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A functioning and related health outcomes module: the tool and testing

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Abstract A functioning and related health outcomes module: the tool and testing

The Functioning and Related Health Outcomes Module is a data capture tool for summary information on functioning. The module is based on the ICF components and qualifiers and essentially summarises the ICF into four tables. The FRHOM is to be tested using a variety of methods in a range of services, settings and specialties over the next few months. This paper will present the plan for testing and the range of test opportunities that have been negotiated.

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Introduction

The purpose of the Functioning and Related Health Outcomes Module (FRHOM) is to collect quantified summary information on the level of functioning of an individual. Information on a person's functioning should enhance data quality for medical purposes. It will complement information on diseases and related health problems in a range of applications (AIHW 2005a).

Kostanjsek and Üstün (2004) point out that to overcome the problem where assessment data acquired in one episode of care cannot be carried over to another episode of care involving a different clinical focus, a common framework is needed. This data capture tool is intended to provide that common framework and convey summary information between care providers. It is designed for use in health, clinical and community services and will be tested in these settings.

The FRHOM is a new, compact module that can provide a summary that reflects the person's current status across all components of functioning as defined in the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). It is not an assessment tool but draws on information collected from a range of sources, including the person and their carers, clinicians and the usual assessment processes.

The information, if gathered over time and by a range of health and community care providers, will result in a complete profile of the person's functioning.

The module was developed following extensive mapping of existing items on functioning to the International Classification of Functioning, Disability and Health (ICF) (WHO 2001).These items included standardised assessment tools (condition specific and generic), functional outcome, health related quality of life and population survey measures. Details of this work can be found in AIHW 2005a.

The FRHOM

The FRHOM comprises four tables for capturing summary information to describe a person's level of functioning:

- Body functioning, qualified by extent;
- Body structure, qualified by extent, location and nature;
- Performance in life areas: activities, qualified by difficulty and need for assistance; and participation, qualified by extent and satisfaction;
- Environmental factors, qualified by extent of influence either as barriers or facilitators to functioning.

Each table represents a component of functioning and has a range of domains and measures of the extent to which that domain is affected.

The rows of the tables are consistent with the corresponding ICF chapters, and the columns provide indicators of the degree to which the person's functioning is

affected.

The FRHOM summarises the experience of functioning irrespective of the number or type of health conditions, which may or may not have influenced the level of functioning. This approach to summarising information on a complex range of experiences underpins a flexible approach to the use of the module so that different tables or parts of the tables can be used in different service settings and for different purposes. However, to record the complete experience of functioning, disability and health, all components need to be used.

The primary source of information should be the individual and people who support and care for them. It is envisaged that components and domains relevant to particular episodes of care will be added so that a person's record is built up over time. Though many people may be involved in the completion of the FRHOM it is essential that it is the individual's summary perspective that is recorded.

The tables are constructed to be consistent not only with the ICF, but also with existing (and proposed) national data standards, with the main concepts found in the tools and literature reviewed, and with relevant Australian population data measures. A suite of metadata items to support the FRHOM, based on the ISO11179 standard (ISO 2004), has been included in the National Community Services Data Dictionary and endorsed, in principle, for inclusion in the National Health Data Dictionary. The metadata items may be found on the Australian metadata online registry METeOR (AIHW 2005b).

The tables have been developed in the light of the proven usefulness of existing tools and capture important qualifier concepts used (e.g. difficulty and need for assistance). It is not possible to reliably map data collected using the range of existing assessment tools used across the range of settings because of the many sources of variation. Thus, the FRHOM is capturing data using the 'ICF as a homogenous assessment base' (Kostanjsek and Üstün 2004), not mapping from a range of incompatible tools.

Broad ranges of percentages are provided for those cases in which calibrated assessment instruments or other standards are available to quantify the level of body function. The percentages aim to make the distinction between functioning below and above a 'clinical' or 'medical' threshold with a 5% margin of error at either end of the scale; the MILD category being below the clinical threshold and MODERATE and SEVERE above. Functioning is described in terms of the duration, frequency and intensity of the problem in functioning. For example, a moderate problem is described as indicating that 'a problem is present less than 50% of the time, with a medium alteration in functioning which happens occasionally over the last 30 days' (WHO 2001:220, Kostanjsek and Üstün 2004).

What does the FRHOM look like?

The FHROM comprises 4 data collection tables relating to body functions, body structures, activity and participation in life areas and environmental factors.

Four qualifiers are provided for use with the activity and participation domains—two for activity and two for participation. Activity and participation are distinguished by qualifiers, not domains (AIHW 2003:39). In this way the FRHOM is using the activity and participation component in line with option 4 in the ICF (WHO 2001:236).

Table 1: Body functions—extent of impairment

Please indicate the extent of impairment compared with accepted population standards for each body function (1–8) by recording only one level (0–9).

