

## Chapter

## 1

# Introduction

Tom Trauer

In this introductory chapter I shall cover the historical and theoretical background to outcome measurement in mental health, provide a road map to the contents of this book, and express my appreciation to contributors. The final chapter will aim to draw conclusions from what has been presented and give some pointers to the future.

## Preliminaries

Before embarking on the main aims of this chapter, I pause to note and explain some conventions I shall adopt. This book is about Outcome Measurement, but this is not a universally agreed term. Some have written about Outcome Assessment (Close-Goedjen and Saunders, 2002), others of Outcome Management (Andrews and Page, 2005, Miller et al., 2005, Puschner et al., 2009) and others of Outcome Evaluation (Ciarlo, 1982, Speer, 1998). While recognizing differences in nuance, we shall treat these terms as interchangeable for the most part, and talk of Outcome Measurement (OM) by default. To some degree, the different terminologies reflect the fact that OM, like the term outcome itself, has no firm or formal definition. At this stage, we may say that OM concerns the use, in a systematic and ongoing way, of standard instruments that assess aspects of mental health for the purpose of promoting the care of service recipients.

## Background

In this section we shall survey the history and theoretical underpinnings of outcome measurement (OM) in mental health. An appreciation of the background of a subject can illuminate its current status. Given that OM can be a time-consuming and costly business, it would be short-sighted not to take the opportunity to learn from the experience of people in other countries and in other times, always remembering that ‘Those who cannot remember the past are condemned to repeat it’ (Santayana, 1905).

When did OM in mental health begin? Certainly OM in health services has been around for a long time. In 1987 there was published an article entitled ‘Outcome assessment 70 years later: are we ready?’ (Schroeder, 1987); this provocative title alluded to origins in attempts to get surgeons and hospitals to publicize the results of their operations in the early twentieth century. The earliest publication in my personal mental health OM database is 1980, when McPheeters (1980) discussed the use of several commonly used scales to evaluate the community impact of mental health services. Shortly thereafter, Ciarlo (1982) wrote about the arrival of client outcome evaluation, noting that ‘Increasingly, these officials [program managers and funders] are becoming concerned with more than just the numbers and targets of services delivered, and the cost involved, and are looking for evidence of positive outcome or impact on clients to justify program implementation and maintenance.’ Outcomes evaluation offered a route to accountability through performance measurement and quality assurance.

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These ideas produced several reactions, one of which sounds eerily contemporary: Newman (1982) noted the importance of good computer technology and for the data to be fed back to clinicians rapidly, and he also warned of a potential problem with practitioner compliance. He cited evidence that ‘both level of functioning and treatment selection judgements increase in reliability when staff have had more training . . . and experience in using a level of functioning scale as an ordinary part of their clinical assessment and communication’.

One of the most influential events around that time was the annual Shattuck lecture, hosted by the venerable Massachusetts Medical Society and reported in its journal, the prestigious *New England Journal of Medicine*. In 1988 the title was ‘Outcomes Management – A technology of experience’. In his address, Paul Ellwood (1988) called for the evaluation of medical services to move away from a focus on expenditure and towards enhanced quality of life. He spoke of a ‘common patient-understood language of health outcomes’ and a national database containing clinical, financial and outcomes information, which would ‘routinely and systematically measure the functioning and well-being of patients, along with the disease specific clinical outcomes, at appropriate times’. Two years later, Epstein (1990), commenting on Ellwood’s clarion call, asked whether outcomes management was the third revolution in medical care, the first two having been the Era of Expansion and the Era of Cost Containment, according to Relman (1988). Noting that Ellwood was a champion of the HMO (Health Maintenance Organization), Epstein identified the origins of the outcomes movement in cost containment, competition between providers, and the wide geographic variations in the use of certain medical procedures. A similar point was made by Mirin and Namerow (1991): ‘Concern about the spiralling cost of mental health care has increased the need for reliable data about the outcomes of such care’.

