21 |
| Single                             | 153 (61)                    | 73 (59)                             | 80 (64)                        |                          |      |
| Separated or divorced              | 30 (12)                     | 18 (14)                             | 12 (10)                        |                          |      |
| Widowed                            | 3 (1)                       | 3 (2)                               | 0 (0)                          |                          |      |
| Highest Level of Educa             | tion attainme               | nt                                  |                                |                          |      |
| School Leaver (no qualifications)  | 40 (16)                     | 21 (17)                             | 19 (15)                        | $\chi^2(5) = 3.97$       | 0.55 |
| GCSE's or equivalent               | 49 (20)                     | 24 (19)                             | 25 (20)                        |                          |      |
| A levels or equivalent             | 47 (19)                     | 26 (21)                             | 21 (17)                        |                          |      |
| HND or professional qualification  | 30 (12)                     | 18 (14)                             | 12 (10)                        |                          |      |
| Degree                             | 53 (21)                     | 23 (18)                             | 30 (24)                        |                          |      |
| Post-Graduate Degree               | 30 (12)                     | 12 (10)                             | 18 (14)                        |                          |      |

<sup>&</sup>lt;sup>a</sup> All results are n (%) unless otherwise indicated

In terms of previous contact with crisis resolution team support, 49% (n= 121) of participants had one other period of support in the community from a crisis resolution team, while 51% (n=128) had two or more periods of support previously. While 15% of participants (n= 38) had been in contact with mental health services

<sup>&</sup>lt;sup>b</sup> variations in N due to missing data

for less than 3 months, the majority (52%; n= 130) had been in contact with services for more than 5 years. A sizeable proportion of all participants (35%; n= 87) had been in contact with services in excess of 10 years.

Table 2. Clinical characteristics at baseline of participants who completed the resilience outcome measure at 18 months

| Variable                                   | Totala      | PeerSupport b<br>N= 125 | Control <sup>b</sup><br>N= 125 | Statistical<br>Test (df) | р     |  |  |
|--|-------------|-------------------------|--------------------------------|--------------------------|-------|--|--|
| Severe Mental Illness                      |             |                         |                                |                          |       |  |  |
| Psychotic Disorder                         | 117 (47)    | 63 (50)                 | 54 (43)                        | $\chi^2(1) = 1.30$       | 0.25  |  |  |
| Other mental illness (non-psychosis)       | 133 (53)    | 62 (50)                 | 71 (57)                        |                          |       |  |  |
| Diagnosis                                  |             |                         |                                |                          |       |  |  |
| Psychosis                                  | 60 (25)     | 32 (26)                 | 28 (23)                        | $\chi^2(4) = 1.49$       | 0.83  |  |  |
| Bipolar Affective Disorder (Manic Episode) | 41 (17)     | 23 (19)                 | 18 (15)                        |                          |       |  |  |
| Depressive/Anxiety Disorder                | 88 (36)     | 44 (35)                 | 44 (37)                        |                          |       |  |  |
| Personality Disorders                      | 37 (15)     | 16 (13)                 | 21 (17)                        |                          |       |  |  |
| Other                                      | 18 (7)      | 9 (8)                   | 9 (8)                          |                          |       |  |  |
| Lifetime admissions to ps                  | ychiatric h | ospital                 |                                |                          |       |  |  |
| Never                                      | 91 (36)     | 40 (32)                 | 51 (41)                        | $\chi^2(3) = 3.02$       | 0.38  |  |  |
| Once                                       | 57 (23)     | 33 (26)                 | 24 (19)                        |                          |       |  |  |
| 2 to 5 times                               | 67 (27)     | 33 (26)                 | 34 (27)                        |                          |       |  |  |
| More than 5 times                          | 34 (14)     | 19 (16)                 | 16 (13)                        |                          |       |  |  |
| Lifetime compulsory admi                   | ssions to   | psychiatric hospi       | ital                           |                          |       |  |  |
| Never                                      | 154 (62)    | 78 (62)                 | 76 (61)                        | $\chi^2(3) = 1.59$       | 0.65  |  |  |
| Once                                       | 42 (17)     | 18 (14)                 | 24 (19)                        |                          |       |  |  |
| 2 to 5 times                               | 41 (16)     | 21 (17)                 | 20 (16)                        |                          |       |  |  |
| More than 5 times                          | 13 (5)      | 8 (7)                   | 5 (4)                          |                          |       |  |  |
| Periods of support from C                  | risis resol | ution teams             |                                |                          |       |  |  |
| 1  | 121 (49)    | 64 (52)                 | 57 (45)                        | $\chi^2(4) = 2.85$       | 0.58  |  |  |
| 2  | 51 (20)     | 24 (19)                 | 27 (22)                        |                          |       |  |  |
| 3 to 5                                     | 52 (21)     | 26 (21)                 | 26 (21)                        |                          |       |  |  |
| 6 to 10                                    | 14 (6)      | 7 (6)                   | 7 (6)                          |                          |       |  |  |
| More than 10                               | 11 (4)      | 3 (2)                   | 8 (6)                          |                          |       |  |  |
| Total length of contact wit                | h services  | ;                       |                                |                          |       |  |  |
| Less than 3 months                         | 38 (15)     | 18 (14)                 | 20 (16)                        | $\chi^2(5) = 11.01$      | 0.051 |  |  |
| 3 months-1 year                            | 22 (9)      | 15 (12)                 | 7 (6)                          |                          |       |  |  |
| 1-2 years                                  | 18 (7)      | 9 (7)                   | 9 (7)                          |                          |       |  |  |
| 2-5 years                                  | 42 (17)     | 13 (10)                 | 29 (23)                        |                          |       |  |  |
| 6-10 years                                 | 43 (17)     | 26 (21)                 | 17 (14)                        |                          |       |  |  |
| More than 10 years                         | 87 (35)     | 44 (35)                 | 43 (34)                        |                          |       |  |  |

<sup>&</sup>lt;sup>a</sup> All results are n (%)

<sup>&</sup>lt;sup>b</sup> variations in N due to missing data

From the clinical outcome measures taken at baseline (Table 3), the majority of these measures were chosen for their ability to reflect change over time. In this present study only some of the measures were of note in relation to a clinical picture of participants. Participants mean symptom scores measured on the BPRS place the group in the "moderately ill" clinical global impression range (Leucht et al., 2005). On the Lubben Social Network Scale all groups scored below 12, the cut- off at which individuals could be considered to be socially isolated.

The data in Table 3 demonstrate that there was no significant difference, in terms of baseline functioning (symptom severity, social capital and recovery) between the two groups, with the exception of the Health and Lifestyles Survey Social Capital Questionnaire (HLSSC) which showed that the peer support group had greater levels of perceived social capital at baseline compared to the control group.

Table 3. Baseline measures of participants who completed the resilience outcome measure at 18 months in each study condition

| Baseline Measure  | Total <sup>a</sup> | Peer<br>Support <sup>ab</sup><br>N= 125 | Control <sup>ab</sup><br>N= 125 | Statistical<br>Test (df) | р     |
|---|--------------------|---|---------------------------------|--------------------------|-------|
| Symptoms  |                    |   |                                 |                          |       |
| BPRS  | 43.35 (10.92)      | 42.76 (10.7) <sup>b</sup>               | 43.95 (11.13)                   | t(246)=0.86              | 0.38  |
| Social Capital  |                    |   |                                 |                          |       |
| Social Outcomes<br>Index (Six)                          | 3.83 (1.37)        | 3.80 (1.36) b                           | 3.86 (1.39)                     | t(246) = 0.39            | 0.70  |
| UCLA Loneliness   | 22.1 (4.5)         | 21.92 (4.6)                             | 22.29 (4.4)                     | t(248) 0.65              | 0.52  |
| Lubben Social<br>Network Scale<br>Health and Lifestyles | 11.20 (5.86)       | 11.04 (5.52)                            | 11.42 (6.19)                    | t(248) = 0.51            | 0.61  |
| Survey Social Capital Questionnaire                     | 2.62 (2.81)        | 3.02 (2.41) <sup>b</sup>                | 2.24 (3.10)                     | t(246) = -2.19           | 0.03* |
| Recovery  |                    |   |                                 |                          |       |
| Questionnaire on<br>Process of Recovery                 | 52.39 (16.19)      | 53.86 (16.39) <sup>b</sup>              | 50.94(15.94)                    | t(246) = -1.42           | 0.17  |
| Illness Management and recovery                         | 46.5 (6.98)        | 47.1 (6.63) <sup>b</sup>                | 45.86(7.28) <sup>b</sup>        | T(241) = -1.38           | 0.17  |

<sup>&</sup>lt;sup>a</sup> All results are M (SD) unless otherwise indicated

<sup>&</sup>lt;sup>b</sup> Variations in N due to missing data

Lastly, the participants who completed the measure of resilience (CD-RISC-10) at 18 months were compared to those that did not go on to complete the study; that is those that dropped out prior to this 18-month time point. There was no difference between the 18-month completers and the main trial group in terms of age, gender, and diagnosis (Table 4).

Table 4. Comparison of baseline characteristics of completers and drop-outs

| Variable                                   | Total <sup>+</sup>   | Completers<br>N=250  | Dropped Out<br>N=148 | Statistical<br>Test (df) | р    |
|--|----------------------|----------------------|----------------------|--------------------------|------|
| Age M(SD)                                  | 40.2<br>(12.9)       | 40.0 (12.31)         | 40.5 (13.96)         | t(396) = -0.45           | 0.71 |
| Gender                                     |                      |                      |                      |                          |      |
| Male<br>Female                             | 160 (40)<br>238 (60) | 101 (40)<br>149 (60) | 59 (40)<br>89 (60)   | $\chi^2$ (1) = 0.01      | 0.92 |
| Diagnosis                                  |                      |                      |                      |                          |      |
| Psychosis                                  | 106 (27)             | 60 (25)              | 46 (30)              | $\chi^2$ (4) = 4.23      | 0.38 |
| Bipolar Affective Disorder (Manic Episode) | 64 (16)              | 41 (17)              | 23 (16)              |                          |      |
| Depressive/Anxiety Disorder                | 137 (35)             | 88 (36)              | 49 (33)              |                          |      |
| Personality Disorders                      | 52 (13)              | 37 (15)              | 15 (10)              |                          |      |
| Other                                      | 33 (8)               | 18 (7)               | 15 (11)              |                          |      |

<sup>&</sup>lt;sup>+</sup> All results are n (%) unless otherwise indicated

Furthermore, an analysis was carried out to investigate if people allocated to one arm of the study, either the treatment or control arm, were more likely to drop out prior to 18 months data collection. Again, there was no significant difference between those that dropped out prior to the 18-month data collection time point in terms of receiving the intervention or not and those that went on to complete outcome data collection at 18 months (Table 5).

Table 5 Association between treatment allocation and drop-outs

| Intervention<br>Arm | Completers<br>N (%) | Dropped out<br>N (%) | Total       | Statistic                 |
|---------------------|---------------------|----------------------|-------------|---------------------------|
| Peer support        | 125 (50.2)          | 76 (49.35)           | 201 (49.88) | $x^2(1)=0.004$ , $p=0.95$ |
| Control             | 125 (50.0)          | 77 (50.33)           | 202 (50.12) |                           |
| Total               | 250                 | 153                  | 403         |                           |

## Effect of Peer Support self-management intervention on resilience

In terms of the primary outcome variable, resilience, contrary to the hypothesis, there was no significant difference between those participants who received the peer support intervention (M= 22.40; SD 8.94) and those that did not (M= 20.22; SD 9.58); t(248)= -1.86; p=0.06, d=0.24).

# Univariate and multivariate analysis of predictors of resilience at 18 months

A correlation matrix of outcome variables revealed no significant correlation between resilience and demographic characteristics: age, gender, length of contact with services, diagnosis and educational attainment. As anticipated there was a small but significant correlation between resilience and those with a psychotic disorder (compared to those with an affective disorder), which was accounted for in the a priori fixed effects of the multilevel model. The clinical predictor outcome variables were all associated with resilience. An example of these associations is illustrated in linear relationship between QPR and CD-RISC-10 is illustrated (Figure 2). The two measures of recovery, the QPR and IMR were inter-correlated (r= 0.61), confirming that they are indeed measuring the same construct. Consequently, the IMR measure was dropped, and QPR, a more general measure of recovery, was retained.

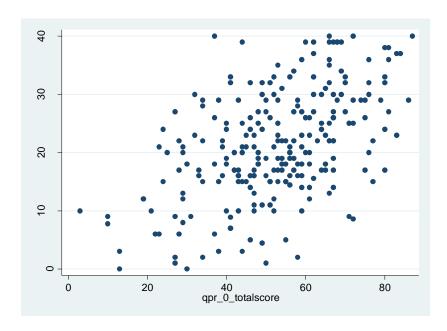


Figure 2. Scatterplot of resilience (CD-RISC-10) at 18 months and baseline measure of recovery (QPR)

A multi-level model of the outcome resilience, with a priori fixed effects for treatment arm, severity of mental health (psychosis or not) and NHS trust was created controlling for random effects of clustering at the level of the peer support worker. Univariate analysis of each predictor variable was conducted (Table 6). Q plots were generated and residuals were considered near normal. Variables that were found to have a statistically significant effect on resilience were entered into the multivariate random effects model (Table 7).

Table 6. Univariate predictors of resilience after 18 months post discharge from CRT care

|   |     |                   | Univariate            |         |  |
|---|-----|-------------------|-----------------------|---------|--|
|   | N   | r                 | B (95% CI)            | р       |  |
| Age   | 250 | 0.09a             | 0.07 (-0.02 – 0.16)   | 0.13    |  |
| Gender  |     |                   |                       |         |  |
| Male  |     |                   | Ref                   | Ref     |  |
| Female  | 250 | 0.09 <sup>b</sup> | -2.01 (-4.46 – 0.31)  | 0.10    |  |
| Education Level   |     |                   |                       |         |  |
| School level qualification                                  |     | Ref               | Ref                   | Ref     |  |
| Post school qualification                                   |     | 0.04 <sup>b</sup> | 0.83 (-1.48 – 3.14)   | 0.48    |  |
| Length of Contact with Services                             |     |                   |                       |         |  |
| ≤ 5 years contact   |     | Ref               | Ref                   | Ref     |  |
| > 6years contact  | 250 | 0.02 <sup>b</sup> | -0.49(-2.79 – 1.81)   | 0.67    |  |
| Intervention Group  |     |                   | , ,                   |         |  |
| Control   |     | Ref               | Ref                   | Ref     |  |
| Peer support intervention                                   |     | 0.12 <sup>b</sup> | 2.02 (-0.41 – 4.45)   | 0.10    |  |
| NHS trust   |     |                   | ,                     |         |  |
| Camden & Islington  | 250 | 0.01 <sup>b</sup> | Ref                   | Ref     |  |
| NELFT   |     |                   | -1.24 (-4.80 – 2.31   | 0.49    |  |
| SLAM  |     |                   | 0.67 (-3.11 – 4.45)   | 0.73    |  |
| WLMHT   |     |                   | 0.60 (-5.7 – 6.96)    | 0.85    |  |
| AWP   |     |                   | 2.24 (-1.61 – 6.10)   | 0.25    |  |
| SABP  |     |                   | -1.65 (-6.43 – 3.12)  | 0.50    |  |
| Severe Mental Illness                                       |     |                   | ,                     |         |  |
| Non-psychosis   |     | Ref               | Ref                   | Ref     |  |
| Psychosis   | 250 | 0.14*b            | 3.11 (0.85 – 5.38)    | 0.007*  |  |
| Clinical Outcomes   |     |                   | ,                     |         |  |
| Symptom Severity (BPRS)                                     | 248 | -0.32*a           | -0.27 (-0.37 – -0.17) | <0.001* |  |
| Social Outcomes Index (Six)                                 | 248 | 0.22*a            | 1.53 (0.71 – 2.35)    | <0.001* |  |
| UCLA Loneliness   | 250 | -0.35*a           | -0.72 (-0.95 – -0.48) | <0.001* |  |
| Lubben Social Network Scale<br>Neighbourhood Social Capital | 250 | 0.23*a            | 0.39 (0.20 – 0.58)    | <0.001* |  |
| (HLSSC)   | 248 | 0.30*a            | 0.99 (0.60 – 1.38)    | <0.001* |  |
| Questionnaire on Process of Recovery                        | 248 | 0.52*a            | 0.30 (0.24 – 0.36)    | <0.001* |  |
| Illness Management and recovery                             | 243 | 0.30*a            | 0.40 (0.24 - 0.56)    | <0.001* |  |

<sup>&</sup>lt;sup>a</sup>Pearson's correlation coefficient

<sup>&</sup>lt;sup>b</sup>Spearmans rank order correlation

Table 7. Multivariate predictors of resilience after 18 months post discharge from CRT care

|                                      | Multivariate         |         |
|--------------------------------------|----------------------|---------|
|                                      | β (95% CI)           | р       |
| Intervention Group                   |                      |         |
| Control                              | Ref                  | Ref     |
| Peer support intervention            | 0.97 (-1.17 – 3.11)  | 0.37    |
| NHS trust                            |                      |         |
| Camden & Islington                   | Ref                  | Ref     |
| NELFT                                | -1.43(-4.46 – 1.62)  | 0.36    |
| SLAM                                 | -1.52(-4.76 – 1.72)  | 0.36    |
| WLMHT                                | -0.68(-6.15 - 4.78)  | 0.81    |
| AWP                                  | 0.82 (-2.44 – 4.08)  | 0.62    |
| SABP                                 | -0.75 (-4.95 – 3.45) | 0.73    |
| Severe Mental Illness                |                      |         |
| Non-psychosis                        | Ref                  | Ref     |
| Psychosis                            | 1.54 (-0.56 – 3.62)  | 0.15    |
| Clinical Outcomes                    |                      |         |
| Symptom Severity (BPRS)              | -0.03 (-0.14 – 0.08) | 0.60    |
| Social Outcomes Index (SIX)          | 0.93 (0.12 – 1.75)   | 0.03*   |
| UCLA Loneliness                      | 0.01 (-0.30 – 0.32)  | 0.95    |
| Lubben Social Network Scale          | 0.01 (-0.21 – 0.20)  | 0.94    |
| Neighbourhood Social Capital (HLSSC) | 0.36 (-0.03 – 0.74)  | 0.06    |
| Questionnaire on Process of Recovery | 0.25 (0.18 – 0.33)   | <0.001* |

Note: N= 242

The coefficients for each of the variables in Table 7 indicates the amount of change one could expect in resilience given a one-unit change in the value of that predictor variable, given that all other variables in the model are held constant. From the multilevel modelling (Table 7) two baseline predictors of resilience were identified. A one-unit increase in social capital/connectedness as measured in the SIX results in a 0.93-point increase in resilience. A one-unit increase in recovery as measured on the QPR will result in a 0.25-point increase in resilience. No other baseline factors were found to be predictive of resilience.

