

The Subjective Experience of Participation in Schizophrenia Research

A Practical and Ethical Issue

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Abstract: Mental health research may pose a risk to those who participate in it, especially for potentially vulnerable groups such as those diagnosed with schizophrenia. The current study aimed to investigate the subjective experience of research participation in this group. Seventy-nine individuals with diagnoses of schizophrenia spectrum disorders who had taken part in research looking at suicide were asked to provide feedback about their experiences. Responses were analyzed using qualitative and quantitative methods. Results indicate that negative feedback concerning participation was rare, occurring in 2.5% to 15.2% of responses. Positive feedback was more frequent, occurring in 45.6% to 60.8% of responses. Qualitative thematic analysis identified 5 key themes in participants' responses: Altruism, Value of being involved in research, Therapeutic effect, Enjoyable experience and Negative experiences. The results support the view that mental health research in this group can be ethically viable.

Key Words: Schizophrenia, suicide, research ethics.

(J Nerv Ment Dis 2010;198: 343–348)

The common purpose of mental health research is to explore and understand mental health difficulties, and to improve the lives of those who use mental health services. However, there are ethical concerns that the process of investigating these issues may expose those being studied to potential harm (National Commission for the Protection of Human Subjects, 1979). Despite this, empirical research assessing participant distress is limited. Of the studies that have been conducted, findings have been encouraging, with a recent systematic review suggesting negative reactions to research participation are rare, occurring in 10% or less of cases (Jorm, Kelly and Morgan, 2007).

Concerns about harm are heightened in cases of potentially vulnerable participants, including those with mental health disorders (Wilson & Stanely, 2006). Such misgivings are substantiated by evidence that individuals with higher levels of psychopathology are more prone to experience distress in research (Boothroyd, 2000; Jorm et al., 2007; Reynolds et al., 2006). In particular, there are reservations about research among individuals diagnosed with schizophrenia (Wilson & Stanely, 2006), which have been endorsed by both psychiatrists and service users alike (Roberts et al., 2000). These participants may be at further risk from experiencing distress

when the research concerns sensitive subjects such as trauma or suicide (Jorm et al., 2007). Despite this, few studies have looked directly at the experience of research participation within this group. Further investigation of the experience of participants diagnosed with schizophrenia spectrum disorders in suicide research is therefore warranted.

In addition to ethical issues, a number of related pragmatic concerns surround the question of the risk posed to clinical participants by research. Difficulties in the development and recruitment stages of a project may stem from individuals' assumptions about the degree of risk. In particular, the number of clients who are referred to clinical research projects may be restricted because of the reservations of clinicians and potential participants about the risk involved in taking part. These misgivings may also create a selection bias whereby particular subsets of clinical groups are excluded from research, such as those who are suicidal (Wilson and Stanely, 2006). Similarly, ethical committees may restrict or even veto clinical research because it is felt that such research will be unduly distressing. Such concerns may be unfounded and ultimately prevent research that is clinically necessary.

Investigations of participant distress have commonly employed basic likert-type measures of negative outcomes (e.g., Boothroyd, 2000; Jorm et al., 2007). However, it has been argued that participants' reactions to research may be highly variable, arising from idiosyncratic sensitivities to particular aspects of the study (Hutchinson et al., 1994). A more qualitative, open-ended methodology will therefore have the advantage of enabling participants to more fully describe the complexities of their experience. This approach was employed by the current study.

This study sought to investigate the subjective experiences of research participation in individuals with a diagnosis of a psychotic disorder. Focus was on the experiences of participants taking part in a clinical study researching psychosis and suicide. A qualitative, open-ended methodology was employed to explore the nature and variety of the negative and positive experiences reported by participants.

METHODS

Participants

The sample consisted of 79 outpatients from the Greater Manchester area who consented to take part in a larger study investigating psychological factors predicting vulnerability to suicide ($M_{age} = 42.3$, standard deviation = 11.7; 23 women). All participants met the following inclusion criteria: (1) a chart diagnosis (ICD-10) of a schizophrenia spectrum disorder, (2) being over the age of 18, (3) psychosis not caused primarily by drug misuse or organic disorder, (4) currently not at very high risk of suicide as judged by their keyworker or other appropriate healthcare professional, and (5) capable of providing informed consent as judged by their keyworker or other appropriate healthcare professional. The majority of participants had a diagnosis of schizophrenia ($n = 72$,

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Supported by the NIHR RECOVERY Programme Group and the Mental Health Research Network.

