

# Outcome measurement in mental health: the views of service users

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## ABSTRACT

Views of service users about outcome measures used to evaluate treatments in mental health are largely unknown. We therefore undertook a literature review and focus groups of service users to draw up a short list of key outcome measures used to assess people with mood disorders and psychosis. We presented these measures to expert panels of service users and used consensus building techniques to obtain ratings for the appropriateness of each measure. Levels of support for 24 outcome measures were calculated and service user views about how outcomes should be assessed were obtained. Panel members expressed concerns about the ability of some outcome measures to capture their experiences. Participants emphasised the importance of patient rather than staff-rated outcome measures and the need to examine negative as well as the positive effects of treatments. Concerns were raised about some widely used measures such as the Global Assessment of Functioning and the European Quality of Life measure 'Euro-QoL'. We believe that it is essential that service user views are taken into account when outcome measures are being selected. Our findings provide a starting point for considering issues which may be important to users of mental health services.

## 1.0 BACKGROUND

The development of effective treatments for health-related problems requires active input from people who use services (Partridge & Scadding, 2004). One of the areas where active service user involvement is essential is in deciding which outcome measures should be used to examine the effectiveness of new treatments (The James Lind Alliance, 2007; Entwistle et al., 1998). Previous studies have demonstrated differences in the way that users and providers of health care judge whether interventions and treatments are effective (Cay 1975; Rothwell et al., 1997). These differences may be greater in mental health, where views about the nature of ill health and its treatment may be more contentious (Faulkner & Thomas, 2002). Differences have been reported between users and providers of mental health services about which outcomes matter most (Fischer, Shumway & Owen, 2002; Crawford et al., 2008) and studies that have actively involved service users report changing the way that interventions were subsequently evaluated (Trivedi & Wykes, 2002). Despite these findings available evidence suggests that most studies examining the effectiveness of interventions and treatments are conducted with little or no involvement from service users (Hanley et al., 2001).

In recent years outcome measurement has gained an even greater level of importance. In addition to the central role that the selection of outcome measures plays in the design of clinical trials, greater emphasis has been placed on

findings from trials in determining health policy (Ham et al., 1995). It has been argued that a greater emphasis on routine outcome measurement in clinical services can increase service quality (The Stationery Office, 2008). In the NHS, funding for services is increasingly linked to the outcomes that services achieve (Department of Health, 2002). Choice of appropriate outcomes is therefore of major importance to both the quality of clinical trials and to efforts to improve the quality of mental health services.

Most outcome measures have been developed without direct input from service users and views of service users about the appropriateness of outcome measures which are widely used are largely unknown. We therefore set out to obtain views of service users about the appropriateness of widely used outcome measures. We focused on outcome measures that have been used to evaluate interventions and services for people with psychosis and mood disorders, due to the prominence of these forms of mental disorder among users of mental health services.

## 2.0 STUDY AIMS

The aims of the study were:

- 1) to obtain the views of people with psychosis and mood disorders about outcome measures which are widely used to examine the effectiveness of interventions and services;
- 2) to develop a consensus about the measures which service users judge to be appropriate and relevant; and
- 3) to identify any gaps where service users believe that appropriate and relevant measures for assessing outcomes have not been developed.

## 3.0 METHODS

### 3.1 Overview

We compiled a list of outcome measures that have been widely used to examine interventions and services for people with mood disorders and psychosis through searching textbooks and online resources and identifying measures in recent and ongoing clinical trials in the UK. We obtained views of service users about the types of outcome measures they value most by conducting focus groups and semi-structured interviews. Results of our search for outcome measures and views of service users were presented to a Project Advisory Group (PAG) comprising study applicants, service users, and their representatives. Views of PAG members were used to draw up a shortlist of 24 outcome measures which were presented to two expert panels who were asked to rate the appropriateness of each measure.

