

# Psychological approaches to understanding and promoting recovery in psychosis and bipolar disorder: a mixed-methods approach

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## Scientific summary

### Recovery in psychosis and bipolar disorder

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# Scientific summary

## Background

Mental health problems are one of the most significant burdens on society in terms of personal distress, disability and economic cost. Recovery in the field of mental health is a relatively new concept given that diagnoses such as schizophrenia have historically been thought of as severe and enduring mental illnesses. However, research over the last two decades has begun to challenge these assumptions and it is becoming more accepted that people can recover from psychosis. Clinical recovery relates to the absence of symptoms whereas the meaning of recovery to service users is much broader and recovery is seen as a process, encompassing many aspects of life. Recovery-orientated services are recommended across treatment settings in adult mental health services, but with little evidence base to support this.

## Objectives

The overall objective of this programme of research was to complete a series of linked projects with the aim of understanding and promoting recovery from psychosis and bipolar disorder (BD), in a manner that is acceptable to and empowering of service users. The programme consisted of six projects and the rationale and objectives for each are outlined below.

### *User-defined recovery conceptualisation and measurement*

Recovery has become an increasingly important concept for mental health service providers and policy-makers following guidance in numerous government policies and implementation. Despite this, a working definition of the concept of recovery has never been formalised. This study aimed to generate a concept of recovery from a service users' viewpoint by adopting an inclusive approach, scrutinising factors that are important to a multidimensional approach to recovery before using this information to develop a service user-generated, self-report scale to assess recovery in relation to symptoms in psychosis.

### *Service user-defined recovery: a consensus study*

There has been consistent agreement that mental health services should aim to be recovery orientated and that it is possible to measure the effectiveness of these services. However, the problem of reaching consensus about what we mean by recovery and producing a definition that is acceptable to service users has yet to be resolved. The aim of the study was to determine the level of consensus regarding service user conceptualisations of recovery.

### *Understanding psychological and social predictors of recovery*

There is a significant body of research examining psychosocial and neuropsychiatric factors that are associated with recovery from psychosis. However, the research has also highlighted that there is a significant difference between clinical- and consumer-defined recovery, strongly suggesting that previous studies may not assess important aspects of recovery that are meaningful for the service user. This study aimed to address the gap in the knowledge regarding subjective judgements of recovery, associated factors and predictors. It explored factors associated with subjective judgements of recovery in people with experience of psychosis before examining psychosocial and neuropsychiatric predictors of recovery judgements in both cross-sectional and longitudinal studies. This allowed examination of whether or not, and to what extent, recovery judgements are stable over time and whether or not the same kind of psychosocial factors that are associated with cross-sectional recovery judgements can predict recovery judgements longitudinally.

### ***Cognitive-behavioural approaches to guided self-help and group therapy for recovery, taking patient preferences into account***

Psychological treatments for psychosis such as cognitive-behavioural therapy (CBT) are currently recommended and their efficacy is supported by well executed randomised controlled trials (RCTs). However, the implementation of CBT for psychosis within NHS services is poor owing to a number of limitations. As a result, further exploration of the best way to deliver psychological support to those who experience psychosis is needed. This study aimed to examine preferences for psychological treatment using a patient preference trial (PPT) and examine cognitive-behavioural approaches to self-help and group therapy for recovery.

### ***Cognitive-behavioural approach to understanding and preventing suicide in people with psychosis***

Suicide and suicide behaviour are of substantial public and social concern. It is well established that risk of suicide is considerably elevated in those suffering from schizophrenia and psychosis. The objective of this project was to explore the psychological mechanisms underlying the link between experience of psychosis and suicidal ideations. This information was then used to inform a novel cognitive-behavioural treatment for suicide prevention for people with experience of psychosis. A RCT was conducted to assess feasibility and efficacy of the new treatment approach.

### ***Cognitive-behavioural approach to recovery from a first episode of bipolar disorder***

The National Institute for Health and Care Excellence recommends the provision of structured psychological therapy for individuals with BD. To date, controlled trials of structured psychological therapy have focused on individuals with a chronic BD, although research suggests that cognitive-behavioural interventions may be more powerful when applied earlier. This study aimed to understand the subjective recovery experiences of people with recent onset BD and to develop a novel measure of recovery in BD and a new intervention for early BD. This project also aimed to establish the acceptability and feasibility of the new intervention [recovery-focused cognitive-behavioural therapy (RfCBT)].