The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health.

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ISSN: 0022-3018/10/19805-0343

DOI: 10.1097/NMD.0b013e3181da8545

91.1%). The remainder had received diagnoses of other schizophrenia spectrum disorders (e.g., schizoaffective disorder, atypical psychosis, and psychosis not otherwise specified). The majority of participants were white British ($n = 63$, 79.7%), with the remainder being either mixed British ($n = 6$, 7.6%), Asian ($n = 3$, 3.8%), Afro-Caribbean ($n = 1$, 1.3%), or other ($n = 4$, 5.1%). Ethnicity data were missing for 2 participants.

Measures

A feedback form was provided to allow written feedback about the experience of taking part in the study. This form included 3 open questions, beneath which there was space for participants to respond: Question 1, How did you find it talking about the issues raised in the study? Question 2, What was your general experience like, taking part in this study? Question 3, How do you feel about research in this area? Questions 1 and 2 both assessed participant's personal experiences of the research. The focus of the first question was on participant's reactions to the content of the research, whereas the second question looked at the overall experience of the research process. The third question assessed general views and attitudes toward clinical psychological research. There was also room for participants to provide any additional comments. The question number is displayed in parenthesis next to all quotes cited in this article. The form was completed by the participant with a researcher present to provide support and answer questions.

Procedure

The larger study was the first in a planned series looking at factors conferring vulnerability to suicidality in schizophrenia. This research was reviewed and approved by an NHS research ethics committee. Informed consent was obtained from all participants before taking part in the study. Participants were informed that their responses would be kept confidential except in circumstances where they suggested they were going to harm themselves or somebody else, in which case a relevant member of their care team would be informed. The study lasted between an hour and an hour and a half with a researcher present throughout. The study involved completing a range of self-report measures, tasks and a clinical interview assessing negative cognitions, attitudes and psychopathology, including depression and suicidality.

At the end of the study, each participant was asked to provide feedback about their experience during the study on the form provided, in particular noting down anything they liked, disliked, or found distressing about the study.

Qualitative Thematic Analysis

The use of qualitative thematic analysis has been advocated within psychology as an analytic tool because of its inherent methodological and theoretical flexibility (Bowling, 2000; Braun and Clarke, 2006). Thematic analysis allows the identification and interpretation of central themes emerging from the data. The main aim of this analysis was to uncover key themes reflecting participants' opinions, motivations, and experiences of taking part in the research. In this instance an inductive, exploratory approach was employed. A realist stance underlined this analysis, whereby participants' responses were assumed to reflect genuine aspects of their experience, motivations, and views.

The qualitative analysis was initially conducted by 2 members of the research team: a service user with personal experience of having a severe and enduring mental health condition, currently working as an Honorary Research Fellow within the Division of Clinical Psychology (University of Manchester) and a Doctoral student in clinical psychology. Responses to each question on the feedback form were studied separately in turn, with responses reread multiple times to identify key features. Data were then hand sorted

and responses with similar content were gathered together into categories, which were then divided into emerging themes. Questions raised in Polit and Hungler's (1997; e.g., "What is going on here?," "What is this?," "What does this mean?") qualitative content analysis framework were applied to each item of data to aid the process of coding and analysis. Themes were then studied and interpretations applied. Themes were based on the prevalence of particular patterns within the data, but also in terms of relevance and importance of these patterns to the research aims (Braun and Clarke, 2006). Further examination, checking and group discussion were carried out by the remaining members of the research team. A single item of data contributed to >1 theme in some cases.

The results were also discussed with the Service User Research Group (SURG) at the University of Manchester. SURG is a body of service users who aid in the development and conduct of mental health research both through providing consultation and feedback and actively conducting research themselves. Consultation of this group provided a form of member checking of the interpretations made by the research team, as advocated by Glaser and Strauss (1967), to assure qualitative validity and rigor.

