

A History of Uniform Data System for Medical Rehabilitation (UDSMR): The Science of Functional Assessment and Outcomes Measurement

Part 1: 1987–2000

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About the Editor

Carl V. Granger, MD, is professor and former chair of the Department of Rehabilitation Medicine, University at Buffalo School of Medicine and Biomedical Sciences, Buffalo, New York. He is also the director and a founder of both the Center for Functional Assessment Research and Uniform Data System for Medical Rehabilitation (UDSMR). Dr. Granger is one of the developers of the (FIM[®] instrument). He is a graduate of Dartmouth College and New York University School of Medicine and is certified in physical medicine and rehabilitation and in electrodiagnostic medicine.

Dr. Granger's academic and administrative appointments have included professor and chair of the physical and rehabilitation medicine department at Tufts University School of Medicine, professor of family medicine and community health at Brown University, and director of the Parkinson Disease Association Information and Referral Center of Rhode Island.

Dr. Granger is past president of the American Academy of Physical Medicine and Rehabilitation and of the International Federation of Physical Medicine and Rehabilitation. He served on the Advisory Board of the National Center for Medical Rehabilitation Research, National Institute of Child Health and Human Development, National Institutes of Health.

His interests and research are in the development and use of measures of disablement and quality of daily living—including physical, mental/emotional, and social functioning—to evaluate outcomes of medical rehabilitation. Dr. Granger is the author of more than 225 publications. In a recent study (*Archives of Physical Medicine and Rehabilitation*, Vol. 91, Issue 5, pp. 806–815, May 2010) covering over 45,700 articles published in 30 rehabilitation-dedicated journals, Dr. Granger was found to have coauthored 10 of the 100 top-cited articles and was the first author of five articles, nearly twice as many as any other author.

A recipient of numerous honors, Dr. Granger received the Frank A. Krusen Award from the American Academy of Physical Medicine and Rehabilitation, which named him the 30th Annual Walter J. Zeiter Lecturer. He won the Elizabeth and Sidney Licht Award for Excellence in Scientific Writing. He is a Fellow (Honoris Causa) of the Australian Faculty of Rehabilitation Medicine of the Royal Australian College of Physicians. The Association of Academic Physiatrists named him Distinguished Academician for his work as a teacher and researcher. In 1999, the SUNY Buffalo School of Medicine and Biomedical Sciences gave Dr. Granger its top faculty recognition, the Stockton-Kimball Award.

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A History of UDSMR

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Preface: Evaluate and Improve

By Carl V. Granger, MD

This book is about an enterprise that is performing a unique mission. This type of operation has not existed previously, particularly on a large scale. This book is dedicated to the men, women, and children who live with disability. It is our honor to serve them in their efforts to improve the quality of their daily lives. This book also is dedicated to the clinicians and administrators in the rehabilitation services provider community, who spend valuable time and effort to learn methods for evaluating their patients and clients with uniform methodologies in order that experiences may be shared and compared meaningfully. Finally, and not least, this book is dedicated to the men and women of UDSMR and the Center for Functional Assessment Research (CFAR), who took a dream and made it happen.

Since their inception, UDSMR and CFAR have strived to be the leading organizations for these important principles and values:

- Maintaining integrity in providing applications of functional assessment and outcomes analyses that improve the ways in which rehabilitation providers identify and serve the needs, and manage the outcomes, of persons with disability across the continuum of care, nationally and internationally
- Providing consultation for training subscribers regarding the uniform use and interpretation of the results of functional assessment to describe the severity of disability and analyses of outcomes
- Supporting the needs of subscribers for accurate and timely patient data services and for accreditation and marketing purposes
- Performing research to develop and maintain innovations in technologies for data acquisition, storage, and reporting and research in measurement technologies in order to render greater value at lower costs and to improve the prediction of outcomes and resource requirements
- Providing a working environment that is committed to the following:
 - Diversity in interests and background of personnel
 - Encouraging staff, employees, and stakeholders to share in shaping the vision and mission and in executing the goals and objectives of UDSMR and CFAR
 - Being personally supportive as a good place in which to work

Although the field of physical medicine and rehabilitation (PM&R; physiatric medicine) is one of the younger specialties, it has been increasingly gaining stature among medical and surgical colleagues. Today, the field of PM&R has the opportunity for more than simple recognition—it can take a leadership role in the measurement of clinical outcomes, including cost-effectiveness.

Timely measurement of outcomes requires that clinical data be well-defined, that the elements have an expected relationship to each other, and that the data be suitably formatted for electronic archiving and retrieval. Methods of measurement are available that are feasible in clinical settings. These measures are sufficiently comprehensive to cover common personal experiences within the domains of physical functioning, cognitive status, affective sense of well-being, and experience with pain. For persons with disability, each domain of functioning must be analyzed for interactions with other domains.

The purposes of such an enterprise are (1) to portray a composite picture of the patient/client as a whole person, (2) to store clinical experiences as data that may be used for comparing healthcare delivery systems and to follow changes over time, and (3) to define the characteristics of best and evidence-based practices. Achievement of these purposes is greatly facilitated through the large, continuously updated, and timely databases that are available through UDSMR and CFAR.

This book is authored by those who have done the work of creating and operating the enterprise as it exists today. They will describe what is done, how it is done, and the results.

Chapter 1: Origin of the FIM[®] Instrument and UDSMR

By Carl V. Granger, MD

As the department chief at Tufts Rehabilitation Institute (1968–1976), I noticed that many high-level clinicians spent half a day once a week reviewing the status of rehabilitation patients, but seldom did the conference summary in any way express the functional change in patients in a quantitative way. Although verbal descriptions of improvements in the functions of persons with disability were customary, they were inconsistent and insufficient for making comparisons among patients and for tracking changes over time in order to document and study rehabilitation outcomes. We had no anchor-points to use to guide the PM&R residents in making crisp judgments concerning discharge. Advice given to family members who were to care for the patient post-discharge was rather general.

