A functioning and related health outcomes module

Testing and refining a data capture tool for health and community services information systems

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Abbreviations

ACAT	Aged Care Assessment Teams
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
CSTDA	Commonwealth State/Territory Disability Agreement
FRHOM	Functioning and Related Health Outcomes Module
HACC	Home and Community Care
ICF	International Classification of Functioning, Disability and Health
NHIG	National Health Information Group
NMDS	National Minimum Data Set
METeOR	Metadata Online Registry
SDAC	Survey of Disability, Ageing and Carers
SIMC	Statistical Information Management Committee
WHO	World Health Organization
WHO-FIC	World Health Organization Family of International Classifications

1 Introduction and background to the Functioning and Related Health Outcomes Module

1.1 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 and will complement information on diseases and related health problems in a range of applications (AIHW 2005a).

This data capture tool is intended to convey summary information between care providers and 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. The information, gathered over time and by a range of health and community care providers, will result in a complete profile of the person's functioning.

This report informs people interested in improving information on human functioning within and across a wide range of fields, and/or interested in testing the FRHOM in 2005–06. Comments on the module are welcomed.

1.2 Background to the project

The project to develop the FRHOM commenced in November 2003 and was supported by the Australian Health Ministers' Advisory Council (AHMAC) and its Statistical Information Management Committee (SIMC) (then the National Health Information Management Group). Developmental work was reported to SIMC in March 2005. Details of this work can be found in *'A Functioning and Related Health Outcomes Module: The Development of a Data Capture Tool for Health Information Systems'* (AIHW 2005a).

The report recommended a module of summary information that:

- can be used to describe human functioning, heath status, outcomes of health interventions, and the need for assistance in relation to human functioning; and
- enables the efficient and effective storage and transmission of data on human functioning in a wide range of human service systems, and among settings within systems; the means of transmission could include electronic health records.

1.3 Potential uses of the FRHOM

Data collection is costly and time consuming so it is important to ensure that information collected is used and, where possible, used to inform multiple purposes. It is important to define clearly the information needs that drive the information collected at the point of care, to be aware of the possibilities of aggregation of clinical data and to consider the need for comparisons with other data such as population survey data. The following areas potentially could benefit from using the FRHOM.

Continuity of care

Improvement in the continuity of care is an important goal under the 2003–08 Australian Health Care Agreements. People with mental health conditions, chronic health conditions, cancers and older people with multiple health conditions tend to move between different sectors of the health and community care system. To fulfil the aim of more seamless care for these people it will be important for reliable and consistent information to be available to each of the service providers. Whilst reliable and consistent information may well exist, it is not available in a standard format and this is what the FRHOM is expected to deliver.

Assessing the impact of health interventions

Australian Health Ministers' Advisory Council (AHMAC) has identified health surveillance and primary prevention of chronic diseases as topics of significant national priority. Change in functioning is the usual precursor to entry into the health system and diagnosis of a disease or chronic health condition. That is, when the individual recognises that they cannot perform in their usual life areas as well as they used to. (Exceptions may be attendance for preventive interventions such as immunisation or genetic counselling.) Collection of summary information on functional status at this time and updating on subsequent occasions of care could help with monitoring change in functional status over time, and thus the outcomes of both primary and secondary preventive management strategies.

Rehabilitation

Rehabilitation is a 'process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and or/social functional levels, thus providing them with the tools to change their lives towards a higher level of independence' (UN 1994). A definition of rehabilitation care as a hospital care type is included in the National Health Data Dictionary (AIHW 2004b). Rehabilitation can be seen on a continuum; with no hard lines between hospital based, community based and vocational rehabilitation, as can human functioning. The ICF is universal in its application, and so a FRHOM based on the ICF may be used to summarise and convey information across the rehabilitation continuum.

Ageing and aged care

The management of ageing and aged care continues to be a high health information priority as the Australian population ages. The Australian Government with state and territory governments provide a range of aged care programs delivered in

residential, community and in-home settings. The aged care sector uses a variety of functional assessment tools and data collections, for example the Resident Classification Scale, the Aged Care Funding Instrument, and the Home and Community Care (HACC) and Aged Care Assessment Team (ACAT) assessments. The ICF has been used as the framework to examine the data collections across some of these programs (AIHW 2004a). The ICF-based FRHOM has the potential to enable meaningful comparisons across programs and support policy development, program planning and performance monitoring. Additionally, national acceptance of the FRHOM as a standard would enable comparisons with national survey data and state and territory data.

Services for people with disabilities

Disability affects many people, directly or indirectly—an estimated 20% of the population. The identification of people with disabilities within generic services is crucial to monitoring their access to and outcomes from the whole services spectrum, and the success of whole-of-government outcomes. The importance of generic services to people with a disability is specifically recognised in the third Commonwealth State/Territory Disability Agreement (CSTDA). All such data collection and analysis require consistent approaches to the definition of disability across a wide range of human services. The FRHOM is consistent with definitions in the disability services National Minimum Data Set (NMDS) and the main Australian population survey on disability.

