Standardizing Assessment and Reporting of Functioning Information for Rehabilitation and Healthy Aging

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On February 16–17, 2024, the National Academies of Sciences, Engineering, and Medicine (National Academies) convened a hybrid workshop, hosted by the University of Lucerne (NASEM, 2024). The workshop focused on the World Health Organization's (WHO) concept of functioning— found in the International Classification of Functioning, Disability and Health (ICF)—as a third indicator of health, augmenting morbidity and mortality (WHO, 2024). The workshop constituted a "call for action" to recognize the essential role of functioning within the healthy aging agenda and for the future of rehabilitation as a health strategy. Supporting the case for the role of functioning, the workshop included a review of the concept of functioning itself, as well as its role in making the investment case for rehabilitation in healthy longevity, improving rehabilitation service delivery, and strengthening comprehensive healthy longevity research. Finally, the workshop emphasized that the success of this call for action depended on extensive and collective advocacy for functioning as the third indicator of health (Bickenbach et al., 2023).

Following this successful workshop, it was apparent that, although the ICF is globally recognized as the reference framework for functioning information and despite academic and clinical efforts over the past two decades to develop and implement ICF-based data collection tools, progress in integrating functioning into rehabilitation practice has been limited. The National Academies accordingly agreed to host a follow-up expert meeting to reflect on the challenges and lessons learned from attempts to implement standardized reporting of functioning. The expert meeting was held in Washington, DC, on October 17–18, 2024, before the National Academy of Medicine Annual Meeting. It consisted of three panels that highlighted: (i) the general challenge of standardized reporting of functioning using the ICF as a reference system; (ii) a research and implementation agenda for ClinFIT, a universal ICF-based clinical tool; and (iii) education and training, awareness, and advocacy for ClinFIT and standardized functioning reporting (Frontera et al., 2019). In this commentary, the authors draw on the points raised during this expert meeting to reinforce the importance of standardized reporting of functioning for the larger societal challenge of strengthening the impact of rehabilitation on healthy longevity.

Internationally, the importance of bringing attention to the third health indicator of functioning is reflected in the general normative framework of both the United Nations Sustainable Development Goal 3 on health and the WHO's recent resolution on the importance of strengthening rehabilitation in global health systems (WHO, 2023). Functioning is a key performance indicator for effective and efficient health and social systems that respond to the needs of diverse populations.

Functioning, moreover, may also be a suitable indicator of individual well-being and a valuable complement to the traditional economic indicators for well-performing societies.

Given an aging population and increasing prevalence of noncommunicable diseases, the need to collect functioning information—information about the actual lived experience of people's health—has become increasingly obvious among health scientists and rehabilitation practitioners. Functioning-based standards and tools exist in rehabilitation practice for the disability determination process, for social security and other benefits, and in population-level health surveys. Yet, although information about functioning is regularly collected, the use of a variety of tools and methods compromises comparability. The solution is either to institute standardized data collection and reporting methods across the board and internationally—which would require fundamental and expensive changes in current practice—or to continue to use existing data collection tools while standardizing this information by using the ICF as a reference framework. The latter is considered more efficient and has been successfully demonstrated to be feasible both for clinical and population data collection (Amatya et al., 2022). Another important consideration is that data collection of this kind of information requires the technology to analyze large amounts of heterogeneous data that can be processed easily and efficiently to provide information relevant to improving clinical management of individuals and to inform policy.

Conceptually, functioning is a health indicator, equally as important as mortality and morbidity for a comprehensive understanding of health at the individual and population levels. Because of this, it is important to make functioning information more accessible by means of natural language processing that can directly extract functioning data from clinical notes in electronic health records or transcriptions from health professional–patient interactions. Natural language processing could address the challenge of managing the large heterogeneity in health status across populations and do so without causing major disruptions in current data collection practices. As the ICF is fundamentally an international common language of functioning, its use as a reference framework can greatly enhance the scope of natural language processing. Robust analysis of these data, moreover, is made possible by novel statistical methods that model trajectories of functioning as well as the application of machine learning and artificial intelligence technologies such as large language models (De Brouwer et al., 2021). These new techniques will greatly improve the linkage to the ICF reference framework.

