



# THERAPY OUTCOME MEASURES FOR REHABILITATION PROFESSIONALS

Speech and Language Therapy,  
Physiotherapy, Occupational Therapy

SECOND EDITION

PAMELA ENDERBY

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FOR REHABILITATION  
PROFESSIONALS**



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**SPEECH AND LANGUAGE THERAPY;  
PHYSIOTHERAPY; OCCUPATIONAL THERAPY;  
REHABILITATION NURSING; HEARING  
THERAPISTS**

Second Edition

**Pamela Enderby**

with

**Alexandra John**

&

**Brian Petheram**

Compatible with ICF and incorporating ICD10



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## **PREFACE**

The Therapy Outcome Measure (TOM) allows therapists to describe the relative abilities and difficulties of a patient/client in the four domains of impairment, activity, participation and well-being in order to monitor changes over time. This approach has been rigorously tested for reliability and clinical validity and can be used by physiotherapists, occupational therapists, speech and language therapists, rehabilitation nurses and hearing therapists. It aims to be quick and simple to use, taking just a few minutes to complete and has been used for treatment planning, clinical management, audit, and research. It allows for the aggregation of data so that comparisons can be made for the purposes of internal and external benchmarking. The approach has been trialed in order to establish the differential outcomes between different client groups and different rehabilitation units.



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# SECTION 1

## **Theoretical Underpinning and Testing**

## INTRODUCTION

This manual is intended to assist with the practical implementation of gathering outcome data on patients/clients receiving treatment.

The data related to the development of this approach, the reliability and validity trials, the development of the scales, and the pilot study results are reported in the accompanying technical report. It is essential that, prior to implementing this method of measuring outcome, a thorough understanding of the philosophical and technical underpinning is achieved.

Over the last decade, there has been a growing awareness of the importance of being able to gather information that could assist in identifying specific gains related to treatment programmes. This should not only help to identify areas for resource change but also enable health care professionals to monitor the effectiveness of their treatments with individual clients.

One of the essential components of this approach is the acknowledgement that therapy endeavours to have an impact on many areas of the client's life. Traditionally, most assessments of patients/clients have concentrated on changes in the deficit/disorder, whereas goals of therapy might also aim to alter the functional components of communication, mobility, activities of daily living (ADL), autonomy, coping skills and adaptation. In order to determine if we are being effective with different client groups, it is necessary that we have a good understanding of the patient's/client's situation prior to, during and following the treatment.

Outcomes have been defined as results or visible effects of interventions. In healthcare, outcomes form part of the quality cycle which can be improved through evaluation. Outcome data can provide information on the impact of interventions, to identify the effectiveness of practices (care pathways, costs of care, resources), and facilitate the design of guidelines (Shaw and Miller, 2000; The College of Speech and Language Therapists, 1991). Information from a number of sources is required in order to build a picture of the outcome of current practice, and to identify the evidence for best practice. By understanding discrepancies between the two, issues for change can be identified, changes effected, and quality of care improved.

Quality assurance requires the health worker to provide a high standard of practice, yet definitions of quality in respect of its application to the provision of healthcare remain ambiguous. The UK Government White Paper (1999) defined quality as providing an equitable, efficient and responsive service, as follows:

- **Equity:** to reduce variation in health by targeting need;
- **Efficiency:** effective care for best use of money; and

- **Responsiveness:** to meet individual needs while responsive to changes in circumstances and knowledge.

Clinical governance has been introduced to the National Health Service in the United Kingdom as a means of ensuring quality (White Paper Department of Health, 1999). As a concept, clinical governance provides a framework to ensure quality of clinical care, so that service users benefit through continued endeavours for improvement (Buetow and Roland, 1999). The five areas needed to be addressed in order to achieve this quality improvement are: good use of information (with education, patient/client liaison and multi-disciplinary involvement); reduction of inequity and variations in care; involvement of individuals in service and care plans; sharing good practice (learning by comparison, benchmarking); and detecting and dealing with poor performance (Swage, 2000 pp. 48–49).