#### **Discussion**

The main finding in this study was that, contrary to the hypothesis, there was no effect of peer support on resilience at 18 months post-randomisation. This is consistent with previous findings which have not shown an effect of peer support on symptomatic measures (Lloyd-Evans et al., 2014) but is in contrast to qualitative studies that report positive effects (Castelein et al., 2015; Gillard, Edwards, Gibson, Owen, & Wright, 2013; Gillard, Foster, & Turner, 2016). Unfortunately, the overall findings of the CORE trial are not currently available. This means it is not possible to assess how the lack of effect of peer support on resilience fits with the other outcomes under investigation in the trial, such as readmission rates, effect on symptomology, social outcomes and participants' subjective sense of recovery.

The present study also found that a SMI diagnosis (psychosis or bipolar) was associated with higher levels of resilience. This is perhaps not what one would expect given the significant challenges those with SMI can experience. Though a key aspect of resilience, that it develops in the context of overcoming adversity, could account for the difference in resilience in this group (Rutten et al., 2013). However, the level of resilience in participants in this study was considerably lower compared to the mean (31.78) reported in a general adult population sample (Campbell-Sills, Forde, & Stein, 2009).

This study contributes to the literature on resilience by examining clinical and social predictors of resilience in a population with significant mental health difficulties: a question that has not previously been investigated. This study found that all baseline clinical outcome variables measuring symptoms, social capital and recovery were significantly associated with resilience 18 months later. It is not surprising that people with less symptomatology, more social links and a greater perceived level of recovery have higher levels of resilience. However, when all of these variables were entered into the random-effects multi-level model (taking into

account clustering at the peer support worker level, and a priori effects of diagnosis, NHS trust, and treatment arm) only two variables were found to be predictive of a resilient outcome: Social Outcomes Index (SIX, which measures employment, accommodation and social contact) and the Questionnaire about the Process of Recovery (QPR, which measures level of self-rated recovery). While these two variables were statistically significant in the model, the amount of change elicited is unlikely to be clinically meaningful in terms of resilience.

The null findings of this study in relation to the provision of peer support are perhaps not surprising given that the typical population of clients in CRTs are seen at a time of high distress. This was reflected in the scores on the BPRS that showed at baseline; that is within one month of discharge from CRT care and at the time of randomisation, the mean symptom level could be classified as "moderately ill". Additionally, this cohort is a group of individuals with enduring mental health difficulties, reflected by the large proportion having had contact with services for over 10 years. It may be that clients were still too unwell to fully benefit from support from a peer or to take on board and process the information presented in the recovery workbook. Furthermore, the development of resilience is not a simple linear trajectory but is the result of complex interrelated factors (Rutten et al., 2013), with disadvantage "not an event that strikes at a single point" (Graham & Power, 2004, p.1) but instead has a cumulative and ongoing impact on the development and utilisation of personal resources. The reality of effecting change in resilience from a relatively brief intervention may have been overly ambitious.

## Limitations

One major limitation of this study is that the primary outcome variable, resilience, was added late in the study design, and therefore data was only available at the 18-month measurement point. This meant that there was no control for

potential post randomisation group differences in this variable. Additionally, it was not possible to adjust for baseline resilience which means it is not possible to differentiate if baseline SIX and QPR are significant predictors or just highly correlated. Joining the CORE research programme later on also meant that there were other aspects of the research that may have been fruitful to explore but were not possible. For instance, it would have been interesting to collect more detailed information on the peer support workers themselves, including a measure of resilience, to investigate if those considered recovered did actually exhibit higher levels of resilience. Demographic characteristics of the peer support workers were gathered, but unfortunately were not available for use in this thesis. Furthermore, it could have been informative to elicit the views of peer support workers themselves to get their perspectives on the intervention, and what they think may or may not have been working for participants. It would have also been useful to analyse what the characteristics of more successful peer relationships were, but unfortunately at the time of writing, these data were not available.

Another limitation is related to the selective participant sample. While this study endeavoured to recruit a sample that was representative of service users from NHS crisis resolution teams, it is likely the sample was subject to both selection and attrition bias. For instance, the eligibility criteria for the study meant that many potential participants were excluded on the basis of capacity to consent, or due to risk. Since those with capacity or risk issues are also likely to be more unwell, then their exclusion may have resulted in an unrepresentative sample. Furthermore, a third of participants randomised to the intervention arm did not receive it. Reasons for withdrawal from the study included participants being unable to be contacted by research staff, withdrawing before the first peer meeting, or discontinuing after 1 or 2 sessions. This attrition suggests the resulting cohort who completed the study may have consisted not only of those who were functionally doing better, but also those

who may have felt more positive about peer support or were more open to building social connections.

In relation to the measurements used in this study most were self-rated (with the exception of the BPRS) and only two focused on recovery oriented outcomes (IMR and QPR). While these do tap the recovery constructs of hope, empowerment, self-efficacy and sense of purpose, the study could have benefited from more specific measures of these constructs. Additionally, there was a large focus on the outcomes related to social connectedness, and while this is valuable to explore (having previously been linked with recovery and resilience; Ozbay et al., 2007), this focus could have impacted on participants by highlighting areas of their lives where they experience a deficit (i.e. in social connectedness). Adding recovery measures of hope and empowerment could be a counter to this deficit focus from the social capital questionnaires.

As is common in this type of complex intervention, maintaining blinding of researchers who conducted the follow-up interview can be challenging. Every effort was made to remind participants not to reveal to the research staff if they had received a peer support worker, though it is inevitable that some participants would inadvertently disclose details that indicated their allocation status.

# **Strengths**

A major strength of this study was its large sample size of 250 participants who were representative of a typical clinical population presenting for CRT care. Analyses of attrition of patients not participating in the 18 month follow up showed that those actually participating were not a select group, nor were they different to those who dropped out in terms of baseline characteristics further confirming the generalisability of the study population. A second strength of the study is the longer term follow up; previous studies have had much shorter follow up periods.

The programme also benefited from extensive input from service users in its design. At all stages of the research, from intervention design to delivery, service user contributions were sought and incorporated through focus groups, piloting of procedures, establishment of a consumer lead working group and employment of a service user "Public involvement coordinator" to offer guidance for the peer support workers who delivered the intervention.

## **Clinical and Research Implications**

Clinically, the empirical evidence for peer support remains mixed. Some evidence has been positive but this tended to be from studies of moderate to low quality (Chinman et al., 2014; Pitt et al., 2013), or for select outcomes only (Lloyd-Evans et al., 2014). The present study did not demonstrate any effect of peer support on resilience. The fact that peer support provision has persisted and continues to grow (Pitt et al., 2013) despite the paucity of consistent evidence supporting its use, suggests that at some level, peer support is meeting a need. Whether this need is a gap in current service provision or in a sense of connectedness that is rapidly becoming rare in our disconnected communities and under-resourced, time-pressed health service. Additionally, this is a need specific to those with severe mental illness, who are disproportionately affected amongst those with mental illnesses with social isolation due to stigma, and the social deficits inherent in SMI (Castelein et al., 2015). Peer support may be a way of reaching clients that services currently struggle to engage and a way to provide a meaningful partnership to develop their ability and confidence to manage their illness.

In terms of further research, as mentioned in the limitations, it could be useful to gather the perspectives of peers, staff and participants themselves on how they feel they are managing following a peer-support intervention. Future studies that better differentiate the unique contribution of peers to the recovery process are

needed. Intuitively, peer support should be beneficial, and qualitative reports support this, so it could be that the positive effects are not detected using the current type and focus of outcome measures. Thus, it might be important to take a more recovery oriented approach with less of a focus on outcomes deemed important to professionals in services, such as reduction in symptoms and admissions. Instead, more of a focus on outcomes important to users of services, such as hope, recovery, and empowerment, may better demonstrate the effects of peer support.

#### References

- American Psychological Association. (2015). The road to recovery. Retrieved June 1, 2017, from http://www.apa.org/helpcenter/road-resilience.aspx
- Bandura, A. (1989). Human agency in social cognitive theory. *The American Psychologist*, *44*(9), 1175–84. http://doi.org/10.1037/0003-066x.44.9.1175
- Barbic, S., Krupa, T., & Armstrong, I. (2009). A randomized controlled trial of the effectiveness of a modified recovery workbook program: preliminary findings. 

  Psychiatric Services (Washington, D.C.), 60(4), 491–497.

  http://doi.org/10.1176/appi.ps.60.4.491
- Birchwood, M., Spencer, E., & McGovern, D. (2000). Schizophrenia: early warning signs. *Advances in Psychiatric Treatment*, *6*, 93–101. http://doi.org/10.1192/apt.6.2.93
- Borkman, T. (1976). Experiential knowledge: a new concept for the analysis of self-help groups. *Social Service Review*, *50*(3), 445–456.
- Bowers, L., Whittington, R., Nolan, P., Parkin, D., Curtis, S., Bhui, K., ... Flood, C. (2006). *The City 128 Study of Observation and Outcomes on Acute Psychiatric Wards: report to the NHS SDO Programme*. London, City University. Retrieved from http://www.kcl.ac.uk/ioppn/depts/hspr/research/ciemh/mhn/projects/city128/city128.pdf
- Castelein, S., Bruggeman, R., Davidson, L., & Van Der Gaag, M. (2015). Creating a supportive environment: peer support groups for psychotic disorders.

  Schizophrenia Bulletin, sbv113. http://doi.org/10.1093/schbul/sbv113
- Chinman, M., George, P., Dougherty, R. H., Daniels, A. S., Ghose, S. S., Swift, A., & Delphin-Rittmon, M. E. (2014). Peer support services for individuals with serious mental illnesses: assessing the evidence. *Psychiatric Services*, *65*(4), 429–441. http://doi.org/10.1176/appi.ps.201300244
- Clark, F., Khattak, S., & Nahal, J. (2008). Crisis Resolution and Home Treatment:

- the service user and carer experience. National Audit Office. London: National Audit Office.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310–357. http://doi.org/10.1037/0033-2909.98.2.310
- Connor, K. M., & Davidson, J. R. T. (2003). Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety*, 18(2), 76–82. http://doi.org/10.1002/da.10113
- Cook, J. A., Copeland, M. E., Hamilton, M. M., Jonikas, J. A., Razzano, L. A., Floyd,
  C. B., ... Grey, D. D. (2009). Initial Outcomes of a Mental Illness SelfManagement Program Based on Wellness Recovery Action Planning.
  Psychiatric Services, 60(2), 246–249. http://doi.org/10.1176/ps.2009.60.2.246
- Davidson, J. R. T., & Connor, K. M. (2015). Connor-Davidson Resilience Scale (CD-RISC) Manual. Unpublished.
- Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice*, 6(August 2015), 165–187. http://doi.org/10.1093/clipsy.6.2.165
- Davidson, L., Chinman, M., Sells, D., & Rowe, M. (2006). Peer support among adults with serious mental illness: A report from the field. *Schizophrenia Bulletin*, 32(3), 443–450. http://doi.org/10.1093/schbul/sbj043
- Deegan, P. (2005). The importance of personal medicine: A qualitative study of resilience in people with psychiatric disabilities. *Scandinavian Journal of Public Health*, 33(5), 29–35. http://doi.org/10.1080/14034950510033345
- Department of Health. (2001). *The Mental Health Policy Implementation Guide*.

  London: Department of Health. http://doi.org/10.1037/e623632007-001
- Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G\*Power 3: a flexible

- statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*(2), 175–91. http://doi.org/10.3758/BF03193146
- Georgiades, A., Farquharson, L., & Ellett, L. (2015). Resilience, recovery style, and stress in early psychosis. *Psychosis*, *7*(2), 183–185. http://doi.org/10.1080/17522439.2014.936028
- Gillard, S., Edwards, C., Gibson, S. L., Owen, K., & Wright, C. (2013). Introducing peer worker roles into UK mental health service teams: a qualitative analysis of the organisational benefits and challenges. *BMC Health Services Research*, 13(1), 188. http://doi.org/10.1186/1472-6963-13-188
- Gillard, S., Foster, R., & Turner, K. (2016). Evaluating the Prosper peer-led peer support network: a participatory, coproduced evaluation. *Mental Health and Social Inclusion*, 20(2), 80–91. http://doi.org/10.1108/MHSI-12-2015-0045
- Glover, G., Arts, G., & Babu, K. S. (2014). Crisis resolution / home treatment teams and psychiatric admission rates in England Crisis resolution / home treatment teams and psychiatric admission rates in England, 441–445.

  http://doi.org/10.1192/bjp.bp.105.020362
- Graham, H., & Power, C. (2004). Childhood disadvantage and health inequalities: A framework for policy based on lifecourse research. *Child: Care, Health and Development*, 30(6), 671–678. http://doi.org/10.1111/j.1365-2214.2004.00457.x
- Hays, R., & DiMatteo, M. (1987). A short-form measure of loneliness. *J Pers Assess.*, *51*(1), 69–81.
- Health Education Authority. (1995). Social Capital Questionnaire. In *Health and Lifestyles: a survey of the UK Population*. London: Health Education Authority.
- Hopkins, C., & Niemiec, S. (2007). Mental health crisis at home: Service user perspectives on what helps and what hinders. *Journal of Psychiatric and Mental Health Nursing*, *14*(3), 310–318. http://doi.org/10.1111/j.1365-

### 2850.2007.01083.x

- Jethwa, K., Galappathie, N., & Hewson, P. (2007). Effects of a crisis resolution and home treatment team on in-patient admissions. *Psychiatric Bulletin*, 31(5), 170–172. http://doi.org/10.1192/pb.bp.106.010389
- Johnson, S., Nolan, F., Hoult, J., White, I. R., Bebbington, P., Sandor, A., ... Pilling, S. (2005). Outcomes of crises before and after introduction of a crisis resolution team. *British Journal of Psychiatry*, 187(JULY), 68–75.
  http://doi.org/10.1192/bjp.187.1.68
- Johnson, S., Nolan, F., Pilling, S., Sandor, A., Hoult, J., McKenzie, N., ...
  Bebbington, P. (2005). Randomised controlled trial of acute mental health care
  by a crisis resolution team: the north Islington crisis study. *BMJ*, 331(7517),
  599–0. http://doi.org/10.1136/bmj.38519.678148.8F
- Keown, P., Tacchi, M. J., Niemiec, S., & Hughes, J. (2007). Changes to mental healthcare for working age adults: impact of a crisis team and an assertive outreach team. *Psychiatric Bulletin*, 31(8), 288–292. http://doi.org/10.1192/pb.bp.106.012054
- Kieffer, C. H. (1984). Citizen Empowerment. *Prevention in Human Services*, *3*(2–3), 9–36. http://doi.org/10.1300/J293v03n02\_03
- Leucht, S., Kane, J. M., Kissling, W., Hamman, J., Etschel, E., & Engel, R. (2005).
  Clinical implications of Brief Psychiatric Rating Scale scores. *The British Journal of Psychiatry*, 187(4), 366–371. http://doi.org/10.1192/bjp.187.4.366
- Liberman, R. P., & Kopelowicz, A. (2005). Recovery from Schizophrenia: a concept in search of research. *Psychiatric Services*, *56*(6), 735–742. http://doi.org/10.1176/appi.ps.56.6.735
- Lloyd-Evans, B., Mayo-Wilson, E., Harrison, B., Istead, H., Brown, E., Pilling, S., ...

  Kendall, T. (2014). A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC*

- Psychiatry, 14(1), 39. http://doi.org/10.1186/1471-244X-14-39
- Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an Abbreviated Version of the Lubben Social Network Scale Among Three European Community-Dwelling Older Adult Populations. *The Gerontologist*, 46(4), 503–513.
  http://doi.org/10.1093/geront/46.4.503
- Luthar, S. S., Cicchetti, D., & Becker, B. (2007). The construct of resilience: a critical evaluation and guidelines for future work. *Child Development*, 71(3), 543–62.

  Retrieved from

  http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1885202&tool=pmcentrez&rendertype=abstract
- Luthar, S. S., Sawyer, J. A., & Brown, P. J. (2006). Conceptual issues in studies of resilience: Past, present, and future research. In *Annals of the New York Academy of Sciences* (Vol. 1094, pp. 105–115). http://doi.org/10.1196/annals.1376.009
- Marmot, M. (2010). Fair society, healthy lives: strategic review of health inequalities in England post-2010. London: The Marmot Review. Retrieved from http://linkinghub.elsevier.com/retrieve/pii/S0033350612001862
- McCrone, P., Johnson, S., Nolan, F., Pilling, S., Sandor, A., Hoult, J., ...

