



# **Integrating what matters to patients into health records based on the ICF: Examining the utility of interRAI to operationalize the ICF Rehabilitation Set as a case in point**

**Birgit Prodinge B<sup>1,2</sup>, Declerq A<sup>3</sup>, Carpenter I<sup>4</sup>, Rastall P<sup>4</sup>**

<sup>1</sup> ICF Research Branch in cooperation with the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI)

<sup>2</sup> Swiss Paraplegic Research; Nottwil, Switzerland)

<sup>3</sup> LUCAS, Center for Care Research and Consultancy, KU Leuven, Kapucijnenvoer Leuven, Belgium

<sup>4</sup> Health Informatics Unit, Royal College of Physicians, UK

## **Annex 11 to SHN Work Package 3 Deliverable D3.3**

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Contact:	Birgit Prodinger <a href="mailto:birgit.prodinger@paraplegie.ch">birgit.prodinger@paraplegie.ch</a> Anja Declercq <a href="mailto:Anja.Declercq@med.kuleuven.be">Anja.Declercq@med.kuleuven.be</a> Iain Carpenter <a href="mailto:Iain.Carpenter@rcplondon.ac.uk">Iain.Carpenter@rcplondon.ac.uk</a> Paul Rastall <a href="mailto:paulrastall@doctors.net.uk">paulrastall@doctors.net.uk</a> Dipak Kalra <a href="mailto:dipak.kalra@eurorec.org">dipak.kalra@eurorec.org</a> Robert Vander Stichele <a href="mailto:robert.vanderstichele@ugent.be">robert.vanderstichele@ugent.be</a>
Editors:	Birgit Prodinger

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Email : [birgit.prodinger@paraplegie.ch](mailto:birgit.prodinger@paraplegie.ch)

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Prepared by Birgit Prodinge<sup>1,2</sup>, Anja Declercq<sup>3</sup>, Iain Carpenter<sup>4</sup> and Paul Rastall<sup>4\*</sup>

<sup>1</sup> ICF Research Branch in cooperation with the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI)

<sup>2</sup> Swiss Paraplegic Research; Nottwil, Switzerland)

<sup>3</sup> LUCAS, Center for Care Research and Consultancy, KU Leuven, Kapucijnenvoer Leuven, Belgium

<sup>4</sup> Health Informatics Unit, Royal College of Physicians, UK

## **1. Background**

Current health systems are challenged to meet the needs of people living with chronic health conditions, where cure of the disease is not the primary outcome of care (World Health Organization, 2010). People living with chronic conditions require integrated and coordinated care from various professionals across all levels of health systems to ensure an efficient and need based care that goes beyond bio-medical treatment. In order to meet their health and related needs most appropriately across their life span and across the continuum of care, health information capturing the lived experience of these people's functioning needs to be routinely collected and subsequently available as foundation for any evidence-based decision making related to finances, service delivery, policy and governance in health systems.

Functioning is an umbrella term and refers to the interaction of a health condition and its attributes, such as aetiology, manifestation and symptoms, with what people do in their daily lives. It includes contextual factors, such as availability and access to health services, support of informal and formal care givers, and personal lifestyle factors and traits (Kostanjsek et al., 2011). Accounting for the interaction of these components in the description of health provides a more comprehensive picture of the lived experience of a person with a given health condition across her or his life (Stucki, 2010).

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The World Health Organization (WHO) has released the International Classification of Functioning, Disability and Health (ICF) in 2001 to serve as the standard for describing and understanding functioning in people with any health condition across the continuum of care. The ICF is complimentary to the International Classification of Diseases (ICD). As a classification, the ICF contains an exhaustive and mutually exclusive set of categories and constitutes a unified and consistent, standard language of human functioning to specify domains of functioning to be described in routine practice. The categories selected for consideration in a routine clinical setting must be as exhaustive as possible and yet remain practical for daily use (Stucki, Kostanjsek, Ustün, & Cieza, 2008). Over the last decade, more than 25 ICF Core Sets have been developed based on a multi-phase international consensus process. ICF Core Sets constitute short lists of ICF Categories most relevant for patients with a particular health condition (Selb et al., 2014). These sets served as a foundation for an empirical study including people over 18 years with the respective health conditions to examine which ICF categories explain functioning in the general population and across patients with varying health conditions. In building upon these sets, an empirical study has been conducted to determine a minimal generic set of ICF categories most relevant across health conditions and the general population to describe health and functioning. Seven ICF categories revealed from this analysis are referred to as the ICF Generic Set (Cieza, Oberhauser, Bickenbach, Chatterji, & Stucki, 2014). When the focus is specifically on clinical populations, these ICF categories can be complemented with 23 ICF categories into a more extended ICF set of 30 ICF categories which is referred to as the ICF Rehabilitation Set (Prodinger, Bickenbach, Stucki, & Cieza, 2014). These 30 ICF categories best describe functioning across various clinical populations and across the continuum from acute, to early post-acute, and long-term care (Table 1). While functioning is to be understood in interaction with the environment, we have focused in this project specifically on the aspects of functioning related to Body functions and Activities and Participation.