## **Methods**

### ***User-defined recovery conceptualisation and measurement***

Initially interviews were conducted with a group of eight service users who had recent experience of psychosis. A qualitative approach [interpretative phenomenological analysis (IPA)] was used to guide the interview structure and analysis. In the second phase of the study, themes identified from the qualitative interviews were used along with themes from the existing literature to inform a Q-methodological study. The Q-method integrates qualitative and quantitative approaches by providing participants with a framework to explore individual importance of specific aspects of recovery and associations between individual viewpoints. A total of 40 participants completed the Q-sort study. Information gathered in phases 1 and 2 was used to generate items for a new self-report scale to assess recovery in psychosis. The final phase of this study piloted the measure with a group of 100 participants to allow evaluation of psychometric properties.

### ***Service user-defined recovery: a consensus study***

This study utilised a Delphi methodology to consult service users about their views on recovery in three rounds. The current literature was first analysed to identify a list of statements felt to be relevant to recovery. This list was then presented to a group of eight service users who were consulted about language used, coverage of statements and any additions or changes. The list was then developed into a questionnaire that was circulated to 381 service users with experience of psychosis. Participants were asked to rate the importance of items to the concept of recovery using a 5-point Likert scale. Items that were rated as essential or important by > 80% of the sample were included as standard. Items that were rated as essential or important by 70–79% of the sample were rerated in the final round.

***Psychological factors associated with recovery from psychosis***

Data for this study were collected in four stages. The first stage was a cross-sectional study on 122 participants with experience of psychosis and 45 control participants. Participants were asked to complete measures relating to recovery, clinical functioning and social functioning and objective ratings of symptoms and functioning were carried out by the researchers. For the second stage, data collected throughout the recovery programme were collated and utilised where appropriate to examine longitudinal predictors of recovery ( $n = 110$ ). In the third stage, a similar cross-sectional approach was utilised to assess recovery, symptoms and functioning at baseline with 68 people with experience of psychosis. Experience sampling methodology (ESM) was then used to measure fluctuations in cognitive and emotional functioning over a period of 6 days using a watch and diary. Results were analysed using multilevel modelling.

***Cognitive-behavioural approaches to guided self-help and group therapy for recovery, taking patient preferences into account***

This project was conducted in three distinct phases. First, a cross-sectional study on 90 participants with experience of psychosis was conducted to assess symptoms and functioning along with preferences for psychological therapy and reasons for these preferences. This informed a proof-of-concept randomised study which was conducted with 29 participants who met criteria for non-affective psychosis. Participants were randomly allocated to treatment as usual (TAU) or therapy (which consisted of a self-help recovery guide, CBT delivered by telephone and peer support sessions). Participants' symptoms and functioning was assessed at baseline and 6 and 12 months post baseline. The final phase was a PPT with 95 participants with a diagnosis of a schizophrenia spectrum disorder. Participants were allocated to TAU, low support (consisting of the self-help recovery guide and weekly telephone CBT) or high support (low support with the addition of group sessions every other week). Participants were assessed for subjective recovery and symptoms and functioning as well as using objective symptoms and functioning measures. Results were analysed using mixed qualitative and quantitative approaches and intention-to-treat analyses.

***Cognitive-behavioural approach to understanding and preventing suicide in people with psychosis***

First, 79 participants with a diagnosis of a schizophrenia spectrum disorder completed a clinical interview and self-report measures. This information was used to identify psychological mechanisms underlying the relationship between psychosis and suicidal ideation. Second, these participants were asked to provide feedback about the subjective experience of taking part in research looking at mental health and suicide. Information from these studies was used to develop CBT for people with experience of psychosis aimed at reducing risk of suicide. The final phase was a RCT to assess the efficacy of the novel treatment.