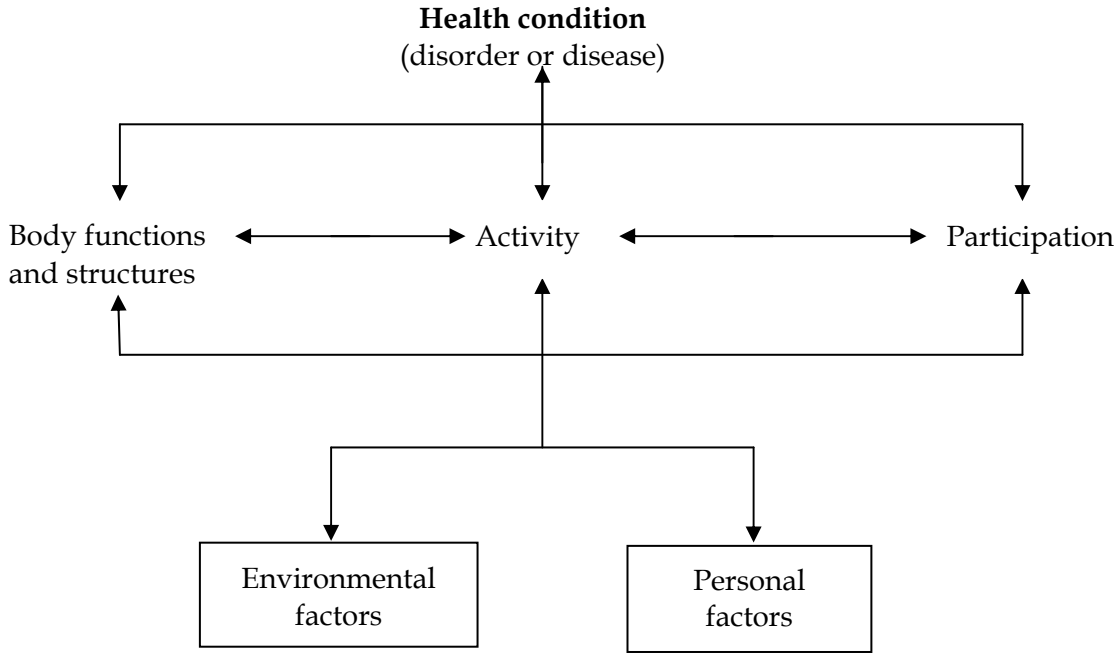
The FRHOM for statistical purposes

So far the FRHOM has been discussed as data capture tool for use across a range of health and community care programs. It is also envisaged that data collected from a wide range of health and community services would be used for statistical purposes. With that in mind the framing of the FRHOM around the ICF will enable comparisons of data with the ABS Survey of Disability, Ageing and Carers (SDAC) and the 2006 Census. Further work on methods of aggregation may need to be undertaken.

FRHOM, ICF and Australian data standards

The FRHOM relates directly to international and national data standards. The ICF model (Figure 1) illustrates that functioning and disability is multi-dimensional and experienced in terms of body functions, body structures, activities and participation and critically the environment.

The ICF is one of two reference classifications in the World Health Organization (WHO) Family of International Classifications (WHO-FIC) and endorsed as a member of the Australian Family of Health and Related Classifications in 2002 (NHIMG Secretariat 2002). The ICF has been used as the basis for national data standards on the Metadata Online Registry METeOR (AIHW 2005b).



Source: WHO 2001:18.

Figure 1: Interactions between components of the ICF

2 The Functioning and Related Health Outcomes Module

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, however information can be gained from a wide variety of sources. Parts of the record may be completed most appropriately by physicians or other health professionals for example the body functions and structures tables. Others, such as participation and environmental factors tables, should reflect the perspective of the individual who is the subject of the data. 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.

The experience of functioning is in relation to a health condition, and does not consider decrements in functioning that may be associated with social factors such as ethnic background or economic status. For example, ability to communicate is recorded in relation to the heath condition, not to the fact that a person does not speak English at home.

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.

The tables have been developed in the light of the intelligence embodied in existing tools and capture important qualifier concepts used in existing tools (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 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).

The four components of the FRHOM are described below.

2.1 Body functions

Body functions are the physiological functions of body systems (including psychological functions). Body refers to the human organism as a whole; hence it includes the brain and its functions, that is, the mind. The biomedical status of the body functions are recorded in relation to accepted population standards. The table can be used to record positive or neutral body functions as well as impairment of body functions.

2.2 Body structures

Body structures are anatomical parts of the body such as organs, limbs and their components. The biomedical status of the body structures are recorded in relation to accepted population standards. The table can be used to record positive or neutral body structure as well as impairment of body structure.

The location of impairments and the nature of the change to the body structure can also be recorded using this table.

2.3 Performance in life areas

Four measures are used to describe performance in life areas; difficulty with activities, assistance needed to perform activities, extent of participation in and satisfaction with participation in life areas.

Difficulty subsumes such matters as pain involved, time taken, effort, number of errors, clumsiness, and modification of the manner in which the activity is performed. Difficulty is the combination of the frequency with which the problem exists, the duration of the problem and the intensity of the problem.

Need for assistance with activities includes personal assistance and/or supervision.

Participation extent indicates the extent of participation restriction in life areas. This corresponds to an externally observable measure of participation. The external observer may be a health care provider, such as a doctor, nurse or allied health professional; a community service provider such as a disability services provider, home and community services provider or a member of a mental health team.

Participation—satisfaction level corresponds to the person's own perspective on their participation, and reflects their attitude to their participation in the various life domains. It is essentially a summary measure in which are embedded the concepts of satisfaction, choice, opportunity and importance. Together information on extent and satisfaction may indicate a 'performance gap' for participation, in that a person may indicate life areas where they are not satisfied, and may indicate environmental factors that could ameliorate the situation.

2.4 Environmental factors

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. Environmental factors are external to the individual and can have a positive or negative influence on a person's participation as a member of society, on performance of activities, or on a person's body function or structure.

Environmental factors represent the circumstances in which the individual lives. These factors are conceived as immediate (e.g. physical features of the environment, social environment) and societal (formal and informal social structures, services and systems). Different environments may have a very different impact on the same individual with a given health condition.

Facilitators are features of the environment that have a positive effect on the experience of functioning and disability. Barriers are features of the environment that have a negative effect on the experience of functioning and disability. Table 4 can be used to record the presence of environmental factors as either facilitators or barriers.

2.5 Collecting information about disability grouping and health conditions in addition to the FRHOM

The collection of data on disability-related metadata items and diagnosis, together, allows the relationship of the components of functioning and related health conditions to be more thoroughly explored.

'Health conditions' can include a disease, condition, injury, poisoning, sign, symptom, abnormal finding, complaint, or other related health problem.

'Disability groupings' constitute a broad categorisation of disabilities in terms of the underlying health condition, impairment, activity limitations, participation restrictions, environmental factors and support needs.

National data standards have been developed to reflect terms in common use. See National Health and Community Services Data Dictionaries, METeOR and the ICF Australian user guide. (AIHW 2004b, AIHW 2004c, AIHW 2005b, AIHW 2003)

3 Draft data collection forms for the Functioning and Related Health Outcomes Module

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).