In the background of health economics, there was a consciousness about the progressively rising cost of healthcare, particularly hospital care. I was concerned that, without accountability for outcomes, financial support for inpatient rehabilitation could become tenuous.

During the inpatient conferences, I began to construct a scale that listed the issues that were commonly discussed and how the clinicians described whether progress was noted. The key items were eating, grooming, dressing, bowel and bladder sphincter functioning, perineal care, transfers, ambulation, and stair climbing. Key categories related to independent functioning with or without extended time, safety concerns, and/or an assistive device; supervision without contact; contact assistance (minimal, moderate, or maximal); and complete dependence.

One of the therapists remarked that I was doing something similar to the Barthel Index. I began using the Barthel Index to rate items based on the rehabilitation team's discussions. This provided a numerical indicator for comparing the physical functioning and personal care status of each patient at admission and at discharge. Graphing the results allowed me to see the patient's overall progress in developing personal care independence and to readily identify items that were lagging in progress. It became evident that functional status on items such as bladder and bowel functioning and ambulation would differ depending on the type of organic impairment—for example, stroke versus spinal cord injury.

When I moved from Tufts to Brown University in 1976, I persuaded the hospital computer manager there to build a primitive reporting system and database for the new rehabilitation unit that was being opened. The clinical members of the new unit staff readily took to learning the Barthel Index and making weekly recordings of functional status. Using the tool helped to focus discussions during the rehabilitation team meetings.

Our next question was, “Is there a common operational denominator across hospital inpatient rehabilitation programs, so that a tool such as the Barthel Index could be used in other hospitals—and, if so, could use of the Barthel Index in several hospitals at the same time be used for sharing the results of outcome measurement?”

An informal agreement was made among 10 hospital programs dispersed about the country to use the same functional assessment data protocol for stroke patients at admission to, and discharge from, rehabilitation. The data from these 10 programs were collected and analyzed at Pawtucket Memorial Hospital. The admission and discharge ratings showed remarkable consistency across venues, thus demonstrating the potential for generalized use of a common assessment tool. The success of this trial led to the enlistment of a national consensus to develop a uniform data set to illustrate the value of inpatient medical rehabilitation.

With Steve Forer, MA, MBA, as cochair of a national task force, Byron Hamilton, MD, PhD, as principal investigator, and myself as project director, we received the endorsement of 13 national rehabilitation organizations and a grant from the National Institute on Disability and Rehabilitation Research (NIDRR). From this 3-year effort emerged the FIM[®] instrument, consisting of 13 motor items and 5 cognitive items. Upon completion of the grant period, UDSMR was born on October 1, 1987. Rehabilitation facilities across the nation were trained by UDSMR's staff in the use of the FIM[®] instrument and began submitting their data for aggregation and compilation into summary reports that were sent to the subscribing facilities quarterly. The usefulness of these reports was greatly enhanced by their division into facility, regional, and national comparison data. As the number of subscribers and the size of the database grew, it became apparent that functional assessment and outcomes measurement could become a science through demonstrations of consistency and predictability.

Why Measure Outcomes?

Given the current state of healthcare in the United States, the ability to measure the cost-effectiveness and quality of medical rehabilitation services that are provided for adults and children across all venues of care is more imperative than ever. Medical rehabilitation concerns itself, in a holistic manner, with addressing the consequences of injury or chronic illness for the person as a whole being who wants to live as fully as possible within the physical and cognitive limitations of his ability. A major emphasis of medical rehabilitation is to help individuals find a balance between functional opportunities (choices, options, and expectations) and functional demands (physical, cognitive, and emotional) in order to enhance that person's fulfillment and quality of daily living. This focus distinguishes medical rehabilitation from preventive or curative medicine.

Treatment of chronic illness, by its nature, requires long-term tracking. The introduction of functional assessment after World War II offered medical rehabilitation a method for measuring function objectively and monitoring its change over time. Thus, the use of functional assessment has aided the achievement of medical rehabilitation's primary goals of maximizing functional independence and preventing institutionalization whenever possible. Careful analysis of the measurement results, in concert with clinical judgment, allows clinicians to devise therapeutic interventions specifically tailored to each person's needs.

At the facility level, functional assessment data reports enable administrators to monitor the overall success of their rehabilitation programs, as well as staff performance. Regional and national aggregate data can pinpoint the effects of state and local practice differences and offer a wealth of opportunities for epidemiological research.

UDSMR's vision:

- To be the internationally recognized expert in outcomes measurement by providing uniform and unbiased information that documents healthcare quality, including results, processes, and perceptions of care
- To provide a common language for communication across disciplines and to provide a basis for benchmarking and comparison of healthcare outcomes
- To conduct and disseminate research that supports evidence-based healthcare practices in terms of meaningful assessments of the domains of human functioning and measurement of outcomes of care, especially for persons with disabilities, chronic health conditions, or both

- To develop strategic partnerships that promote synergies within, and benefits to, healthcare organizations
- To utilize our strengths and partnerships to work toward influencing policy and policy makers in support of the industries and persons that we serve and to enhance quality-driven care

UDSMR's values:

- Accountability
- Integrity and credibility
- Creativity and innovation
- Orientation to meeting the needs of customers
- Advancement of quality healthcare
- Teamwork
- Productivity
- Shared pursuit of excellence
- Commitment to UDSMR's mission, vision, and success

Thus, the overall mission is to enable healthcare providers and related entities to document and improve the outcomes, processes, and perceptions of care in uniform ways.