	0 – No impairment 1 – Mild impairment 2 – Moderate impairment 3 – Severe impairment 4 – Complete impairment 8 – Not specified 9 – Not applicable
1 Mental functions	☐
2 Sensory functions and pain	☐
3 Voice and speech functions	☐
4 Functions of the cardiovascular, haematological, immunological and respiratory systems	☐
5 Functions of the digestive, metabolic and endocrine systems	☐
6 Genitourinary and reproductive functions	☐
7 Neuromusculoskeletal functions	☐
8 Functions of the skin and related structures	☐

Table 2: Body structures—extent, nature and location of impairment

1 Please indicate the **extent of impairment** compared with accepted population standards for each **body structure** (1–8) by recording only **one** level (0–4) in column 1.

2 Please indicate the **nature of impairment** compared with accepted population standards by placing a number (0–9) against each body structure in column 2.

3 Please indicate **the location of the impairment** by placing a number (0–9) against each body structure in column 3.

	1 Extent of Impairment 0.– No impairment 1 – Mild impairment 2 – Moderate impairment 3 – Severe impairment 4 – Complete impairment 8 – not specified 9 – not applicable	**2 Nature of change** 0 - no change 1 – total absence 2 – partial absence 3 – additional part 4 – aberrant dimensions 5 – discontinuity 6 – deviating position 7 – qualitative change 8 – not specified 9 – not applicable	**3) Location of impairment** 0 – more than one region 1 – right 2 – left 3 – both sides 4 – front 5 – back 6 – proximal 7 – distal 8 – not specified 9 – not applicable
1) Structures of the nervous system			
2) Eye, ear and related structures			
3) Structures involved in voice and speech			
4) Structures of the cardiovascular, immunological and respiratory systems			
5) Structures related to the digestive, metabolic and endocrine systems			
6) Structures related to the genitourinary and reproductive systems			
7) Structures related to movement			
8) Skin and related structures			

Table 3: Activities and participation—limitations and restrictions

1 Please indicate the **level of difficulty** experienced for each life area by placing a number in column 1 against each life area (1-9).

2 Please indicate the level of need for **personal assistance** by placing a number in column 2 against each life area (1-9).

3 Please indicate an **independent view** (judged by health care or community service provider, or an assessment process) of the level of participation by placing a number in column 3 against each life area (1-9).

4 Please indicate the **person's view** (judged by the individual, with advocate if necessary) of their satisfaction with participation in terms of duration, frequency, manner or outcome by placing a number in column 4 against each life area (1-9).

	1) Level of Difficulty 0 No difficulty in this life area 1 Mild difficulty 2 Moderate difficulty 3 Severe difficulty 4 Complete difficulty 8 Not specified 9 Not applicable	**2) Need for personal assistance** 0 Does not need help/supervision 1 Sometimes needs help/supervision 2 Always needs help/supervision 3 Unable to do this life area, even with assistance 8 Not specified 9 Not applicable	**3) Extent of participation** 0 Full participation 1 Mild participation restriction 2 Moderate participation restriction 3 Severe participation restriction 4 Complete participation restriction 8 Not specified 9 Not applicable	**4) Satisfaction with participation** 0 High satisfaction 1 Moderate satisfaction 2 Neither satisfied nor dissatisfied 3 Moderate dissatisfaction 4 Extreme dissatisfaction 5 Complete restriction and dissatisfaction 8 Not specified 9 Not applicable
1) Learning, applying knowledge				
2) General tasks and demands				
3) Communication				
4) Mobility				
4) Self-care				
6) Domestic life				
7) Interpersonal interactions and relationships				
8) Major life areas				
9) Community, social and civic life				

Table 4: Environmental factors—facilitators and/or barriers

Please indicate the extent to which each environmental factor presents either as a barrier or facilitator to functioning by recording only one level.

The following **environmental factors** influence the person's functioning either: • as facilitators • as barriers	Facilitators	Barriers
	+0 – No facilitator +1 – Mild facilitator +2 – Moderate facilitator +3 – Substantial facilitator +4 – Complete facilitator +8 – Facilitator not specified 9 – Not applicable	0 – No barrier 1 – Mild barrier 2 – Moderate barrier 3 – Severe barrier 4 – Complete barrier 8 – Barrier not specified 9 – Not applicable

Products and technology		**Natural environment and human made changes to the environment**		**Support and relationships**	
Personal consumption		Physical geography		Immediate family	
Personal use in daily living		Population		Extended family	
Personal indoor and outdoor mobility and transportation		Flora and fauna		Friends	
Communication		Climate		Acquaintances, peers, colleagues, neighbours and community members	
Education		Natural events		People in positions of authority	
Employment		Human-caused events		People in subordinate positions	
Culture, recreation and sport		Light		Personal care providers and personal assistants	
Practice of religion and spirituality		Time-related changes		Strangers	
Design, construction and building for public use		Sound		Domesticated animals	
Design, construction and building for private use		Vibration		Health professionals	
Land development		Air quality		Other professionals	
Assets					

Continued

The following **environmental factors** influence the person's functioning either: • as facilitators • as barriers	Facilitators	Barriers
	+0 – No facilitator +1 – Mild facilitator +2 – Moderate facilitator +3 – Substantial facilitator +4 – Complete facilitator +8 – Facilitator not specified 9 – Not applicable	0 – No barrier 1 – Mild barrier 2 – Moderate barrier 3 – Severe barrier 4 – Complete barrier 8 – Barrier not specified 9 – Not applicable