  Bebbington, P. (2009). Impact of a crisis resolution team on service costs in the

  UK. *Psychiatric Bulletin*, 33(1), 17–19. http://doi.org/10.1192/pb.bp.107.018648
- McCrone, P., Johnson, S., Nolan, F., Pilling, S., Sandor, A., Hoult, J., ...
  Bebbington, P. E. (2009). Economic evaluation of a crisis resolution service: a randomised controlled trial. *Epidemiologia E Psichiatria Sociale*, *18*(1), 54–58.
  Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19378700
- Mental Health Strategic Partnership. (2013). *Building resilient communities: Making every contact count for public mental health*. London: Department of Health.

#### Retrieved from

- http://mentalhealth.org.uk/content/assets/PDF/publications/building-resilient-communities.pdf
- Mueser, K. T., & Gingerich, S. (2005). Illness Management and Recovery (IMR) scales. In T. Campbell-Orde (Ed.), *Muesuring the Promise: A Compendium of Recovery Measures Volume II* (p. 32). Cambridge Mass.: Human Services Research Institute.
- Mueser, K. T., & Gingerich, S. (2011). Illness self management programmes. In G.
  Thornicroft, G. Szmukler, K. Mueser, & E. Drake (Eds.), *The Oxford textbook of community mental health*. Oxford: Oxford University Press.
- National Audit Office. (2007). Helping people through mental health crisis: the role of Crisis Resolution and Home Treatment services. London: TSO.
- Neil, S. T., Kilbride, M., Pitt, L., Nothard, S., Welford, M., Sellwood, W., & Morrison, A. P. (2009). The questionnaire about the process of recovery (QPR): A measurement tool developed in collaboration with service users. *Psychosis*, 1(2), 145–155. http://doi.org/10.1080/17522430902913450
- Nezlek, J. B. (2008). An introduction to multilevel modeling for social and personality psychology. *Social and Personality Psychology Compass*, 2: 842–860. doi:10.1111/j.1751-9004.2007.00059.x
- NICE. (2014). Psychosis and schizophrenia in adults: the NICE guideline on treatment and management. Retrieved May 5, 2017, from https://www.nice.org.uk/guidance/cg178
- Ochocka, J., Nelson, G., Janzen, R., & Trainor, J. (2006). A longitudinal study of mental health consumer/survivor initiatives: Part 3—A qualitative study of impacts of participation on new members. *Journal of Community Psychology*, 34(3), 273–283. http://doi.org/10.1002/jcop.20099
- Overall, J. E., & Gorham, D. R. (1962). the Brief Psychiatric Rating Scale.

- Psychological Reports, 10(3), 799–812. http://doi.org/10.2466/pr0.1962.10.3.799
- Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatry (Edgmont (Pa. : Township))*, *4*(5), 35–40. http://doi.org/None
- Perkins, R., & Rinaldi, M. (2007). *Taking Back Control: Planning Your Own Recovery.*
- Pitt, V., Lowe, D., Hill, S., Prictor, M., Hetrick, S. E., Ryan, R., & Berends, L. (2013).
  Consumer-providers of care for adult clients of statutory mental health services.
  The Cochrane Database of Systematic Reviews, 3, CD004807.
  http://doi.org/10.1002/14651858.CD004807.pub2
- Priebe, S., Watzke, S., Hansson, L., & Burns, T. (2008). Objective social outcomes index (SIX): A method to summarise objective indicators of social outcomes in mental health care. *Acta Psychiatrica Scandinavica*, *118*(1), 57–63. http://doi.org/10.1111/j.1600-0447.2008.01217.x
- Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health (Abingdon, England)*, 20(4), 392–411. http://doi.org/10.3109/09638237.2011.583947
- Rutten, B. P. F., Hammels, C., Geschwind, N., Menne-Lothmann, C., Pishva, E., Schruers, K., ... Wichers, M. (2013). Resilience in mental health: Linking psychological and neurobiological perspectives. *Acta Psychiatrica Scandinavica*, *128*(1), 3–20. http://doi.org/10.1111/acps.12095
- Simoni, J. M., Franks, J. C., Lehavot, K., & Yard, S. S. (2013). Peer Interventions to Promote Health: Conceptual Considerations. *Am J Orthopsychiatry.*, *81*(3), 351–359. http://doi.org/10.1111/j.1939-0025.2011.01103
- Torgalsbøen, A. K. (2012). Sustaining full recovery in schizophrenia after 15 years:

- Does resilience matter? *Clinical Schizophrenia and Related Psychoses*, *5*(4), 193–200. http://doi.org/10.3371/CSRP.5.4.3
- Windle, G., Bennett, K. M., & Noyes, J. (2011). A methodological review of resilience measurement scales. *Health and Quality of Life Outcomes*, *9*(1), 8. http://doi.org/10.1186/1477-7525-9-8
- Wood, J. V. (1989). Theory and research concerning social comparisons of personal attributes. *Psychological Bulletin*, *106*(2), 231–248. http://doi.org/10.1037/0033-2909.106.2.231

Part 3 - Critical Appraisal

This final part of the thesis focuses on the challenges inherent in the design, delivery, evaluation and implementation of complex interventions. In addition to considering the empirical study in Part 2 of the thesis, I will also draw on my experience working as a research associate on two large mental-health, multicentre randomised controlled trials over the past 8 years and previously working in clinical trials and the natural sciences. These experiences, have led me to question the suitability of applying strict scientific methods to the study of complex mental health interventions. Although new interventions and approaches are clearly needed, questions arise such as: is this the best use of government funding, can we actually make the differences that we hope to make, measure the changes that we hope to see, and how much can an intervention at the individual level truly make a difference when systemic and social factors perpetuate the conditions that contribute to mental health difficulties?

Before critically appraising this study, it is important to acknowledge the limitations of the term 'Severe Mental Illness' (SMI) used throughout this thesis. This is a much contested term, with no agreed definition. Some argue that all mental illnesses have the potential to be serious in terms of the implications and impact on individuals functioning and quality of life (National Registry of Evidence-based Programs and Practices, 2016). Furthermore, while the term SMI is designed to encompass a more chronic and persistent presentation, not all severe mental illnesses are chronic or persistent and recovery is a possibility (Slade & Longden, 2015). Alternative terms to SMI include 'serious mental illness' (often used interchangeably), chronic mental disorders, and severe and persistent mental illness- all considered to be equally problematic. I continued with the use of this term (whilst acknowledging its limitations) for simplicity and in line with the nomenclature used in the psychiatry department that this research was conducted and the psychiatric literature where the use of this term is commonplace.

I will first address some specific practical challenges in this study and then move on to address some of the wider issues encountered.

#### Practical challenges in the conduct of large complex interventions

#### Recruitment

As anticipated, recruitment in this study was a challenge: follow up was not only over a long time period, but also had to be extended by 3 months. There were also substantial gaps between follow up interviews with participants. Recruiting and retaining participants over any length of time will always be a challenge, however this specific population poses unique challenges. For instance, due to the stage and complexity of their illness, that is immediately following a crisis, often participants' lives can be chaotic, compounded by issues with accommodation and employment. Several strategies were employed to minimise attrition: upon entry to the study, participants were asked to nominate family members, friends or involved staff whom researchers could contact if unable to contact the participant directly for follow up; and to give permission for researchers to seek data about their service use from other health service providers, if the participant has moved or records were otherwise unavailable from the Trust. Additionally, update letters asking participants to let the research team know if any contact details had changed were sent periodically to participants. When organising follow-up interviews, a varied schedule of phone contact, including after-hours contact, was used to maximise the ability to get hold of participants. A final follow-up rate of 60% was achieved in this study. This is a very good follow up for a study of this nature.

#### Impact on the present study

Delays with recruitment had a major effect on the present study. In my original research proposal, I intended to focus on social (i.e. demographic, social

and neighbourhood capital) predictors of outcomes (symptoms, relapse, readmission, functioning, self-rated recovery and resilience) at 18-months.

Recruitment was scheduled to be completed in January 2017, which would allow time to complete data checks and allow me to access the trial data and conduct the analysis. Unfortunately, recruitment needed to be extended until March 2017. As such the full 18-month data required for my original proposal was not available for use at that point in time. As such, I reverted to a contingency plan that focused more narrowly on the effect of peer support on resilience, and investigating baseline predictors of resilience.

#### Data management

The difficulty of being unable to extract data easily from NHS patient records is one that needs to be highlighted. It is disappointing that we have a National Health Service, but in reality, its functioning is not truly national in the way one would expect. There is very little uniformity across the NHS, particularly in terms of information systems. This presents two issues: firstly, the administration of the study was challenging because the research was conducted across multiple research sites and trusts which meant multiple site-specific approvals and training were required for research staff (despite the 'streamlined' research passport system).

Secondly, the lack of uniformity of the data received from patient records meant that a lot of manual retrieval and manipulation of data was required, which meant the data became more vulnerable to human error discussed above. This additional layer of bureaucracy and inadequacy of basic data retrieval from information systems in trusts takes valuable time and resources. This is a missed opportunity to benefit from the richness of such a large potential data set.

Scandinavian Countries (Lynge, Sandegaard, & Rebolj, 2011; Webster, 2014) along with Canada (Kisely, Adair, Lin, & Marriott, 2015) have nationally linked

data which is achieved through a personal identification number which enables anonymous linking of data across agencies. This has recently been identified by an NHS England independent Mental Health Taskforce report: "The five year forward view for mental health" strategy (NHS England, 2016). This taskforce has identified "the inadequacy of good national mental health data and the failure to address this issue until recently has meant that decisions are taken and resources allocated without good information, perpetuating a lack of parity between physical and mental health care" (NHS England, 2016; p. 51). The taskforce goes on to conclude that the quality of mental health services and their ability to meet the needs of service users is reliant on the collection of routine data in an accurate, timely manner for every person with mental health difficulties receiving care and that this should be linked to other data public data sets such as physical and social care (NHS England, 2016). If such a dataset were available we would have a better understanding of areas of need. Not only would it make research studies like these much simpler (or even parts of them unnecessary), but it could also significantly contribute to clinical innovation and improvement of mental health services in the UK.

#### **Research Design Issues**

The current study was conducted as a randomised controlled trial (RCT) in order to generate 'gold standard', definitive data on the effectiveness of peer support. Randomised controlled trials, despite their design however cannot be fully objective or definitive; there will always be power dynamics (financial, social and organisational) that influence the design, length of intervention, choice of comparators and outcome measures (Wolff, 2000; p.105). A particular weakness of RCT design in relation to mental health interventions is that the key concept of RCTs, control of confounders, is difficult to achieve in a complex social context that has no clear boundary (Wolff, 2000). Thus, when a trial result is negative it actually

leaves us with many questions: was the intervention inherently ineffective (due to the specific intervention in this trial or because all similar interventions are ineffective), was it inadequately implemented, or implemented in an inappropriate context, or whether the trial used inappropriate design, comparison groups or outcomes (Campbell et al., 2007)?

A partial solution to these problems is to do a mixed methods study that combines both quantitative and qualitative data. Mixed methods designs have been widely recommended (Hill, Chui, & Baumann, 2013; Lewin, Glenton, & Oxman, 2009) and are becoming standard with large RCTs. They can help inform researchers on how participants experienced the intervention or untangle potential mechanisms of action of the intervention (Lewin et al., 2009). A mixed methods design was used in the CORE study and qualitative interviews have been carried out. Unfortunately, I do not have access to this data for use here.

It is only while searching the literature for my initial idea that RCTs may not be an ideal fit for socially complex mental health interventions that I have come across an alternative interpretation of the concept of self-management. Whilst completing my systematic review and during the peer support study, I understood self-management to be a way of liberating and empowering individuals to take control of their illness. Harper and Speed (2012) however argue that in actuality self-management moves the responsibility for social factors such as unemployment, poverty and poor health onto individuals packaged as a problem of "self-care", or lack thereof (Lemke, 2001). This can be compounded by large RCTs like the present study that further negate the systemic and social aspects, and firmly place the responsibility with the individual.

Perhaps a wider, community-level peer based intervention could be a better target than one-to-one support. There are already some examples in practice, such as the 'Gardening Project' where men with mental health difficulties get together to

garden (Robinson, Raine, Robertson, Steen, & Day, 2015), and the 'Coping Through Football Project' (Mason & Holt, 2012) which aims to improve wellbeing and reduce social isolation for young people with SMI through football. In the CORE study, the fact that one-to-one support ends, and is conditional, in that peer supporters are instructed to have no further contact post-intervention, could be experienced quite negatively by service users. Group-based interventions, that offered more informal, ongoing meet-ups might link individual in with peers in a more organic way that fosters more lasting relationships and addresses issues of social isolation.

#### Focus of intervention

One of the aims of the CORE program was to develop a peer delivered self-management intervention to "bridge the gap" between crisis and continuing care. On reflection, should a 10-week peer-support intervention be expected to fill a gap in services and reduce re-admission? Particularly when it is unclear whether CRT care itself has actually reduced admissions and bed usage or if it is simply the reduction in bed numbers (on the expectation that CRT care would decrease the need; and in order to fund these new services) that bed usage has reduced (Lodge, 2012). The other criticism of CRT care- again one that peer support was hypothesised may bridge the gap- was in terms of providing a sense of continuity of care to service users (Lodge, 2012). Since the intervention was limited to ten sessions, it is important to assess how much can this type of intervention actually contribute to continuity of care, and what is the effect of the ending of the peer-support relationship on service users.

Potentially one of the benefits of peer support is that it is experienced as separate to mental health services; however, I wonder to what extent service users experienced the peer support worker as just another mental health worker coming

in, and 'doing to' rather than truly 'doing with' and being service-user led. Peers were not matched to participants in terms of age, gender, diagnosis or experience of services. Whether this could have made a difference in terms of meaningful connection is still to be explored. Moreover, it is unknown whether mutuality of the relationship can develop when there may be a power dynamic present that is similar to that in services. It may be that interventions can never be truly service-user led and bespoke in a trial setting, where control and replicability is at the essence of its ability to assess effectiveness (Bird et al., 2014).

#### Length of intervention and follow-up

The timing and duration of an intervention in relation to expected rate and pattern of change is an important factor (Craig et al., 2006) that must be balanced against the pragmatics and cost of delivering such an intervention. The current emphasis on brief, time-limited interventions may be setting interventions up to fail from the start. From the systematic review in chapter 1, the average duration of a self-management intervention was 12 weeks, which is similar to the present study. However, the face-to-face contact time was 23 hours, more than twice the amount of contact that service users had with peers in this study. Accordingly, I feel the current study could probably have benefited from a longer intervention period.

Particularly for the population in this study, the inherent complexity and variability in the clinical course of illness, means response to treatment can take from 1 to 2 years for progression from the acute to the recovery phase (Liberman & Kopelowicz, 2005). Subsequently, the need for support is not confined to the newly diagnosed, but is often an ongoing issue (Lodge, 2012). Moreover, recovery is typically defined as a process or journey that can take many years (Castelein, Bruggeman, Davidson, & Van Der Gaag, 2015) rather than a static outcome (Drake & Whitley, 2014).

#### Outcome Measures

We currently do not have a good understanding of how peer support might work and if it does even work. Best scientific practice is to opt for objective measures of outcomes with sound psychometric properties. This does not translate well to concepts such as 'recovery' which are not linear (Slade & Longden, 2015), but heavily influenced by context such as socio-economic background, health service systems, the population, the prevalence and severity of the condition studied and how these factors change over time (Campbell et al., 2007). Outcomes such as relapse, in symptoms and readmission, often become the focus of research because they are more easily observable, and measured, than other outcomes. Fonagy (1999; p294) argues that symptoms are merely "proxy variables for the more important but far more slowly changing concerns of most patients, which have to do with work, family relationships, capacity for coping and general quality of life".

In relation to the specific outcomes in this thesis, that is resilience, it has been argued that mental health programmes confront a challenge building individual resilience within fractured local communities (Robinson et al., 2015). Furthermore, the focus on resilience in this study has the potential to further obfuscate the role that social injustice and inequalities play in mental ill health. Resilience in the modern positive psychology sense is a construct consisting of psychological processes and personal strengths that are considered to be protective or ameliorative in the face of adversity (Harper & Speed, 2013). This emphasis on positives and strengths necessitate the existence of negatives or weaknesses (Harper & Speed, 2013), and again pull focus on individual qualities that should be developed or changed and does little to address the structural causes of distress (Marmot, 2010).

#### Conclusion

Slade and Longden (2015) state that in many research approaches there is an "assumption that mental illness resides in the person" and that the "continued effort to individualise socially-caused phenomena represents a reasoning bias in mental health research". As a career-long researcher and, more recently, a clinician in training, this is an uncomfortable realisation. A world health organisation report reiterated that while there is much that can be done to improve mental health in the future, doing so will depend less on specific interventions and more on a policy sea change (Friedli, 2009). Accordingly, there has been a promising movement in clinical psychology recently: away from the therapy room and into the community to actively engage and intervene at a policy systems level to address social inequalities at the root of individual distress (Browne, 2016).