The evaluation of outcomes is an important part of clinical governance. Outcome data can provide a baseline of current practice, against which comparisons over time or with other similar services can be made in order to identify useful information on practice. If the data is to inform change, it is essential that it is seen to be relevant as well as being accessible to stakeholders. The use of any outcome indicators requires those using the method to be trained to use it reliably as well as appreciating its clinical relevance.

Recent radical changes in health service delivery have increased the pressure on all service providers to examine their methods for reporting results relating to the impact of health services (Wilkin et al. 1992). There is greater awareness of the disparity of health care, widely differing costs and concerns about demonstrable effectiveness. Information reflecting the effects of treatment is essential in order to modify methods of provision, influence purchasing patterns and assist in monitoring contracts along with harnessing efforts to improve care (Ware, 1991; Ware and Sherbourne, 1992). Hence, professionals are becoming more conscious of their social as well as clinical responsibility to account for the value and benefits of interventions.

The importance of basing health care on a firm knowledge base to improve cost-effectiveness and efficiency is highly laudable. However, moving towards gathering information in a formal and reliable way that will clarify health gain is a complex process. There has been a tendency in collecting data to focus on input, throughput and output, to equate the outcome of an activity with the rate at which patients/clients are being referred or discharged rather than determining the impact of particular care packages on an individual's health (Hopkins, 1993).

“Purchasers are not indifferent to the question of quality but they are stymied by the ‘current state of the art’ in quality measurement” (Health Care Advisory Board, 1994, p. 32); this is due both to clinical and technological limitations and different views regarding what constitutes quality. Replicable and meaningful data are hard to find and even harder to decipher.

Outcome measurement is complex because it is difficult to define the effects of care, and frequently there is little agreement regarding what health programs are endeavouring to achieve with different client groups. For example, with a patients/client with progressive neurological disease, it may be more appropriate for a clinician to be concerned with appropriate pain management and the assurance that death is going to be handled appropriately rather than with a “cure”.

Most outcome measures have concentrated on negative outcomes, such as the reduction of morbidity and mortality, and have failed to reflect the quality of care received by the majority of patients/clients who are influenced positively by their treatment. Further difficulties arise when one examines the complexity of what health services try to deliver. Health care programmes frequently include aspects such as prevention of disease, information for patients/clients and relatives and supporting, counselling and managing secondary complications. Thus, the measures of outcome that are used currently may be seen as reflecting a simplistic view of the aims of the health intervention.

Informing investment for health care on objective evidence has led to a greater reliance on published research. In most medical and rehabilitation fields, there is a limited amount of conclusive research that can be used alone to inform practice. Frequently, research attracts specific cohorts of patients/clients that do not reflect the range of difficulties requiring health service involvement in a wide range of settings. Furthermore, although research is essential, purchasers and managers have difficulty using research as a benchmark for their own practices if there are no methods to continually monitor the performance of patients/clients within localities on a regular basis for comparative purposes. The Cochrane Systematic Reviews, Evidence Based Medicine Reviews, Database of Abstracts of Reviews of Effects and the OT Seeker – Occupational Therapy Systematic Review of Evidence – have been developed to provide a ready source of quality research applicable to effectiveness of care.

Many health status/outcome and assessment scales purport to provide objective data on populations and specific subgroups. Donovan et al. (1993) gave an overview of health status measures divided into six categories:

1. **General health measures.** These provide global profiles of health, including well-being, function and social and emotional health (e.g. General Health Questionnaire (Goldberg, 1992), Nottingham Health Profile (Hunt and McEwen, 1980), Medical Outcomes Study Instrument SF36 (Reisenberg and Glass, 1989)).
2. **Measures of physical function.** These reflect the level of physical impairment and disability within general populations (e.g. Lambeth Disability Screening Questionnaire (Patrick et al. 1981)), or for specific groups (e.g. a unified ADL evaluation form (Donaldson et al. 1973)). These assess functions such as dressing, mobility and self-care.