### 3.2 Identifying outcome measures

We searched for outcome measures used in studies of people with psychosis and mood disorders using the following sources:

- ongoing trials – database of studies examining mental health outcomes adopted by the Mental Health Research Network ([www.mhrn.info/pages/research-we-support.html](http://www.mhrn.info/pages/research-we-support.html)), UK Clinical Trials Gateway ([www.controlled-trials.com/ukctg/](http://www.controlled-trials.com/ukctg/)) and the NHS R&D Health Technology Assessment Programme ([www.hta.ac.uk/project/](http://www.hta.ac.uk/project/));
- textbooks – including *Handbook of Psychiatric Measures* (American Psychiatric Association, 2005), *Rating Scales in*

*Mental Health* (Sajatovic & Ramirez, 2003) and *Handbook of Psychological Assessment* (Groth-Marnat, 2003);

- findings of systematic review of controlled trials in schizophrenia (Thornley & Adams, 1998);
- *The Outcomes Compendium* (National Institute for Mental Health, 2008);
- contact with researchers, including members of the Project Advisory Group.

Information about the psychometric properties of outcome measures that have been used in clinical trials or service evaluations was obtained from primary or secondary sources. We drew up a long list of outcome measures with acceptable psychometric properties which have been used in recent or ongoing clinical trials or service evaluations. This long list was presented to a meeting of the Project Advisory Group, who then decided which outcome measures were to be presented to the expert panels using the criteria listed below.

### 3.3 Focus group and interviews with service users

To ensure that the decisions made by the PAG were informed by the views of service users, we collated views about outcome measurement from people who had used mental health services for treatment of psychosis and/or mood disorders. Two focus groups of people with severe mental illness were conducted among people recruited by the Service User Research Enterprise (SURE) at the Institute of Psychiatry, and semi-structured interviews with people with mood disorders were conducted by a researcher employed by the Mental Health Foundation. Twenty-one people attended one of two focus groups conducted at SURE and the Mental Health Foundation conducted interviews with 20 service users, mainly with depression.

Topic guides for the interviews and focus group were designed by study applicants to obtain the views of service users about what outcomes people believe should be included in research examining the effectiveness of treatments and services. Questions and prompts explored expectations about the impact of pharmacological and psychosocial treatments and views regarding the relative importance of different types of outcomes. We asked participants if they had taken part in clinical trials and, if so, what their experience of research participation was like.

### 3.4 Selecting outcome measures

The decision about which of the long listed outcome measures should be presented to the expert panels was made by members of the Project Advisory Group (PAG). Members of the PAG comprised study applicants together with additional service users and their representatives. This group had a broad representation of service users and providers including representatives of national patient groups and mental health charities and a number of service user researchers.

Criteria used by the PAG to determine which outcome measures should be presented to the expert panels were:

- 1) focus of the outcome measure – we selected outcome measures that examined outcomes identified as important by service users who took part in the focus groups;
- 2) psychometric properties – validity and reliability of the outcome measure needed to have been tested and

the results published in a peer reviewed journal;

3) previous use in a published or ongoing clinical trial or service evaluation;

4) frequency of use – where a large number of measures were available that measured the same construct and satisfied the first three criteria, we selected the outcome measures that have been used most widely.

Having restricted the outcome measures to those with published data on psychometric properties that focused on a domain identified as important by service users, we planned to use the criteria of frequency of use to make our final selection.

### 3.5 Expert panels

We convened two expert panels to consider the appropriateness and relevance of outcome measures which met the criteria listed above. We contacted six organisations; The BiPolar Organisation (formerly the Manic Depressive Fellowship), the Mental Health Foundation, the National Institute for Mental Health Mental Health Research Network, Mind, Rethink and the Service User Research Enterprise at the Institute of Psychiatry, King's College London, and asked for volunteers who had direct experiences of mood disorder and/or psychosis and had used secondary care mental health services. Previous involvement in a research study was considered helpful, but was not a requirement to become a panel member.

We aimed to recruit between eight and 12 people to each expert panel and to ensure representation of men and women of different ages and from different ethnic and cultural backgrounds. The first panel meeting was set up to examine outcome measures used in studies on mood disorders and the second focused on psychosis. Potential panel members had often experienced both mood disorder and psychosis and chose which group they wanted to attend. Members of the group were sent written information prior to the meeting. At the start of the meeting, panel members were asked to provide written informed consent to participate in the study.