#### References

- Bird, V. J., Le Boutillier, C., Leamy, M., Williams, J., Bradstreet, S., & Slade, M. (2014). Evaluating the feasibility of complex interventions in mental health services: standardised measure and reporting guidelines. *The British Journal of Psychiatry*, 204(4), 316–321. http://doi.org/10.1192/bjp.bp.113.128314
- Browne, N. (2016). *Practice to Policy: Clinical psychologists' experiences of macro-level work*. University College London. Retrieved from http://discovery.ucl.ac.uk/1532884/1/Volume1\_Finalsubmission\_NinaBrowne\_0 91216.pdf
- Campbell, N. C., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., ...
  Kinmonth, A. L. (2007). Designing and evaluating complex interventions to
  improve health care. *British Medical Journal*, 334(7591), 455–459.
  http://doi.org/10.1136/bmj.39108.379965.BE
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2006).

  Developing and Evaluating Complex Interventions: New Guidance. In MRC

  Framework for the Development and Evaluation of RCTs for Complex

  Interventions to Improve Health. London: Medical Research Council. Retrieved from http://discovery.ucl.ac.uk/103060/
- Friedli, L. (2009). Mental health, resilience and inequalities. World Health

  Organisation. Retrieved from

  http://www.mentalhealthpromotion.net/resources/mental-health-resilience-and-inequalities.pdf
- Harper, D., & Speed, E. (2013). Uncovering recovery: The resistible rise of recovery and resilience. *Studies in Social Justice*, *6*(1), 9–26. http://doi.org/10.1057/9781137304667.0008
- Hill, C. E., Chui, H., & Baumann, E. (2013). Revisiting and reenvisioning the

- outcome problem in psychotherapy: An argument to include individualized and qualitative measurement. *Psychotherapy*, *50*(1), 68–76. http://doi.org/10.1037/a0030571
- Kisely, S., Adair, C. E., Lin, E., & Marriott, B. (2015). Routine outcome measures in Canada. *International Review of Psychiatry*, 27(4), 286–295. http://doi.org/10.3109/09540261.2014.994594
- Lemke, T. (2001). "The birth of bio-politics": Michel Foucault's lecture at the Collège de France on neo-liberal governmentality. *Economy and Society*, *30*(2), 190–207. http://doi.org/10.1080/713766674
- Lewin, S., Glenton, C., & Oxman, A. D. (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. *Bmj*, *339*(sep10 1), b3496–b3496. http://doi.org/10.1136/bmj.b3496
- Liberman, R. P., & Kopelowicz, A. (2005). Recovery from Schizophrenia: a concept in search of research. *Psychiatric Services*, *56*(6), 735–742. http://doi.org/10.1176/appi.ps.56.6.735
- Lodge, G. (2012). How did we let it come to this? A plea for the principle of continuity of care. *The Psychiatrist*, *36*(10), 361–363. http://doi.org/10.1192/pb.bp.112.038562
- Lynge, E., Sandegaard, J. L., & Rebolj, M. (2011). The Danish National Patient Register. *Scandinavian Journal of Public Health*, *39*(7 Suppl), 30–33. http://doi.org/10.1177/1403494811401482
- Marmot, M. (2010). Fair society, healthy lives: strategic review of health inequalities in England post-2010. London: The Marmot Review. Retrieved from http://linkinghub.elsevier.com/retrieve/pii/S0033350612001862
- Mason, O. J., & Holt, R. (2012). A role for football in mental health: the Coping Through Football project. *The Psychiatrist*, *36*, 290–293.

- http://doi.org/10.1192/pb.bp.111.036269
- National Registry of Evidence-based Programs and Practices. (2016). Behind the Term: Serious Mental Illness. Retrieved June 5, 2017, from <a href="http://www.nrepp.samhsa.gov/Docs/Literatures/Behind\_the\_Term\_Serious">http://www.nrepp.samhsa.gov/Docs/Literatures/Behind\_the\_Term\_Serious</a> Mental Illness.pdf
- NHS England. (2016). The five year forward view for mental health. *The Mental Health Taskforce*, (February), 82.
- Robinson, M., Raine, G., Robertson, S., Steen, M., & Day, R. (2015). Peer support as a resilience building practice with men. *Journal of Public Mental Health*, 14(4), 196–204. http://doi.org/10.1108/JPMH-04-2015-0015
- Slade, M., & Longden, E. (2015). Empirical evidence about recovery and mental health. *BMC Psychiatry*, *15*(1), 285. http://doi.org/10.1186/s12888-015-0678-4
- Webster, P. C. (2014). Sweden's health data goldmine. *CMAJ: Canadian Medical Association Journal = Journal de l'Association Medicale Canadienne*, 186(9), 4713. http://doi.org/10.1503/cmaj.109-4713
- Wolff, N. (2000). Using randomized controlled trials to evaluate socially complex services: problems, challenges and recommendations. *J Mental Health Policy Econ.*, 109, 97–109.

#### Appendix 1: PRISMA Search strategy

#### PRISMA, database searches only:

9547 records identified through database searching

6365 records after duplicates removed

#### 1.1 Databases: Embase, Medline, PreMedline, PsycINFO

Interface: OVID SP

Search Strategy

#### # searches

- 1 "explode schizophrenia"/ or (psychosis\$ or psychotic\$).hw.
- 2 1 use emez
- paranoid disorders/ or exp psychotic disorders/ or exp schizophrenia/ or "schizophrenia and disorders with psychotic features"/
- 4 3 use mesz, prem
- 5 exp psychosis/ or exp schizophrenia/
- 6 5 use psyh
- ((chronic\$ or serious\$ or sever\$) adj2 mental\$ adj2 (ill\$ or disorder\$)).ti,ab,hw,id. or
- 7 (delusional disorder\$ or hebephreni\$ or oligophreni\$ or psychoses or psychosis or psychotic\$ or schizo\$).ti,ab,id.
- 8 akathisia/ or dyskinesia/ or neuroleptic malignant syndrome/
- 9 8 use emez
- 10 akathisia, drug-induced/ or dyskinesias/ or dyskinesia, drug-induced/ or neuroleptic malignant syndrome/
- 11 10 use mesz, prem
- 12 akathisia/ or exp dyskinesia/ or neuroleptic malignant syndrome/
- 13 12 use psyh

(akathisi\$ or acathisi\$ or (neuroleptic\$ and ((malignant and syndrome) or (movement adj2 14 disorder))) or (tardiv\$ and dyskine\$)).ti,ab,id. or ((parkinsoni\$ or neuroleptic induc\$).ti,ab,id. not (parkinson\$ and disease).ti.)

15 or/2,4,6-7,9,11,13-14

16 exp self care/ or self evaluation/

17 16 use emez

18 self administration/ or self care/ or self-help groups/ or self medication/

- 19 18 use mesz, prem
- 20 self care skills/ or self evaluation/ or exp self help techniques/ or self monitoring/ or self regulation/ or self reinforcement/
- 21 20 use psyh
- ((self adj (administer\$ or assess\$ or attribut\$ or care or change or directed or efficacy or help\$ or guide\$ or instruct\$ or manag\$ or medicat\$ or monitor\$ or regulat\$ or reinforc\$ or re inforc\$ or support\$ or technique\$ or therap\$ or train\$ or treat\$)) or selfadminister\$ or selfassess\$ or selfattribut\$ or selfcare or selfchange or selfdirected or selfefficacy or
- 22 selfassess\$ or selfattribut\$ or selfcare or selfchange or selfdirected or selfefficacy or selfhelp\$ or selfguide\$ or selfinstruct\$ or selfmanag\$ or selfmedicat\$ or selfmonitor\$ or selfregulat\$ or selfreinforc\$ or self re inforc\$ or selfsupport\$ or selftechnique\$ or selftherap\$ or selftrain\$ or selftreat\$).ti,ab.
- (expert patient\$ or (hearing voices adj2 (group\$ or network\$ or support\$)) or (minimal adj 23 (contact or guidance)) or helpseek\$ or (help\$ adj2 seek\$) or (mutual adj (aid\$ or help or support\$)) or recovery model\$ or smart recovery).ti,ab.
- health education/ or health literacy/ or health promotion/ or patient education/ or psychoeducation/
- 25 24 use emez
- 26 exp consumer health information/ or health education/ or health knowledge, attitudes, practice/ or health promotion/ or patient education as topic.sh.
- 27 26 use mesz, prem
- 28 client education/ or health education/ or health knowledge/ or health literacy/ or health promotion/ or psychoeducation/
- 29 28 use psyh
- (booklet\$ or brochure\$ or leaflet\$ or pamphlet\$ or poster\$ or psychoeducat\$ or psychoeducat\$ or workbook\$ or work book\$ or ((adult\$ or client\$ or consumer\$ or health or 30 inpatient\$ or outpatient\$ or participant\$ or patient\$ or service user\$) adj2 (educat\$ or focus\$ or information\$ or knowledge or learn\$ or literac\$ or promot\$ or taught or teach\$)) or empower\$ or ((oral or printed or written) adj3 (material\$ or inform\$))).ti,ab.
- 31 adaptive behavior/
- 32 31 use emez
- 33 exp adaptation, psychological/
- 34 33 use mesz, prem
- 35 adaptive behavior/
- 36 35 use psyh
- 37 (((behav\$ or psychologic\$) adj3 (adapt\$ or adjust\$)) or cope or copes or coping).ti,ab.
- 38 patient participation/
- 39 38 use emez
- 40 exp consumer participation/

- 41 40 use mesz, prem
- 42 client participation/
- 43 42 use psyh
- ((adult\$ or client\$ or consumer\$ or inpatient\$ or outpatient\$ or participant\$ or patient\$ or service user\$) adj2 (involv\$ or participat\$)).ti,ab.
- 45 or/17,19,21-23,25,27,29-30,32,34,36-37,39,41,43-44
- 46 exp "clinical trial (topic)"/ or exp clinical trial/ or crossover procedure/ or double blind procedure/ or placebo/ or randomization/ or random sample/ or single blind procedure/
- 47 46 use emez
- 48 exp clinical trial/ or cross-over studies/ or double-blind method/ or placebos/ or random allocation/ or "randomized controlled trials as topic"/ or single-blind method/
- 49 48 use mesz, prem
- 50 (clinical trials or placebo or random sampling).sh,id.
- 51 50 use psyh
- 52 (clinical adj2 trial\$).ti,ab.
- 53 (crossover or cross over).ti,ab.
- 54 (((single\$ or doubl\$ or trebl\$ or tripl\$) adj2 blind\$) or mask\$ or dummy or doubleblind\$ or singleblind\$ or trebleblind\$ or tripleblind\$).ti,ab.
- 55 (placebo\$ or random\$).ti,ab.
- 56 treatment outcome\$.md. use psyh
- 57 animals/ not human\$.mp. use emez
- 58 animal\$/ not human\$/ use mesz, prem
- 59 (animal not human).po. use psyh
- 60 (or/47,49,51-56) not (or/57-59)
- 61 15 and 45 and 60

#### 1.2. Database: CENTRAL Search strategy

Interface: Wiley

Search strategy:

- #1 mesh descriptor: [paranoid disorders] single term only
- #2 mesh descriptor: [schizophrenia and disorders with psychotic features] single term only

- #3 mesh descriptor: [psychotic disorders] explode all trees
- #4 mesh descriptor: [schizophrenia] explode all trees
- #5 ((chronic\* or sever\*) and mental\* and (ill\* or disorder\*)):ti,ab,kw
- #6 ("delusional disorder\*" or hebephreni\* or oligophreni\* or psychoses or psychosis or psychotic\* or schizo\*):ti,ab
- #7 mesh descriptor: [akathisia, drug-induced] single mesh term
- #8 mesh descriptor: [dyskinesias] single mesh term
- #9 mesh descriptor: [dyskinesia, drug-induced] single mesh term
- #10 mesh descriptor: [neuroleptic malignant syndrome] single mesh term
- #11 (akathisi\* or acathisi\* or (neuroleptic\* and ((malignant and syndrome) or (movement n2 disorder))) or (tardiv\* and dyskine\*)):ti
- #12 (akathisi\* or acathisi\* or (neuroleptic\* and ((malignant and syndrome) or (movement n2 disorder))) or (tardiv\* and dyskine\*)):ab
- #13 mesh descriptor: [movement disorders] explode all trees
- #14 (parkinsoni\* or "neuroleptic induc\*"):ti,ab,kw
- #15 (parkinson\* and disease):ti
- #16 #14 not #15
- #17 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #16
- #18 mesh descriptor: [self administration] single mesh term
- #19 mesh descriptor: [self care] single mesh term
- #20 mesh descriptor: [self medication] single mesh term
- #21 mesh descriptor: [self-help groups] single mesh term
- #22 ((self near/1 (administer\* or assess\* or attribut\* or care or change or directed or efficacy or help\* or guide\* or instruct\* or manag\* or medicat\* or monitor\* or regulat\* or reinforc\* or "re inforc\*" or support\* or technique\* or therap\* or train\* or treat\*)) or selfadminister\* or selfassess\* or selfattribut\* or selfcare or selfchange or selfdirected or selfeficacy or selfhelp\* or selfguide\* or selfinstruct\* or selfmanag\* or selfmedicat\* or selfmonitor\* or selfregulat\* or selfreinforc\* or "self re inforc\*" or selfsupport\* or selftechnique\* or selftherap\* or selftrain\* or selftreat\*):ti
- #23 ((self near/1 (administer\* or assess\* or attribut\* or care or change or directed or efficacy or help\* or guide\* or instruct\* or manag\* or medicat\* or monitor\* or regulat\* or reinforc\* or "re inforc\*" or support\* or technique\* or therap\* or train\* or treat\*)) or selfadminister\* or selfassess\* or selfattribut\* or selfcare or selfchange or selfdirected or selfeficacy or selfhelp\* or selfguide\* or selfinstruct\* or selfmanag\* or selfmedicat\* or selfmonitor\* or selfregulat\* or selfreinforc\* or "self re inforc\*" or selfsupport\* or selftechnique\* or selftherap\* or selftrain\* or selftreat\*);ab
- #24 ("expert patient\*" or ("hearing voices" near/2 (group\* or network\* or support\*)) or (minimal near/1 (contact or guidance)) or helpseek\* or (help\* near/2 seek\*) or (mutual near/1 (aid\* or help or support\*)) or "recovery model\*" or "smart recovery"):ti
- #25 ("expert patient\*" or ("hearing voices" near/2 (group\* or network\* or support\*)) or (minimal near/1 (contact or guidance)) or helpseek\* or (help\* near/2 seek\*) or (mutual near/1 (aid\* or help or support\*)) or "recovery model\*" or "smart recovery"):ab
- #26 mesh descriptor: [consumer health information] explode all trees

#27 mesh descriptor: [health education] single mesh term #28 mesh descriptor: [health knowledge, attitudes, practice] single mesh term #29 mesh descriptor: [health promotion] single mesh term #30 mesh descriptor: [patient education as topic] single mesh term #31 (booklet\* or brochure\* or leaflet\* or pamphlet\* or poster\* or psychoeducat\* or "psycho educat\*" or workbook\* or "work book\*" or ((adult\* or client\* or consumer\* or health or inpatient\* or outpatient\* or participant\* or patient\* or "service user\*") near/2 (educat\* or focus\* or information\* or knowledge or learn\* or literac\* or promot\* or taught or teach\*)) or empower\* or ((oral or printed or written) near/3 (material\* or inform\*))):ti #32 (booklet\* or brochure\* or leaflet\* or pamphlet\* or poster\* or psychoeducat\* or "psycho educat\*" or workbook\* or "work book\*" or ((adult\* or client\* or consumer\* or health or inpatient\* or outpatient\* or participant\* or patient\* or "service user\*") near/2 (educat\* or focus\* or information\* or knowledge or learn\* or literac\* or promot\* or taught or teach\*)) or empower\* or ((oral or printed or written) near/3 (material\* or inform\*))):ab #33 mesh descriptor: [adaptation, psychological] single mesh term #34 (((behav\* or psychologic\*) near/5 (adapt\* or adjust\*)) or cope or copes or coping):ti #35 (((behav\* or psychologic\*) near/5 (adapt\* or adjust\*)) or cope or copes or coping):ab #36 mesh descriptor: [consumer participation] single mesh term #37 ((adult\* or client\* or consumer\* or inpatient\* or outpatient\* or participant\* or patient\* or "service user\*") near/2 (involv\* or participat\*)):ti #38 ((adult\* or client\* or consumer\* or inpatient\* or outpatient\* or participant\* or patient\* or "service user\*") near/2 (involv\* or participat\*)):ab #39 #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 #40 #17 and #39