Further information for completing this item is included in the FRHOM user's guide.

Table 1: Body functions—extent of impairment

	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.

Further information for completing this item is included in the FRHOM user's guide.

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

	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			

Source: WHO 2001.

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 (0–9).

2 Please indicate the level of need for **personal assistance** by placing a number in column 2 against each life area (0–9).

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 (0–9).

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).

Further information for completing this item is included in the FRHOM user's guide.

Table 3: Activities and participation—limitations and restrictions

	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				
5 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.

Table 4: Environmental factors—facilitators and/or barriers

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

4 FRHOM user's guide

This is a draft FRHOM User's guide developed to support consultation and testing. Changes may be made as a result of feedback from the test process.

Functioning and disability is a multi-dimensional concept universal in its coverage. It is conceived as 'the complex relationship between an individual's health condition and personal factors and of the external factors in which the individual lives' (WHO 2001:17).

There are four components to the FRHOM. For a complete profile of a person's functioning all components should be completed.

4.1 The people who are subjects of data

The FRHOM is intended for anyone entering the health and welfare system whose functional status needs to be described. For people accessing care across a range of services, such as hospitals, general practice, home and community care and day therapy services, the FRHOM will be useful for conveying summary information between professionals and settings.

The FRHOM will be important for those with health conditions that are intermittent in intensity, such as mental health and other chronic conditions.

4.2 When to make a record

The FRHOM is designed for use within the normal process of care. An initial record should be made at the beginning of an episode of care. To monitor progress during an episode of care additional ratings may be made. A final rating can be made on completion of an episode of care or on transfer from one service or setting to another.

To get an indication of outcome of an episode of care at least two ratings need to be made.

4.3 Sources of information to complete the FRHOM

The usual standardised or non-standardised assessment methods will provide the information necessary to complete the FRHOM including: information from a carer or other person significant to the individual; information from clinical records and letters of referral and the results of tests and previous interventions from other health and community care providers.

The key source of information for the completion of the FRHOM is the individual who is the subject of the information and it is the outcomes for the individual, irrespective of their health condition(s) or the program or service that they are receiving, that are being monitored.

It is recommended that the ratings are made by clinicians or service providers that have been involved in the assessment of the person so that the record is a true reflection of the person's functioning. Though many people may be involved in the completion of the FHROM it is essential that it is the individual's summary perspective that is recorded.

There are other ICF based instruments for recording disease specific functioning (Cieza et al 2004), and clinician specific perspectives of a person's functioning (Skeat et al 2003). The FROHM takes a wholistic individual perspective.

4.4 Data collection using the FRHOM

Body functions—extent of impairment (Table 1)

This table records the level of physiological functioning (including psychological functioning) of the body.

Examples of body functions: the complete range of domains and definitions may be found in the ICF (WHO 2001) or the ICF Browser <*http://www3.who.int/icf/onlinebrowser/icf.cfm*>.

1	Mental functions	Orientation, intellectual psychosocial, attention, memory and energy
2	Sensory functions and pain	Seeing, hearing, proprioception, pain
3	Voice and speech functions	Voice, articulation, fluency and rhythm
4	Functions of the cardiovascular, haematological, immunological and respiratory systems	Heart and blood vessels, respiration, exercise tolerance
5	Functions of the digestive, metabolic and endocrine systems	Digestion, defecation, weight maintenance, metabolic functions and thermoregulation
6	Genitourinary and reproductive functions	Urinary excretory, menstruation and procreation functions
7	Neuromusculoskeletal functions	Functions of joints and bones, muscles, control of movement motor reflexes and gait pattern
8	Functions of the skin and related structures.	Protective and repair functions of skin, functions of hair and nails

The question

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

Guide for use

0	No impairment	Is recorded when there is **no significant** variation from accepted population standards in the biomedical status of the body.	[0–4%]
1	Mild impairment	Is recorded when there is a **slight or low** variation from accepted population standards in the biomedical status of the body.	[5–24%]
2	Moderate impairment	Is recorded when there is a **medium (significant but not severe)** variation from accepted population standards in the biomedical status of the body.	[25–49%]

3	Severe impairment	Is recorded when there is an **extreme** variation from accepted population standards in the biomedical status of the body.	[50–95%]
4	Complete impairment	Is recorded when there is a **total** variation from accepted population standards in the biomedical status of the body.	[96–100%]
8	Not specified	Is recorded when the person has an impairment of body structure but there is **insufficient information** to record against codes 0-4	
9	Not applicable	Is recorded when it is **inappropriate** to record this body function, for example menstruation functions are not applicable in females before or beyond a certain age.	

For further information see <*http://meteor.aihw.gov.au/content/index.phtml/itemId/288437*>.

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

Body structures can deviate from accepted population standards in terms of loss or absence, reduction, addition or excess, or deviation. These deviations can be recorded in Table 2.

Examples of body structures: the complete range of domains and definitions may be found in the ICF (WHO 2001) or the ICF Browser <*http://www3.who.int/icf/onlinebrowser/icf.cfm*>.

1	Structures of the nervous system	The brain, meninges, sympathetic and parasympathetic nervous system, spinal cord and related structures
2	The eye, ear and related structures	The eye socket, eyeball, structures around the eye, the external, middle and inner ear structures
3	Structures involved in voice and speech	The nose, mouth, pharynx, and larynx
4	Structures of the cardiovascular, immunological and respiratory system	The heart and blood vessels, the lymphatic nodes and vessels, thymus spleen and bone marrow, the trachea, lungs thoracic cage and muscles of respiration
5	Structures related to the digestive, metabolic and endocrine systems	The oesophagus, stomach intestines, pancreas, liver, gall bladder and endocrine glands
6	Structures related to the genitourinary and reproductive systems	The kidneys and associated structures, the pelvic floor, the ovaries, uterus, breast and nipple, the vagina and external genitalia, the testes, penis and prostate
7	Structures related to movement	The bones, joints, muscles, ligaments and fasciae of the regions of the body
8	Skin and related structures	The skin of the regions of the body, the skin glands, nails and hair

The question

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.