Table 1: Overview of the ICF categories contained in the ICF Generic and Disability Set

ICF Code	Title
b130	Energy and drive functions (G)
b134	Sleep functions
b152	Emotional functions (G)
b280	Sensation of pain (G)
b455	Exercise tolerance functions
b620	Urination functions
b640	Sexual functions

b710	Mobility of joint functions
b730	Muscle power functions
d230	Carrying out daily routine (G)
d240	Handling stress and other psychological demands
d410	Changing basic body position
d415	Maintaining a body position
d420	Transferring oneself
d450	Walking (G)
d455	Moving around (G)
d465	Moving around using equipment
d470	Using transportation
d510	Washing oneself
d520	Caring for body parts
d530	Toileting
d540	Dressing
d550	Eating
d570	Looking after one's health
d640	Doing housework
d660	Assisting others
d710	Basic interpersonal interactions
d770	Intimate relationships
d850	Remunerative employment (G)
d920	Recreation and leisure

(G) indicates categories of ICF Generic Set

The ICF Generic and Disability Sets can be applied as minimal standards for aspects of functioning to be assessed in clinical practice and population-based health surveys, as well as for monitoring the impact of interventions at the clinical, service, and public health level. However, these sets only specify the relevant domains to be reported but not prescribe how to assess them. interRAI is one example for a widely used and complex assessment instrument of an assessment battery that has been used for monitoring functioning in people with chronic health conditions over time and across settings. interRAI generates aggregatable data for use in care planning and resource allocation, reimbursement, as well as quality improvement and evaluation (Carpenter & Hirdes, 2013). A previous study has shown that interRAI can be linked to the ICF and is a promising tool for the operationalization of the ICF (Berg et al., 2009). Now that the ICF Rehabilitation Set is available, the question remains whether interRAI could inform the operationalization of the ICF Rehabilitation Set.

## 2. Methods

The interRAI™ Community Mental Health (CMH) Assessment, interRAI™ Long-Term Care Facilities Assessment (LTCF), and interRAI™ Home Care (HC) were used for this project. Two researchers, one interRAI expert, one ICF expert, applied established ICF linking rules (Cieza et al., 2002; Cieza et al., 2005) to identify items that are suitable for the operationalization of the 30 ICF categories in the ICF Rehabilitation Set. As interRAI assessments are widely used for the assessment of needs, and ICF aims to describe functioning from the perspective of impairment in body functions and structures, or limitations and restrictions which people experience in performing certain tasks or activities, the proposed refinements to the linking rules were also applied (Cieza, Fayed, Bickenbach, & Proding, 2015). These refinements include documenting the perspective from which the question is asked and the approach taken to quantify this information. The perspectives identified refer to a descriptive perspective which constitutes information stating, for example, the extent of a problem a person experiences in performing a certain activity or task, an appraisal perspective which points to information about the extent to which personal expectations and hopes have been achieved, and the perspective of needs or dependency which outlines information on the need or dependency of e.g. assistive devices are needed to perform certain activities or tasks. With regard to quantification of response options, the most prominent approaches identified were intensity, frequency, and duration, as well as response options asking for qualitative attributes without implying any order in response options. The refinements provide additional information most valuable in determining comparability of information linked to a common ICF category. The two researchers then discussed the identified items and presented the results to the research team which consisted of people having basic to advanced knowledge in either interRAI or ICF, or both.