#### 1.3. Database: CINAHL Search strategy

**Interface: Ebsco Host** 

#### Search strategy:

| s30 | s9 and s19 and s29                            |
|-----|---|
| s29 | s28 not s27                                   |
| s28 | s20 or s21 or s22 or s23 or s24 or s25 or s26 |
| s27 | (mh "animals") not (mh "human")               |

| s26 | (pt "clinical trial") or (pt "randomized controlled trial")   |
|-----|---|
| s25 | ti ( placebo* or random* ) or ab ( placebo* or random* )  |
| s24 | ti ( single blind* or double blind* or treble blind* or mask* or dummy* or singleblind* or doubleblind* or trebleblind*) or ab ( single blind* or double blind* or treble blind* or mask* or dummy* or singleblind* or doubleblind* or trebleblind*)  |
| s23 | ti ( crossover or cross over ) or ab ( crossover or cross over )  |
| s22 | ti clinical n2 trial* or ab clinical n2 trial*  |
| s21 | (mh "crossover design") or (mh "placebos") or (mh "random assignment") or (mh "random sample")  |
| s20 | (mh "clinical trials+")   |
| s19 | s10 or s11 or s12 or s13 or s14 or s15 or s16 or s17 or s18   |
| s18 | ti ( ((adult* or client* or consumer* or inpatient* or outpatient* or participant* or patient* or service user*) n2 (involv* or participat*)) ) or ab ( ((adult* or client* or consumer* or inpatient* or outpatient* or participant* or patient* or service user*) n2 (involv* or participat*)) )  |
| s17 | (mh "consumer participation")   |
| s16 | ti ( (((behav* or psychologic*) n3 (adapt* or adjust*)) or cope or copes or coping) ) or ab ( (((behav* or psychologic*) n3 (adapt* or adjust*)) or cope or copes or coping) )  |
| s15 | (mh "adaptation, psychological")  |
| s14 | ti ( (booklet* or brochure* or leaflet* or pamphlet* or poster* or psychoeducat* or "psychoeducat*" or workbook* or "work book*" or ((adult* or client* or consumer* or health or inpatient* or outpatient* or participant* or patient* or "service user*") n2 (educat* or focus* or information* or knowledge or learn* or literac* or promot* or taught or teach*)) or empower* or ((oral or printed or written) n3 (material* or inform*)))) or ab ( (booklet* or brochure* or leaflet* or pamphlet* or poster* or psychoeducat* or "psycho educat*" or workbook* or "work book*" or ((adult* or client* or consumer* or health or inpatient* or outpatient* or participant* or patient* or "service user*") n2 (educat* or focus* or information* or knowledge or learn* or literac* or promot* or taught or teach*)) or empower* or ((oral or printed or written) n3 (material* or inform*)))) |
| s13 | (mh "consumer health information") or (mh "health education") or (mh "patient discharge education") or (mh "patient education") or (mh "patient education (iowa nic) (noncinahl)") or (mh "mental health promotion (saba ccc)") or (mh "health promotion") or (mh "health promotion (saba ccc)") or (mh "health knowledge") or (mh "health knowledge (iowa noc) (non-cinahl)") or (mh "knowledge: health behaviors (iowa noc)")   |
| s12 | ti ( ("expert patient*" or ("hearing voices" n2 (group* or network* or support*)) or (minimal adj (contact or guidance)) or helpseek* or (help* n2 seek*) or (mutual n1 (aid* or help or support*)) or "recovery model*" or "smart recovery") ) or ab ( ("expert patient*" or ("hearing voices" n2 (group* or network* or support*)) or (minimal adj (contact or guidance)) or helpseek* or (help* n2 seek*) or (mutual n1 (aid* or help or support*)) or "recovery model*" or "smart recovery") )  |

| s11 | ti ( ((self n1 (administer* or assess* or attribut* or care or change or directed or efficacy or help* or guide* or instruct* or manag* or medicat* or monitor* or regulat* or reinforc* or re inforc* or support* or technique* or therap* or train* or treat*)) or selfadminister* or selfassess* or selfattribut* or selfcare or selfchange or selfdirected or selfefficacy or selfhelp* or selfguide* or selfinstruct* or selfmanag* or selfmedicat* or selfmonitor* or selfregulat* or selfreinforc* or "self re inforc*" or selfsupport* or selftechnique* or selftherap* or selftrain* or selftreat*) ) or ab ( ((self n1 (administer* or assess* or attribut* or care or change or directed or efficacy or help* or guide* or instruct* or manag* or medicat* or monitor* or regulat* or reinforc* or re inforc* or support* or technique* or therap* or train* or treat*)) or selfadminister* or selfassess* or selfattribut* or selfcare or selfchange or selfdirected or selfefficacy or selfhelp* or selfguide* or selfinstruct* or selfmanag* or selfmedicat* or selfmonitor* or selfregulat* or selfreinforc* or "self re inforc*" or selfsupport* or selftechnique* or selftherap* or selftrain* or selftreat*) ) |
|-----|--|
| s10 | (mh "self administration") or (mh "self care") or (mh "self care agency") or (mh "self medication")  |
| s9  | s1 or s2 or s3 or s4 or s5 or s8   |
| s8  | s6 not s7  |
| s7  | ti parkinson* and disease  |
| s6  | ti ( parkinsoni* or "neuroleptic induc*" ) or ab ( parkinsoni* or "neuroleptic induc*" )   |
| s5  | ti ( akathisi* or acathisi* or (neuroleptic* and ((malignant and syndrome) or (movement n2 disorder))) or (tardiv* and dyskine*) ) or ab ( akathisi* or acathisi* or (neuroleptic* and ((malignant and syndrome) or (movement n2 disorder))) or (tardiv* and dyskine*) )   |
| s4  | (mh "akathisia, drug-induced") or (mh "dyskinesia, drug-induced") or (mh "dyskinesias") or (mh "movement disorders+") or (mh "neuroleptic malignant syndrome")   |
| s3  | ti ( "delusional disorder*" or hebephreni* or oligophreni* or psychoses or psychosis or psychotic* or schizo* ) or ab ( "delusional disorder*" or hebephreni* or oligophreni* or psychoses or psychosis or psychotic* or schizo* )   |
| s2  | ti ( ((chronic* or sever*) and mental* and (ill* or disorder*)) ) or ab ( ((chronic* or sever*) and mental* and (ill* or disorder*)) ) or mw ( ((chronic* or sever*) and mental* and (ill* or disorder*)) )  |
| s1  | (mh "paranoid disorders") or (mh "psychotic disorders") or (mh "schizoaffective disorder") or (mh "schizophrenia+")  |

Appendix 2. Full Risk of Bias Assessment

| Anzai 2002                | Random sequence generation (selection bias) | Allocation concealment (selection bias) | Blinding of participants and personnel (performance bias) | Blinding of outcome assessment (detection bias) | Incomplete outcome data (attrition bias) | Selective reporting (reporting bias) | • Other bias |
|---------------------------|---|---|---|---|--|--------------------------------------|--------------|
| Atkinson 1996             | ?   | •                                       |   | ?   | •  |                                      | •            |
| Barbic 2009               | ?   | ?                                       |   | •   | •  | •                                    | •            |
| Chan 2007                 | •   | ?                                       |   | •   | ?  | ?                                    | •            |
| Chien 2013                | •   | ?                                       |   | •   | •  | ?                                    | •            |
| Chien 2014                | •   | •                                       | •   | •   | •  | •                                    | •            |
| Colom 2003                | •   | ?                                       | •   | •   | •  | ?                                    | •            |
| Cook 2011                 | •   | •                                       | •   | •   | •  | •                                    | •            |
| Cook 2012                 | •   | •                                       | •   | •   | •  | •                                    | •            |
| Cook 2013                 | •   | •                                       | •   | •   | ?  | •                                    | •            |
| Eckman 1992               | ?   | ?                                       | •   | •   | •  | •                                    | •            |
| Fardig 2011               | •   | ?                                       | •   | •   | •  | •                                    | •            |
| Hasson 2007               | •   | •                                       | •   | •   | ?  | ?                                    | •            |
| Kopelowicz 1998           | ?   | ?                                       | •   | ?   | •  | ?                                    | •            |
| Levitt 2009               | •   | ?                                       | •   | •   | •  | ?                                    | •            |
| Lin 2013                  | •   | ?                                       | •   | •   | •  | ?                                    | •            |
| Perry 1999                | •   | ?                                       |   | •   | •  | ?                                    | •            |
| Proudfoot 2012            | •   | •                                       | •   | •   | •  |                                      | •            |
| Sajatovic 2009            | •   | •                                       | •   | •   | •  | ?                                    | •            |
| Salyers 2010              | •   | •                                       | •   | •   | •  | ?                                    | •            |
| Salyers 2014              | ?   | ?                                       | •   | •   | •  | ?                                    | •            |
| Schaub 2016               | •   | •                                       | •   | •   | •  | ?                                    | •            |
| Shon 2002                 | ?   | •                                       | •   | •   | •  | •                                    | •            |
| Smith 2011                | •   | ?                                       | •   | •   | •  | •                                    | •            |
| Todd 2014                 | •   | •                                       | •   | •   | •  | •                                    | •            |
| Torrent 2013              | •   | ?                                       | •   | •   | •  | •                                    | •            |
| Van Gestel-Timmermans2012 | •   | •                                       | •   | •   |  | •                                    | •            |
| Vreeland 2006             | •   | ?                                       | •   | •   | ?  | ?                                    | •            |
| Wirshing 2006             | ?   | ?                                       |   | •   |  | ?                                    | •            |
| Xiang 2006                | •   | ?                                       | •   | •   | •  | ?                                    | •            |
| Xiang 2007                | ?   | ?                                       | •   | •   | •  | ?                                    | •            |
| Zhou 2014                 | •   | ?                                       |   | •   | •  | ?                                    | •            |
|                           | _   | _                                       |   | _   | _  |                                      | _            |

#### Appendix 3. Forest Plots for select outcomes of meta-analysis

#### Positive and Negative symptoms

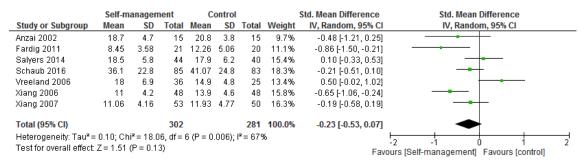
#### 3.1 Positive Symptoms: End of Treatment

|                                   | Self-m   | anagen    | nent    | С        | ontrol  |       |        | Std. Mean Difference | Std. Mean Difference                                  |  |  |  |  |  |
|-----------------------------------|----------|-----------|---------|----------|---------|-------|--------|----------------------|---|--|--|--|--|--|
| Study or Subgroup                 | Mean     | SD        | Total   | Mean     | SD      | Total | Weight | IV, Random, 95% CI   | IV, Random, 95% CI                                    |  |  |  |  |  |
| Anzai 2002                        | 13.5     | 5.2       | 15      | 18.3     | 5.1     | 15    | 11.9%  | -0.91 [-1.66, -0.15] | <del></del>   |  |  |  |  |  |
| Fardig 2011                       | 6.25     | 3.19      | 21      | 9.58     | 5.21    | 20    | 14.1%  | -0.76 [-1.40, -0.12] | <del></del>   |  |  |  |  |  |
| Xiang 2006                        | 9        | 2.7       | 48      | 9.5      | 3.5     | 48    | 19.2%  | -0.16 [-0.56, 0.24]  | <del></del>   |  |  |  |  |  |
| Xiang 2007                        | 8.7      | 2.54      | 53      | 8.3      | 3.99    | 50    | 19.6%  | 0.12 [-0.27, 0.51]   | <del>- </del>   |  |  |  |  |  |
| Salyers 2014                      | 14.1     | 6.2       | 44      | 12.6     | 4.9     | 40    | 18.6%  | 0.26 [-0.17, 0.69]   | +•  |  |  |  |  |  |
| Vreeland 2006                     | 16.6     | 6         | 36      | 14.2     | 5.3     | 25    | 16.6%  | 0.41 [-0.10, 0.93]   | <del>  •</del>  |  |  |  |  |  |
| Total (95% CI)                    |          |           | 217     |          |         | 198   | 100.0% | -0.10 [-0.46, 0.26]  | •   |  |  |  |  |  |
| Heterogeneity: Tau <sup>2</sup> = | 0.13; Ch | i² = 15.8 | 33, df= | 5 (P = 0 | .007);1 |       |        |                      |   |  |  |  |  |  |
| Test for overall effect:          | Z = 0.57 | (P = 0.5  | 7)      |          |         |       |        |                      | -2 -1 0 1<br>purs [Self-Management] Favours [control] |  |  |  |  |  |

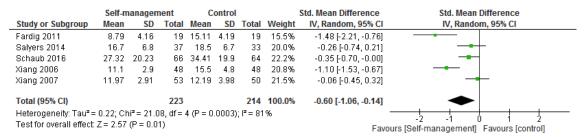
#### 3.2 Positive Symptoms: Follow Up

|                                   | Self-m   | anagen       | nent       | C        | ontrol |          | !      | Std. Mean Difference | Std. Mean Difference                     |
|-----------------------------------|----------|--------------|------------|----------|--------|----------|--------|----------------------|--|
| Study or Subgroup                 | Mean     | SD           | Total      | Mean     | SD     | Total    | Weight | IV, Random, 95% CI   | IV, Random, 95% CI                       |
| Fardig 2011                       | 5.74     | 3.31         | 19         | 9.74     | 5.35   | 19       | 20.6%  | -0.88 [-1.55, -0.21] |  |
| Salyers 2014                      | 13.5     | 5.2          | 37         | 13       | 5.3    | 33       | 25.4%  | 0.09 [-0.38, 0.56]   | <del>-  -</del>                          |
| Xiang 2006                        | 8.9      | 2.4          | 48         | 11.6     | 4      | 48       | 26.7%  | -0.81 [-1.23, -0.40] | <del></del>                              |
| Xiang 2007                        | 8.76     | 2.68         | 53         | 8.83     | 4.58   | 50       | 27.4%  | -0.02 [-0.41, 0.37]  |  |
| Total (95% CI)                    |          |              | 157        |          |        | 150      | 100.0% | -0.38 [-0.87, 0.12]  |  |
| Heterogeneity: Tau <sup>2</sup> = | 0.19; Ch | $i^2 = 13.3$ | 36, df = 3 | 3 (P = 0 | .004); | l² = 789 | %      |                      | -2 -1 1 2                                |
| Test for overall effect:          | Z = 1.50 | (P = 0.1)    | 3)         |          |        |          |        | Favo                 | ours [Self-management] Favours [control] |

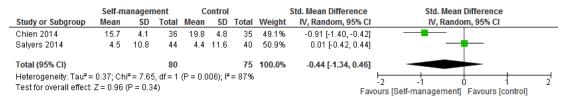
#### 3.3 Negative Symptoms: End of treatment



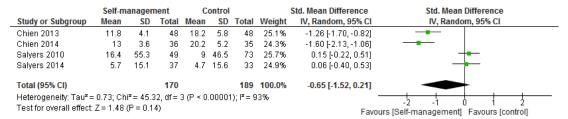
#### 3.4 Negative Symptoms: Follow Up



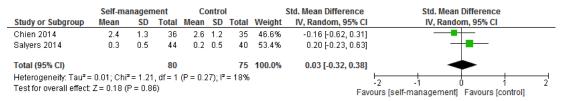
#### Relapse and length of hospitalisation



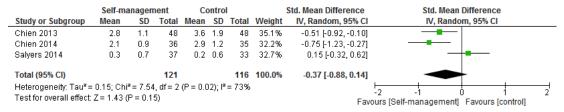
#### 3.5 Length of admission at end of treatment



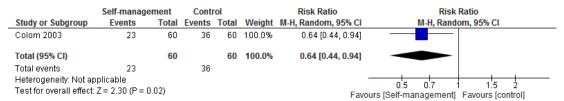
#### 3.6 Length of admission at follow-up



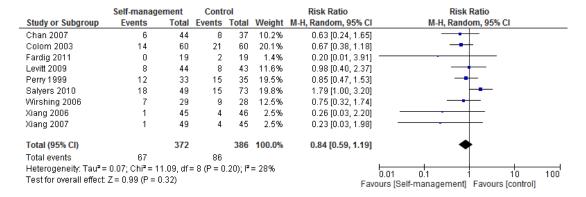
#### 3.7 Mean number of relapses (of symptoms or hospitalised) at end of treatment



#### 3.8 Mean number of relapses (of symptoms or hospitalised) at follow-up



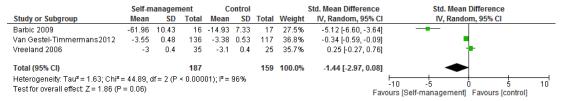
# 3.9 Total number of participants who relapsed during the study period at end of treatment



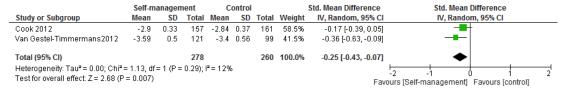
#### 3.10 Total number of participants who relapsed during the study period at follow up

#### Self-rated recovery outcomes

#### **Empowerment**

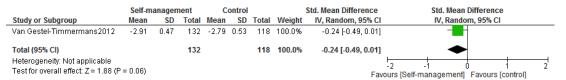


#### 3.11 Empowerment at end of treatment



#### 3.12 Empowerment at follow-up

#### Hope

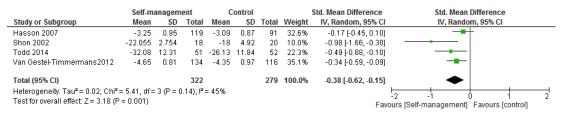


#### 3.13 Hope at end of treatment

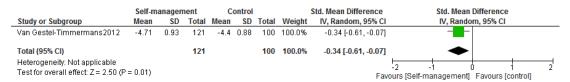
|                           | Self-m   | anagen | nent  | C      | ontrol |       |        | Std. Mean Difference | Std. Mea                       | n Difference              |  |
|---------------------------|--|--------|-------|--------|--------|-------|--------|----------------------|--------------------------------|---------------------------|--|
| Study or Subgroup         | Mean   | SD     | Total | Mean   | SD     | Total | Weight | IV, Random, 95% CI   | IV, Rand                       | lom, 95% CI               |  |
| Cook 2011                 | -22.76   | 4.68   | 212   | -22.16 | 4.21   | 222   | 37.3%  | -0.13 [-0.32, 0.05]  | -                              | <b>I</b>                  |  |
| Cook 2012                 | -23.24   | 3.92   | 155   | -22.66 | 4.71   | 161   | 33.9%  | -0.13 [-0.35, 0.09]  | -                              | <b>+</b>                  |  |
| Van Gestel-Timmermans2012 | -2.97  | 0.46   | 120   | -2.73  | 0.48   | 97    | 28.8%  | -0.51 [-0.78, -0.24] | -                              |                           |  |
| Total (95% CI)            |  |        | 487   |        |        | 480   | 100.0% | -0.24 [-0.46, -0.02] | •                              | •                         |  |
|                           | k 2011 -22.76 4.68<br>k 2012 -23.24 3.92<br>Gestel-Timmermans2012 -2.97 0.46 |        |       |        |        |       |        | Fav                  | -2 -1<br>/ours [Self-managemen | 0 1<br>t] Favours [contro |  |