We commenced the panels with a general introduction in which we presented the background and aims of the study and described how the rest of the meeting was structured. We then asked panel members to complete a short questionnaire which asked them about their demographic background, use of mental health services and previous involvement in research. We used a nominal group technique (Jones & Hunter, 1995) to try to develop a consensus about the appropriateness of the different outcome measures that we presented. When considering whether an outcome measure was 'appropriate' we asked panel members to ask themselves whether the outcome measure included items that were relevant and important to them and, for questionnaire and interview schedules, whether the items were phrased in a way that made sense to them and was acceptable. We started by presenting outcome measures and then asked panel members to read through them and rate their appropriateness on an 11-point Likert scale (see Appendix A). Each outcome measure was then discussed, and feedback on the mean response of the group in round one was provided.

Members of the group were then asked to rate the appropriateness of each measure again, and invited to consider the score the measure was given in round one. During each panel, a service user researcher kept a written record of points raised by panel members.

### 3.6 Data analysis

Median ratings for each outcome measure in round one and two were calculated together with interquartile ranges. Qualitative data collected during the panel meetings was used to examine views of service users about the use of outcome measures, to help interpret the quantitative data we collected and to describe aspects of outcome measures that service users believe make them appropriate.

### 3.7 Ethical issues

Research ethics committee approval was obtained from Imperial College Research Ethics Committee prior to the start of the study. Only those willing to provide written informed consent took part in the study. Members of the expert panels were paid £100 for taking part in each day-long meeting.

## 4.0 RESULTS

A flow chart illustrating the selection of outcome measures presented to the expert panel is provided in Appendix B. The search strategy described above generated 132 outcome measures (see Appendix C). Of these, 63 (47.7%) were selected for the long list and reviewed in detail by the Project Advisory Group.

Focus groups and individual interviews highlighted the importance that people place on the process of care. When prompted to consider the types of outcomes which people felt were important to include in studies examining the effects of treatments and services, participants highlighted four domains: mental health/symptoms of emotional distress; quality of relationships/social functioning; quality of life; and side effects of treatments (both pharmacological and psychological).

At a meeting of the Project Advisory Group, we agreed that each expert panel should not be asked to review more than 12 outcome measures. Group members selected three measures of depressive symptoms, three measures used to assess symptoms of schizophrenia, three measures of general mental health, four measures of social function, four measures of quality of life and three measures of side-effects of antipsychotic medication. We also decided to include three other measures which have been widely used in clinical trials or in the evaluation of mental health services – the Clinical Global Impression Scale (Guy, 1976), the Global Assessment of Functioning (Patterson & Lee, 1995) and the Health of the Nation Outcome Scale (Wing et al., 1998). Members of the Project Advisory Group were concerned that our selection criteria, which favoured measures which have been widely used in previous or ongoing trials, meant that we would not be presenting outcome measures which have been developed more recently and have involved a greater degree of collaboration with service users in their development. In response to these concerns we

included two final measures – the Outcomes Star ([www.outcomesstarsystem.org.uk](http://www.outcomesstarsystem.org.uk)) and the Warwick-Edinburgh Wellbeing scale (Tennant et al., 2007). The Outcomes Star was included because of the collaborative approach that it takes to assessing patient outcomes. The Warwick-Edinburgh Wellbeing scale was selected because data from a focus group of service users was used to develop the instrument. A total of 24 (38.1%) of the 63 long listed outcome measures were therefore presented to the expert panels.

### *Expert panels*

Twenty-five people attended the two nominal groups. Twelve people attended the first group and 15 attended the second (two of whom had also participated in the first group). Participants ranged in age from 26 to 66 (mean = 44 years). Eleven (44%) were female and 14 (56%) were male. In terms of ethnicity, 15 (60%) identified themselves as British white, five (20%) as British black, three (12%) as British Asian and two (1%) as other. All 25 participants had had previous contact with secondary care mental health services, with most (N = 22, 88%) having had more than 10 years contact with services. Twenty-two (88%) participants had had some previous involvement in research or service evaluation.