RESULTS

Descriptive Statistics

Six (7.6%) participants failed to provide any feedback. Reasons for this were not formally recorded, but anecdotally the most common reason cited was that participants had nothing they wanted to say. A further 3 participants completed the feedback form for questions 1 and 2, but left the third question blank and a single participant did not respond to question 1 alone. Responses to each question were rated for the presence of negative and positively valenced content. Table 1 reports the frequency of positive and negative content in responses to each question. It should be noted that some responses included both positive and negative content (e.g., "I found it interesting although difficult at times (Q1)," "Quite depressing, overall positive (Q1)") and were subsequently rated separately for both positive and negative content. This was only apparent in 3 cases for the first question and 1 for the second question. If a conservative approach is taken, whereby these mixed responses are classified just as negative, then for the first question 33 (41.8%) responses were positive and 12 (15.2%) responses negative, whereas for the second question, 36 (45.6%) responses were positive and 7 (8.9%) responses negative. These results are very similar to those obtained when positive and negative elements were considered separately (Table 1). A second independent judge rated a subset of the responses ($n = 47$, 59.5%). Inter-rater agreement between judges was good, with kappa scores averaging at $\kappa = 0.92$. These are

TABLE 1. Frequencies and Percentages of Positive and Negative Content Associated With Each Question

Question	Positive, n (%)	Inter-Rater Agreement (κ)	Negative, n (%)	Inter-Rater Agreement (κ)
How did you find it talking about the issues raised in the study?	36 (45.6)	0.90	12 (15.2)	0.88
What was your general experience like, taking part in this study?	38 (48.1)	0.90	7 (8.9)	1.00
How do you feel about research in this area?	48 (60.8)	0.85	2 (2.5)	1.00

TABLE 2. Themes and Associated Responses

Themes	Responses
Altruism	Overall positive, enjoyed helping. It was okay, glad that they did it (Q2) If it helps people with illness I am all for research (Q3) Good, how else will the helpers help people without understanding (Q3) Very interesting and helpful for other sufferers (Q3) Little bit more help for people like me (Q3) If it helps other people in the long run then it's worth it (Q3) Happy to help others (additional comments) I hope it(s) benefit(s) (beneficial) to mental health Good idea to maybe think I'd you could stop these problems for people (Q3) Good because people need help (Q3) I feel like it is helping other's if it stop's somebody from comiting (committing) suicide. It's a good thing (Q3) I was glad to help (Q3) Helpful on both sides (Q3)
The value of research	Necessary and needed (Q3) Very important (Q3 x3) Worthwhile (Q3) Think it's a good thing (Q3) Think it's great (Q3) Good thing (Q3) It's something that needs to be done. Psychology is in it's infancy (Q3) Very good idea (Q3) Very useful (Q3) Should be more research (Q3) Could be quite useful (Q3) About time (additional comments) More researches should be done (additional comments) Positive and promising (Q3) Important (Q3) The research is necessary and ongoing (Q3) It's one way of finding out about things (Q3) Not enough of it (Q3) Worthwhile (Q3) I agree (Q3)
Therapeutic	It helps me with my problems when discussing issues with my health (Q1) Comfortable, makes me aware of myself (Q1) Helpful (Q1) Released (Q1) The interview reminded me of some of my problems in the past, but I found it helpful to talk about them (Q1) Didn't bother me, glad to get it out of my system (Q1) Very good, it helps me gain clarity (Q2) Made me think (Q2) I felt released and calm (Q2) Helpt (helped) me (Q2) Very helpful (Q2) I really enjoyed it, remembered a lot of things in my life (Q2)