3. ***Pain measures.*** These are instruments that are generally used with specific client groups and reflect the intensity/duration of pain (e.g. McGill Pain Questionnaire (Melzack, 1983), the Visual Analogue Scale (Scott and Huskisson, 1979)).
4. ***Social health measures.*** The Social Health Battery (Williams et al. 1981) and similar batteries assess the strength of people's social support mechanisms and networks.
5. ***Quality of life measures.*** The Four Single Items of Well-being (Andrews and Crandall, 1976) and the Quality of Life Index (Spitzer et al. 1981) measure the elusive "satisfaction of individuals with life".
6. ***Specific disease measures.*** These measures assess issues relevant to particular client groups in order to establish the impact and/or severity of conditions (e.g. the Arthritis Impact Measurement Scale (Meenan et al. 1980), The Frenchay Dysarthria Assessment (Enderby, 1981)).

These are a few of the plethora of different tools and approaches used to monitor the performance of patients/clients who have different diseases/health difficulties and who are receiving input from numerous health professionals. However, collecting, pooling and comparing these data are difficult and end up being less than informative for those who wish to make decisions. Traditional clinical indicators used in health research and outcome measurement have several major shortcomings: they tend to focus on rare negative outcomes and omit the degrees of benefit of certain treatments. Furthermore, other traditional measures focus on biological outcomes, for example, reductions in spasticity, infections or amputations. It is well known that health is considerably more to an individual than the reduction of disease alone. "Health is a slippery concept (Anderson et al. 1990, p. 205), a complex combination of lack of illness, well-being, control over life, and autonomy".

Despite considerable work on devising and validating impairment scales (Ebrahim et al. 1985; Wade, 1992), their use in the clinic and in clinical trials has sometimes failed to reflect improvement where clinical judgement and other evidence suggests that therapy has been beneficial (Harewood et al. 1994). Most studies on the efficacy of different nursing and therapy professions have used measures of impairment: for example, the accuracy of articulation, muscle power or range of movement. However, examination of what nursing and therapy try to achieve demonstrates that modifying impairment is only one component of the therapeutic target (Enderby, 1992). Thus, the primary goal of health care for many patients/clients, particularly those with long-term chronic conditions, is to maximise function in everyday life and to achieve the highest level of well-being (Stewart et al. 1989; Austin and Clark, 1993; Sarno, 1993).

The work presented here was stimulated by the desire to have a single, simple measure that would reflect the status of an individual more broadly than is possible with other assessment procedures: the degree of "disorder" (i.e. impairment), the

everyday limitations in function (i.e. activity) and the social consequences (i.e. participation). Previously, therapists had to turn to different tools if they wished to assess the patient/client holistically. This often caused difficulties because the various tools were not designed to dovetail and might give different weightings to different components.

The starting point of outcome measurement should be a greater understanding about what is to be achieved within a health care program. There is a need for multi-dimensional outcome measures in order that the effect of different health services in all aspects of management can be reflected. Assessment of treatment outcomes is complicated by the multiplicity of objectives in most treatment programmes that are not readily measured, as they involve goals other than those assessed by the standard procedures for assessing impairment.

Health service authorities have been charged with the responsibility of purchasing a pattern of health care provisions that accords with the needs of the local population (Department of Health, 1989, 1999a, 1999b). This stimulated a resurgence of interest in surveying population needs along with the effort to establish effectiveness of services. The measures outlined by Donovan et al. (1993) have occasionally been used to survey health needs as well as to measure effectiveness. However, most measures were originally designed for one or the other purpose and do not necessarily transfer readily. Even when contained in the field of establishing health needs, Donovan et al. argued that they may be less effective than hoped, as the level of generalisable characteristics of health status measures makes their interpretation difficult and possibly inadequate to support purchasing decisions, as it is not possible to map general measures of pain, mobility or distress to the requirements for specific services. We would suggest that this places an even higher demand on the need for service outcome data.