## 3. Results

interRAI items from all three assessment instruments could be identified that link to the ICF Rehabilitation Set as illustrated in Table 2. This table provides a comprehensive overview of which items from the various interRAI assessments were identified to link to a specific ICF category. For six ICF categories – *b710 Mobility of joint functions*, *b730 Muscle power*

*functions, d240 Handling stress and other psychological demands, d415 Maintaining a body position, d660 Assisting others, and d770 Intimate Relationships* – no item could be identified. For 16 ICF categories we identified one item, for 4 ICF categories two items, for *d710 Basic personal interactions* three items, for *b152 Emotional functions* four items, and for *b280 Sensation of pain* five items. For 12 ICF categories there was at least one relevant item in all three assessment instruments, for 8 ICF categories at least one item in 2 out of the 3 instruments, and for 4 ICF categories only item from one across the three instruments (*b640 Sexual functions, d455 Moving around, d850 Remunerative employment, and d920 Recreation and leisure*). It is worth reminding that the interRAI assessment systems is constructed around a set of assessment that are present in various combinations to create the three interRAI assessment instruments.

[Table 2: displayed at the end of the document]

Table 2 shows the perspectives and the quantification of the responses. The perspectives deployed in the interRAI assessments are the descriptive or needs/ dependency perspective. Items from both perspectives have been identified for only 1 ICF category, namely *d570 Looking after one's health*. The descriptive perspective was the sole perspective in the 9 ICF categories within the component body functions. For 13 of the 21 ICF categories within the activities and participation component, items could be identified from the perspective of needs/dependency, and for 3 ICF of the 21 categories (*d710 Basic interpersonal interactions, d850 Remunerative employment, and d920 Recreation and leisure*) from the descriptive perspective. It is worth mentioning that two groups of items were identified that could not be linked to a specific ICF category, but a block within the ICF. These were items related to Locomotion/Walking that could be linked to the block *d450-d469 Walking and moving around*, and items related to Balance which link on to the block *d410-d429 – Changing and maintaining body position*.

With regards to the scoring in the information gathered, the most frequent perspective was intensity; for 16 out of the 30 ICF categories from the ICF Rehabilitation Set items adopting an intensity approach to scoring was identified. No item was identified asking for the scoring frequency or duration of doing something or something occurring. For two ICF categories items were identified that provided a general statement with which one can (dis-) agree, one was linked to *d850 Remunerative employment* which asked for different qualitative attributes

(e.g. being employed, unemployed, seeking for employment, etc.). Furthermore, for three ICF categories several items were identified that adopted different perspective combinations, e.g. *b134 Sleep functions* (intensity and frequency), *b152 Emotional functions* (Frequency and Confirmation/Agreement), *d770 Basic interpersonal interactions* (Confirmation/Agreement and Intensity), as well as two ICF categories – *b280 Sensation of pain* (Intensity, Frequency, Confirmation/Agreement), *d570 Looking after one's health* (Intensity, Duration, Frequency).

#### **4. Discussion**

The linking has shown that except for 6 ICF categories, the 30 ICF categories contained in the ICF Rehabilitation Set could be operationalized with items from interRAI assessment instruments. The analysis reveals varying levels of granularity between interRAI and ICF. While certain interRAI items would provide a rather specific way of operationalizing ICF categories, other interRAI items serve more as an indicator. For instance, several items could be linked to *b280 Sensation of pain*; each covering a particular aspect of pain such as frequency, consistency, or intensity of pain. For the ICF category *d570 Looking after one's health*, several interRAI items could be identified. Each of these items, Managing medication, Patterns of drinking, Hours of exercise etc. provide an indicator of the extent to which a person is ensuring appropriate levels of physical activity and avoids harms to health rather than assessing the extent of limitation. In contrast to the pain items, such indicators provide some indication but it does not directly link the impact of a health condition, as other aspects, such as not pursuing regular exercises because of a busy working schedule. The challenge of operationalizing 'd' categories of the ICF have been described previously (Jette, Haley, & Kooyoomjian, 2003; Whiteneck & Dijkers, 2009).

The refinement of the linking rules have added value as they reveal more insight into the nature of information gathered in relation to a specific construct. Items in the interRAI assessments inhabit either a descriptive perspective, which reveal information about the extent of problems a person experiences in performing a certain task or a need's perspective. The first is aligned with the aim of the ICF to describe functioning. Whether a need's perspective is associated with or indicative of the extent of problems a person experiences remains for further empirical investigation.

A vast number of patient reported outcome measures exist that address aspects of functioning; some of these instruments are presented as quality of life scales. Quality of life or the appraisal perspective is different from a descriptive perspective as it focuses on the person's judgment on the extent to which personal goals and expectations are met given the personal, social and cultural context in which the person is situated in. Items and instruments from both perspectives have their value in health care and are complimentary. For instance, in services and programs provided within a curative or rehabilitative strategy, functioning is targeted as the primary outcome and quality of life can be considered as a secondary outcome. Whereas within a palliative strategy, quality of life becomes more important as a primary outcome and functioning secondary (Stucki, Cieza, & Melvin, 2007). Hence, documenting the perspectives contained in an item or instrument as part of the linking process is most valuable to enhance transparency not only on the content of the instruments but also for which context the instrument might be best suited for.