Median ratings for each outcome measure (with interquartile range) in round one and round two are presented in the table below. Levels of agreement were higher in round two (as indicated by a smaller interquartile range in round two for most outcome measures). Eight outcome measures in round two had a median score of seven or higher and two had a median rating of 3.3 or lower. The eight most highly regarded outcome measures were: a measure of depressive symptoms (Beck Depression Inventory); a measure of symptoms of schizophrenia (Positive And Negative Symptom Scale); two measures of general mental health (CORE-Outcome Measure (CORE-OM) and the Warwick-Edinburgh Wellbeing scale); two measures of side effects of medications (the Liverpool University Neuroleptic Side Effect Rating Scale (LUNERS) and the Antipsychotic Non-Neurological Side-Effects Rating Scale (ANSERS)); and two measures of quality of life (WHO-Quol and the Manchester Short Assessment of Quality of Life (MANSA)). The highest ratings were for side effects of medication, and members of the expert panel on mood disorder stated that they would have liked the chance to see measures that had been used to assess side effects of mood stabilisers and antidepressants. No measure of social functioning achieved a score higher than 4.5. The three outcome measures to achieve the lowest rating were the 'Short Form-12' measure of social functioning, the Global Assessment of Functioning and the Euro-Quol.

### *Qualitative data*

Possible reasons why individual outcome measures achieved the ratings they did emerged from an analysis of the qualitative data that were collected during these two meetings. A series of features were identified as contributing to the appropriateness of an outcome measure. These are summarised in table 2. Firstly, panel members expressed a strong preference for outcome

measures which are rated by service users themselves. Panel members expressed surprise, and in some instances disbelief, that outcome measures based entirely on the judgments of researchers or clinicians could be used to judge a person's response to treatment. Others stated that people may not be able to make ratings without help from others at times when they were most unwell. Some panel members supported the idea that outcome measures might be completed by service users working together with staff (as when completing the Outcomes Star), though others felt that outcome measures should be based entirely on the experiences of the service user.

Several discussions took place about the length of questionnaires or assessment schedules. Concerns were expressed at the length of some measures, but greater concerns were expressed about very short outcome measures such as the Euro-QoL which panel members believed were too short to properly assess the complex outcomes they are designed to measure. An exception to this was measures of side effects of medication, which panel members felt needed to be long in order to fully capture the wide range of negative effects of treatments which panel members had experienced.

Another recurring theme concerned the dominance of what were perceived as too many 'negative' items in most questionnaires. Panel members remarked that they found it upsetting to be asked long lists of questions about different aspects of mental ill health. The Warwick-Edinburgh Wellbeing scale was commended for asking questions about aspects of good mental health, where poor emotional health is indicated by not endorsing these 'positive' items. However one panel member commented that it might seem strange to be asked about aspects of good mental health if you were depressed. There was widespread support for questionnaires that included a range of 'positive' and 'negative' items.

Panel members raised concerns about outcome measures which laid down criteria about what a 'good outcome' should be. This applied particularly to measures of quality of life and social functioning. For instance, some panel members felt that it should not be assumed that people who got on well with family members had better social functioning, because some people made a conscious choice not to have contact with family members. Some panel members felt that outcome measures should not judge what aspects of relationships with others or ways that people spend their time indicated a 'better' outcome. Rather than specifying which aspects of social functioning meant that someone had a good outcome, panel members felt that people should be asked whether people were happy with these aspects of their lives.

Views of panel members varied about the inclusion of items on sensitive matters including sex. Some panel members felt that they would not be happy to answer such questions for the purpose of assessing outcomes. They felt that the use of 'intrusive' questions in outcome measures such as the Social Functioning Questionnaire could impact on people's willingness to take part in research. Others disagreed and felt that issues such as sex were important to their quality of life and needed to be included.