In most specialities there are wide variations in clinical practice, with limited agreement as to the most effective treatment, limited criteria to indicate the appropriate level, type or amount of intervention and a lack of information that the intervention itself is justified. The small amount of research in some fields fuels only debate, rather than giving answers that would help to define the best practice. Thus, there is a continued tendency to equate the outcome of activity with process measures, such as throughput and activity levels, rather than determining the effect of the care package in its totality, which is the aim of collecting information on outcomes as presented here (Øvretveit 1992, 1998).

## WORLD HEALTH ORGANISATION CLASSIFICATION

World Health Organisation International Classification of Impairment, Disability and Handicap (WHO ICIDH) (World Health Organisation, 1980) reflected the concept that health problems impact on many areas of an individual's life, and this classification made explicit that medical conditions produce multiple difficulties for the individual and any outcome measure must reflect these different areas. The realisation that health care systems were attempting to have a broader impact than the reduction and prevention of disease alone necessitated the development of a language that could capture an extension to the sequence of events underlying illness-related phenomena. Wood and Badley (1978) and Wood (1980) suggested the following profile:

**Disease → Impairment → Disability → Handicap.**

A problem at the level of the organ could result in an impairment, which caused a disability, which impacted on the individual's life resulting in a handicap.

Each dimension can be summarised as follows:

• Impairment	Dysfunction resulting from pathological changes in system.
• Disability	Consequence of impairment in terms of functional performance (disturbance at the level of person).
• Handicap	Disadvantages experienced by the individual as a result of impairment and disabilities. It reflects interaction with an adaptation to the individual's surroundings.

This form of classification allowed one to reflect on the different impacts on the health of an individual. For example, some conditions will "impair" slightly but cause severe "disability" and "handicap", whereas others may show major "impairment" but limited "disability" and "handicap".

However, studies have indicated poor correlations between the impairments, disabilities and handicaps in some individuals from particular client groups. For example, in heart failure there may be no relation between cardiac output (impairment) with treadmill-exercise tolerance, timed walking tests (disabilities), and social activity (handicap) (Cowley et al. 1991). This lack of direct relationship between impairment, disability and handicap also applies in chronic airway disease (Williams and Bury, 1989). From the patient's/client's point of view, impairment may be of less importance than the restrictions placed on everyday life. The following case histories (Tables 1-1

**Table 1-1. CASE STUDY 1: Mr K.**

Impairment	Mr K has a mild expressive and receptive language disorder, dysphasia/aphasia.
Disability/activity	Although he speaks quite freely, he has difficulty making himself understood quickly in a group of people and has stopped using the telephone. Mr K occasionally misunderstands meanings, particularly if there is a rapid change of subject. He is dependant on others being attentive and patient/client listeners.
Handicap/participation	Mr K is now unable to be employed as he had been previously, has withdrawn from social situations, has given up all hobbies, and no longer contributes to decision-making.
Summary	This gentleman could be seen as having a mild impairment, a moderate limitation in the activity of communication and quite a severe social disadvantage.

**Table 1-2. CASE STUDY 2: Mr SP.**

Impairment	Mr SP has had a stroke, has a mild hemiplegia with some loss of dexterity in his left hand and has increased tone in his left leg.
Disability/activity	Mr SP is able to undertake all tasks for himself but prefers his wife to help him with most activities, and he requires extra time and encouragement in all ADL.
Handicap/participation	Mr SP has lost confidence and no longer makes decisions on finance or social matters, and his wife has taken over all household and social tasks. He has retired early and withdrawn from previously enjoyed social activities.
Summary	This gentleman has a mild/moderate motor impairment. His performance in daily activities or in social participation matches his capabilities.

and 1-2) illustrate the impact of a cerebral vascular disease on different individuals and how, from the individual's point of view, impairment may be of less importance than the restrictions these place on everyday life.