***Cognitive-behavioural approach to recovery from a first episode of bipolar disorder***

An initial qualitative study was carried out to explore individuals' views of recovery in early BD. A semistructured interview was carried out with nine people who had been given a recent diagnosis of BD. IPA was used to identify key themes. The second phase utilised these themes to develop a Bipolar Recovery Questionnaire (BRQ), which was then piloted with 60 participants. Psychometric properties of the questionnaire along with its relationships with other key variables were assessed. The final phase of the study was a RCT with 69 participants with a diagnosis of BD to evaluate a novel RfCBT.

**Results*****User-defined recovery conceptualisation and measurement***

The Subjective Experience of Psychosis Scale is a reliable and valid tool that can be used to evaluate outcome from treatment and reflects the multidimensional experience of psychosis.

***Service user-defined recovery: a consensus study***

A total of 94 statements about recovery were rated as essential or important by > 80% of respondents including items which define recovery, factors which help recovery, factors which hinder recovery and factors which show that someone is recovering. Key areas that are important to service users included knowledge and understanding of mental health problems; coping and help-seeking skills; social support and relationships; support from mental health services; choice and control; having goals, meaning and purpose; quality of life, even in the context of continued mental health problems; hope for the future and feeling positive about yourself and your future; self-esteem; and having a good, safe place to live.

***Psychological factors associated with recovery from psychosis***

Concurrently, moment to moment in everyday life and prospectively, negative emotions, self-esteem, hopelessness but also symptoms (hallucinations and paranoia) predicted subjective recovery judgements.

***Cognitive-behavioural approaches to guided self-help and group therapy for recovery, taking patient preferences into account***

Service users had strong preferences for treatment; however, the lack of treatment effects on the primary outcome measure suggests the therapy itself may need additional refinements.

***Cognitive-behavioural approach to understanding and preventing suicide in people with psychosis***

The relationship between positive symptoms of psychosis and suicidal ideation is mediated by perceptions of defeat and entrapment while positive self-appraisals were found to buffer the impact of hopelessness. Cognitive-behavioural suicide prevention for psychosis was superior on the primary outcomes of suicidal ideation and hopelessness and secondary outcomes of depression, symptoms of psychosis and self-esteem.

***Cognitive-behavioural approach to recovery from a first episode of bipolar disorder***

The BRQ was developed with extensive input from individuals with personal experience of BD and the resulting questionnaire appears to be a reliable and valid measure of recovery in those with BD. RfCBT is feasible and has potential clinical benefits for people with BD, demonstrating improvements in personal ratings of recovery and substantial improvements in time to relapse for both depressive and manic relapses.

**Conclusions**

This programme of research has provided significant advances in our understanding and facilitation of recovery in both psychosis and BD. In terms of conceptualisation and measurement of user-defined recovery, we have demonstrated the reliability and validity of several patient-reported outcome measures. Our 'experts by experience' consensus study examining service user-defined recovery found a high level of agreement about factors which define, help and hinder recovery, and we have found consistent psychological factors that are associated with recovery from psychosis, including negative emotions, hope and self-esteem. Our work on cognitive-behavioural approaches to the promotion of recovery have demonstrated that recovery-focused trials are feasible with these populations, and it is apparent that service users have strong preferences for treatment. This programme of research has resulted in a number of deliverables for the NHS that will improve services and patient experience, including assessments, intervention, recommendations and treatment manuals. There are a variety of implications for clinical practice that have emerged from this programme, which are discussed in detail.

There are several recommendations for future research that have arisen from this programme, including (1) given the clear feasibility of the cognitive-behavioural approaches to recovery from BD and the prevention of suicide in psychosis, definitive trials should be conducted; (2) the factors that help and hinder recovery, which were identified by our consensus study, should be evaluated at both individual and service level with large-scale quantitative research; (3) further work is required on the understanding of the development of, and the role played by, preferences in uptake of and response to treatment; (4) the development and evaluation of methods to help service users to make informed choices and express treatment preferences; (5) the evaluation of training packages on the topic of understanding and promoting recovery that incorporate the results from this programme and are jointly delivered by service users and clinicians; and (6) the use of ESMs could be further developed in order to evaluate their potential for use in routine assessment and monitoring of recovery.

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