Our foray into some of the early history of OM has revealed that practically all of that work was from the United States of America. This may simply be a reflection of the dominance of the USA of the medical literature, and maybe of medical innovation, but it may also relate to the economic climate in which health care, including mental health care, operated, and continues to operate. Health care costs in the USA are among the highest of developed nations, and it is clear that a large part of the early motivation for OM was economic.

## The rise of Outcome Measurement

Since its origins in the 1980s, OM has expanded rapidly. The idea has spread internationally, and one section of this book contains accounts of how it is currently manifested in Australia, Canada, Germany, Italy, New Zealand, Norway, the United Kingdom and the USA. At this point it is worth noting that this set of countries is not meant to suggest that OM doesn’t exist in some form in other countries; the countries reported herein represent those where OM has been most clearly developed and where it has been best reported. Furthermore, even within the countries that are represented by chapters, OM practices are not necessarily uniformly distributed. For example, the Canada chapter reports developments in the province of Ontario, and the Italy chapter focuses largely on work done in Verona.

The rise of OM can also be seen from the growth of the OM literature. Two literature searches were undertaken of the PsycInfo and Medline databases of the period 1988 to 2007 inclusive. One search was on the terms Psychiatry or Mental Health, and the other was on those terms and Outcome. Figure 1.1 shows the results.

It can be seen that, between 1988 and 1990, about 5% of citations matching Psychiatry or Mental Health also matched Outcome as a search term. This had risen to about 10% by 1995, and has been consistently above 15% since 2000. Of course, not all of the citations matching

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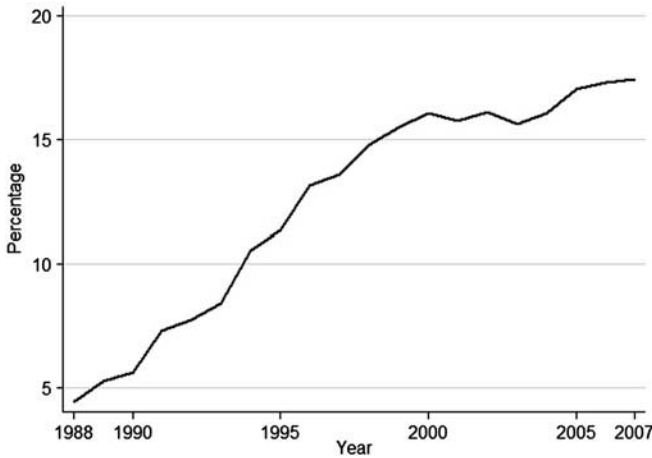
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**Figure 1.1** Percentage of citations on Psychiatry or Mental Health that were also about Outcome, 1988 to 2007.

Outcomes were concerned with the narrower concept of OM as understood here, but it is nevertheless clear that there has been a steadily increasing focus on outcome in the mental health literature.

## What is an outcome?

Having established that there has been steadily increasing interest in outcome, we now turn to the more difficult question of what outcome actually means in the present context. At one level, everyone knows what an outcome is – it is a result, effect or product, usually of some action. The idea of an outcome as a consequence of action is echoed in the most widely cited definition of outcome in mental health: ‘the effect on a patient’s health status that is attributable to an intervention’ (Andrews et al., 1994). The straightforwardness of this definition has no doubt contributed to its popularity. However, a number of commentators have suggested that things may not be so simple.