Many of the comments made by panel members extended beyond the design of specific outcome measures and were related to broader issues concerning the rationale and process of collecting outcome data. Many respondents expressed scepticism about the ability of standardised closed questionnaires or interview schedules to capture an individual patient's experience or response to treatment. How could a 'universal' outcome measure capture the individual nature of a person's health and response to treatment? Panel members felt that aspects of their life that go beyond the treatments they received had a greater impact on their health and questioned how it was possible to attribute changes in health or quality of life to the interventions and treatments being tested in studies. Some members felt that a good questionnaire or interview needed to include open questions or space where people could add additional comments about the treatments they were given. Panel members stated that their emotional health also varied at different times of the day or different times of the year, and felt that when outcomes were being measured, consideration needed to be taken of when the outcome was being assessed.

Concerning the process of outcome measurement, panel members repeatedly stated that it was not so much the content or length or an interview or questionnaire that mattered, as much as the personal qualities of the clinician or researcher who was making the assessment. As one panel member stated, an outcome measure was 'only as good as the doctor who uses it'. Panel members stated that researchers needed to be sensitive to the needs of people experiencing mental distress and to treat people with dignity and respect. In relation to questionnaires, panel members spoke of previous occasions on which they had been asked to complete poorly prepared questions that were badly photocopied. Panel members stated that, if they were asked to complete such questionnaires, it made them wonder about how seriously their responses would be taken, or whether services valued the information they were being asked to provide.

## 5.0 DISCUSSION

By using nominal group methods with expert panels of users of mental health services, we have generated data on service user perspectives on the appropriateness of widely used outcome measures. These data, together with comments made by people attending these meetings, have helped us explore factors which influence service users' views about key features of a good outcome measure. Panel members believed that the outcomes of interventions and treatments needed to be assessed using patient-rated measures. They highlighted the importance of assessing negative as well as positive effects of interventions and treatments and were critical of outcome measures that presented people with only negative questions about how bad they may be feeling. Panel members were critical of very long outcome measures, but were even more critical of very short questionnaires or interview schedules that they believed could not capture the complex and important outcomes they were attempting to measure.

Many of the comments of service users concerned the process of collecting outcome measures rather than the content of individual measures. The personal qualities and training of staff using questionnaires and checklists were highlighted, as were the presentation and format of questionnaires.

While the measures of side effects of medication that panel members rated were all relatively highly regarded, it is of concern that some of the most widely used outcome measures in mental health, including the Euro-Quol and the Global Assessment of Functioning received such low ratings. In addition to being rated by staff, the Global Assessment of Functioning was criticised for trying to combine a measure of functioning with a measure of mental health. Panel members commented that there had been times when the functioning had been reasonably good but their mental health poor, and others had continued to function poorly even after their symptoms of emotional distress had subsided. Panel members questioned whether it was possible to assess these outcomes with a single score. This concern has also been raised by clinicians and researchers using the Global Assessment of Functioning (GAF) (Williams, 2005).

#### *Limitations of the study*

The limited resources we had to conduct the study meant that it has several important limitations. Firstly, we were only able to present a small number of outcome measures to the panels. While we were able to include many widely used outcome measures for assessing outcomes of people with mood disorders and psychosis in studies in the UK, there were many other widely used measures that we were not able to get panel members to rate. Several of the outcome measures we assessed are available in differing formats. We attempted to use the versions of these outcome measures that have been most widely used. For example, we asked panel members to consider the appropriateness of the 12-item General Health Questionnaire, rather than the 28- or 60-item version of this questionnaire (Goldberg & Williams 1991). We presented panel members with the 34-item version of the CORE-OM and do not know how members would have rated shorter versions of this measure that are also available (Evans et al., 2002). We presented panel members with the staff-rated version of the Psychotic Symptom Rating Scales (PSYRATS). A self-complete version of the PSYRATS is also available, and given the preference of panel members for patient-rated outcome measures, the self-completed version of the measure may have received a higher median rating.

Our focus on outcome measures used in studies among people with psychosis and mood disorders means that we do not have data on outcome measures used to assess other mental health related problems such as anxiety, substance misuse or personality-related problems. While we presented several measures that assess depressed mood we were unable to explore service user views of outcome measures used to assess mania.