Themes	Responses
	Said things I've not said to my psychiatrist, because it's confidential it was a bit of a release (Q2) I felt quite comfortable talking about my issues. The suicide attempt was a few months ago, but being asked these question(s) makes me realize I'm not alone and my thought and emotion are quite common (Q1) Great. The talking did me good (Q2) Great, I feel much better now I can open up about things that have happened in my life. Before, I couldn't let it out and that made me depressed (Q1) Very easy. Especially feeling you can confide. To tell the truth (Q1) Brilliant. Good therapy (Q1) I found it quite therapeutic (Q1) Therapeutic (Q2) Relaxing (Q2)
Enjoyable experiences	Alright, enjoyed doing it (Q2) Fun (Q2) I enjoyed it (Q2) I am enjoying myself thoroughly all question and find that good think with one and another (Q3) I enjoyed the session with Judith and Peter (additional comments) Enjoyed the experience (Q1) I enjoyed the first part of the course (Q1) I found it quite enjoyable (Q3) Enjoyed it (Q1)
Negative experiences	Alright. Asking questions about the devil were distressing (Q1) Quite depressing (Q1) Distressing to some degree (Q1) I found it interesting although difficult at times (Q1) Always difficult to talk about, overall okay (Q1) I was scared at first, but alright during the study (Q2) Not good to some degree (Q2) Anxious, didn't like cards or words (Q2) Felt a bit nervous (Q1) It was a bit difficult for me to talk about my issues but I had no problems with it (Q1) I was a bit nervous but the researcher was friendly and explained the research process to me (Q2) Fine, a little difficult when asked to talk about my "breakdown" (Q1) I got very tired (Q2) Difficult (Q1, Q3) A little bit difficult, but on the whole OK (Q1) Uneasy (Q1) Hard, OK (Q1) On the whole alright, but I had some difficulty thinking of the memories (Q2) Find it hard to bother with (Q3)

Words and letters in parentheses provided for clarification, to indicate multiple responses or report question number; Q1 = How did you find it talking about the issues raised in the study? Q2 = What was your general experience like, taking part in this study? Q3 = How do you feel about research in this area?

reported by question and valence in Table 1. The remainder of responses were neutral in content (e.g., “Okay (Q1),” “Alright (Q1),” “I didn’t mind, it was fine (Q1)”).

Thematic Analysis

Five key themes were identified through the qualitative analysis of the feedback data. These themes were reviewed and validated by members of SURG. A summary of these themes and associated responses is displayed in Table 2.

Altruism

This theme included comments which revealed a desire to participate in the research not particularly for personal gain, but rather for “the greater good” of others in the future [“Happy to help others (additional comment),” “If it helps other people in the long run then it’s worth it (Q3),” “I was glad to help (Q3)”. Sometimes this included a particular desire to help those with similar experiences and mental health problems to the participants themselves [“Very interesting and helpful for other sufferers (Q3),” “If this helps people with illness I am all for research (Q3),” “A little bit more help for people like me (Q3),” “Good, how else will the helpers help people without understanding (Q3)”].

Value of Being Involved in Research

This theme captured positive comments related to the value and benefits of research in general. This theme is distinct from the previous one in that responses were not linked to a specific motive for participating in research. Responses reflected the belief that clinical research was a worthwhile and valuable pursuit [“Worthwhile (Q3),” “Very important (Q3)”, was necessary [“Necessary and needed (Q3),” “It’s something that needs to be done, psychology is in its infancy (Q3),” “The research is necessary and ongoing (Q3)”, and of which more is required [“More research should be done (additional comment),” “Should be more research (Q3),” “Not enough of it (Q3)”].

Therapeutic Effect

Many service users described a personal therapeutic effect that they associated with taking part the research [“It helps me with my problems when discussing issues with my health (Q1),” “I felt quite comfortable talking about my issues. The suicide attempt was a few months ago, but being asked these question(s) makes me realize I’m not alone and my thought and emotion are quite common (Q1),” “Brilliant. Good therapy (Q1),” “Therapeutic (Q2)”. In particular, a subset of participants suggested the interview had cathartic properties, expressing a feeling of relief and release related to talking to the researcher about their mental health problems and experiences [“Didn’t bother me, glad to get it out of my system (Q1),” “I felt released and calm (Q2),” “Very easy. Especially feeling you can confide. To tell the truth (Q1)”. In 1 instance, awareness of the confidentiality of the research was highlighted as an important factor in allowing the participant to talk openly and experience catharsis [“I said things that I have not said to my psychiatrist, because it’s confidential it was a bit of a release (Q2)”. Therapeutic gains were linked to other psychological domains, including enhanced awareness of past problems [“The interview reminded me of some of my problems in the past, but I found it helpful to talk about them (Q1)”] and increased self-awareness [“Makes me aware of myself (Q1),” “Very good, it helps me gain clarity (Q2)”].

Enjoyable Experience

A number of participants simply reported that they enjoyed taking part in the study [“Alright, enjoyed doing it (Q2),” “Fun

(Q2),” “I enjoyed the session with Judith & Peter (the researchers) (additional comment),” “I found it quite enjoyable (Q3)”].

