

# Who decides the definition of a 'good outcome'?

**Researchers routinely use a variety of standard questionnaires to assess people's mental health, their symptoms, side effects of medication and people's quality of life. The questionnaires are used in studies to gauge the success of new treatments and packages of care, and also in evaluations that may determine future funding of NHS services. But does the concept of success – a 'good outcome' – differ between professionals and people who have experience of mental health problems?**

The Mental Health Research Network commissioned a team led by Dr Mike Crawford at Imperial College London to find out what people who use services for mood disorders and psychosis think of questionnaires designed to assess their state-of-being, and whether,

in their opinion, they do the job they are supposed to do accurately.

In the world of research, the questionnaires are called 'measures' or 'scales' and are either completed by a professional who interviews an individual, or completed by the individual themselves. They

are mostly designed by researchers and aim to measure change or improvement, or set out to give an insight into someone's mental health. But the project showed that a professional's view of what constitutes a 'good outcome' doesn't always tally with the opinion of the individual whose life is being assessed.

Two expert panels of people with experience of mental health problems discussed and analysed a sample of two-dozen questionnaires that are commonly used in research studies, and increasingly by mental health professionals working with people with psychosis and people with mood disorders. The 25 people on the panels were recruited through the Bipolar Organisation, the Mental Health Foundation, the Mental Health Research Network, MIND, Rethink and the Service User Research Enterprise at the Institute of Psychiatry, King's College London. All volunteers had personal experience of mood disorders and/or psychosis.

They gave each tool used by professionals a mark out of 10 – and only seven of the 24 questionnaires gained a score of seven or above. Some of the most widely used outcome measures in mental health, including the *Euro-QoL* and the *Global Assessment of Functioning* – received very low scores.

The panels were particularly critical of questionnaires designed to measure ‘social functioning’ – giving them scores of between 3 and 4.5, and challenging the definitions of a ‘normal life’ contained within them. People with experience of mental health problems may disagree with professionals about what constitutes a ‘good outcome’ in terms of getting on with their everyday lives, they said.

The panels suggested questionnaires about social functioning should be designed to find out whether people are happy in certain areas of their life, rather than asking specific questions that take no account of individual preferences and are based on a professional’s judgement of ‘normality’. Some of the questions included in these measures were considered by the panels to be not only irrelevant, but also intrusive – questions about people’s sex lives, for example.

In all the questionnaires, the panels felt there was a focus on mental ill health rather than mental good health. And the questionnaires should also ask about the negative effects of treatments and packages of care, instead of just concentrating on potential improvements, they said.

In addition to analysing whether the questions posed were relevant and important, the panel members discussed the language used and the presentation of ‘outcome measures’.

They said that some questionnaires they been asked to complete themselves were shoddily presented – badly photocopied, for example – which gave the impression that

their responses were not valued. All questionnaires should be presented in a professional manner, they said. They also expressed concern that some questionnaires were far too long, and that others were far too short to be comprehensive.

However, when an interviewer was involved in completing a questionnaire, the panels stressed that the social skills of the researcher or mental health professional asking the questions were more important than the content or length of the questionnaire. Professionals should treat people with mental health problems with dignity and respect, and be sensitive to their needs, they said. They should also be properly trained to complete the questionnaire.

‘There is widespread agreement that the development of effective treatments for health-related problems requires active input from people who use services,’ said Mike Crawford. ‘One of the areas where active service user involvement is essential is in deciding which measures should be used to examine the effectiveness of new treatments.

‘Funding of health services is often linked to ‘outcomes’ – so the choice of what constitutes a good outcome and way of measuring it is important for health services as well as trials and studies. We believe it is essential that service user views are taken into account when outcome measures are selected,’ he said.

Some questionnaires have been developed more recently in collaboration with people who have experience of mental health problems, but these were not included in this project.

■ *Outcome measurement in mental health: the views of service users*, May 2010. For more information about the study, email [l.thana@imperial.ac.uk](mailto:l.thana@imperial.ac.uk).

## ■ The Mental Health Research

**Network** supports research in England carried out with the help of people who use NHS services and people who work in them. Teams of clinical studies officers based at eight regional offices called ‘Hubs’ work with mental health professionals in NHS services to recruit people to MHRN-supported studies. They also offer practical support to research teams. Service Users in Research (SUiR) is part of the MHRN and can put research teams in touch with people with experience of mental health problems who are willing to advise or be involved in studies. The MHRN is part of the National Institute for Health Research and is known as the NIHR MHRN. For more information, visit [www.mhrn.info](http://www.mhrn.info)

## ■ The measures assessed within this project (and the scores they were given) were:

Beck Depression Inventory (7)  
Hamilton Depression Rating Scale (6)  
Patient Health Questionnaire (5)  
Psychotic Symptom Rating Scales (5)  
Positive and Negative Syndrome Scale (7)  
Scale for the Assessment of Positive Symptoms (6)  
Warwick-Edinburgh Wellbeing Scale (7.5)  
CORE Outcome Measure (7)  
General Health Questionnaire (4)  
Work and Social Adjustment Scale (4.5)  
Social Functioning Questionnaire (3.5)  
WHO Disability Assessment Schedule (3.5)  
12-item Short-Form Health Survey (3)  
World Health Organisation Quality of Life Assessment (7.5)  
Manchester Short Assessment of Quality of Life (7)  
Quality of Life Scale (6)  
European Quality of Life Scale (3)  
Liverpool University Neuroleptic Side Effect Rating Scale (8)  
Antipsychotic Non-Neurological Side Effects Rating Scale (7)  
Udvalg for Kliniske Undersøgelser (6.5)  
Outcomes Star (6.5)  
Clinical Global Impression – Improvement (5)  
Health of the Nation Outcome Scale (4.5)  
Global Assessment of Functioning (3)



The Mental Health Research Network is part of the National Institute for Health Research and supports studies in England.

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