#### 3.14 Hope at follow-up

#### Self -Efficacy



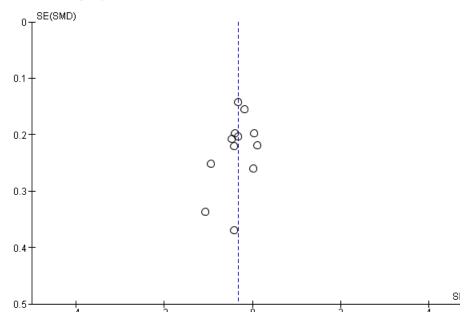
#### 3.15 Self-efficacy at end of treatment



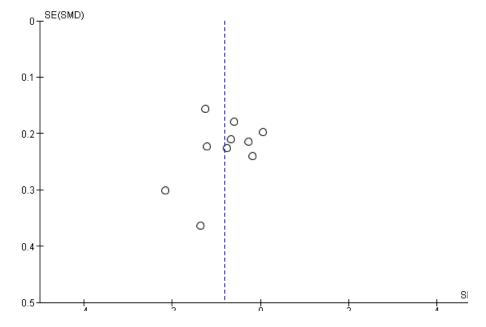
#### 3.16 Self-efficacy at follow up

# Appendix 4 Funnel Plots for assessment of Publication Bias (of meta-analyses with 10 or more studies)

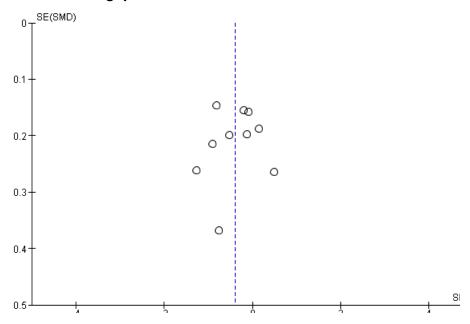
## 4.1 Total Symptoms: Post Treatment



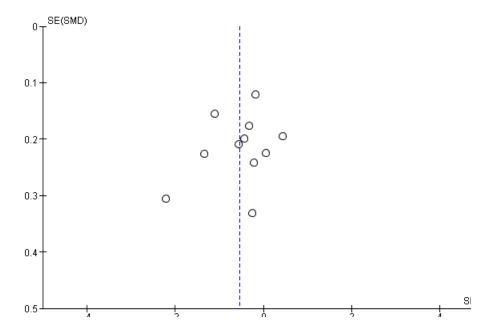
### 4.2 Total Symptoms: Follow Up



## 4.3 Functioning: post-treatment



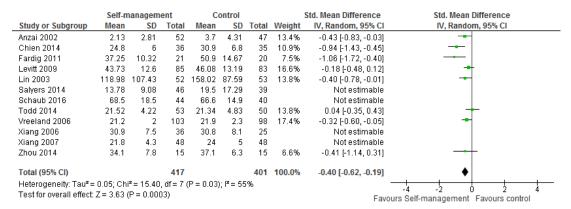
## 4.4 Functioning: Follow Up



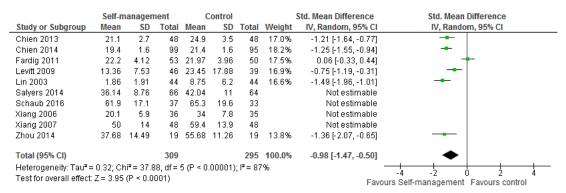
# Appendix 5. Post-hoc sub-group analysis of TAU only and active control studies

#### Studies with treatment as usual control only

#### 5.1 Total Symptoms at end of treatment



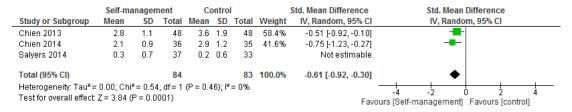
#### 5.2 Total Symptoms at follow up



#### 5.3 Mean number of relapses at end of treatment

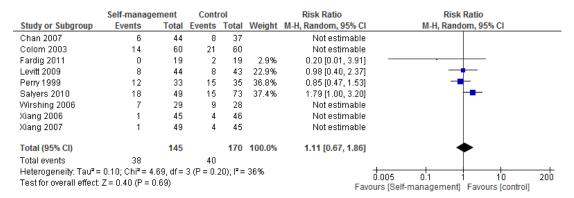
|                       | Self-ma | Co  | ontro | I    |     | Std. Mean Difference | Std. Mean Difference |                     |                    |
|-----------------------|---------|-----|-------|------|-----|----------------------|----------------------|---------------------|--------------------|
| Study or Subgroup     | Mean    | SD  | Total | Mean | SD  | Total                | Weight               | IV, Random, 95% CI  | IV, Random, 95% CI |
| Chien 2014            | 2.4     | 1.3 | 36    | 2.6  | 1.2 | 35                   | 100.0%               | -0.16 [-0.62, 0.31] | -                  |
| Salyers 2014          | 0.3     | 0.5 | 44    | 0.2  | 0.5 | 40                   |                      | Not estimable       | T                  |
| Total (95% CI)        |         |     | 36    |      |     | 35                   | 100.0%               | -0.16 [-0.62, 0.31] | •                  |
| Heterogeneity: Not ap | 1)      |     |       |      |     | _                    | -4 -2 0 2 4          |                     |                    |

#### 5.4 Mean number of relapses at follow up



## 5.5 Total number of participants who relapsed at end of treatment No data available

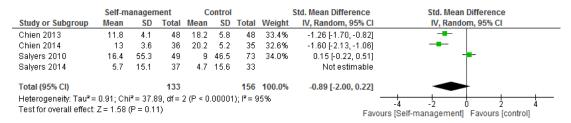
#### 5.6 Total number of participants who relapsed at Follow up



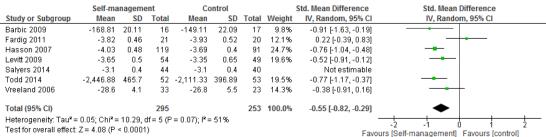
#### 5.7 Length of hospitalisation at end of treatment

|                          | Self-m  | anagen   | nent  | C    | ontrol |       |        | Std. Mean Difference | Std. Mean Difference |              |         |         |      |  |
|--------------------------|---------|----------|-------|------|--------|-------|--------|----------------------|----------------------|--------------|---------|---------|------|--|
| Study or Subgroup        | Mean    | SD       | Total | Mean | SD     | Total | Weight | IV, Random, 95% CI   |                      | IV, Rand     | om, 95% | CI      |      |  |
| Chien 2014               | 15.7    | 4.1      | 36    | 19.8 | 4.8    | 35    | 100.0% | -0.91 [-1.40, -0.42] |                      | -            |         |         |      |  |
| Salyers 2014             | 4.5     | 10.8     | 44    | 4.4  | 11.6   | 40    |        | Not estimable        |                      |              |         |         |      |  |
| Total (95% CI)           |         |          | 36    |      |        | 35    | 100.0% | -0.91 [-1.40, -0.42] |                      | •            |         |         |      |  |
| Heterogeneity: Not ap    | (D 00   | 000      |       |      |        |       |        | -4                   | <del>-2</del>        | <del> </del> | 1 2     | 4       |      |  |
| Test for overall effect: | ∠= 3.04 | (P = 0.0 | 003)  |      |        |       |        | Favo                 | urs [Self-           | management   | Favou   | s [cont | rol] |  |

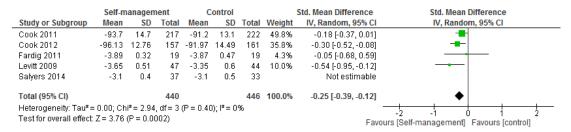
#### 5.8 Length of hospitalisation at follow up



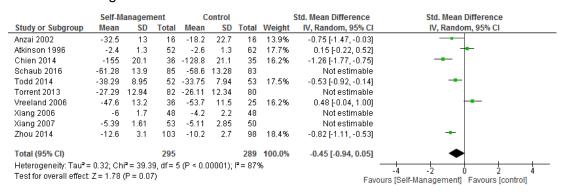
#### 5.9 Self-rated recovery at end of treatment



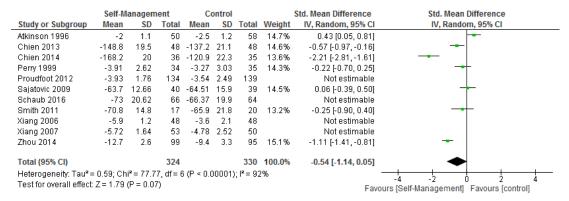
#### 5.10 Self-rated recovery at follow up



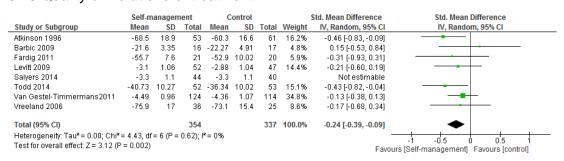
#### 5.11 Functioning at end of treatment



#### 5.12 Functioning at follow up



#### 5.13 Quality of life at end of treatment

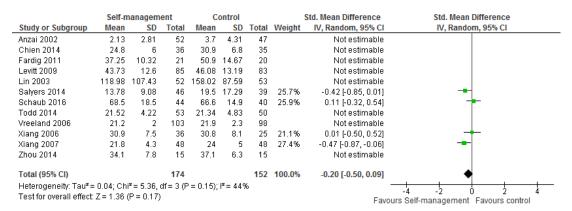


#### 5.14 Quality of life at follow up

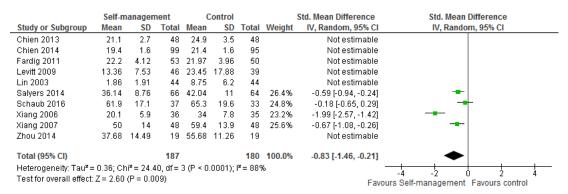
|                                      | Self-m | anagen | nent  | C      | ontrol |                                       |        | Std. Mean Difference | Std. Mean Difference |
|--------------------------------------|--------|--------|-------|--------|--------|---------------------------------------|--------|----------------------|----------------------|
| Study or Subgroup                    | Mean   | SD     | Total | Mean   | SD     | Total                                 | Weight | IV, Random, 95% CI   | IV, Random, 95% CI   |
| Atkinson 1996                        | -67.9  | 20.7   | 51    | -58.2  | 19     | 57                                    | 11.6%  | -0.49 [-0.87, -0.10] | <del></del>          |
| Cook 2011                            | -14.1  | 2.83   | 212   | -13.4  | 2.97   | 219                                   | 47.6%  | -0.24 [-0.43, -0.05] | -                    |
| Fardig 2011                          | -53.94 | 7.68   | 19    | -49.53 | 10.05  | 19                                    | 4.1%   | -0.48 [-1.13, 0.16]  | <del></del>          |
| Levitt 2009                          | -3.43  | 0.84   | 44    | -3.19  | 1.1    | 44                                    | 9.7%   | -0.24 [-0.66, 0.18]  | <del></del>          |
| Salyers 2014                         | -3.5   | 1      | 37    | -3.3   | 1.3    | 33                                    |        | Not estimable        |                      |
| Smith 2011                           | -256.6 | 52.7   | 17    | -259.2 | 63.2   | 20                                    | 4.1%   | 0.04 [-0.60, 0.69]   | <del></del>          |
| Van Gestel-Timmermans2011            | -4.63  | 0.97   | 111   | -4.39  | 1.05   | 97                                    | 22.9%  | -0.24 [-0.51, 0.04]  |                      |
| Total (95% CI)                       |        |        | 454   |        |        | 456                                   | 100.0% | -0.27 [-0.40, -0.14] | •                    |
| Heterogeneity: Tau² = 0.00; Chi²     | = 0%   |        |       |        | _      | -1 -0.5 0 0.5 1                       |        |                      |                      |
| Test for overall effect: Z = 4.00 (F |        |        |       |        | Favour | s [Self-management] Favours [control] |        |                      |                      |

#### **Studies with Active Control only**

#### 5.15 Total Symptoms at end of treatment



#### 5.16 Total Symptoms at follow up



#### 5.17 Mean number of relapses end of treatment

|   | Self-ma | Co  | ontro | I    |     | Std. Mean Difference | Std. Mean Difference |                    |                   |                 |                |              |        |   |
|---|---------|-----|-------|------|-----|----------------------|----------------------|--------------------|-------------------|-----------------|----------------|--------------|--------|---|
| Study or Subgroup   | Mean    | SD  | Total | Mean | SD  | Total                | Weight               | IV, Random, 95% CI |                   | IV, Ran         | dom, 959       | 6 CI         |        |   |
| Chien 2014  | 2.4     | 1.3 | 36    | 2.6  | 1.2 | 35                   |                      | Not estimable      |                   |                 | $\perp$        |              |        |   |
| Salyers 2014  | 0.3     | 0.5 | 44    | 0.2  | 0.5 | 40                   | 100.0%               | 0.20 [-0.23, 0.63] |                   |                 | -              |              |        |   |
| Total (95% CI)  |         |     | 44    |      |     | 40                   | 100.0%               | 0.20 [-0.23, 0.63] |                   |                 | •              |              |        |   |
| Heterogeneity: Not applicable<br>Test for overall effect: Z = 0.90 (P = 0.37) |         |     |       |      |     |                      |                      | Favo               | -4<br>urs [self-m | -2<br>ianagemei | 0<br>nt] Favou | 2<br>Irs [co | ntrol] | 4 |

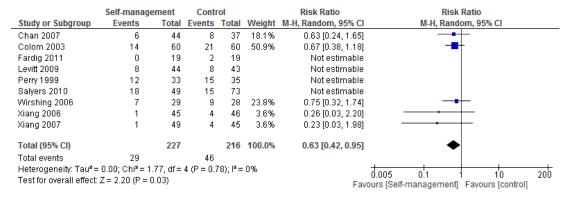
## 5.18 Mean number of relapses at Follow up

|   | Self-ma | nagen   | nent  | Co   | ntro | I     |        | Std. Mean Difference |                   | Std. M        | ean Differ     | ence          |       |
|---|---------|---------|-------|------|------|-------|--------|----------------------|-------------------|---------------|----------------|---------------|-------|
| Study or Subgroup                                 | Mean    | SD      | Total | Mean | SD   | Total | Weight | IV, Random, 95% CI   |                   | IV, Ra        | ndom, 959      | % CI          |       |
| Chien 2013  | 2.8     | 1.1     | 48    | 3.6  | 1.9  | 48    |        | Not estimable        |                   |               |                |               |       |
| Chien 2014  | 2.1     | 0.9     | 36    | 2.9  | 1.2  | 35    |        | Not estimable        |                   |               |                |               |       |
| Salyers 2014                                      | 0.3     | 0.7     | 37    | 0.2  | 0.6  | 33    | 100.0% | 0.15 [-0.32, 0.62]   |                   |               | -              |               |       |
| Total (95% CI)                                    |         |         | 37    |      |      | 33    | 100.0% | 0.15 [-0.32, 0.62]   |                   |               | •              |               |       |
| Heterogeneity: Not ap<br>Test for overall effect: |         | P = 0.5 | 3)    |      |      |       |        | Favo                 | -4<br>urs (Self-r | -2<br>managem | 0<br>entl Favo | 2<br>urs (con | troll |

## 5.19 Total number of participants who relapsed at end of treatment

|   | Self-manage | ment  | Contr         | ol    |        | Risk Ratio          | Risk                              | Ratio                  |   |
|---|-------------|-------|---------------|-------|--------|---------------------|-----------------------------------|------------------------|---|
| Study or Subgroup                                 | Events      | Total | <b>Events</b> | Total | Weight | M-H, Random, 95% CI | M-H, Rand                         | om, 95% CI             |   |
| Colom 2003  | 23          | 60    | 36            | 60    | 100.0% | 0.64 [0.44, 0.94]   | _                                 |                        |   |
| Total (95% CI)                                    |             | 60    |               | 60    | 100.0% | 0.64 [0.44, 0.94]   | -                                 |                        |   |
| Total events                                      | 23          |       | 36            |       |        |                     |                                   |                        |   |
| Heterogeneity: Not ap<br>Test for overall effect: |             | 0.02) |               |       |        | Fav                 | 0.2 0.5<br>ours [Self-management] | 2<br>Favours [control] | 5 |

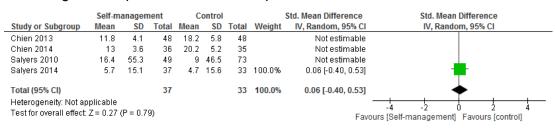
## 5.20 Total number of participants who relapsed at Follow up



