

SPECIAL REPORT

ICF LINKING RULES: AN UPDATE BASED ON LESSONS LEARNED

Alarcos Cieza,¹ Szilvia Geyh,¹ Somnath Chatterji,² Nenad Kostanjsek,² Bedirhan Üstün²
and Gerold Stucki^{1,3}

From the ¹ICF Research Branch, WHO FIC CC (DIMDI), Institute for Health and Rehabilitation Sciences, Ludwig-Maximilians-University Munich, Munich, Germany, ²Classification, Assessment, Surveys and Terminology Team, World Health Organization, Geneva, Switzerland and ³Department of Physical Medicine and Rehabilitation, University Hospital Munich

Objective: Outcome research seeks to understand the end results of health services. Researchers use a wide variety of outcome measures including technical, clinical and patient-oriented measures. The International Classification of Functioning, Disability and Health (ICF) as a common reference framework for functioning may contribute to improved outcome research. The objective of this paper is to provide an updated version of the linking rules published in 2002 and illustrate how these rules are applied to link technical and clinical measures, health-status measures and interventions to the ICF.

Results: Three specific linking rules have been established to link health-status measures to the ICF and one specific linking rule has been created to link technical and clinical measures and interventions. A total of 8 linking rules have been established for use with all different outcome measures and with interventions.

Conclusion: The newly updated linking rules will allow researchers systematically to link and compare meaningful concepts contained in them. This should prove extremely useful in selecting the most appropriate outcome measures among a number of candidate measures for the applied interventions. Further possible applications are the operationalization of concrete ICF categories using specific measures or the creation of ICF category-based item bankings.

Key words: ICF, health-status measures, linking rules, outcome assessment, outcome research.

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Correspondence address: Gerold Stucki, Department of Physical Medicine and Rehabilitation, University Hospital Munich, Marchioninistr. 15, 81377 Munich, Germany.
E-mail: gerold.stucki@med.uni-muenchen.de

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INTRODUCTION

Outcome research seeks to understand the end results of health services. The patient and consumer perspective thereby plays an

essential role (1, 2). Researchers use a wide variety of outcome measures, including technical, clinical and patient-oriented measures.

Technical measures comprise, for example, laboratory, imaging and electro-physiological examinations. Clinical measures include tests of physical and cognitive impairment and tests to assess activities such as walking. Patient-oriented measures include patient and proxy self-reports on health status, quality of life and health preferences.

Many different international initiatives have been introduced recently to create recommendations on which outcomes to address and which outcome measures to use in studies in patients with determined health conditions. However, there are still a number of challenges with regard to a more unified approach within outcome research.

First, the concepts health status, functional status, well-being, quality of life and health-related quality of life are often applied interchangeably in discourse and in outcome research (2), which makes it difficult to understand, interpret and compare study results. With the International Classification of Functioning, Disability and Health (ICF) (3) a common conceptual understanding of patient-oriented outcome measures is now emerging. Based on the ICF, the concept of functioning will be seen as distinct from quality of life and health preferences in the future. While functioning refers to limitations and restrictions related to a health problem, quality of life refers to how someone feels about these limitations and restrictions. Health preferences refer to the personal value given to these limitations and restrictions.

Secondly, a vast number of often competing, condition-specific and generic instruments have been developed over the last decades (4) and new versions of old instruments are continuously appearing. Thus, it has become very difficult for investigators and clinical researchers to select the most appropriate outcome measures for their studies and for readers to interpret and compare the results of different studies.

Thirdly, many recommendations do not consistently distinguish outcomes from outcome measures. This distinction has only been applied by a few initiatives, e.g. OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials; 5) initiative, which emphasized 2 steps in outcome research,

namely, to define first “what to measure” and only then “how to measure”. In line with this approach, ICF Core Sets have been developed (6). ICF Core Sets aim to define the ICF domains or categories out of the whole classification, which can serve as minimal standards for the reporting of functioning and health, that is, they define “what to measure” for functioning. This seems to be the appropriate approach because, while recommendations regarding “what to measure” will persist, any recommendation regarding a specific instrument is likely soon to be outdated.

Fourthly, there is often no or only a vague association between interventions and outcome measures, which limits the efficiency of the investigations. Outcome measures at least have to address specifically the aims with which interventions are applied.

To address these challenges, a common reference framework for functioning is of utmost importance and may, indeed, contribute to improved outcome research.