It may appear that the minimum requirement for an outcome is that something must have changed. However, it has pointed out that ‘Maintaining a patient’s health status may in some circumstances be considered a positive outcome’ (Jacobs, 2009, p. 3). This is especially pertinent for consumers with enduring, or even deteriorating, conditions, who are not realistically expected to make significant gains. Even when changes on measures are obtained, there can be technical issues with judging whether a change in the score yielded by an instrument corresponds with a change in the consumer. This issue is considered in greater depth in the chapter on assessing change, but the point here is that some judgement needs to be made as to whether a change in score is merely random, clinically trivial fluctuation, or measurement imprecision, or a true and significant change in health status. One useful perspective on the centrality of change was proposed by Eagar (2002), who distinguished between ‘before and after’ and ‘with and without’. The former (‘before and after’) models the outcome as the change in scores before and after an intervention. But, as Eagar argues, the ‘with and without’ approach is ‘of particular relevance to chronic diseases where the goal of the intervention may be to maintain current health status . . . which would be rated as a good outcome if the alternative were a possible decline’ (p. 143).

The requirement for a change to be attributable to an intervention has attracted a number of reservations. It has been noted that ‘Although routine measurement of outcomes will tell

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us something about what is being achieved by health care, the difficult question is one of attribution. . . . Methodological flaws in routine outcomes data preclude strong assertions on attribution' (Davies and Crombie, 1997). That an intervention precedes a change does not mean that it must have caused it. In focus groups conducted by Stedman et al. (1997), consumers and service providers expressed concern over 'the extrapolation of data collected on these measures to judgements concerning the effectiveness of service provision. That is, attributing change in a person's mental health condition to the efficacy of treatment' (p. 93); a similar point was made by Rissel et al. (1996). Stedman et al. felt that 'to reduce the emphasis on attribution may assist the promotion of the use of routine consumer outcomes measurement' (p. 93). Proof of causality in the human sciences is difficult; the strongest evidence comes from randomized controlled trials, and only a handful of such studies have been conducted in the OM field. Some 'outcomes' may be largely a product of self-help, or of informal, non-professional care, and others could occur after no obvious intervention, i.e. spontaneous remission. Even when appropriate, targeted treatment appears to work, one cannot always be sure who should take the credit; to paraphrase the sixteenth-century physician Ambroise Paré 'I treated him, but God healed him' (Strauss, 1968, p. 627). Trauer (1998) has suggested that when the focus of the outcome is the intervention itself, attribution may be straightforward ('The operation was a success'); it is when the focus is on the consumer ('She is less depressed') that attribution becomes problematic. He therefore suggested that the requirement for attribution be omitted from the definition of outcome. An attribution-free definition of outcomes was put forward by Charlwood et al. (1999, p. 3): '... changes in health, health related status or risk factors affecting health, or lack of change when change is expected'.

Another component of the Andrews et al. definition of outcome to come under scrutiny is the intervention. Sonnanburg (1996) pointed out the difficulty of knowing what are the real change agents since there are so many influences in real life. I (Trauer, 1998) noted that even standard mental health care comprises many components, such as medication, psychological therapy and case management, so 'Since we generally cannot disentangle the active ingredients of therapy, we cannot unequivocally specify the intervention'. I went on to suggest that 'This problem is resolved if we break the link with interventions and regard outcome as, say, the change in health status between two points in time. The two points need not be random, but can have particular significance in the patient's career, such as pre-operation and post-operation, or admission and discharge. The establishment of a causal connection between any change in health status and the intervening activity then becomes an empirical question which can be studied scientifically'.

The last issue relating to the understanding of outcome that we shall consider here is that of mixed outcomes. It is by no means unusual for some things to get better while other things are getting worse. I (Trauer, 1998) gave the examples of psychotic symptoms reducing at the expense of side-effects, and hospitalization increasing safety at the expense of independence. Detailed assessments of the different elements of symptoms, functioning and experience can track their separate movements. Aggregated scores, on the other hand, may have improved reliability, but will lose much of the nuances; also, summing improvements and deteriorations in multi-item scales can lead to 'cancelling out', which will give a false impression of less change than actually occurred.

**Why measure outcomes?**

In this section we shall review some of the models and principles that have been put forward as to why outcomes should be measured. As was suggested earlier, all stakeholders in

the health care enterprise have a natural interest in outcome (although what they mean by that term may differ in certain important ways). Therefore, why go to the extra expense and trouble in subjecting outcomes to measurement?