Since Wood and Badley's work in 1978 and Wood's in 1980, there has been considerable discussion with regard to the aspect of emotional distress/well-being

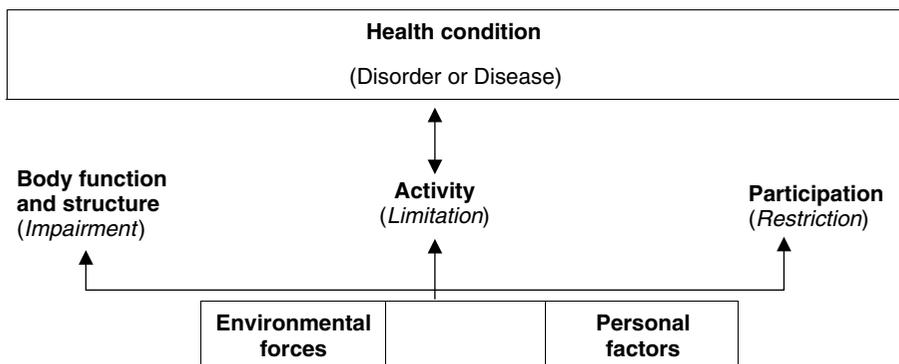
associated with disease and dysfunction. While the ICDH acknowledges the impact on a person's well-being, the emotional consequences were not included in the classification. We found in the study of therapy goals (Enderby and John, 1997) that frequently there were goals associated with improving the emotional status of the patient/client and relatives, and therefore in an early stage of our work we decided that this dimension has to be identified separately. After all, if a rehabilitation programme for a severely disabled person is focussed on improving their adjustment and coping strategies, it is important to be able to identify the impact of this intervention.

## INTERNATIONAL CLASSIFICATION OF FUNCTIONING

A revision of the ICIDH was undertaken by the WHO coordinated by the WCC WHO Collaborating Centre in the Netherlands and resulted in the production of the WHO's International Classification of Functioning, Disability, and Health (World Health Organisation, 2001) (ICF). The revised classifications correspond with the original three dimensions of the ICIDH with the addition of environmental impact on the individual and personal factors. The ICIDH dimensions have been renamed following consultation with users.

The International Classification of Functioning (ICF) organises the classification system in two parts. Part 1 classifies functioning and disability and Part 2 deals with contextual factors. Functioning and disability in Part 1 includes the dimensions of body systems and body structure and activity and participation (BAP) denoting functioning from an individual perspective and that of their society. Figure 1-1 illustrates the interactions between the different dimensions of ICF.

The dimension of impairment is renamed body and related to body functions and structures (*impairments*); disability is renamed activity (*limitations*), while handicap is renamed participation (*restrictions*). This more positive terminology is favoured by many disability groups and moves the classification from a medical to a more social model. ICF has now two parts. Part 1 concerns functioning and disability while Part 2 concerns the contextual factors of environment and personal factors. Table 1-3 shows an overview of the ICF. The ICF has components which can be viewed as positive or negative, each component consists of domains which are units of classification. Thus, health and health related states can be recorded by selecting a category code and



**Figure 1-1.** Interactions between the dimensions of ICF Parts 1 and 2 (WHO-ICF 2001).

**Table 1-3.** An overview of ICF.

Components	Part 1: Functioning and Disability		Part 2: Contextual Factors	
	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	<b>Body functions:</b> physiological and psychological functions of body systems <b>Body structures:</b> anatomical parts of body	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences of functioning and disability
Constructs	Change in body functions (physiological) Change in body structure (anatomical)	<i>Capacity</i> Executing a task in a normal environment <i>Performance</i> Executing tasks in current environment	Facilitating or hindering	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities participation	Facilitators	N/A
	Functioning			
Negative aspect	<b>Impairments:</b> problems in body function or structure as a significant deviation or loss	<b>Activity Limitation:</b> difficulties an individual may have in executing activities <b>Participation Restrictions:</b> problems an individual may experience in involvement in life situations	Barriers/hindrances	N/A
	Disability			