Mental Health Outcome Measures

In memory of Judi Chamberlain and John K. Wing,
who have both contributed so much to our understanding of which outcomes
are most important to assess

Mental Health Outcome Measures

Third edition

Edited by Graham Thornicroft
and Michele Tansella

RCPsych Publications

CAMBRIDGE
UNIVERSITY PRESS

Shaftesbury Road, Cambridge CB2 8EA, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi – 110025, India

103 Penang Road, #05–06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of Cambridge University Press & Assessment,
a department of the University of Cambridge.

We share the University's mission to contribute to society through the pursuit of
education, learning and research at the highest international levels of excellence.

www.cambridge.org
Information on this title: www.cambridge.org/9781904671923

First edition published by Springer Verlag (Berlin, Heidelberg), 1996

RCPsych Publications is an imprint of the Royal College of Psychiatrists,
17 Belgrave Square, London SW1X 8PG
http://www.rcpsych.ac.uk

A catalogue record for this publication is available from the British Library

ISBN 978-1-904-67192-3 Hardback

The Royal College of Psychiatrists is a charity registered in England and Wales (228636) and in Scotland (SC038369).

Contents

Part III. Symptom severity outcome measures

Part IV. International approaches to outcome assessment

Tables, boxes and figures

Tables

Boxes

Figures

Contributors

Thomas Becker Department of Psychiatry, University Medical Center Groningen, University of Groningen, The Netherlands

Rohan Borschmann clinical psychologist and research worker at the Institute of Psychiatry, King's College London, UK

Elaine Brohan Health Service and Population Research Department, Institute of Psychiatry, King's College London, UK

Traolach (Terry) S. Brugha Professor of Psychiatry, and Deputy Head, Department of Health Sciences, University of Leicester; Honorary Consultant Adult General Psychiatrist, Leicestershire Partnership NHS Trust, Leicester, UK

David J. Castle holds the Chair of Psychiatry at St Vincent's Hospital and The University of Melbourne, Australia.

Sarah Clement Health Service and Population Research Department, Institute of Psychiatry, King's College London, UK

Emese Csipke Research Associate at the Institute of Psychiatry, King's College London, UK

Farifteh F. Duffy Director of Quality of Care Research at the American Psychiatric Institute for Research and Education, Arlington, Virginia, USA.

Graham Dunn Professor of Biomedical Statistics, Health Methodology Research Group, School of Community Based Medicine, University of Manchester, UK

David Goldberg Professor Emeritus, Institute of Psychiatry, King's College, London, UK

Juan Luis González-Caballero Professor of Statistics and Operational Research, University of Cadiz, Spain.

Aleksandar Janca Winthrop Professor and Head of School of Psychiatry and Clinical Neurosciences, University of Western Australia, Perth, Australia.

Rachel Jenkins Director, WHO Collaborating Centre and Head, Section of Mental Health Policy, Institute of Psychiatry, King's College London, and Visiting Professor, London School of Hygiene, UK

Sonia Johnson Professor of Social and Community Psychiatry, Department of Mental Health Sciences, University College London, and Camden and Islington NHS Foundation Trust, London, UK

Thomas Kabir Service Users in Research Coordinator for the National Institute for Health Research (NIHR) Mental Health Research Network (MHRN) at the Institute of Psychiatry, King's College London, UK

Antonio Lasalvia Department of Medicine and Public Health, Section of Psychiatry and Clinical Psychology, University of Verona, Verona, Italy

Anthony F. Lehman Professor and Chair, Department of Psychiatry, University of Maryland School of Medicine in Baltimore, Maryland, USA

Paul McCrone Health Service and Population Research Department, Institute of Psychiatry, King's College London, UK

Graham Mellsop Professor of Psychiatry, Waikato Clinical School, School of Medicine, Faculty of Medical and Health Sciences, University of Aukland, New Zealand

Paul Moran Clinical Senior Lecturer at the Institute of Psychiatry, King's College London, and Honorary Consultant Psychiatrist at South London & Maudsley NHS Foundation Trust, London, UK

William E. Narrow Associate Director of the Division of Research at the American Psychiatric Association and the American Psychiatric Institute for Research and Education, USA

Lindsay Oades Director of the Australian Institute of Business Wellbeing at the Sydney Business School, University of Wollongong, New South Wales, Australia

Michael Phelan Consultant Psychiatrist, West London Mental Health NHS Trust, London, UK