### (a) The information needs of managers

In a section entitled ‘What Performance Areas Does a Manager Need to Know About’, Leginski et al. (1989, p. 23) enunciated their informational needs thus:

*Who receives what from whom at what cost and with what effect.*

The italicized words represent the informational domains. ‘Who’ refers to the consumers; a service will need to know how many of them there are, plus certain basic demographic and clinical (e.g. diagnostic) details. This information is generally readily available through the medical records system, or equivalent. Sometimes the ‘who’ may refer to the population served, as in a catchment area, and sometimes the people served include carers and/or family members, as in child and adolescent services. Generally, however, the ‘who’ information is not problematic. The ‘what’ refers to the services provided, in the sense of elements such as inpatient beds, residential places, day programmes, outpatient clinics, case management, emergency teams, and maybe additional specialist teams. The ‘what’ may include property, such as buildings and equipment. Mostly, these elements are easy to catalogue since they describe the settings where services are delivered. Services are not always direct to identified consumers; in preventive work, such as community consultation, and health promotion, the activity is directed to individuals and organizations other than registered service recipients. Nevertheless, as with the ‘who’, this element is relatively straightforward. The ‘from whom’ refers to the staff. Leginski et al. advise that this should be all staff working in the organization, not just the direct care component. For the clinicians, however, this will include the mix of professions, perhaps supplemented by details of their levels of training, qualifications and experience. For the sake of judging how well the clinical staff reflect the composition of the consumers served, one might also be interested in further descriptions, such as age, gender and ethnic background. ‘At what cost’ is obviously the available budget, an element that most managers are only too acutely aware of.

It is with the last element of the group, ‘with what effect’, that measured outcomes are concerned. As Leginski et al. say in their chapter on assessing impact, ‘Assuming that managers within the organization have ample information on the other components of this knowledge model, i.e. clientele, services, finances and staff, it is quite logical for them to pose the question, So what?’ (p. 89). Indeed, they go further and assert that ‘Managers have a responsibility to assess’.

This formulation has the value of showing, in a succinct way, the relationship of outcomes to other fundamental aspects of complex human services. In addition, it alerts one to the need to take clientele, services, finances and staff into account when evaluating the performance of a service. The Leginski model has proved attractive as explaining the rationale of outcome measurement in Australia; it has been cited in the informational priorities in the Second National Mental Health Plan (Department of Health and Aged Care, 1999) and in the model for outcome measurement in private psychiatric hospitals in Australia (Morris-Yates and The Strategic Planning Group for Private Psychiatric Services Data Collection and Analysis Working Group, 2000).

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**(b) Assisting with decision-making**

While there may be legitimate interest in quantifying the magnitude of treatment effects in scientific studies, one clear reason for measuring outcomes has been to provide a guide for action. Sutherland and Till (1993) distinguish three levels of decision-making: micro (clinical), meso (agency, institutional or regional) and macro/meta (governmental). Stedman et al. (1997, p. 12) suggested the following kinds of decision associated with each level: ‘What treatment goals are necessary to meet the needs of this individual?’ (clinical); ‘What are the best treatment approaches for addressing the needs of this group of people?’ (agency); and ‘What are the best treatment approaches for meeting the needs of this population of people?’ (governmental).

There are many expressions of the intention or hope that the measurement of outcomes will assist decision-makers in some way. Ellwood (1988) envisaged opportunities for each decision-maker to have access to the analyses that are relevant to the choices they must make. Benjamin et al. (1995, p. AS299) said that ‘outcomes research is meant to be used to make better decisions about health care in the context of social, political, economic, and regulatory forces’. Mirin and Namerow (1991) saw the study of outcomes as rationalizing clinical decision-making, a view challenged by Gale (1997) on the grounds that services do not have sufficient control over all the relevant functions and factors. So important is this purpose that Speer and Newman (1996) went so far as to propose that relevance for decision-makers must take priority over scientific rigour. This is similar to the position characterized by Iezzoni (1994): ‘Given the dearth of information currently available about the relative merits of health care providers, one needs to start somewhere, even if the data are not perfect’.