One challenge which we faced in this project was linking items related to the managing of an impairment of a body function to the ICF. One of the strengths of the ICF is that it distinguishes between body functions and structures, and activities and participation. This, in turn, allows to examine the relationship between these components. However, the question revealed on whether for instance *bladder continence* is a question about *b620 Urination functions* or *d5300 Regulating urination* which refers to coordinating and managing urination. It requires further psychometric work to see to which category such an item would best fit.

In this project, we have disassembled the items contained in the various interRAI assessments to examine whether interRAI can inform the operationalization of the categories contained in the ICF Rehabilitation Set. Based on this analysis we have evidence that interRAI is suitable for this purpose. This project does not conclude with how one could create a total score based on the items identified. Rather, this project has started with a normative approach on what should be assessed routinely along the continuum of care in persons with varying health conditions as reflected in the ICF Rehabilitation Set. Based on this information, we have proceeded with a pragmatic approach to see whether existing instruments, as illustrated with interRAI, would be suited for the operationalization of this set. The application of the ICF linking rules facilitates investigation of the content of instruments to inform the development or evaluation of existing instruments. This work serves as a foundation for further

psychometric work required to examine whether the information gained from these items can be aggregated into a meaningful and reliable sum score.

In conclusion, this project provides evidence that in principle, items from existing interRAI assessments can be used to operationalize most of the categories contained in the ICF Rehabilitation Set. These findings support the comprehensiveness and scope of the interRAI assessments on one hand, and provide a foundation for further psychometric work toward operationalizing the ICF Rehabilitation Set. We have used interRAI as a case in point in this project. Hence, this work comparing comprehensiveness and scope of interRAI items in relation to ICF serves as a foundation for the classification of a person's functioning using other assessment instruments.

Table 2: Linking of interRAI items to the categories of the ICF Rehabilitation Set

ICF Category		interRAI item	Response format	Perspective adopted in item	Quantification of information	interRAI Home Care (HC)	interRAI Long-Term Care Facilities (LTCF)	interRAI Community Mental Health (CMH)
b130	Energy and drive functions	Fatigue	None to Unable to commence any normal day-to-day activity	Descriptive	Intensity	Section J_5	Section_J_5	Section_J_4
b134	Sleep functions	Sleep problems	Coded for presence in last 3 days from 0 Not present to 4 Exhibited daily in last 3 days	Descriptive	Frequency	Section J_3_o & p	Section_J_3_o & p	
		Time asleep during day	0 Awake all or most of time to 4 Largely asleep or unresponsive	Descriptive	Intensity		Section_M_3	
b152	Emotional functions	Acute change in mental status from person's usual functioning	0 No, 1 Yes	Descriptive	Confirmation/Agreement	Section C_4		
		Indicators for possible depressed, anxious, or sad mood	0 Not present to 3 Exhibited daily in last 3 days	Descriptive	Frequency	Section E_1	Section_E_1	
		Mental state indicators (Mood disturbance, anxiety, psychosis, negative symptoms, other indicators)	0 Not present to 3 Exhibited daily in last 3 days	Descriptive	Frequency			Section_C_1
		Self-reported mood	0 Not in last 3 days to 3 Daily in the last 3 days; 8 Person could not (would not) respond	Descriptive	Frequency	Section_E_2	Section_E_2	Section_C_4

b280	Sensation of pain	Frequency with which person complains or shows evidence of pain	Coded for presence in last 3 days from 0 Not present to 3 Exhibited daily in last 3 days	Descriptive	Frequency	Section J_6_a	Section J_6_a	Section_J_11_a
		Intensity of highest level of pain present	0 No pain to 4 Times when pain is horrible or excruciating	Descriptive	Intensity	Section J_6_b	Section J_6_b	Section_J_11_b
		Consistency of pain	0 No pain to 3 Constant	Descriptive	Intensity	Section J_6_c	Section J_6_c	Section_J_11_c
		Breakthrough pain	0 No, 1 Yes	Descriptive	Confirmation/ Agreement	Section J_6_d	Section J_6_d	
		Pain control	0 No pain issue to 4 Therapeutic regimen followed, but pain control not adequate; 5 No therapeutic regimen being followed for pain; pain not adequately controlled	Descriptive	Intensity	Section J_6_e	Section J_6_e	Section_J_11_d
b455	Exercise tolerance functions	Physical function improvement potential	0 No, 1 Yes	Descriptive	Confirmation/ Agreement	Section G_5	Section_G_4	Section_H_4
b620	Urination functions	Bladder Continence	0 Continent to 5 Incontinent; 8 Did not occur	Descriptive	Intensity	Section H_1	Section_H_1	Section_J_12
b640	Sexual functions	Sexual activity_Reports persistent difficulty	0 No, 1 Yes	Descriptive	Confirmation/ Agreement			Section J_6_b