Negative Experiences

Seventeen participants raised points which reflected negatively on their experience of being involved in the study [“Quite depressing (Q1),” “Distressing to some degree (Q1),” “I got very tired (Q2)”. Participant’s negative experiences included difficulty and distress associated with disclosure and discussion of their mental health difficulties [“It was a bit difficult for me to talk about my issues, but I had no problems with it (Q1),” “Fine, a little difficult when asked to talk about my “breakdown” (Q1),” “Always difficult to talk about, overall okay (Q1)”. It should be noted in the above responses that despite the instances of distress, participants asserted that they found this questioning and the research generally acceptable. In 1 instance, this distress was linked in particular to a discussion about the participant’s auditory hallucinations where they would see the devil, suggesting a particular sensitivity to this topic [“Asking questions about the devil were distressing (Q1)”. Negative experiences also included anxiety and nervousness [“Felt a bit nervous (Q1),” “Anxious, didn’t like cards or words (Q2)”, although 2 participants also suggested these feelings could be successfully allayed [“I was a bit nervous but the researcher was friendly and explained the research process to me (Q2),” “I was scared at first, but alright during the study (Q2)”].

Three responses suggested a sixth theme, which was the need to be heard, whereby participants indicated that their involvement in the research process gave them “a voice” or an opportunity to talk openly about their experiences [“It gave me a chance to tell my story (Q2),” “It’s about time we were asked (Q3),” “It enabled me to talk about something I know a little about (Q1)”. This theme was underrepresented in the data, but was considered interesting and could be an area of focus for future research.

DISCUSSION

The current study aimed to investigate the subjective experiences of taking part in research for participants with a diagnosis of a psychotic disorder. The findings of this study are largely positive. Negative content was apparent in only a minority of responses, with prevalence ranging between 2.5% and 15.2% across questions. In contrast, positive content was more frequent, with prevalence ranging between 45.6% and 60.8% across questions. These findings are in line with a recent review suggesting a similar prevalence of negative and positive reactions to research in patient samples (Jorm et al., 2007).

The qualitative analysis of feedback responses allowed an investigation into the nature and range of individuals’ experiences during the study. This analysis supports previous qualitative findings that research can have a number of benefits for those who participate. These include a sense of catharsis and therapeutic gain and a perception of helping others (Dyregrov, 2004; Hutchinson et al., 1994). It should be clarified that the therapeutic effect reported by participants reflects their subjective experiences. Whether or not this therapeutic effect endures after the study and translates into a genuine improvement in wellbeing requires further investigation.

The theme of therapeutic effect may stem in part from the unique interpersonal context of the research. The research environment may provide a context where issues pertaining to mental health and suicide can be discussed in a confidential, open, and nonjudgmental way. Fear of treatment and involuntary hospitalization may prevent some service users from discussing aspects of their mental health with healthcare professionals (Hahm and Segal, 2005; Sussman et al., 1987), whereas for others certain issues may not be raised in routine assessments (Jobes et al., 2004). The research environ-

ment may differ in that the focus is not primarily on treatment, and confidentiality is emphasized along with the boundaries of this confidentiality. Consequently, some participants may see research as an additional forum to voice their problems, which lies outside of the usual context of care and treatment. Of course, research can not be seen to provide any form of alternative to participants' standard care.

The current study also supports past findings that patients with diagnoses of schizophrenia predominantly express positive views about mental health research, viewing it as an important and valuable endeavor (Roberts et al., 2000), and rating the possible benefit to others as an important reason for participating (Roberts et al., 2000, 2004). This motivation for participation in mental health research has also been endorsed by other populations, such as bereaved parents (Dyregrov, 2004).

Anxiety and nervousness surrounding participation was also reported. However, it seems that for a few participants at least, these feelings were only present at the beginning of the study, and were successfully reduced once the study began. It seems likely that the researcher may play an important role in quelling such anxieties, through careful explanation of the study procedure and identification of any particular concerns. Other negative experiences included distress and difficulty linked with the disclosure and discussion of personal mental health problems. The specific features of the study content that lead to distress may be idiosyncratic, reflecting personal sensitivities to certain topics (Hutchinson et al., 1994). Consequently, it may not always be possible to ascertain who will or won't be distressed by a particular feature of the study and therefore raises the importance of having adequate procedures in place for dealing with instances of participant distress. Such procedures need to be flexible enough to deal with the potential variation in the nature and degree of distress experienced.