Bernd Puschner Senior Researcher at the Mental Health Services Research Unit, Department of Psychiatry II, University of Ulm, Germany

Mirella Ruggeri Department of Medicine and Public Health, Section of Psychiatry and Clinical Psychology, University of Verona, Verona, Italy

Luis Salvador-Carulla Professor of Psychiatry, Department of Neurosciences, University of Cadiz, and Head of the Reseacrh Unit, Fundacio Villablanca, Spain

Norman Sartorius holds professorial appointments at a number of universities. Previously Director of the WHO Mental Health Programme, President of the World Psychiatric Association and of the European Psychiatric Association, currently President of the Association for the Improvement of Mental Health Programmes.

Shekhar Saxena Director of the Department of Mental Health and Substance Abuse at the World Health Organization, Geneva, Switzerland

Aart H. Schene Department of Psychiatry, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Bruce Singh Deputy Dean, Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Australia

Mike Slade Reader in Health Services Research at the Institute of Psychiatry, King's College London, UK

Michele Tansella Professor of Psychiatry, Department of Public Health and Community Medicine, Section of Psychiatry and Clinical Psychology, University of Verona, Italy

Graham Thornicroft Professor of Community Psychiatry, Health Service and Population Research Department, Institute of Psychiatry, King's College London, UK

Tom Trauer is Professorial Fellow in the Department of Psychiatry, The University of Melbourne and St Vincent's Hospital, Melbourne, and holds an adjunct professorial appointment in the School of Psychiatry and Psychology, Monash University, Melbourne, Australia

T. Bedirhan Üstün is responsible for the World Health Organization's Family of International Classifications at the WHO in Geneva, Switzerland

Bob van Wijngaarden Trimbos Institute (Netherlands Institute of Mental Health and Addiction), Utrecht, The Netherlands

Scott Weich Health Sciences Research Institute, Warwick Medical School, University of Warwick, UK

Durk Wiersma Professor in Clinical Epidemiology of Psychiatric Disorders, Department of Psychiatry, University Medical Center Groningen (UMCG), University of Groningen, The Netherlands

John K. Wing (deceased) formerly Director of the MRC Social Psychiatry Unit at the Institute of Psychiatry for 25 years, and Professor at the London School of Hygiene, UK

Til Wykes Professor of Clinical Psychology and Rehabilitation at the Institute of Psychiatry, King's College London, UK, Director of NIHR Mental Health Research Network, and Editor of the *Journal of Mental Health*

Cambridge University Press & Assessment
978-1-904-67192-3 — Mental Health Outcome Measures
Edited by Graham Thornicroft, Michelle Tansella
Frontmatter
More Information

Foreword

In my years as a junior doctor in a general medical ward, I was often impressed by the gap between what the patient had originally complained of and the leads followed by the medical team in pursuing an unexpected abnormality in a routine investigation, which in fact had little relevance to the patient's actual concerns. Later, while training in psychiatry, I was interested to observe how clinical psychiatry followed a similar pattern: procedures were carried out which made sense to the clinical team but had little relevance to the patient.

This new edition of Thornicroft and Tansella's review of outcome measures marks an important step in the development of mental health services, in that major emphasis is now given to aspects of outcome that are valued by the service users themselves. In Chapter 1, Kabir and Wykes review this important field, and point out that users are more interested in recovery and happiness than in remission of presenting symptoms. Even measures of 'satisfaction with services' that are not devised in collaboration with users come in for a critical examination.

However, another new area of interest, identified by the editors in the Introduction, is indeed the currently fashionable concept of 'recovery', which gets an extended treatment in Chapter 4. As a retired psychiatrist, I found the new enthusiasm for full recovery rather strange, as it appears to imply that such an aim is something new and (worse still) always achievable. However, it emerges from Chapter 4 that there are in fact a range of meanings ascribed to the concept of 'recovery', ranging from the fairly modest aim of living as well as possible to the more utopian one of having a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination.

Failure to achieve 'full recovery' may not be due either to incompetence on the part of the clinician or to lack of motivation on the part of the patient; it is often due to the severity of the underlying disorder. It seems to me important that, rather than inwardly apologising to themselves for incomplete recovery, clinicians should adapt their energies to enabling users to achieve more personal autonomy. But for the most disabled patients with long-term severe mental disorders, enabling them to make personal choices about what they eat and giving them a more active involvement in the choices they can make in their personal lives are worthy objectives. An example of this is given in Fig. 4.1 (p. 71), where a user sets her own goals for an improvement in her autonomy.