Guide for use

0	No impairment	Is recorded when there is **no significant** variation from accepted population standards in the biomedical status of the body.	[0–4%]
1	Mild impairment	Is recorded when there is **a slight or low** variation from accepted population standards in the biomedical status of the body.	[5–24%]
2	Moderate impairment	Is recorded when there is a **medium (significant but not severe)** variation from accepted population standards in the biomedical status of the body.	[25–49%]
3	Severe impairment	Is recorded when there is an **extreme** variation from accepted population standards in the biomedical status of the body.	[50–95%]
4	Complete impairment	Is recorded when there is a **total** variation from accepted population standards in the biomedical status of the body.	[96–100%]
8	Not specified	Is recorded when the person has an impairment of body structure but there is **insufficient information** to record against codes 0-4	
9	Not applicable	Is recorded when it is **inappropriate** to record body structure, for example structures of the female reproductive system for males and vice versa.	

The question

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

Guide for use

0	No change	Is recorded when the structure of the body part is within the range of the population standard.
1	Total absence	Is recorded when the body structure is not present. For example total absence of the structures of the lower leg following a thorough knee amputation.
2	Partial absence	Is recorded when only part of a body structure is present. For example partial absence of the bones of the lower leg following below knee amputation.
3	Additional part	Is recorded when a structure not usually present in the population is present, for example a sixth lumbar vertebra or an sixth digit on one hand.
4	Aberrant dimensions	Is recorded when the shape and size of a body structure is significantly different from the population standard. For example radial aplasia where the shape and size of the radial bone does not develop.
5	Discontinuity	Is recorded when parts of a body structure are separated, for example cleft palate or fracture.
6	Deviating position	Is recorded when the location of a structure is not according to population standard; for example, transposition of the great vessels, where the aorta arises from the right ventricle and the pulmonary vessels from the left ventricle.
7	Qualitative change	Is recorded when the structure of a body part is altered from the population standard. This includes accumulation of fluid, changes in bone structure as a result of osteoporosis or Paget's disease.
8	Not specified	Is recorded when the person has an impairment of body structure but there is **insufficient information** to record against codes 0-7
9	Not applicable	Is recorded when there it is **inappropriate** to record body structure

The question

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

Guide for use

0	More than one region	Is recorded when the impairment is present in more than one body location; for example when burn scars affect many areas of skin.
1	Right	Is recorded when the impairment is present to the right of the midline of the body when viewed from either the back or the front (sagittal axis).
2	Left	Is recorded when the impairment is present to the left of the midline of the body when viewed from either the back or the front (sagittal axis).
3	Both sides	Is recorded when the impairment is present on both sides of the midline (sagittal plane) of the body, for example bilateral amputations.
4	Front	Is recorded when the impairment is present in front of a line passing through the midline of the body when viewed from the side (coronal plane).
5	Back	Is recorded when the impairment is present behind a line passing through the midline of the body when viewed from the side (coronal plane).
6	Proximal	Is recorded when the impairment is present nearer the head than a line passing midway between the top of the head and the soles of the feet (transverse plane).
7	Distal	Is recorded when the impairment is present nearer the feet than a line passing midway between the top of the head and the soles of the feet (transverse plane).
8	Not specified	Is recorded when the person has an impairment of body structure but there is **insufficient information** to record against codes 0–7
9	Not applicable	Is recorded when there it is **inappropriate** to record body structure.

For further information see

<*http://meteor.aihw.gov.au/content/index.phtml/itemId/288437*>

<*http://meteor.aihw.gov.au/content/index.phtml/itemId/288474*>

<*http://meteor.aihw.gov.au/content/index.phtml/itemId/288458*>.

Activities and participation—limitations and restrictions (Table 3)

Activities and participation are the two components of function collected using Table 3. Performance describes what the individual does in his or her current environment. The environmental factors affecting performance are described using Table 4.

Examples of life areas: the complete range of domains and definitions may be found in the ICF (WHO 2001) or the ICF Browser <*http://www3.who.int/icf/onlinebrowser/icf.cfm*>.

1	Learning, applying knowledge	Understanding new ideas, remembering, problem solving, decision making, paying attention
2	General tasks and demands	Undertaking single or multiple tasks, carrying out daily routine, handling stress and other psychological demands
3	Communication	Making self understood, in own native language or preferred method of communication if applicable, and understanding others
4	Mobility	Moving around the home and/or moving around away from home (including using public transport or driving a motor vehicle), getting in or out of bed or a chair

5	Self-care	Washing oneself, dressing, eating, toileting
6	Domestic life	Organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance
7	Interpersonal interactions and relationships	Actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions
8	Major life areas	The actions, behaviours and tasks an individual performs at school, college, or any educational setting, tasks to obtain and retain paid employment and economic life
9	Community, social and civic life	Recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money

1 Level of difficulty with performing in life areas

The term 'difficulty' is an abstract term that subsumes such matters as pain involved, time taken, effort, number of errors, clumsiness, and modification of the manner in which the activity is performed. 'Difficulty' is a combination of the frequency with which the problem exists, the duration of the problem and the intensity of the problem.

The question

Please indicate the **level of difficulty** experienced for each life area by placing a number in column 1 against each life area (0–9).

Guide for use

0	No difficulty in this life area	Is recorded when there is no difficulty in performing this activity. This scale has a margin of error of 5%.	[0–4%]
1	Mild difficulty	Is recorded when the level of difficulty is below the threshold for medical intervention, the difficulty is experienced less than 25% of the time, with a low alteration in functioning which happens occasionally over the last 30 days.	[5–24%]
2	Moderate difficulty	Is recorded when the level of difficulty is experienced less than 50% of the time with a significant, but moderate affect on functioning (Up to half the scale of total performance) which happens regularly over the last 30 days.	[25–49%]
3	Severe difficulty	Is recorded when performance in this life area can be achieved, but with only extreme difficulty, and an extreme effect on functioning which happens often over the last 30 days.	[50–95%]
4	Complete difficulty	Is recorded when the person can not perform in this life area due of the difficulty in doing so. This scale has a margin of error of 5%.	[96–100%]
8	Not specified	Is recorded where a person has difficulty with activities in a life area but there is insufficient information to use codes 0–4.	
9	Not applicable	Is recorded where a life area is not applicable to this person, e.g. domestic life for a child under 5.	