The use of the ICF as a reference framework in outcome research to address the above-mentioned issues intrinsically requires the availability of a sound, standardized procedure that enables interventions and outcome measures to be linked to the ICF. Rules to link health-status measures to the ICF were proposed by Cieza et al. in 2002 (7). These rules have been applied during the last 2 years not only to link health-status measures to the ICF, but also to link a large number of clinical measures (8–12) and interventions (13). When applied beyond the purpose for which they were originally developed, a number of critical issues, as well as the necessity to simplify them, arose. Thus, the original linking rules have been redefined and simplified, and the contexts in which they can be applied have been expanded.

The objective of this paper is to provide an updated version of the linking rules and examples on how these rules are applied to link technical and clinical measures, health-status measures and interventions.

METHODS

Four specific linking rules have been established to link health-status measures to the ICF, and one specific linking rule was created to link technical and clinical measures and interventions. Table I lists these specific rules with respective examples.

A total of 8 linking rules have been established for use with all different outcome measures (health-status measures, technical and clinical measures) and with interventions. These 8 linking rules are to be applied after having used the 3 specific rules for health-status measures or the specific rule for technical and clinical measures and interventions. Table II shows the 8 linking rules and provides an example for each.

All these rules have been developed based on the experience gathered during the process of linking hundreds of health-status measures and clinical measures (9–12) and dozens of interventions (13) with the original linking rules within the WHO collaboration project for the development of ICF Core Sets (6).

RESULTS

Table III shows the results of the linking process when applied to the Short Form-12 (SF-12) (14). Since the linked Short Form-36 (SF-36) (15) was provided as an example in the paper presenting the original version of the linking rules (7) and the SF-12 represents a selection of items of the SF-36, interested readers

can compare the results of applying both the original and the updated version of the linking rules to the same items.

Table IV shows examples of the linking process when the corresponding rules are applied to technical and clinical measures and interventions.

DISCUSSION

The linking rules presented in this paper can be applied not only to link health-status measures, but also clinical measures and interventions to the ICF. This provides certain advantages when planning an investigation.

The ICF can serve as a connecting framework between interventions and outcome measures, facilitating the selection of the most appropriate outcome measure for the aim of the intervention. This premises the availability of the linking results of both the aim(s) of the intervention(s) and the different candidate outcome measures. Different studies have already been published in which the results of the linking between the most widely used condition-specific health-status measures to the ICF have been presented (16–20). The proliferation of such studies addressing the linking not only of health-status measures, but also of clinical measures, can facilitate the process of selecting outcome measures in the future.

The application of the ICF as a connecting framework between interventions and outcome measures can be extremely useful when comparing different investigations with respect to the interventions administered and the results obtained. In a recent review of studies containing explanatory models of functioning in patients with rheumatoid arthritis, Cieza & Stucki (21) showed that even if the outcomes addressed and the outcome measures used in the different investigations were very diverse, the ICF and its model of functioning, disability and health for the depiction of the independent and dependent variables helped to address the diversity of the studies and the complexity of the different possible interactions among variables.

The fact that the concepts health status, functional status, well-being, quality of life and health-related quality of life are often applied interchangeably in the literature is less irritating when the measures for which these concepts are applied are linked to the ICF. The use of the ICF as a reference framework for all measures, irrespective of the concept used for their description, provides a clear picture of which health domains are addressed by each of the measures. This information is far more valuable when selecting an outcome measure for a determined study than the umbrella term under which the outcome measure was allocated, since it is information on the content and clinical validity of the instrument(s).

In the updated rules, neither the so-called “other specified” nor the “unspecified” categories of the ICF are used. This reduces the ambiguity of the results of the linking process. The user of the linking results no longer needs to ponder on the possible meaning of “other specified” and “unspecified”. This modification represents an essential contribution to the simplification of the rules.

Table I. Specific rules for the linking of health-status measures, clinical measures and interventions to the ICF