## 5.21 Length of hospitalisation at end of treatment

|   | Self-m | anagen   | nent  | C    | ontrol |       |        | Std. Mean Difference |                    | Std. Me        | an Differ     | ence         |        |
|---|--------|----------|-------|------|--------|-------|--------|----------------------|--------------------|----------------|---------------|--------------|--------|
| Study or Subgroup                                 | Mean   | SD       | Total | Mean | SD     | Total | Weight | IV, Random, 95% CI   |                    | IV, Rai        | ndom, 959     | % CI         |        |
| Chien 2014  | 15.7   | 4.1      | 36    | 19.8 | 4.8    | 35    |        | Not estimable        |                    |                |               |              |        |
| Salyers 2014                                      | 4.5    | 10.8     | 44    | 4.4  | 11.6   | 40    | 100.0% | 0.01 [-0.42, 0.44]   |                    |                | -             |              |        |
| Total (95% CI)                                    |        |          | 44    |      |        | 40    | 100.0% | 0.01 [-0.42, 0.44]   |                    |                | •             |              |        |
| Heterogeneity: Not ap<br>Test for overall effect: | •      | (P = 0.9 | 7)    |      |        |       |        | Favo                 | -4<br>ours [Self-r | -2<br>manageme | 0<br>nt] Favo | 2<br>urs [co | ntrol] |

## 5.22 Length of hospitalisation at follow up



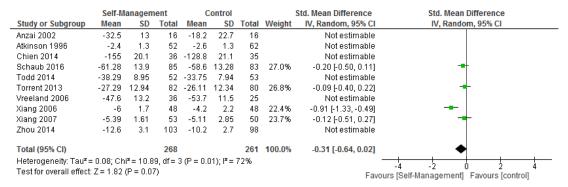
#### 5.23 Recovery at end of treatment

|                         | Self-m    | nanagen   | nent  | C      | ontrol |       |        | Std. Mean Difference | Std. Mean Difference |
|-------------------------|-----------|-----------|-------|--------|--------|-------|--------|----------------------|----------------------|
| Study or Subgroup       | Mean      | SD        | Total | Mean   | SD     | Total | Weight | IV, Random, 95% CI   | IV, Random, 95% CI   |
| Cook 2011               | -93.7     | 14.7      | 217   | -91.2  | 13.1   | 222   |        | Not estimable        |                      |
| Cook 2012               | -96.13    | 12.76     | 157   | -91.97 | 14.49  | 161   |        | Not estimable        |                      |
| Fardig 2011             | -3.89     | 0.32      | 19    | -3.87  | 0.47   | 19    |        | Not estimable        |                      |
| Levitt 2009             | -3.65     | 0.51      | 47    | -3.35  | 0.6    | 44    |        | Not estimable        | <u></u>              |
| Salyers 2014            | -3.1      | 0.4       | 37    | -3.1   | 0.5    | 33    | 100.0% | 0.00 [-0.47, 0.47]   | <b>-</b>             |
| Total (95% CI)          |           |           | 37    |        |        | 33    | 100.0% | 0.00 [-0.47, 0.47]   | •                    |
| Heterogeneity: Not as   | pplicable |           |       |        |        |       |        |                      | <del></del>          |
| Test for overall effect | Z = 0.00  | (P = 1.0) | 0)    |        |        |       |        | Favo                 | -2 -1 U 1 2          |

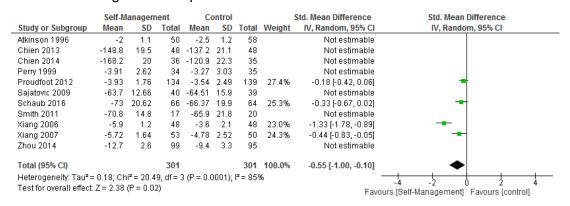
## 5.24 Recovery at follow up

| Study or Subgroup   | Self-m<br>Mean | anagen<br>SD | nent<br>Total | Co<br>Mean | ontrol<br>SD |     | Weight | Std. Mean Difference<br>IV, Random, 95% CI |                  | Std. Mean<br>IV, Rand |            |                    |    |
|---|----------------|--------------|---------------|------------|--------------|-----|--------|--|------------------|-----------------------|------------|--------------------|----|
| Barbic 2009   | -61.96         | 10.43        | 16            | -14.93     | 7.33         | 17  | 27.5%  | -5.12 [-6.60, -3.64]                       |                  | -                     |            |                    |    |
| Van Gestel-Timmermans2011   | -3.55          | 0.48         | 136           | -3.38      | 0.53         | 117 | 36.8%  | -0.34 [-0.59, -0.09]                       |                  |                       |            |                    |    |
| Vreeland 2006   | -3             | 0.4          | 35            | -3.1       | 0.4          | 25  | 35.7%  | 0.25 [-0.27, 0.76]                         |                  |                       | <u>*</u>   |                    |    |
| Total (95% CI)  |                |              | 187           |            |              | 159 | 100.0% | -1.44 [-2.97, 0.08]                        |                  | •                     | -          |                    |    |
| Heterogeneity: Tau² = 1.63; Chi²:<br>Test for overall effect: Z = 1.86 (P |                | if= 2 (P     | < 0.000       | 01); l²=   | 96%          |     |        | Fav  | -10<br>/ours [Se | -5<br>elf-managementj | 0<br>Favou | 5<br>urs [control] | 10 |

## 5.25 Functioning at end of treatment



## 5.26 Functioning at follow up



# 5.27 Quality of life at end of treatment

|                                      | Self-m  | anagen | nent  | C      | ontrol |       |        | Std. Mean Difference | Std. Mean I       | Difference |   |
|--------------------------------------|---------|--------|-------|--------|--------|-------|--------|----------------------|-------------------|------------|---|
| Study or Subgroup                    | Mean    | SD     | Total | Mean   | SD     | Total | Weight | IV, Random, 95% CI   | IV, Randor        | n, 95% CI  |   |
| Atkinson 1996                        | -68.5   | 18.9   | 53    | -60.3  | 16.6   | 61    |        | Not estimable        |                   |            |   |
| Barbic 2009                          | -21.6   | 3.35   | 16    | -22.27 | 4.91   | 17    |        | Not estimable        |                   |            |   |
| Fardig 2011                          | -55.7   | 7.6    | 21    | -52.9  | 10.02  | 20    |        | Not estimable        |                   |            |   |
| Levitt 2009                          | -3.1    | 1.06   | 52    | -2.88  | 1.04   | 47    |        | Not estimable        |                   | _          |   |
| Salyers 2014                         | -3.3    | 1.1    | 44    | -3.3   | 1.1    | 40    | 100.0% | 0.00 [-0.43, 0.43]   |                   | _          |   |
| Todd 2014                            | -40.73  | 10.27  | 52    | -36.34 | 10.02  | 53    |        | Not estimable        |                   |            |   |
| Van Gestel-Timmermans2011            | -4.49   | 0.96   | 124   | -4.36  | 1.07   | 114   |        | Not estimable        |                   |            |   |
| Vreeland 2006                        | -75.9   | 17     | 36    | -73.1  | 15.4   | 25    |        | Not estimable        |                   |            |   |
| Total (95% CI)                       |         |        | 44    |        |        | 40    | 100.0% | 0.00 [-0.43, 0.43]   |                   |            |   |
| Heterogeneity: Not applicable        |         |        |       |        |        |       |        | _                    | -1 -0.5           | 0.5        | _ |
| Test for overall effect: Z = 0.00 (P | = 1.00) |        |       |        |        |       |        | Favours              | [Self-management] |            |   |

# 5.28 Quality of life at follow up

|   | Self-ma   | anagen | nent  | C      | ontrol |       |        | Std. Mean Difference | Std. Mean Difference |
|---|-----------|--------|-------|--------|--------|-------|--------|----------------------|----------------------|
| Study or Subgroup   | Mean      | SD     | Total | Mean   | SD     | Total | Weight | IV, Random, 95% CI   | IV, Random, 95% CI   |
| Atkinson 1996   | -67.9     | 20.7   | 51    | -58.2  | 19     | 57    |        | Not estimable        |                      |
| Cook 2011   | -14.1     | 2.83   | 212   | -13.4  | 2.97   | 219   |        | Not estimable        |                      |
| Fardig 2011   | -53.94    | 7.68   | 19    | -49.53 | 10.05  | 19    |        | Not estimable        |                      |
| Levitt 2009   | -3.43     | 0.84   | 44    | -3.19  | 1.1    | 44    |        | Not estimable        |                      |
| Salyers 2014  | -3.5      | 1      | 37    | -3.3   | 1.3    | 33    | 100.0% | -0.17 [-0.64, 0.30]  | <del></del>          |
| Smith 2011  | -256.6    | 52.7   | 17    | -259.2 | 63.2   | 20    |        | Not estimable        | _                    |
| Van Gestel-Timmermans2011   | -4.63     | 0.97   | 111   | -4.39  | 1.05   | 97    |        | Not estimable        |                      |
| Total (95% CI)  |           |        | 37    |        |        | 33    | 100.0% | -0.17 [-0.64, 0.30]  |                      |
| Heterogeneity: Not applicable<br>Test for overall effect: Z = 0.72 (F | 9 = 0.47) |        |       |        |        |       |        | Favo                 | -1 -0.5 0 0.5        |

## **Appendix 6. Ethics Approval**



#### NRES Committee London - Camden & Islington

North East REC Office Room 002 TEDCO Business Centre Rolling Mill Road Jarrow Tyne & Wear NE32 3DT

Telephone: 0191 428 3566 Facsimile: 0191 428 3432

19 July 2012

Professor I. Sonia Johnson
Professor of Social and Community Psychiatry
University College London
Mental Health Sciences Unit
Charles Bell House
67-73 Riding House Street
London
W1W 7EJ

Dear Professor Johnson

Study title: Optimising team functioning, preventing relapse and

enhancing recovery in Crisis Resolution Teams (CRTs): the CORE Programme (Crisis team Optimisation and RElapse prevention)Phase 3: Randomised controlled trial of a peer-provided, self-management intervention

for people leaving CRT services

IRAS project number: 108770 REC reference: 12/LO/0988

Thank you for your letter of 17 July 2012, 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.

#### 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.

#### 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 been notified of the outcome of 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 one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

#### Conditions of the favourable opinion

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

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

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 <a href="http://www.rdforum.nhs.uk">http://www.rdforum.nhs.uk</a>.

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

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).

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document   | Version | Date             |
|--|---------|------------------|
| Covering Letter  |         | 01 June 2012     |
| Investigator CV  |         | 09 February 2011 |
| Letter from Statistician                                 |         | 30 May 2012      |
| Other: Letter to Clinical Team - Pilot Trial             | 1       | 16 May 2012      |
| Other: Letter to Clinical Team - Main Trial              | 1       | 16 May 2012      |
| Other: Letter from Funder - NIHR Contract                |         | 06 June 2012     |
| Other: NIHR Peer Review                                  |         |                  |
| Other: Peer Review - Joanne Moncrieff                    |         | 31 May 2012      |
| Other: Peer Review - Helen Killaspy                      |         | 01 June 2012     |
| Other: Baseline Data from Patient Records                | 1       | 16 May 2012      |
| Other: Baseline Questionnaire                            | 1       | 16 May 2012      |
| Other: Follow-up Questionnaire - Pilot Study             | 1       | 16 May 2012      |
| Other: Follow-up Questionnaire - Main Trial              | 1       | 16 May 2012      |
| Other: Follow-up Data from Patient Records - Pilot Trial | 1       | 16 May 2012      |
| Other: Follow-up Data from Patient Records - Main Trial  | 11      | 16 May 2012      |

| Other: Peer Researcher's Contact Log        | 1                       | 16 May 2012  |
|---|-------------------------|--------------|
| Other: GP Letter - Pilot Trial              | 1                       | 17 July 2012 |
| Other: GP Letter - Main Trial               | 1                       | 17 July 2012 |
| Participant Consent Form: Pilot Trial       | 1.2                     | 17 July 2012 |
| Participant Consent Form: Main Trial        | 1.2                     | 17 July 2012 |
| Participant Information Sheet: Pilot Trial  | 1.2                     | 17 Júly 2012 |
| Participant Information Sheet: Main Trial   | 1.2                     | 17 July 2012 |
| Protocol                                    | 1                       | 16 May 2012  |
| REC application                             | 108770/3298<br>94/1/227 | 01 June 2012 |
| Response to Request for Further Information | Response<br>letter      | 17 July 2012 |

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

#### <u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/LO/0988 Please quote this number on all correspondence

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

Yours sincerely



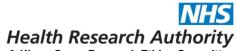
Email:

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: Ms Angela Williams, Camden and Islington NHS Foundation Trust

151

## Appendix 7. 18-month Ethics Approval



London - Camden & Kings Cross Research Ethics Committee

Room 001 Jarrow Business Centre Rolling Mill Road Tyne & Wear NE32 3DT

Tel: 0191 428 3444

18 December 2015

Dr Brynmor Lloyd-Evans Lecturer in Mental Health and Social Care Division of Psychiatry, UCL 6th Floor, Maple House 149 Tottenham Court Road London W1T 7NF

Dear Dr Lloyd-Evans

Study title:

Optimising team functioning, preventing relapse and enhancing recovery in Crisis Resolution Teams (CRTs): the **CORE Programme (Crisis team Optimisation and RElapse** prevention)Phase 3: Randomised controlled trial of a peerprovided, self-management intervention for people leaving

CRT services

**REC** reference: 12/LO/0988

Amendment number: SA 4

19 November 2015 Amendment date:

108770 IRAS project ID:

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Summary of amendment

This amendment was submitted to inform the Committee of the successful application to NIHR for an extension and extra funding for the study, which will run until 30 April 2017. This extension would allow the study team to repeat the study outcome measures assessed originally at 4 month follow up and evaluate the longer term outcomes of the trial intervention.

In addition to this, one additional outcome measure would be added - a brief questionnaire assessing participants' resilience.

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

| Document  | Version | Date             |
|---|---------|------------------|
| Letter from funder [Letter from NIHR]                                   |         | 03 November 2015 |
| Notice of Substantial Amendment (non-CTIMP)                             | SA 4    |                  |
| Participant consent form [CORE Phase 3 Consent Form 18 Month Follow-Up] | 4       | 04 November 2015 |
| Participant information sheet (PIS) [CORE Phase 3 PIS Main Trial]       | 4       | 04 November 2015 |
| Research protocol or project proposal [CORE Phase 3 Protocol]           | 5       | 04 November 2015 |
| Validated questionnaire [CORE Phase 3 18 Month Follow-Up Questionnaire] | 4       | 04 November 2015 |

#### **Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

#### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

#### 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.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

12/LO/0988:

Please quote this number on all correspondence

Yours sincerely pp

Heidi Chandler Vice-Chair

E-mail: nrescommittee.london-camdenandkingscross@nhs.net

Enclosures: List of names and professions of members who took part in the

review

Copy to:

Professor I. Sonia Johnson, University College London

Mrs Angela Williams, North Central London Research Consortium

# London - Camden & Kings Cross Research Ethics Committee Attendance at Sub-Committee of the REC meeting held in correspondence

#### **Committee Members:**

| Name              | Profession   | Present | Notes |
|-------------------|--|---------|-------|
| Ms Heidi Chandler | Research Co-ordinator  | Yes     | Chair |
| Ms Catherine Max  | Independent Consultant (sustainability, health and social care). | Yes     |       |

## Also in attendance:

| Name                | Position (or reason for attending) |
|---------------------|------------------------------------|
| Miss Kirstie Penman | REC Assistant                      |

| Appendix 8. Patient Information Statement and Infor | med Consent Form |
|---|------------------|
|   |                  |
|   |                  |
|   |                  |
|   |                  |
|   |                  |



# SERVICE USER INFORMATION SHEET FOR CORE PHASE 3 TRIAL Version 4, 04 November 2015

Study Title: Optimising team functioning, preventing relapse and enhancing recovery in crisis resolution teams: the CORE programme (CRT Optimisation and RElapse prevention)

Phase 3: a randomised controlled trial of a peer-provided, self-management programme for people leaving Crisis Resolution Team (CRT) services

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

## What is the purpose of the study?

Crisis Resolution Teams (CRTs) provide short-term support to people during a mental health crisis. In this study, we will test whether support from someone who has used mental health services themselves (peer support) will help people develop ways to manage problems and stay well. We will investigate whether this peer-provided help to develop your own recovery plan is more useful than just giving people a booklet with advice and suggestions of ways to help recovery. In both cases, the other services received will not be affected. We now want to see how you are getting on 18 months after you first entered the study by completing another set of questionnaires with a researcher.

#### Why have I been asked to take part?

You have been invited to take part because you have used one of the CRTs participating in this study and have taken part in an early stage of the study. During this earlier stage you were randomly allocated to receive either a self-help recovery workbook or a peer support worker to help you work through the recovery booklet. During this earlier stage of the study you also indicated that you were happy to discuss further participation in the study with a researcher.

## Do I have to take part?

It is completely up to you to decide whether or not you would like to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive now or in the future. If a researcher is unable to contact you for the follow-up interview, or if you decide you do not want to take part in a follow up interview, the research team will continue to use information you have already provided and information from your patient records, unless you let the research team or mental health staff involved in your care know that you do not want this to happen.

#### What will happen if I take part?

If you agree to take part in this research you will be asked to participate in a research interview (lasting about an hour) which will be held about 18 months after you first entered the study. The researcher who meets you for your follow-up interview will not know whether you were allocated to get a peer support worker and will ask you not to tell them. It is also possible that another researcher might want to contact you to conduct another in-depth interview up to 2 years from now. You can choose not to give this additional consent. A researcher will also collect information from your NHS patient records about what mental health services you have used since you join the study; however this will not need your active involvement. More detailed information on the study that you have participated in previously is provided at the end of this information sheet.

#### Taking Part in CORE Phase 3 18 month follow-up: What is involved?

1. A researcher will tell you more about the study, answer any questions and send you an information sheet.

٧

2. If you are still interested, the researcher will arrange to meet you, answer any further questions and take your written consent to take part.