2 Need for assistance with performing life areas

This question records information about a person's **overall** need for help or supervision in the life areas. The person can undertake activities in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available).

A need for assistance or supervision in a particular area may, or may not, be directly relevant to the interventions being provided during this episode of care.

The need must be due to the person's disability or health condition.

It must relate to the extent of need **over and above** that which would usually be expected due to their age, i.e. it should be evaluated in relation to a **person of the same age without a health condition**.

Where a life area includes a range of examples, (e.g. domestic life includes cooking, cleaning and shopping), if a person requires assistance in any of the areas then the highest level of assistance should be recorded.

Where need for assistance vary markedly over time (e.g. episodic psychiatric disability) please record the level of support needed during the reference week.

The question

Please indicate the level of need for **personal assistance** by placing a number in column 2 against each life area (0–9).

Guide for use

0	Does not need help/supervision	Is recorded when the person has no need for supervision or help and can undertake the activity independently.
1	Sometimes needs help/supervision	Is recorded when the person sometimes needs assistance to perform an activity.
2	Always needs help/supervision	Is recorded when the person always needs assistance to undertake the activity and cannot do the activity without assistance.
3	Unable to do this life area, even with assistance	Is recorded when the person cannot do the activity even with assistance.
8	Not specified	Is recorded where a person has needs assistance with activities in a life area but there is insufficient information to use codes 0–3.
9	Not applicable	Is recorded where the need for help or supervision is due to the person's age. For example, Education for persons less than 5 years and work for persons less than 15 years.

For further information see <*http://meteor.aihw.gov.au/content/index.phtml/itemId/288309*>.

3 Extent of participation

For **extent of participation** the standard or norm to which an individual's participation in life situations is compared is that of an individual without a similar health condition in that particular society. A value is attached to restriction of participation (i.e. a participation restriction is a disadvantage). The value is dependent on cultural norms, so that an individual can be disadvantaged in one group or location and not in another place. The rating is made in relation to the extent of participation in terms of duration, frequency, manner or outcome.

The participation restriction records the discordance between the experienced participation and the expected participation of an individual without a health condition.

The definition of 'particular society' is not specified and will inevitably give rise to different interpretations. If limiting the interpretation, it will be necessary to state the factors which are taken into account, for example, age, gender, ethnicity, religion, education, locality (town, state, rural, remote, urban).

Note that age may be a consideration for example participation in work is not expected for a young child. The range of domains covered may not be complete because of life stage and choices of the person rather than being associated with the health condition.

Extent of participation is always associated with a health condition. For example, a restriction in participation in exchange of information may be recorded when the person has had a stroke, but not when the restriction is associated only with linguistic diversity, without a related health condition.

The question

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 (0–9).

Guide for use

0	Full participation	Is recorded when the person participates in this life area in the same way in terms of duration, frequency, manner or outcome as other individuals without a similar health condition in that particular society	[0–4%]
1	Mild participation restriction	Is recorded when the person is restricted in their participation less than 25% of the time, with a low alteration in functioning which happens occasionally over the last 30 days	[5–24%]
2	Moderate participation restriction	Is recorded when the person is restricted in their participation less than 50% of the time with a significant, but moderate affect on functioning (Up to half the scale of total performance) which happens regularly over the last 30 days	[25–49%]
3	Severe participation restriction	Is recorded when participation in this life area can be achieved, but only rarely, and with an extreme effect on functioning which happens often over the last 30 days	[50–95%]
4	Complete participation restriction	Is recorded when the person can not participate in this life. This scale has a margin of error of 5%	[96–100%]
8	Not specified	Is recorded where a person participation is restricted in a life area but there is insufficient information to use codes 0-4.	
9	Not applicable	Is recorded when participation in a life area is not relevant, such as employment for an infant.	

For further information see:
<*http://meteor.aihw.gov.au/content/index.phtml/itemId/288534*>

4 Satisfaction with participation

For **satisfaction with participation** the rating is the person's degree of satisfaction with participation in a domain of life, in relation to their current life goals. Choice and autonomy are key aspects of satisfaction and quality of life for all people. Satisfaction with participation may also be affected by duration, frequency, manner or outcome of participation. Duration and frequency may be less than or more than desired by the individual.

The areas of importance to the person are likely to change over time. A person who is successful at improving participation in mobility may develop new goals in different life situations. Data collectors will need to consider the frequency of their collection to reflect the person’s changing goals as a result of interventions or changed life circumstances.

The question

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).

Guide for use

0	High satisfaction	Is recorded if a person is involved in the specified life situation as he or she wishes, in order to fulfil his or her current life goals in terms of duration, frequency, manner and outcome.
1	Moderate satisfaction	Is recorded if the person is reasonably satisfied with their participation in this life situation, in terms of duration, frequency, manner and outcome. This could occur if one of the criteria (duration, frequency, manner or outcome) is not fulfilled and that criterion is not critical to the person's goals. For example, the person does not participate in the specified life situation as frequently as wished, but the other criteria are met and the frequency is not so affected that it is critical to the person's satisfaction.
2	Neither satisfied nor dissatisfied	Is recorded if the person is neither satisfied nor dissatisfied with their participation in this life situation, in terms of duration, frequency, manner and outcome.
3	Moderate dissatisfaction	Is recorded if two or three criteria (duration, frequency, manner or outcome) are not fulfilled, but are not so badly affected, in relation to the person's goals in that life area, that the person is extremely dissatisfied. For example, a person is able to participate in work, but not in line with the person's goals, so that the manner and outcome of the participation are not fulfilled.
4	Extreme dissatisfaction	Is recorded when all criteria (duration, frequency, manner and outcome) are not fulfilled for the specified life situation, or where any of the criteria are so badly affected in relation to the person's goals that they consider themselves to be extremely dissatisfied with this life area. An example of the latter would arise when a person is extremely dissatisfied with participation in interpersonal activities because his/her goal in terms of duration of social visits is never fulfilled, although other criteria (frequency and manner) may be fulfilled.
5	Complete restriction and dissatisfaction	Is recorded when the person does not participate in this life situation in line with his or her own goals, i.e. in an area where they wish to participate and is completely dissatisfied with not participating in this life situation.
8	Not specified	Is recorded when there is insufficient information to record against codes 0–4.
9	Not applicable	Is recorded when participation in a life situation is not relevant, such as employment of an infant or where there is no participation and the person has no desire to participate in this area; for example, a personal preference not to participate in specific areas of community, social and civic life such as sport or hobbies. The area may not be applicable to the person's current life goals.