Notation	Specific rules for health-status measures	Example
a.	Before starting the process of linking health-status measures to the ICF categories, identify all meaningful concepts within each item of the health status measure under consideration.	Item 4 of the Oswestry Low Back Pain Disability Questionnaire: “Pain doesn’t prevent me from walking any distance” Two different meaningful concepts are identified in this item, “pain” and “walking any distance”. The same procedure is followed for all the items of Oswestry Low Back Pain Disability Questionnaire.
b.	The response options of an item are linked if they contain meaningful concepts.	Item “Self-care” of the EQ-5D: “Self-care I have no problems with self-care I have some problems washing or dressing myself I am unable to wash or dress myself” In this Item not only “self-care” but also the meaningful concepts “washing myself” and “dressing myself” are linked to the ICF categories.
c.	The interval of time to which the item refers such as “during the last week” is not linked to the ICF.	
d.	If a meaningful concept of an item is explained by examples, both the concept and the examples are linked. However, the ICF category to which the examples have been linked will be put within parentheses. Examples are usually introduced with “e.g.” “for example”, or “such as” or appear in parentheses.	Item 2 of the Dallas Pain Questionnaire – 16: “How much does pain interfere with your personal care (getting out of bed, teeth brushing, dressing etc.)?” This item is linked to: b280 “Sensation of pain” d5 “self care” (d4100) “lying down” (the additional information “out of bed is documented”) (d5201) “caring for teeth” (d540) “dressing”.
Notation	Specific rules for technical and clinical measures and interventions	Examples
e.	Before starting the process of linking technical or clinical measures or interventions to the ICF categories, define the aim with which the corresponding technical or clinical measure is used or the aim with which the intervention was applied in the concrete investigation in form of a meaningful concept. Please consider that the aims can vary from investigation to investigation.	In investigation A the clinical measure vertebral fractures as detected by X-ray was used with the aim “osteoporosis severity”. In investigation B the clinical measure vertebral fractures as detected by X-ray was used with the aim “Bone structure”. In investigation A the clinical measure pulse rate was used with the aim “exercise tolerance”. In investigation B the clinical measure pulse rate was used with the aims “heart rate” and “heart rhythm”. In investigation A the nursing intervention mobilization was used with the aim “mobility improvement”. In investigation B the nursing intervention mobilization was used with the aims “prevention of skin ulcer”.

The updated linking rules also enable the identification of personal factors, even if these have not yet been classified in the ICF. This also makes the linking process more precise, since personal factors are now differentiated from further meaningful concepts that are not yet covered in the ICF and are, therefore, assigned “nc” (not covered). In addition, a formalized documentation of all meaningful concepts assigned to the abbreviation “pf” (personal factors) can be used for the development of a classification of this component in future versions of the ICF.

Also the 2 specifications added to rule 5 increase the precision of the linking process. Meaningful concepts referring to health and to quality of life in general are differentiated from those that

do not provide enough information to make a decision about which ICF category to link.

It is important to emphasize that all the meaningful concepts contained in a health-status measure are linked to the ICF, based on these linking rules. Since the items often refer to more specific concepts than the highest level of specification mentioned in the ICF categories (e.g. the 2 concepts in the item 2 of the SF-12 “bowling” and “playing golf” are linked to the ICF category d9201 sports) and the examples and, in some cases, the response categories are also linked to the ICF, it is frequently the case that a single item addresses a determined ICF category more than once and that a health-status measure addresses a determined ICF category several times. How the data analyses