For the most part, these early expectations related to decision-making at the agency and governmental level, and were expressed in quite general terms, with little detail as to what those outcome-based decisions might be. One example was offered by Bilbrey and Bilbrey (1995), who interviewed 49 health care payors. They identified the selection of which providers to make contracts with as the primary type of decision that would be most influenced by outcomes data. At that time, this primary strength of outcomes data for purchasers of services was also one of the primary threats to the providers; Iezzoni (1994, p. 350), in her list of common concerns of providers, included that ‘These imperfect data may be used wrongly to threaten providers or make punitive decisions (e.g., withdrawing third-party reimbursements)’.

In parallel with meso- and macro-level uses, outcomes information is expected to have decision-making uses at the micro, or individual, clinical, level. Slade (2002) identified ‘the ongoing measurement and use of outcome data to inform decisions about whether to continue, change or curtail treatment’ as a central purpose. The notion of ongoing measurement implies that it is the trajectory that these measurements reveal that will form the basis of action on the part of the clinicians. This is at the heart of the system developed by Michael Lambert and colleagues, and detailed in his chapter in this book. Lueger et al. (2001) talk of the ‘expected treatment response’ as the predicted path of progress, against which the actual path can be compared. This leads directly to the concepts of ‘on track’ and ‘off track’ (Lambert et al., 2001), which can be communicated immediately to the clinician, along with suggestions for corrective action. This is particularly valuable in the early identification of consumers at risk for treatment failure, a risk that therapists systematically underestimate (Hannan et al., 2005).

There are examples of outcome measures obtained at single points in time being used in assisting with decisions in the individual case. Prowse and Coombs (2009) described the use

of high or low severity scores on the Health of the Nation Outcome Scales (HoNOS, Wing et al., 1998) to suggest transfer to (respectively) more or less intensive forms of care. Prowse and Hunter (2008) used a measure of functioning and disability (the Life Skills Profile, LSP, Rosen et al., 1989, 2006) to assist in choosing the form of psychological treatment for consumers with Borderline Personality Disorder. Slattery and Anstey (2008) described the discussion of HoNOS results in multidisciplinary team meetings as contributing to the development of consumer care plans and assessing readiness for discharge. It is also proper to acknowledge that there have been some doubts expressed over the suitability of outcome measures to guide treatment decisions. Iezzoni (1994) has noted that ‘Most existing severity measures were intended to be used across groups of patients and are not well suited to making inferences about individual case’ (p. 202). Others (e.g. Gifford, 1996) have questioned whether measures on standard instruments are sufficiently sensitive to the unique qualities and needs of consumers.

### (c) Incorporating the consumer’s perspective

Part of the impetus for outcome measurement came from the recognition of the importance of the consumer perspective in the treatment process. This is of course true in all aspects of health care, but no less so in mental health, where many of the issues and problems are not readily visible to clinicians, who are especially reliant on personal reports from service recipients. While much of the rationale for outcome measurement has revolved around the needs of funders, managers and clinicians, the increasingly prominent and effective consumer constituency, as well as many non-consumers, have pointed out that the service recipients, and their interests, should be central to the outcome measurement enterprise. Sometimes the motivation appears to be that involving the consumer aids the objectives of the provider; Eisen et al. (1991) have suggested that patients can be recruited as evaluators of their own progress, and their satisfaction with services received can be an indicator of acceptability. Other possible benefits of including the consumer’s point of view can be the enhancement of the clinician–consumer relationship. Greenhalgh et al. (2005, p. 834), however, have reviewed evidence suggesting that while feedback of quality of life scores to clinicians may increase their discussion within sessions, it generally does not influence (clinicians’) decisions concerning treatment.