V

3. The researcher will then complete an interview with you lasting about an hour, involving a number of questionnaires. You will be offered a gift of £20 for your time and help.

## What are the possible benefits of taking part?

We hope that the peer-provided self management support will help people's recovery, increase their satisfaction with services overall and reduce future use of crisis services. Reading through the study self-management booklet, even without meeting a peer support worker, may also be helpful to people. People who take part in this study are helping us to find out more about what support is useful for people following a mental health crisis. People will be offered a £20 gift in cash after the follow-up interview, to acknowledge their time and help with the study.

## What are the possible disadvantages of taking part?

It is possible you will not find meeting with a researcher and completing the questionnaires helpful and this could be disappointing. Many people feel it is helpful to talk about their experiences but thinking about a recent crisis may raise issues that are distressing. If you find any topic in the questionnaire interview unhelpful or upsetting, you do not have to complete it and you are free to stop at any point.

#### Will my taking part be kept confidential?

All the information that is collected about you by the researchers during the research interviews will be kept strictly confidential and anonymised. The only circumstances in which a researcher would not maintain confidentiality is if you told a member of the research team something which made us believe there was a serious risk to your or someone else's safety. In those circumstances, we would discuss our concerns with

staff at the Crisis Resolution Team you have used, who would decide whether any further action was required.

#### Where can I get further information?

If you require any further information or have any questions not answered by this information sheet, or if you have any comments or concerns, please do not hesitate to contact a member of the research team. The research team representatives could be the researcher who is conducting the interview or:

**Study Chief Investigator: Professor Sonia Johnson** Division of Psychiatry, University College London

**Programme Manager: Bryn Lloyd-Evans**Division of Psychiatry, University College London

For independent advice about participating in research or this study, please contact the Mental Health Research Network Patient and Public Involvement (PPI) section. This is a national organisation designed to support the involvement of service users and carers in research.

#### What if I am unhappy with the research?

If you change your mind about participating in the study, you can withdraw your consent at any time, in which case all information collected about you would be deleted and not used in the research. If you have any concerns about the way you have been treated during the course of the research, the researcher will be very happy to discuss this with you. You could also contact the Study Lead or the Programme manager, whose contact details are above. If you wish to complain formally, or have any unresolved concerns about any aspect of the way you have been approached or treated during the course of this study, you can contact your local NHS Advice and Complaints service:

Advice and Complaints Service Camden and Islington NHS Foundation Trust FREEPOST 1<sup>st</sup> Class (LON 12613) London NW1 0YT

Tel: 020 3317 3117

E-mail: <a href="mailto:complaints@candi.nhs.uk">complaints@candi.nhs.uk</a>

#### What happens to the results of the research study?

The results of the study will be written up in a report for the Department of Health. They are also likely to be reported in scientific journals, presentations at conferences and articles in other relevant magazines or web publications. None of these reports will contain any personal information from which you could be identified. The information about you collected by the researchers will be stored securely at

University College London and will be archived then destroyed after completion of the study. If you are interested in the study, a copy of the report will be made available to all participants and other local service users.

## Who is organising and funding the research?

The research is being organised by Camden and Islington NHS Foundation Trust and carried out by a research team based mainly at University College London. It is funded by the NHS National Institute for Health Research.

## Who has reviewed the study?

The study has been reviewed favourably by researchers in the UK with considerable research experience. It has ethical approval from the London Camden and Islington Research Ethics Committee (Ref: 12-LO-0988).

Thank you for reading this information sheet

#### Additional Information

A detailed description of the study is described below. There are four stages to the study, and stages 1 to 3 are now complete. We are asking you to participate in stage 4:

## 1) Before the treatment stage (Groups A and B)

Once you have talked initially to a member of staff from the Crisis Resolution Team about the study and agreed to be contacted by a researcher, a study researcher will contact you. This will take place just before or soon after your period of support from the Crisis Resolution Team ends. The researcher will tell you more about the study and discuss the pros and cons of taking part. If you are still interested, the researcher will send you an information sheet about the study and arrange to meet you at least two days later.

If at this point you decide to take part, you will be asked to sign the study consent form. You will then complete an interview with the researcher lasting about an hour. The researcher will ask you about your background and what mental health services you have used. He or she will complete a number of questionnaires with you. These will ask about your satisfaction with mental health services and experience of care, how you feel your recovery is going, your mental health symptoms, your drug and alcohol use and your general health. You will only be able to enter the study if you are prepared to complete this interview and also give consent for the research team to access details of your diagnosis and your use of services over the coming year from your NHS patient records. When you sign your consent to take part in the study, you will also be asked to give consent to two more things: a) Being contacted by a researcher after the four month follow up interview for a further research interview. (A researcher would explain what any further interview involved and you would be able to decide separately whether you wanted to take part in any further interview then.) b) For a researcher to try to contact you via a family member or mental health staff member working with you, if unable to contact you directly for the four-month follow up interview.

Following the interview with the researcher, you will be offered £20 as a cash gift to acknowledge your time and help with the study.

We want to make sure that taking part in this study does not influence what other care you are offered by mental health services. For this reason, we will not let you or the Crisis Resolution Team know whether you have been allocated to the group who will be offered a peer support worker until you have been discharged from the Crisis Resolution Team. A researcher will contact you again once you have been discharged from the CRT to let you know which group you have been allocated to.

## 2) The treatment stage (This is different for Groups A and B)

**Group A:** A peer support worker – someone who has used mental health services themselves – will contact you to introduce themselves and arrange to meet. Meetings may take place at your home, in NHS premises or elsewhere and at times agreed between you and the peer support worker. Altogether you will be offered 10 weekly meetings of up to an hour. During these meetings, the peer support worker will go through with you a booklet with ideas to help you plan things you can do which may help your recovery and how you might increase the support available to you. Paper or electronic versions of the booklet may be available. The booklet will involve things you can discuss together in sessions and that you can do on your own between them.

The peer support worker will also discuss with you if and how you could involve any mental health staff and your family or other support people. You will decide with the peer support worker how much of the booklet you want to use and how quickly to work through it. There will be time to talk more generally with the peer support worker about how you are feeling, the crisis you've been through or your hopes for the future.

**Group B:** The researcher will send you a booklet with ideas to help you plan things you could do to help your recovery and increase the support available to you. Paper or electronic versions of the booklet may be available. You will not be offered any help from the study team to use this booklet; however you could show it to any mental health staff or your family or other support people if you wish.

#### 3) The four month follow-up stage (Groups A and B)

About 4 months after you agreed to take part in the study, a researcher will contact you again about meeting for another, follow-up research interview. The researcher will discuss the study with you again and explain to you what the follow-up interview would involve. If you agree, the researcher will arrange to meet you again, at least two days later. At this meeting you will be asked to give your written consent again. You will then complete an interview with the researcher, lasting about an hour and involving the same questionnaires you completed at the first research interview. You can choose not to participate in the follow-up interview, without giving a reason. If you are unwilling or unable to complete the follow-up interview, the research team would still use the other information about you collected for the study unless you withdraw your consent to take part in the study altogether.

Following the interview with the researcher, you will be offered £20 as a cash gift to acknowledge your time and help with the study.

The researcher who completes the follow-up interview with you will not know whether you were allocated to receive a peer support worker or not. The researcher will ask you to try not to let them know during the follow up interview. If you were allocated to receive a peer support worker, a different study researcher, who does know which group you were allocated to, will contact you by phone or email. You will be asked to complete one more brief questionnaire about how you found working with the peer support worker. This will be confidential in the same way as the previous interviews and will not be shared with the peer support worker. You can choose not to take part in this additional questionnaire without giving a reason.

#### 4) The Eighteen month follow-up stage (Groups A and B)

About 18 months after you agreed to take part in the study, a researcher will contact you again about meeting for another, follow-up research interview. The researcher will discuss the study with you again and explain to you what the follow-up interview would involve. If you agree, the researcher will arrange to meet you again, at least two days later. At this meeting you will be asked to give your written consent again. You will then complete an interview with the researcher, lasting about an hour and involving the same questionnaires you completed at the first research interview. You can choose not to participate in the follow-up interview, without giving a reason. If you are unwilling or unable to complete the follow-up interview, the research team would still use the other information about you collected for the study unless you withdraw your consent to take part in the study altogether.

Following the interview with the researcher, you will be offered £20 as a cash gift to acknowledge your time and help with the study.

The researcher who completes the follow-up interview with you will not know whether you were allocated to receive a peer support worker or not. The researcher will ask you to try not to let them know during the follow up interview.



CORE Phase 3: consent form for participation in randomised controlled trial of a peer-provided, self-management intervention for people leaving Crisis Resolution Teams

Version 4: 04 November 2015

Study Title: CORE: Crisis Team Optimisation and Relapse Prevention - Phase 3

Principal Investigator: Professor Sonia Johnson, UCL, Research worker:

| 1.   | I have read and understood the study information sheet dated 04 November 2015  |     |
|------|--|-----|
| 2.   | I have had the opportunity to ask questions about the study  |     |
| 3.   | I understand that my participation is voluntary and that I can withdraw at any time, without giving any reason, without the services provided to me being affected.  |     |
| 4.   | I understand that the Crisis Resolution Team (CRT) which supported me will be informed that I am taking part in the study.   |     |
| 5.   | I agree to my GP being informed of my participation in the study   |     |
| 6. I | consent to a researcher contacting a family member or a member of staff, if I have named them below, if this is necessary to make contact with me for tha study follow-up interview.   |     |
| 7.   | I consent to the information collected about me for this study being stored securely at University College London  |     |
| 8.   | I understand that I will be offered a £20 gift in cash for my participation in the research interview, once I have taken part in it.   |     |
| 9.   | I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities and/or the NHS Foundation Trust where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records.  |     |
| 10.  | I consent to the research team having access to information about my diagnosis and my use of mental health services from my electronic patient records. If information about my use of services is not available from my electronic patient records in the NHS Trust whose services I am currently using, I consent to study researchers collecting this information where possible from other NHS services. |     |
| 11.  | I consent to a researcher contacting me up to 2 years after my follow-up interview to ask me about taking part in a further research interview for this study, or a separate follow-on study relating to this one.   |     |
|      |  | 1 1 |

12. I agree to take part in the study My preferred contact details: Name: Address: Phone number(s): E-mail address: Preferred method of contact: Phone E-mail Letter Contact details of family members or carers I am happy for a researcher to contact if necessary to contact me for a follow-up interview: (If possible, please provide details of any family members or carers whom researchers could contact if unable to contact you directly for a follow-up interview.) Family contact #1 Family contact #2 Name Relationship to participant Address Phone number(s) email

Contact details of mental health staff working with me I am happy for a researcher to contact if necessary to contact me for a follow-up interview:

(If possible, please provide details of any mental health staff whom researchers could contact if unable to contact you directly for a follow-up interview.)

Name: Job title:

Service:

Contact details (if known)

| I would like a copy of a report with the study findings when the study is over:  Yes No |                      |                                       |    |
|---|----------------------|---------------------------------------|----|
| Please sign this consent for  | orm below to confirm | your consent to take part in the stud | ly |
|   |                      |                                       |    |
| Name of participant   | Date                 | Signature                             |    |
| Name of records   | Data                 | Cirrotura                             |    |
| Name of researcher  | Date                 | Signature                             |    |

Appendix 9. Recovery Workbook

Selection of example pages

My personal recovery plan.

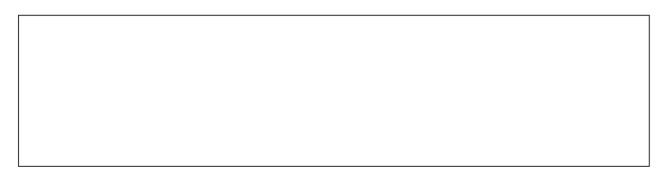


| Name | Date |
|------|------|
|      |      |

Introduction

This booklet provides a space to develop and keep a record of your personal recovery plan.

# To me recovery means



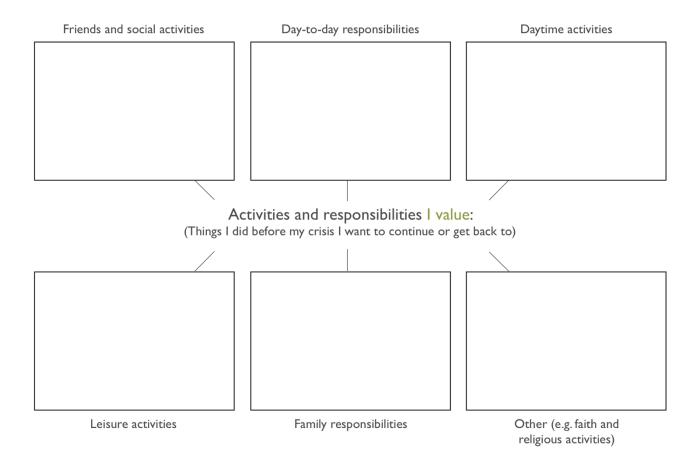


# Contents

| Part I | Moving on again after a crisis               | p. 7                     |
|--------|--|--------------------------|
| Part 2 | Keeping well                                 | р. 17                    |
| Part 3 | Managing ups and downs                       | p. 25                    |
| Part 4 | Goals and dreams                             | p. 31                    |
|        |  |                          |
| Part 5 | Making a personal recovery plan              | p. 37 – 55               |
| Part 5 | Making a personal recovery plan Part I notes | p. 37 – 55<br>p. 40 – 45 |
| Part 5 | 7 1  | ·                        |
| Part 5 | Part I notes                                 | p. 40 – 45               |

Blank space is provided at the end of each section for your own pictures and notes

| Things to do every day to help my life after a crisis: | Things to do on some day(s) each week after a crisis and which days I will do them on: |
|--|--|
|  |  |
|  |  |
|  |  |
|  |  |
| Things to avoid while I am recovering from my          | crisis:  |
|  |  |
|  |  |



| My triggers: | The action | I will take: |
|--------------|------------|--------------|
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |
|              |            |              |

#### Using this guide

The purpose of this guide is to suggest how you might go about developing a recovery plan for yourself.

We have provided a **Personal Recovery Plan** booklet to accompany this guide. This booklet includes forms you can use to draw up your recovery plan.

Throughout this guide we will refer to sections of the booklet. You may find it helpful to go through the *Personal Recovery Plan* booklet as you are reading this guide.

Your recovery plan is not the same as a 'care plan'. You draw up your care plan with a mental health worker and it outlines the treatment and support that you will receive. Your recovery plan is your own plan about how you can take control over your own life.

You might like to ask someone you trust to help you develop your recovery plan (like your family, friends or mental health workers). But it is your plan and you who decides what goes into it. You do not have to consult anyone else about your plan or show it to other people unless you want to.

Although this is your recovery plan for yourself, many people find it helpful to share their plan with their relatives, close friends and mental health workers.

Sharing your plan with your supporters puts them in a better position to assist you in your recovery. It helps them to better understand what you want and the sort of help you would like. Remember, these are your plans so you should do whatever suits you.

Planning your own recovery and taking back control over your own life are not always easy. It can be painful and frightening. But it is also a process of self-discovery, self renewal and growth.

"Recovery to me is not only coming to terms with what has happened in my life the dark side of me and the things I have done but having grown as an individual because of my experiences. Focusing on this experience as a source of growth has been the source of inspiration for recovery. I can now look back in time and know that everything that happened helped me to become the person I am today".

"Recovery is a process of healing... of adjusting one's attitudes, feelings, perceptions, beliefs, roles and goals in life. It is a painful process, yet often one of selfdiscovery, self-renewal and transformation. Recovery is a deeply emotional process. Recovery involves creating a new personal vision for one's self".

#### Part I: Moving on again after a crisis

Moving on again after a crisis can be hard.

It is always difficult to re-start things that you have not done for a while. It can take symptoms and problems a while to disappear completely. Your confidence is likely to have been shaken by your crisis. There may be bridges to be re-built.

#### Because of your crisis:

- you may not have seen people who are important to you for some time
- maybe you have upset some of your friends, relatives and others who you care about
- perhaps you may have behaved in uncharacteristic ways and now feel embarrassed about what you did

Whether you were in hospital during your crisis, or at home, it is probably sensible to start thinking about your plan for moving on again after the crisis as soon as you are able to.

| Appendix 10: Full baseline interview schedule |
|---|
| Removed due to copyright restrictions         |
|   |

| Appendix 11. Connor | Davidson Resilience Scale (CD-RISC-10) |
|---------------------|--|
|                     | Removed due to copyright restrictions. |
|                     |  |
|                     |  |

## Appendix 12. Statement of Joint working

While this project is not a traditional joint working D.Clin.Psy. project, it was part of a programme of research conducted within a large research team. Data collection assistance was provided by research assistants employed on the study, along with a PhD student who was investigating loneliness in this cohort using the UCLA Loneliness Scale (ULS-8), Lubben Social Network Scale (LSNS-6) and the HLS Social Capital questionnaires, which were also collected as part of the standard data collection for the CORE. There was sharing of data collection duties only. My contribution to the work involved adding to the follow up research design with the addition of the resilience measure to the study protocol, along with obtaining substantial amendments to the existing ethics approval, and creating updated versions of the protocol, patient information statement, informed consent form and questionnaires for participating trusts. During data collection, I worked in a coordinator role overseeing progress of recruitment and data collection, providing consultation in relation to ways to streamline and increase recruitment. I also contributed to recruitment by contacting "difficult to reach" participants outside of business hours (i.e. in the early evening) to catch participants who may work during the day. All other aspects of the research were distinct and independent.