Table II. Updated linking rules with examples

Number	Rule	Example
1.	Before one links meaningful concepts to the ICF categories, one should have acquired good knowledge of the conceptual and taxonomical fundamentals of the ICF, as well as of the chapters, domains, and categories of the detailed classification, including definitions.	
2.	Each meaningful concept is linked to the most precise ICF category.	Item C4 of the West Haven-Yale Multidimensional Pain Inventory: "Play cards and other games". This item is linked to the 3rd level category d9200 "Play" and not to the 2nd level category d920 "Recreation and Leisure".
3.	Do not use the so-called "other specified" ICF categories, which are uniquely identified by the final code 8. If the content of a meaningful concept is not explicitly named in the corresponding ICF category, the additional information not explicitly named in the ICF is documented.	Item 17 of the Stait-Trait Anxiety Inventory: "I am worried". This item is linked to b152 "Emotional functions" and the additional information "worried", which is not explicitly named in the ICF, is documented. Item 5.1 of the Aberdeen Low Back Pain Scale: "In your right leg, do you have pain in the foot/ankle?". The meaningful concept "pain in right foot/ankle" identified in this item is linked to b28015 "Pain in a lower limb" and the additional information "right foot/ankle" not contained in that category is documented.
4.	Do not use the so-called "unspecified" ICF categories, which are uniquely identified by the final code 9 but the lower level category.	Item 14 of the Dallas Pain Questionnaire: "How much do you think your pain has changed your relationship with others". The meaningful concept "your relationship with others" is linked to d7 "Interpersonal interactions and relationships" and not to d799 "Interpersonal interactions and relationships, unspecified".
5.	If the information provided by the meaningful concept is not sufficient for making a decision about the most precise ICF category it should be linked to, the meaningful concept is assigned nd (not definable). Special cases of this rule: a. Meaningful concepts referring to health, physical health or mental (emotional) health in general, are assigned nd-gh, nd-ph or nd-mh (not definable-general health, not definable-physical health, not definable-mental health), respectively. Meaningful concepts referring to quality of life in general are assigned nd-qol (not definable-quality of life).	Item of section 5 of the St. George's Hospital Respiratory Questionnaire: "I have unpleasant side effects from my medication". The meaningful concept "side effects" is assigned "nd". Item 1 of the SF-36: "In general, would you say your health is . . .?". The meaningful concept "health" is assigned "nd-gh". Item 1 of the WHOQoL-Breff: "How would you rate your quality of life?". The meaningful concept "quality of life" is assigned nd-qol.
6.	If the meaningful concept is not contained in the ICF, but it is clearly a personal factor as defined in the ICF, the meaningful concept will be assigned pf (personal factor). Personal factors are defined in the ICF as follows: "The particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behaviour pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level".	Item 29 of the Quality of Life Index - cardiac version IV: ". . . Your faith in God?". The meaningful concept "faith in God" is assigned pf.
7.	If the meaningful concept is not contained in the ICF and it is clearly not a personal factor, this meaningful concept is assigned nc (not covered by ICF).	Item 3 of the Hamilton Rating Scale for Depression: ". . . attempts at suicides". This meaningful concept is assigned nc.
8.	If the meaningful concept refer to a diagnosis or a health condition, the meaningful concept will be assigned hc (health condition)	Item 8 of the Asthma Quality of Life Questionnaire: "How often during the past two weeks did you feel short of breath as a result of your asthma?". The meaningful concept "asthma" is assigned hc.

Table III. Short-Form-12 linked with the updated rules. (See Tables I and II)

Item	ICF category	Additional information
1. In general, would you say your health is: (excellent, very good, good, fair, poor)	nd-gh	
2. Does your health now limit you in these activities?	nd-gh	
a. Moderate activities, such as, moving a table pushing a vacuum cleaner bowling or playing golf	A&P* (d430) Lifting and carrying objects (d4451) Pushing (d9201) Sports (d9201) Sports	Moderate A table A vacuum cleaner Bowling Playing golf
b. Climbing several flights of stairs	d4551 Climbing	Several flights of stairs
3. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	d850 Remunerative employment d230 Carrying out daily routine nd-ph	
a. Accomplished less than you would like		
b. Were limited in the kind of work or other activities		
4. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	d850 Remunerative employment d230 Carrying out daily routine b152 Emotional functions (b152) Emotional functions (b152) Emotional functions	Depressed Anxious
a. Accomplished less than you would like		
b. Didn't do work or other activities as carefully as usual		
5. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?	b280 Sensation of pain d850 Remunerative employment d640 Doing housework	
6. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week:		
a. Have you felt calm and peaceful?	b152 Emotional functions	Calm and peaceful
b. Did you have a lot of energy?	b1300 Energy level	
c. Have you felt downhearted and blue?	b152 Emotional functions	Downhearted and blue
7. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	nd-ph b152 Emotional functions d9205 Socializing	

* A&P = Activities and Participation.

are performed and the frequencies with which the ICF categories are addressed in a determined health-status measure are calculated can differ from investigation to investigation, depending on the study aim.

The linking rules presented in this paper also have a number of limitations that need to be addressed.

First, they relate only to the content of outcome measures. Therefore they can only be used to perform content comparisons among outcome measures. Further essential criteria that must be taken into account when comparing outcome measures, such as psychometric properties, are disregarded. In addition, since they relate only to the content of outcome measures, the response categories of, for example, items are also disregarded.

Secondly, the current rules are based on 4 different applications: technical and clinical measures, health-status measures and interventions. Even if they have also been applied to link conceptual models (22), answers of experts in Delphi exercises

(23) and patients' statements in interviews to the ICF¹, additional applications may pose new challenges which will require new rules or the redefinition and specification of existing rules. Therefore, researchers applying the linking rules are encouraged to contact the authors of this paper if a new challenge is encountered.