For further information see:
<*http://meteor.aihw.gov.au/content/index.phtml/itemId/288509*>

influence of environmental factors on human functioning (Table 4)

Environmental factors may affect the person at the level of the body (e.g. poor air quality affects respiration functions) at the level of the person (e.g. floor surface affects walking) and at the level of the person in society (e.g. attitudes of society affect participation in sport).

In some circumstances an environmental factor may be both a facilitator and a barrier, for example, curb cuts facilitate mobility for wheelchair users, but may present a barrier for those who are blind. Recording whether an environmental factor is a facilitator or barrier may not provide all the information needed including whether it is a barrier by nature of its presence or absence. It will record areas of concern.

The complete range of domains and definitions of environmental factors may be found in the ICF (WHO 2001) or the ICF Browser <*http://www3.who.int/icf/onlinebrowser/icf.cfm*>.

The question

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

Note that products and technology may be those especially produced for people with disabilities or those generally available.

Guide for use

+0	No facilitator	Is recorded when the environment factor(s) do not impact in a positive way on the impairment, activity or participation of a person.
+1	Mild facilitator	Is recorded when the environmental factor(s) impact in a positive way on the impairment, activity or participation of a person between 5–24% of the time the person participates in the specified area.
+2	Moderate facilitator	Is recorded when the environmental factor(s) impact in a positive way on the impairment, activity or participation of a person between 25–49% of the time the person participates in the specified area.
+3	Substantial facilitator	Is recorded when the environmental factor(s) impact in a positive way on the impairment, activity or participation of a person between 50–95% of the time the person participates in the specified area.
+4	Complete facilitator	Is recorded when the environmental factor(s) impact in a positive way on the impairment, activity or participation of a person between 96–100% of the time the person participates in the specified area.
+8	Facilitator not specified	Is recorded when there is insufficient information to record the extent of environmental influence in classes +1 to +4.
0	No barrier	Is recorded when the environment factor(s) do not impact in a negative way on the impairment, activity or participation of a person
1	Mild barrier	Is recorded when the environmental factor(s) impact in a negative way on the impairment, activity or participation of a person between 5–24% of the time the person participates in the specified area.
2	Moderate barrier	Is recorded when the environmental factor(s) impact in a negative way on the impairment, activity or participation of a person between 25–49% of the time the person participates in that specified area.
3	Severe barrier	Is recorded when the environmental factor(s) impact in a negative way on the impairment, activity or participation of a person between 50–95% of the time the person participates in that specified area.
4	Complete barrier	Is recorded when the environmental factor(s) impact in a negative way on the impairment, activity or participation of a person between 96–100% of the time the person participates in the specified area.
8	Barrier not specified	Is recorded when there is insufficient information to record the extent of environmental influence in classes 1 to 4.
9	Not applicable	Is recorded when environmental factors impacts in neither a positive or negative way on the impairment, activity or participation of a person or for between 0–4% of the time the person participates in that specified area.

For further information see <*http://meteor.aihw.gov.au/content/index.phtml/itemId/288430*>.

5 Pilot testing the Functioning and Related Health Outcomes Module

5.1 Introduction

The FRHOM project has two phases. The first phase, completed in March 2003, reviewed existing frameworks for health information and performance monitoring to determine an appropriate framework for the development of the module. Existing clinical and population based functional assessment tools, both condition-specific and generic were reviewed to confirm the relevant parameters for the module.

The second phase revised the draft module presented in the Phase 1 report to SIMC, in light of comments received from stakeholders.

Internal AIHW consultation assisted in refining the module and determining the most appropriate test sites and methods. Consultation and pilot testing with a broader range of stakeholders, including consumers and their representatives, clinicians, government representatives and information advisory groups, will follow.

The FRHOM module will undergo further refinement in light of the pilot testing before reporting to SIMC and the National Health Information Group (NHIG).

5.2 Field trials

The purpose of field trials is to test the meaning and relevance of the proposed FRHOM in the field, and the feasibility of its collection. The field trials, to begin in October 2005, 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 report to SIMC in March 2005 identified a range of program areas where information on functioning is required, these include, the National Health Priority Areas program, National Health Performance and the continuity of care programs for older Australians being developed under the Australian Health Care Agreements.

The field trials 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.

Evaluation of the FRHOM needs to include:

Appropriateness	Refers to the match of the FRHOM to the purpose for which it is to be used namely; conveying meaningful summary information on human functioning consistently.
Reliability	Refers to the reproducibility of reporting when same person is measured twice or more.
Validity	Refers to whether the FRHOM records what it purports to record.
Responsiveness	Refers to whether the measures in the FRHOM are sensitive enough for the summary to make visible major distinctions between the functioning of one person and another.
Precision	Refers to whether there is sufficient distinction between the levels of functioning defined in the FRHOM.
Interpretability	Refers to how meaningful the components of the FRHOM are to those that are being asked to complete the data module and to readers of the summaries.
Acceptability	Refers to how acceptable the FRHOM is to those that are providing information and those completing the module.
Feasibility	Refers to the effort, time, expense, training for implementation and administration of the module.

It is anticipated that the results of field trials will lead to refinements of the FRHOM and the supporting data collection materials before the data collection module is incorporated in information systems.