To be sure, there remain technical issues raised by a common metric of functioning (Prodinger et al., 2018). Primary among these is the need to create a common metric of functioning. This metric is "common" in the sense that it measures the underlying construct that all functioning instruments attempt to measure. Technically, a common metric would ensure interoperability across functioning data collection instruments. Among the technical issues raised by such a metric is the importance of distinguishing intrinsic capacity from actual functioning performance in the collection of population data, in order to track population health trends and analyze the impact of environmental factors on performance. Also important is the necessity for identifying measurable anchoring items across the spectrum of functioning in order to facilitate semantic interoperability in all data collection settings and methodologies. Finally, natural language processing may make it possible to continuously refine meaningful ICF categories going forward.

There are already a wide variety of instruments that collect functioning information, both generic and specialized. What is missing is a *clinical tool* that is both universal (using the international standard of ICF domains) and versatile (tailored by domain and response option to a wide variety of applications). ClinFIT was designed to be such a versatile and universal ICF-based clinical tool (Frontera et al., 2019). ClinFIT, so far, is the only such tool, although others may be in different stages of development and the authors are unaware of

this. What is known is that the development and implementation of ClinFIT has been guided by the International Society of Physical and Rehabilitation Medicine (ISPRM), the umbrella organization for physical and rehabilitation medicine. Moreover, the 30-item standard version of ClinFIT tool appears to be highly attractive to rehabilitation clinicians as it covers a range of functioning aspects to assess and report (e.g., sleep, pain, walking, dressing, relationships, and work), is simple to understand and use, was developed by the rehabilitation community itself, and is nonproprietary and free (Amatya et al., 2022).

During the expert meeting, participants from China, Australia, and Italy detailed their experiences in implementing the ClinFIT tool clinically, in different health systems, across the continuum of care and with various patient populations, such as older persons, cancer patients, and stroke patients. Evidence of the practical application of ClinFIT is essential as it reveals further developmental directions. For example, having iterations of the standard 30-item version of ClinFIT and tailoring scoring options to concrete application needs may provide practical added value. The same would be true of any tool developed in the future. Any such tool, in order to realize its full potential, would need to define meaningful cut-off scores, create practical subscales, and identify minimal clinically important differences (Amatya et al., 2022). This, and repeated validations, would be needed before such a tool could be used for longitudinal analyses by creating trajectories of functioning for clinical decision making and epidemiology. These functioning trajectories were deemed particularly useful for establishing benchmarks for specific groups, as well as evaluating the effectiveness and quality of interventions over time.

Eventually, to maximize clinical and research benefits from ClinFIT, or any other potential functioning tool, ordinal scores need to be transformed into interval-scale scores. This measurement requirement, once again, points to the need for the parallel development of a common metric of functioning. Such a metric would serve as the basis for the ClinFIT tool's interval-scale scores

and as a guide in the development of ICF-based functioning tools that can reliably and validly measure functioning for different clinical and research applications.

Perhaps the most significant challenge to realize the potential and promise of standardized reporting and assessment of functioning information is an increased awareness, among clinicians, researchers, and all health scientists, of the importance of recognizing functioning as the third health indicator, as well as the challenge of collecting and analyzing functioning information. Advocacy directed at these users is needed to highlight the benefits of using a standardized tool for measuring functioning and facilitating better patient outcomes and more consistent research findings. Recent examples of this advocacy, focused on the clinical use of ClinFIT, suggest that what may be needed are innovative educational and training techniques to raise awareness of functioning and functioning tools.

In conclusion, like other calls for action to inspire and motivate practitioners and researchers to look beyond their standard practice and seek out the opportunities presented by innovation and the shifting of paradigms, this call for action on the benefit of the concept of functioning primarily points to the need for advocacy and educational resources. Innovations in training manuals, the use of videos and other e-learning tools, and hands-on workshops will be needed for this challenge. Existing developments in functioning measurement will be key to convincing both clinicians and researchers alike that it is feasible not only to use existing functioning data, but to meet the challenge of interoperability of data and to create standardized methodologies to measure functioning. There is no doubt, moreover, that these technical innovations to capture and measure functioning will ultimately redound to the benefit of persons with disabilities and their goal of social inclusion. And finally, advocacy for functioning information for rehabilitation and healthy aging at the health system-level and across settings is a necessary precondition for realizing the "functioning revolution" (Bickenbach et al., 2023).

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