b710	Mobility of joint functions							
b730	Muscle power functions							
d230	Carrying out daily routine	Cognitive Skills for daily decision making	0 Independent to 4 Severely impaired; 5 No discernable consciousness, coma	Need/ Dependency	Intensity	Section C_1	Section_C_1	Section G_1
d240	Handling stress and other psychological demands							
d410	Changing basic body position	Transfer toilet	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_g	Section_G_1_g	Section_H_2_c
d415	Maintaining a body position							
d420	Transferring oneself	Bed mobility	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_i	Section_G_1_i	
d450	Walking	Walking	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_e	Section_G_1_e	

d455	Moving around	Stairs	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_1_f		
d465	Moving around using equipment	Locomotion	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_f	Section_G_1_f	Section_H_2_b
d470	Using transportation	Transportation	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_1_h		Section_H_1_g
d510	Washing oneself	Bathing	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_a	Section_G_1_a	
d520	Caring for body parts	Personal hygiene	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_b	Section_G_1_b	Section_H_2_a
d530	Toileting	Toilet use	0 Independent to 6 Total dependence; 8 Activity did not occur	Need /Dependency	Intensity	Section_G_2_h	Section_G_1_h	Section_H_2_d
d540	Dressing	Dressing upper body	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_c	Section_G_1_c	
		Dressing lower body	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_d	Section_G_1_d	

d550	Eating	Eating	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_2_j	Section_G_1_j	Section_H_2_e
d570	Looking after one's health	Managing medications	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_1_d		Section D_1_d
		Total hours of exercise or physical activity in last 3 days	0 None to 4 More than 4 hours	Descriptive	Duration	Section_G_4_a	Section_G_3_a	Section_H_3
		Smokes tobacco daily	0 No, 1 Not in last 3 days, 2 Yes	Descriptive	Frequency	Section_J_9_a	Section_J_9_a	
		Alcohol	0 None to 3 5 or more	Descriptive	Intensity	Section_J_9_b	Section_J_9_b	
		Alcohol, Injection drug use, Patterns of drinking, Withdrawal symptoms, Caffeine use, Tobacco, Gambling	varies	varies				Section D_1-10
d640	Doing housework	Ordinary housework	0 Independent to 6 Total dependence; 8 Activity did not occur	Need/ Dependency	Intensity	Section_G_1_b		Section_H_1b
d660	Assisting others							

d710	Basic interpersonal interactions	Unsettled relationships	0 No, 1 Yes	Descriptive	Confirmation/ Agreement		Section_F_3_a-c	Section_O_5_a-c
		Strengths_Strong and supportive relationship with family	0 No, 1 Yes	Descriptive	Confirmation/ Agreement		Section_F_5_c	Section_O_6_c
		Social relationships	0 Never, 1 More than 30 days ago, to 4 In last 3 days; 8 Unable to determine	Descriptive	Intensity		Section_F_1_a-c	Section_0_7
d770	Intimate relationships							
d850	Remunerative employment	Employment status	1 Employed, 2 Unemployed - seeking employment, 3 Unemployed - not seeking employment	Descriptive	Qualitative attributes			Section_P_1
		Employment arrangements (exclude volunteering)	1 Competitive, 2 Supportive, 3 Vocational, 4 NA	Descriptive	Qualitative attributes			Section_P_2
d920	Recreation and leisure	Average time involved in activities	0 None to 3 Most (more than 2/3 of time)	Descriptive	Intensity		Section_M_1	
		Activity preferences and involvement	0 No preference, not involved in last 3 days to 4 Preferred, involved in last 3 days	Descriptive	Intensity		Section_M_2_a-p	

Note: these items are the property of interRAI and are protected by the U.S. copyright and trademark laws.

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