Attitudes		**Services, systems and policies**			
Immediate family		Production of consumer goods		Social security	
Extended family members		Architecture and construction		General social support	
Friends		Open space planning		Health	
Acquaintances, peers, colleagues, neighbours and community members		Housing		Education and training	
People in positions of authority		Utilities		Labour and employment	
People in subordinate positions		Communication		Political	
Personal care providers and personal assistants		Transportation			
Strangers		Civil protection			
Health professionals		Legal			
Other professionals		Associations and organisations			
Societal attitudes		Media			
Social norms, practices and ideologies		Economic			

Testing the FRHOM

Consultation and pilot testing the FRHOM with a broad range of stakeholders, including consumers and their representatives, clinicians, government representatives and information advisory groups, will be conducted in late 2005 and early 2006.

The purpose of pilot testing is to evaluate the meaning and relevance of the proposed FRHOM in the field, and the feasibility of its collection. The field trials have been designed to elicit systematic information on the utility of the FRHOM and to inform its further development.

The range of service systems for which the FRHOM may be useful is extensive. The earlier FRHOM report (AIHW 2005a) identified a range of program areas where information on functioning is required. These include the National Health Priority Areas Programs and the continuity of care programs for older Australians being developed under the Australian Health Care Agreements.

The pilot tests will enable the project team to gain an understanding of the practices and methods of data collection of the potential users of the FRHOM and may serve to enhance the channels of communication between the project team and stakeholders in the project. The results of the trials should confirm that data collected using the FRHOM are relevant for transferring summary information on human functioning across settings and between health care providers.

Methodology

The type of testing undertaken will depend on the capacity of the stakeholders to incorporate testing into their existing work programs. There are a range of possible tests, from those that are simple and have low resource requirements (human, financial and time), to those that are more resource intensive. The types of tests proposed are:

- Structured discussions during committee meetings
- Key informant interviews
- Consensus conference
- Mapping exercises
- Completing FRHOM from case records
- Pilot testing in projects that are about to happen
- Clinical test by interested clinicians
- Testing the FRHOM with existing data

Test sites

A range of possible pilot testing opportunities have been identified by means of an AIHW workshop and consultations with key committees and stakeholders. These include:

Cardiovascular disease monitoring	• Structured discussion during committee meetings • Key informant interviews/survey • Clinical test by interested clinicians (stroke) • Completing FRHOM from case records
Diabetes monitoring	• Structured discussion during committee meetings • Key informant interviews/surveys
Community care	• Analysis of alignment of community care data sets
Aged care	• Key informant interviews/surveys • Dementia work • The FRHOM as a means of relating data from across service settings
Mental health	• Mapping of mental health outcomes measure to the FRHOM
Rehabilitation	• Clinical test by interested clinicians (ABI) • Key informant interviews/surveys • Completing FRHOM from case records
Disability	• Structured discussion during committee meetings • Consensus conference • Key informant interviews/surveys
Insurance	• Key informant interviews/surveys
General practice	• Key informant interviews/surveys • Mapping of data items in the General Practice Survey to the FRHOM
National survey program	• Consultation with Australian Bureau of Statistics on aspects of the FRHOM that intersect with the survey program whilst this program is under review
e-health	• Development of an archetype for functioning and disability

Test materials

A set of test materials has been developed.

1 A document for consultation and testing (AIHW 2005c) will be distributed, together with a survey form with a set of key questions, to interested persons to provide feedback to the project team.

2 A FRHOM User's Guide gives information about the purpose of the FRHOM and how to collect information. It is envisaged that the User's Guide will be revised in the light of information gained during testing.

3 The set of key questions will form the basis of key informant interviews. Key informants include:

- GPs and other medical practitioners
- Health care providers, such as nurses, allied health professionals and social workers
- Australian Government departments e.g. DoHA, DVA, FaCS
- State and territory government departments
- Health care consumers and people with disabilities
- Community services providers
- Clinical experts on cardiovascular disease, diabetes and other chronic diseases
- Research experts

4 A set of vignettes is available for coding using the FRHOM. Reporting forms for completion by those undertaking the tests have also been developed.

Feedback

The project team is keen to receive feedback on the approach they are taking to implement the ICF. The following issues are for discussion by the Implementation Committee at the World Health Organization Family of International Classifications Network meeting in Tokyo.

1 The FRHOM looks to be an instrument that is feasible to apply in the clinical setting.

2 The information gathered at the clinical interface is likely to be useful for statistics.

3 Ideally the FRHOM could have a drill down capacity, much like the ICF, that allows the use of the module at the level of detail suitable for the purpose. Would a drill down facility improve the usefulness of the FRHOM?

4 We have discussed recording the Environmental factors table using the facilitator/barrier scale, but in the absence of many assessments of the environment we have considered using an indication of whether the factor is present or absent. This could provide considerably more information than is usually collected at present, but compromises the purity of the

implementation of ICF.

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