There is abundant evidence that consumers’ priorities in mental health care are often at some variance with those of providers, hence when we speak of outcomes there can be the unspoken question: ‘According to whom?’. Very broadly, clinicians tend to prioritize symptoms and functioning, while consumers, and often their family members and carers as well, prioritize clear information and involvement in decision-making (Graham et al., 2001, Noble and Douglas, 2004). Unfortunately, there is now considerable evidence that clinicians tend to consistently misread their consumers’ wants, while confidently believing that they appreciate them accurately (Noble et al., 1999, Trauer and Callaly, 2002).

Even when the relevant parties agree on what the important problems are, consumers can, and do, argue that their evaluations are the more valid – in effect, they are the ‘experts by experience’ (Faulkner, 1998). This issue becomes even more acute when trying to judge the outcomes of consumers who belong to certain ethnic and cultural subpopulations, which may hold quite different conceptions of health and illness from the mainstream (e.g. Maori, Durie and Kingi, 1997). There exists wide variation in the extent to which the consumer perspective is formally incorporated into outcome systems; some systems rely exclusively or predominantly on consumer self-report (see chapters by Michael Lambert and by Jim Healy and

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Dee Roth in this book), while others are more heavily weighted toward clinician-completed measures, such as the HoNOS.

**About this book**

Any new book needs to justify its existence. There are already several excellent, substantial and authoritative works on outcome measurement, such as Sederer and Dickey (1996), Lyons et al. (1997), Speer (1998), Tansella and Thornicroft (2001) and IsHak et al. (2002). But these works all appeared some time ago and, as was shown earlier, much has happened in the field of outcome measurement since then. In addition, much of the more recent work has been done in Australasia. So one of the purposes of this book has been to bring some of the more recent developments together into a single source.

It is apparent from the table of contents that this book is organized into three main sections. The first presents implementations of outcome measurement in large jurisdictions, countries or (American) states. The objective here is to demonstrate how the same concept can be manifested in different settings, and how the principles are realized differently according to national policy, local leadership and the economic and cultural organization of health, and mental health, services. The jurisdictions represented are those that are best known to myself through the literature and through personal contacts. The absence of a country or region should not be taken to mean that outcome measurement does not happen there; indeed, there are a number of such local implementations of outcome measurement, but generally at a relatively small and limited level, making it difficult to justify a full treatment in this book.

Outcome measurement cannot be undertaken in an identical fashion in all parts of a mental health system; it must be adapted to the specific requirements of the population served. The second section comprises chapters describing how outcome measurement has been and can be delivered in three main age categories (Child and Adolescent, Adult and Older Persons), as well as to indigenous consumers, and those in private hospitals, non-government services (NGOs) and drug and alcohol services.

The third section deals with several central themes in most of which there is as yet no clear consensus. The ‘applications and utility’ chapter presents examples of what outcome measurement has to offer to various stakeholders, followed by a chapter reviewing stakeholders’ attitudes and opinions in relation to OM. The ‘assessment of change’ chapter deals with some of the issues involved in the judgement of individual and group change. A chapter is devoted to training and workforces issues, and another presents an overview of the domains that are covered by some of the leading instruments; the section concludes with a chapter on outcome measurement from an economics point of view.

It will be apparent that there is no chapter written by a service recipient; all of the contributions are from people with predominantly clinical and/or academic backgrounds. The book is primarily intended for a clinical, managerial and academic readership, and the selection of content and authors reflects this.

The previous paragraph spoke of the service recipients. This raises the question of what is the respectful and proper way to describe those who receive mental health services. Patient, consumer, user and survivor are just some of the terms that have been used, and there are sometimes strong preferences and aversions to some of them among different stakeholders in different countries. In some countries there are national conventions: the common usage in mental health services in Australia and New Zealand is ‘consumer’, and in the United Kingdom it is ‘user’. In this book, contributors have been free to choose their own terminology. Being from Australia, I have used ‘consumer’ in this chapter.

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