5.3 Methodology

A range of possible field trial opportunities have been identified by means of an AIHW workshop. These include:

- Rehabilitation;
- acquired brain injury;
- cardiovascular disease and diabetes monitoring;
- aged care services;
- community aged care;
- mental health;
- national survey program;
- assessments for insurance purposes;
- additional national health priority areas, possibly asthma;
- general practice; and
- e-health.

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 include:

- 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

Details of these tests are below.

A Structured discussions during (committee) meetings

Key questions (Appendix 1) can be addressed during meetings of stakeholder groups. The sorts of information that can be derived from this method include the conceptual basis, coverage, and suggestions for refinements to the module.

The usefulness of this method will depend on the composition of the group. Where possible, clinicians and other health and community services professionals working 'at the coalface' should be included.

Method

Allocate time during an existing meeting to address key issues for the specific committee. It will be important to have sufficient time to allow discussion and determine the suggestions from the committee.

The range and scope of questions will need to be carefully selected to optimise the information gained in the time available in a meeting.

The points to be discussed should be circulated ahead of the meeting together with the FRHOM report for consultation.

Reporting format

Record the suggestions of the committee and any discussion points that reveal the rationale for the suggestions. Dot point format is sufficient.

Record a description of the committee members, which includes the following information:

- demographic information on the members (age, sex, occupation, and so on);
- experience with functioning and disabilities: including discipline of the participants;

- experience with the ICF; and
- any other important information about the participants.

B Key informant interviews and surveys

Key informants may include consumers of health and community care services, clinicians and other health care providers, carers, health administrators, officials from health and community service departments.

Method

The key questions in Appendix 1 will form the basis of a structured interview. Interviews may be conducted in person or over the telephone. A survey form is available for paper based or electronic completion.

The points to be discussed should be circulated ahead of the interview together with the FRHOM report for consultation and testing.

Key informants

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

Reporting format

Both the opinion and the rationale or supporting evidence for the opinion should be recorded. Where the informant authorises, a tape recorder may be useful.

A description of the informant, which includes the following information:

- demographic information on the informant (age, sex, occupation, and so on);
- experience with functioning and disabilities; including discipline of the service provider;
- experience with the ICF; and
- any other important information about the informant.

C Consensus conference

The purpose of the consensus conference is to evaluate the available evidence on a range of issues concerning the conceptual basis for the FRHOM and to develop a

consensus statement that advances the understanding of the issues and which will be useful for the future development and application of the FRHOM.

The consensus response should be based on all available data and information. The statement should reflect the unified view of a panel of thoughtful people who understand the issues before them.

Method

The following guidelines for the conduct of consensus conferences may be used.

- A broad-based panel should be assembled for each conference to give balanced, objective, and knowledgeable attention to the topic; the panel should represent divergent views, but the conference is a panel of experts, not advocates of particular views. Representatives of health and social service professionals, of Non-Governmental Organisations concerned with functioning and disabilities, and family members or other caregivers for persons with altered levels of functioning and disabilities may be included. It is of particular importance to include individuals with altered levels of functioning and disabilities.
- An individual should be selected to chair the meeting. The chair should be a strong moderator and a skilful leader of small group discussions. This person needs to be able to keep the session on task and have leadership skills to assist the group in reaching consensus statements. The chair, however, should avoid unduly influencing the group with his or her own views.
- The panel will meet for the presentation of background information, discussion, and to prepare the consensus responses. A member of the project team will be available to present the background information and record the proceedings.
- The key questions (Appendix 1) determine the scope and direction of the conference. These questions should be circulated and known to all participants prior to the conference.
- It may be helpful to assign each basic question to a person who will present the question and open the discussion. The question presenter will be responsible for presenting the basic questions, providing additional information on the issue as requested, and for explaining any issues relating to the question.
- It is important that sufficient time be allotted for each question and, especially, for drafting the consensus response for each issue raised. This may mean arranging the order of the questions or assigning priorities should time be insufficient to cover all of them.
- The chair should ensure that speakers adhere to time limits, provide opportunity for discussion, and invite comments from participants. The chair is responsible for managing the group discussion and providing the impetus to arrive at a clear and consensual answer to the questions.

- The participants should attempt to reach consensus on each question based on the evidence presented. To produce a firm response, the panel should be encouraged to draw conclusions and form recommendations whenever feasible. If consensus cannot be achieved, minority or alternative views should be included.
- A member of the project team will be responsible for preparing the initial consensus answers, and the rationales for those answers for presentation to the panel for discussion, refinement and adoption.
- At the close of the conference, the draft consensus report will be prepared by the project team representative. Following discussion and any needed revisions, the report is the record of the conference.

Reporting format

Using the following structure for the report of a consensus conference will assist the project team in making comparisons across different conferences and should be adhered to where possible. The report for the consensus process should include the following sections:

1. Background information

This section will provide details about the participants in the consensus review, and information on how the consensus review was conducted. The section should contain:

- A description of the date, time, and place of the conference, including the length of the conference, and the total number of participants in each question discussion session.
- A description of the participants, which includes the following information:

  demographic information on the members (age, sex, occupation, and so on);

  experience with functioning and disabilities; including discipline of the participants;

  experience with the ICF; and

  any other important information about the participants.
- A description of the geographical representation of the participants. In some cases, the consensus review will draw people from an entire nation. In other cases, it will include regional and local, but not national representation. Each of these cases should be described to provide a better understanding of the group that is providing the consensus data.

2. Question-by-question consensus answers

The report should provide a detailed written answer to each of the questions. The answer should be clear and should describe:

the actual consensus answer;

the basis for the consensus support of the answer (research data, personal experience, cultural values, and other evidence, wherever available); and

any strong opposing positions taken by members of the group.

There are four ways that the questions can be answered.

The consensus is unanimous or nearly unanimous and there is no opposing view. In this case, the answer would provide the rationale for the answer, the wording of the answer, and would note that there is no opposing view.

There is a strong consensus among a majority of the participants. There is a smaller opposing view that disagrees with the larger consensus. In this case, the report would provide the rationale for the answer. It would also note that there was a smaller opposing view and would provide the rationale for that view (research data, personal experience, cultural values) as well as the actual wording of the opposing answer.