This new edition is indispensable to researchers in health services research, as it is strikingly comprehensive, with every aspect of outcome covered, and includes all the most recent developments in the field. New measures are constantly being developed, and old measures are often re-evaluated, so that even those chapters that are similar to those in previous editions have new and important information. An example of this appears in Chapter 2, on statistical methods for measuring outcomes. Novices to the field are stepping over a statistical minefield when they rely on single, small evaluations – Dunn emphasises the importance of multicentre trials in order to achieve adequate power.

The book does what needs to be done – it brings the whole field up to date, and in doing so expands our horizons.

David Goldberg
Professor Emeritus
Institute of Psychiatry, King's College London

Foreword

Many different themes dominate the current literature on mental health services. Services should facilitate meaningful outcomes. The mission should be recovery. Interventions should be evidence based. Care should be client centred or self-directed. The mental health system should diminish stigma and foster social inclusion. Information technology should enhance efficiency. And many more! Each of these represents an endangered species. Why endangered? Simply put, philosophical movements easily become transient fads when they are not grounded in measures, numbers and data. Ideas, goals, guidelines, missions, benchmarks and plans require measurement to attain any hope of enduring reality. If nothing is measured, nothing changes. Instead, the next year brings a new commitment to yet another banner idea.

Mental health has long suffered from lack of measurement – a tradition extending back to the days when lack of measurement was valorised by clinicians who argued that the entire enterprise was too personal, ethereal or mystical to measure. Mental healthcare has, though, emerged from the dark ages. Although we still lack clear biological and physiological standards, measurement must be at the core of what we do. And measurement is no simple matter.

As the authors of the following chapters argue, measurement in mental health is serious and arduous work. We need measures that are reliable and valid, that address meaningful processes and outcomes, that uphold and reinforce our values, and that enhance rather than impede the enterprise of behavioural health. Developing, refining, testing, comparing and instantiating such measures are essential tasks if the field is to move forwards, rather than recycle old ideas in new terminology.

I commend the editors for their persistent efforts to encourage high-quality research. The chapters herein describe progress on many important fronts.

Robert E. Drake MD PhD
Andrew Thomson Professor of Psychiatry
Dartmouth Medical School, Lebanon, New Hampshire, USA

Preface: an evolving perspective of mental health outcome measures

Since the appearance of the two previous editions of *Mental Health Outcome Measures* (first published by Springer Verlag in 1996, with a second edition published by the Royal College of Psychiatrists in 2001), there have been several intriguing developments in the field. First, an even wider range of important outcome domains are now measurable using well standardised instruments than were measurable before. Second, a greater emphasis upon positive outcomes has evolved (for example referring to the concept of recovery) among researchers, service users and clinicians. Third, the voice of the service user/consumer is now centre stage to a much greater extent than in earlier years. This third edition refers to these three core themes throughout its pages. Nevertheless, the fundamentals remain unchanged, namely:

- the scales used must have known and strong psychometric properties (Chapter 2)
- evidence (both qualitative and quantitative) needs to be ascertained from the most rigorously scientifically designed studies (Chapter 3), taking into account the complexity of the intervention (Campbell *et al*, 2000, 2007; Tansella *et al*, 2006)
- in many outcome studies, symptom and social domains (such as quality of life and employment) need to be assessed concurrently (Chapters 5, 8, 9, 11, 13, 14 and 16)
- scales need to be applicable and relevant to a wide of settings to allow valid international comparisons (Chapter 17)
- an inclusive approach to the whole range of mental disorders is required, so that people are included whose conditions have sometimes been excluded from care, such as personality disorders (Chapter 15).

At the same time, a clear trend is now identifiable not so much to look at mental disorders in terms of their producing chronicity, impairment and severe disability but instead to emphasise the hope of recovery (Chapter 4). Central to this view is the participation of service users in research (Chamberlin, 2005) and a more nuanced approach to potential collaboration between people disclosing experience of mental illness, and others, in the development and use of outcome measures (Sweeney *et al*, 2009). In other words, people with direct experience of mental illnesses (both service users and family members) are gradually coming to be seen less as the 'subjects' or 'objects' of research, and more as those in fact with the greatest depth of knowledge and experience of the conditions. They are therefore in the strongest position to give valid ratings of which treatments and services confer benefit (Chapters 1, 6 and 7). This change of perspective is of fundamental importance (Rose *et al*, 2006).