In the study from which the current feedback was taken, these procedures involved concluding the study with a detailed and interactive debriefing. This included a brief task designed to restore positive mood through encouraging a focus on the participant's favored activities and positive characteristics. This study also made use of multiple follow-up calls to assess individuals' wellbeing after the study. In 2 instances, these calls led to concerns about a participant's wellbeing. In these cases, these concerns were passed on to the participant's keyworker or other relevant healthcare professional with the participant's consent. Maintaining strong links with a participant's care team was therefore another important factor in managing participant distress.

Interestingly, negative responses were more frequent for the first 2 questions, which assessed personal experiences of the research, compared with the third, which assessed more general views toward clinical psychological research. This suggests participants may experience distress related to particular aspects of the study, but still maintain the overall value of such research. This possibility is supported by the observation that a number of participants reporting distress also stated in the same response that they found the study acceptable. It is therefore relevant for future research of this nature to recognize that participants may hold mixed and dissonant views of this nature.

These results may have implications for how informed consent is obtained. It is important for a potential participant to be fully aware of the nature and content of the study, particularly where the focus is on personal mental health issues, as this is an area some may find distressing. An awareness of this content will allow individuals to predict the degree of distress the study may cause them and subsequently whether or not to participate. In the current study, participants were provided with information sheets at least 24 hours before consent was sought. These outlined the study procedure and content, and provided examples of the questions participants would

be asked. Unfortunately, it was beyond the scope of the current study to assess participant's satisfaction with the informed consent process, although this is an important issue which has received attention elsewhere (e.g., Anderson and Mukherjee, 2006).

Adequate debriefing procedures are important after research, including encouragement of participant feedback, so that negative experiences can be identified and discussed with the researcher. Such debriefings may also have an educational or informative value to participants (Brody et al., 2000). Considering the finding that many participants may engage in research with altruistic motives, a reiteration of the research's purpose and aims, may also be beneficial, allowing participants to determine whether their involvement has been worthwhile. As a final point, researchers should show caution in describing the possible benefits of research participation. Although positive experiences are frequent, they can not be guaranteed and research should not be viewed in any way as a substitute for clinical therapeutic interventions.

Several limitations of this study need to be recognized. First, it is possible that some participants may have been uncomfortable or in other ways unwilling to report on the negative aspects of their experience. This may partly account for the low rates of such experiences apparent in the feedback responses. In such cases participants may have provided neutral responses, rather than describe their true negative experiences. Similarly, negative responses that were intermixed with neutral content [e.g., "Always difficult to talk about, overall okay (Q1)"] may simply reflect participants trying to ameliorate the impact of their negative comments (or soften the blow). Still, such acquiescent or deferential responding seems less likely to account for the substantial numbers of positive responses identified in the study. Second, the written feedback format resulted in often quite terse responses from participants. It is likely a semistructured interview methodology would have provided a deeper and more detailed exploration of participant's experiences. However, participants had already endured 1 to 1.5 hours of questions and an additional detailed interview may have overburdened some individuals. Future research investigating participant distress could employ semistructured interviews conducted a few days following the study, so as to assess the ongoing impact of participation on the individual.

CONCLUSIONS

In conclusion, this study suggests that individuals diagnosed with schizophrenia endorse a variety of positive views concerning mental health and suicide research. Such research was seen by many as a valuable and positive endeavor, which could be an enjoyable, therapeutic and cathartic experience. Nevertheless, a relevant subset of participants did find this type of research difficult, distressing or anxiety provoking. This study suggests such negative experiences were rare, although further larger scale research will be necessary to confirm the proportion of individuals likely to have such negative experiences. Consequently, these findings support the view that research investigating schizophrenia and suicide can be ethically viable, although researchers need to be mindful of the possibility of negative reactions in some participants.

ACKNOWLEDGMENTS

The authors thank the members of the SURG for their assistance in this study. This article outlines independent research commissioned by the National Institute for Health Research under its Programme Grants for Applied Research. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. The authors would also like to thank the RECOVERY Programme Group and the Mental Health Research Network for their support.

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