A large number of other outcome measures have been used in studies of people with mood disorders and psychosis but were not included in this study.

The criteria we set for developing our shortlist was designed to ensure that we examined outcome measures which have been widely used. This meant that measures which have only recently been developed were generally excluded. An unfortunate consequence of this was that a range of recently developed outcome measures which have been developed in partnership with service users were excluded (Allott, 2005; Rose et al., 2009). The only measure that we examined which made explicit reference to incorporating views of service users during its development was the Warwick-Edinburgh Wellbeing scale (Tennant et al., 2007). It is therefore of note that this outcome measure achieved the second highest rating by panel members (after the LUNSERS).

While each panel was well attended by a range of people reporting high levels of contact with mental health services, these findings are based on the views of a relatively small number of service users. We made a considerable effort to include people from a range of different backgrounds and experiences and made provision for regular breaks during the meetings. However, the length of the panel meetings, which extended to a full working day, may have deterred people who were currently experiencing high levels of emotional distress from attending the meetings.

#### *Implications of findings*

One of the clearest findings of the study was the preference of panel members for patient-rated outcome measures. This finding contrasts with extensive reliance on staff-rated outcome measures which is seen in mental health services (Gilbody, House & Sheldon, 2002). Concerns have been raised about the reliability and validity of patient-rated outcome measures in mental health (Becker et al., 1993), and current efforts to examine service quality are often centred on staff-rated outcome measures such as the Health of the Nation Outcome Scale (HONOS) (Fairbairn, 2007). This contrasts with other areas of healthcare where patient-rated outcome measures are the norm. The service users who took part in this study challenged the idea that the quality of services or outcomes of interventions could be measured appropriately by using staff-rated measures and we believe that these data strengthen the argument for using patient-rated outcome measures in mental health. Ongoing research to develop and refine a patient-rated HONOS is therefore to be welcomed (Trauer & Callaly, 2002).

Another clear finding was the emphasis that service users in both the focus groups, individual interviews and expert panels placed on assessing the side effects of treatments. Previous studies which have compared stakeholder priorities for outcome measurement have also found that service users are concerned about the side effects of the treatment they are given (Lee et al., 2000; Shumway et al., 2003). Panel members felt it was important to examine negative effects of psychological as well as drug treatments. Members of the panel that focused on mood disorder stated that they would have liked to have seen an outcome measure assessing the side effects of mood stabilisers and antidepressants. These findings support the inclusion of measures of negative as well as positive effects of interventions and treatment used in mental health (Rose et al., 2008).

Concerns have long been expressed about the validity and utility of widely used measures of quality of life. While outcome measures such as the Euro-QoL have been specifically developed to allow comparison across medical settings, members of our expert panels felt that this measure was not detailed enough to capture the quality of life of people with mental disorders, and preferred longer measures such as the WHO-QoL which includes items that address a larger range of factors that service users judged important when assessing quality of life.

The domain where panel members' ratings of the outcome measures were lowest was social functioning. Service users had identified social functioning as a domain that was particularly important to assess when judging the outcomes of interventions and treatments. However, panel members were critical of the normative nature of these measures. Panel members told us that they wanted to be asked about whether they were satisfied with different aspects of their social functioning rather than having assumptions made that fewer contacts with others or involvement in fewer occupational activities was necessarily an indicator of a poorer outcome. Some panel members also raised concerns about inclusion of 'intrusive' items such as questions about sex life in such outcome measures. While there are already a large number of outcome measures used in mental health, we believe that these findings suggest that a measure of social functioning which focuses on areas of function that service users consider appropriate and relevant, and does not use normative standards is required.

### Conclusions

Among outcome measures which have been widely used in studies of people with psychosis and mood disorder, users of mental health services considered some to be more appropriate than others. Our data emphasise the importance service users place on patient-rated outcome measures. Service users who took part in our expert panels stated that studies should examine the negative as well as the positive effects of interventions and treatments. Concerns were raised about some widely used outcome measures such as Euro-QoL and GAF, and about all four measures of social functioning that we examined.

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