In a global context, this edition documents the continued and rapid production of new scales and the translation of psychometrically well established scales into new languages (Sartorius & Kuyken, 1994; Thornicroft *et al*, 2003). Even so, the number of effectiveness studies does not distribute equitably across international settings; in particular, few, as yet, have been carried out in low-income countries (Saxena *et al*, 2004; Patel *et al*, 2007; de Jesus *et al*, 2009).

There is another sense in which outcomes are important, namely how far the results of research are used to shape and improve routine clinical practice. This applied end of the research spectrum has been referred to as 'implementation science', and is itself at present underdeveloped, under-researched and underfunded (Tansella & Thornicroft, 2009). For example, although many hundreds of papers refer to the creation of clinical guidelines, few studies have explored under what conditions clinicians actually put such guidelines into practice (Madon *et al*, 2007; Proctor *et al*, 2009).

The operational linkages between policy and practice are therefore now being scrutinised as never before, both to identify interventions which are effective and cost-effective, and to judge how to realise behavioural changes on the part of practitioners that lead to better outcomes for people with mental health problems (Chapters 10 and 18).

When the first edition of this book was published in 1996, we wrote that 'research instruments are the basic tools of health service evaluation'. We would now add that the skilful use of these tools requires, as for artists or craftsmen, a clear eye for design, a steady and relentless focus upon the needs of the consumer, and the skill to realise the creative intent – in this case better mental health (Thornicroft & Tansella, 2009).

References

Campbell, M., Fitzpatrick, R., Haines, A., *et al* (2000) Framework for design and evaluation of complex interventions to improve health. *BMJ*, **321**, 694–696.

Campbell, N. C., Murray, E., Darbyshire, J., *et al* (2007) Designing and evaluating complex interventions to improve health care. *BMJ*, **334**, 455–459.

Chamberlin, J. (2005) User/consumer involvement in mental health service delivery. *Epidemiologia e Psichiatria Sociale*, **14**, 10–14.

de Jesus, M. J., Razzouk, D., Thara, R., *et al* (2009) Packages of care for schizophrenia in low- and middle-income countries. *PLoS Medicine*, **6**, e1000165.

Madon, T., Hofman, K. J., Kupfer, L., *et al* (2007) Public health. Implementation science. *Science*, **318**, 1728–1729.

Patel, V., Araya, R., Chatterjee, S., *et al* (2007) Treatment and prevention of mental disorders in low-income and middle-income countries. *Lancet*, **370**, 991–1005.
Proctor, E. K., Landsverk, J., Aarons, G., *et al* (2009) Implementation research in mental health services: an emerging science with conceptual, methodological, and training challenges. *Administration and Policy in Mental Health and Mental Health Services Research*, **36**, 24–34.
Rose, D., Thornicroft, G. & Slade, M. (2006) Who decides what evidence is? Developing a multiple perspectives paradigm in mental health. *Acta Psychiatrica Scandinavica*, suppl. 429, 109–114.
Sartorius, N. & Kuyken, J. (1994) Translation of health status instruments. In *Quality of Life Assessment in Health Care Settings* (eds J. Orley, & J. Kuyken), vol. 1, pp. 3–18. Springer-Verlag.
Saxena, S., Sharan, P. & Saraceno, B. (2004) Research for change: the role of scientific journals publishing mental health research. *World Psychiatry*, **3**, 66–72.
Sweeney, A., Beresford, P., Faulkner, A., *et al* (eds) (2009) *This Is Survivor Research*. PCCS Books.
Tansella, M. & Thornicroft, G. (2009) Implementation science: understanding the translation of evidence into practice. *British Journal of Psychiatry*, **195**, 283–285.
Tansella, M., Thornicroft, G., Barbui, C., *et al* (2006) Seven criteria for improving effectiveness trials in psychiatry. *Psychological Medicine*, **36**, 711–720.
Thornicroft, G. & Tansella, M. (2009) *Better Mental Health Care*. Cambridge University Press.
Thornicroft, G., Becker, T., Knapp, M., *et al* (2003) *International Outcome Measures in Mental Health. Quality of Life, Needs, Service Satisfaction, Costs and Impact on Carers*. Royal College of Psychiatrists.

Michele Tansella and Graham Thornicroft