Thirdly, these linking rules have not been tested systematically with regard to their reliability in the hands of different researchers applying them. However, there have been a number of papers reporting the reliability when applying these rules (18, 19). Since reliability is something not inherent to either the ICF or a health-status measure, but to a specific application,

¹ Stamm TA, Cieza A, Coenen M, Machold KP, Nell VPK, Smolen JS, Stucki G. Validating the Comprehensive ICF Core Set for Rheumatoid Arthritis from the Patient Perspective: A Qualitative Study. Unpublished.

Table IV. Examples of linking process when the corresponding rules are applied to technical and clinical measures, and interventions

	Aims defined as a meaningful concept	ICF category
Technical measures		
Albumin concentration in urine	Renal function	b610 Urinary excretory functions
Arthroscopy	Joint structure	s7701 Joints
Vertebral fractures as detected by X-ray	Osteoporosis severity	nc
Vertebral fractures as detected by X-ray	Bone structure	s7600 Structure of vertebral column
Polysomnography	Sleep	b134 Sleep functions
Clinical measures		
Blood pressure at rest	Blood pressure	b420 Blood pressure functions
Postoperative analgesic consumption	Pain	b280 Sensation of pain
Dietary intake (kcal) from 7-days dietary diary	Compliance with diet	d5701 Managing diet and fitness
6-minute walk test	Walking	d450 Walking
Grooved pegboard test	Visual-motor coordination	b7602 Coordination of voluntary movements
Sleep disturbances	Fibromyalgia symptom severity	hc
Sleep disturbances	Sleep quality	b1343 Quality of sleep
Duration of morning stiffness	Duration of morning stiffness	b7800 Sensation of muscle stiffness
Liver function tests	Alcohol abuse	hc
Liver function tests	Liver function	nd
Pulse rate	Heart rate	b4100 Heart rate
	Heart rhythm	b4101 Heart rhythm
Pulse rate	Exercise tolerance	b455 Exercise tolerance functions
Interventions		
Mobilization	Mobility improvement	d4 Mobility
Mobilization	Prevention of skin ulcer	s810 Structure of areas of skin
Massage	Influence muscle tone	b735 Muscle tone functions
Electrotherapy	Influence muscle tone	b735 Muscle tone functions
Thermotherapy	Influence muscle tone	b735 Muscle tone functions
Cryotherapy	Influence inflammation of joints	s7701 Joints
Isometric exercises	Influence balance and coordination	b2351 Vestibular function of balance
	Prevention of falls	b760 Control of voluntary movement functions
Balance and coordination exercises		nd

nc = not covered, hc = health condition, nd = not definable.

the reliability based on Kappa statistics as used in some papers (18, 19) should always be examined.

As inferred from the linking rules and the examples presented in this paper, the linking of clinical measures and interventions requires an additional step to the linking of health-status measures, that is, the definition of the aim with which the clinical measure and intervention is performed. This additional step has to be considered when studying the inter-rater reliability of the linking procedure. Not only the precision of the selected ICF category, but also the defined aims need to be analysed.

Fourthly, there are some conceptual issues that cannot be addressed based on the linking rules presented in this paper. The relationship among the concepts contained in an item is not documented and analysed. For example, in the SF-36 item "During the past week, have you had any of the following problems with your work or daily activities as a result of your physical health", 3 different meaningful concepts are identified ("problems with your work", "daily activities" and "physical health") and linked to the ICF according to the proposed rules. However, information regarding the causal relationship (the item only refers to problems caused by the physical health) contained in this item is not documented. One could even say that the information regarding whether an item is etiologically neutral is not addressed with the proposed linking rules.

Additional information that is also not considered based on these linking rules is the extent to which items and health-status measures conform a biopsychosocial perspective of functioning, that is, to what extent an item and, consequently, health-status measures address the relationship between environmental or personal factors and functioning.

In the items that contain meaningful concepts that address aspects of the component activities and participation, the differentiation between activity and participation is not made according to these rules. The information as to what extent an item refers to activity, to participation, or to both, as well as the information as to whether an item addresses activity or participation from the perspective of capacity or from the perspective of performance, is also not addressed in these linking rules.

All these underscore the necessity of developing conceptual linking rules that go beyond the meaningful concepts contained in the items.

The newly updated linking rules for linking health-status measures, technical and clinical measures, and interventions to the ICF will allow researchers systematically to link and compare meaningful concepts contained in them. This should prove extremely useful in selecting the most appropriate outcome measures among a number of candidate measures for the applied interventions. Further possible applications are the

operationalization of concrete ICF categories using specific measures or in the creation of ICF category-based item bankings.

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