C. There is no consensus, only two or more opposing views. In this case, the answer would identify each of the opposing views, provide a rationale for each of those views, and would provide the alternative answers for each viewpoint.

*D. The question was not considered important enough to produce significant discussion or debat*e. In this case, the reason that the question was not considered important should be explained. If the group wishes to comment on the question, those comments could be provided as the answer.

D Mapping exercise

The aim of a mapping exercise would be to assess the coverage of the FRHOM by relating assessment tools used in a specific work area to the FRHOM.

Method

Formal rules for mapping of instruments to the ICF have been developed (Table 2) and may be used to guide the process (Cieza et al. 2002). Examples of how the rules have been applied to specific items from standardised health status measures may be found in the paper.

Table 5: Rules for linking health status measures with the ICF

1	Before one links measures to the ICF categories, one should have acquired good knowledge of the conceptual and taxonomical principles of the ICF, as well as the chapters, domains and categories of the classification including definitions.
2	Each item of a measure should be linked to the most precise ICF category.
3	If a single item encompasses different constructs, the information in each construct should be linked.
4	All constructs of the item to be linked should be highlighted.
5	The response options of an item are linked if they refer to additional constructs.

(Continued)

6	If the content of an item is not explicitly named in the corresponding ICF category, then the 'other specified' option at the third and fourth coding level of the ICF is linked. The additional information not covered by the ICF classification is documented. Two special cases are to be distinguished with in this rule: When the 'other specified' rule option in the two level classification is not available, then the 'other specified and unspecified' option is linked. The additional information not covered by the ICF will be documented. When the content of an item is not explicitly named in the corresponding ICF category, but at the same time is included in the ICF category, then the item is linked to this ICF category and the additional information not covered by the ICF will be documented.
7	If the content of an item is more general than the corresponding ICF category, then the code of the higher level is linked.
8	If the content of an item is more general than an ICF category bt otherwise the item specifies by examples partial aspects of the concept contained in one or more ICF categories, then the 'unspecified 'option of the ICF classification is linked (code 99 for the second coding level, Code 9 for third and fourth coding levels). A statement or part of an item will be considered an example when it is introduced with 'e.g.' appears between parentheses, is introduced with 'for example', or with 'such as'.
9	If the information provided by the item is not sufficient for making a decision about which ICF category the item should be linked to, this item is assigned *nd* (not definable).
10	If an item is not contained in the ICF classification, then this item is assigned *nc* (not covered by ICF).

Source: Cieza et al. 2002.

Reporting format

The following table with the components and domains of the FRHOM in the vertical axis and the items of the assessment tools across the horizontal axis, may be used.

Table 6: Reporting format for mapping between assessment tools and the ICF

Assessment tool items	FRHOM component (b, f, a, p, e nd, or nc)	ICF code	Additional information

Note: b—body structure, f—body function, a—activity, p—participation, e—environmental factor, nd—not defined, nc—not classified.

E Coding FRHOM from case records or vignettes

The purpose of this test is to show whether information routinely collected by health and community care providers in the course of their usual consultations with health care recipients can inform the completion of the FRHOM. This test may indicate gaps in the data collected in the course of care provision and help identify those professionals that are best qualified to complete different components of the FRHOM.

Method

Complete the FRHOM tables using the information provided in the clinical record or the vignette.

Vignettes can be provided by the project team. The vignettes address a range of concerns across many disabilities and health conditions.

Complete the proforma below.

Test-retest reliability can be measured by second and subsequent professionals completing the FRHOM tables from the same clinical record.

Reporting format

Case No: Completed by:

Professional qualification: Date:

Time taken to complete the FRHOM:

Table 7: Reporting format for coding FRHOM from case records

Sources of information	
History from the individual	
Letters of referral from other health care providers	
History from carer or significant other	
Observed signs	
Standardised clinical assessments	
Results of tests	
Other	

(Continued)

Completion of the body functions component	
Was there any information that you did not have, i.e. was missing from the record?	
Was there key information on body functions that the FRHOM did not capture?	
Completing this section was easy/manageable/difficult	
Comment	
Completion of the body structures component	
Was there any information that you did not have, i.e. was missing from the record?	
Was there key information on body functions that the FRHOM did not capture?	
Completing this section was easy/manageable/difficult	
Comment	
Completion of the activities component	
Was there any information that you did not have, i.e. was missing from the record?	
Was there key information activities that the FRHOM did not capture?	
Completing this section was easy/manageable/difficult	
Comment	

(Continued)

Completion of the participation component	
Was there any information that you did not have, i.e. was missing from the record?	
Was there key information on participation that the FRHOM did not capture?	
Completing this section was easy/manageable/difficult	
Comment	
Completion of the environmental factors component	
Was there any information that you did not have, i.e. was missing from the record?	
Was there key information on environmental factors that the FRHOM did not capture	
Completing this section was easy/manageable/difficult	
Comment	
Administration	
When should the FRHOM be completed? a. Whenever a person is referred from one health care provider to another b. On admission to a service setting c. On discharge from a service setting d. Other (Please specify) (Tick all relevant)	How important is this to you? Yes, definitely Perhaps No Yes, definitely Perhaps No Yes, definitely Perhaps No Yes, definitely Perhaps No
Do you see FRHOM being useful as: a quantified summary for case records a standardised case summary for referrals a record that can be aggregated for statistical analysis Other (Please specify) (Tick all relevant)	How important is this to you? Yes definitely Perhaps Not at all Yes definitely Perhaps Not at all Yes definitely Perhaps Not at all Yes definitely Perhaps Not at all

(Continued)

Was the value of the record worth the time taken to complete (Circle one)	Yes, definitely Perhaps No, definitely not
	Comment
Suggestions for change	
Comments	
Many thanks for your assistance in completing this form.	

F Clinical test by interested clinicians

A clinical test of the FRHOM will require using the module to summarise information on human functioning at the point of care. This will assist with:

I. Coverage—can all areas of functioning relevant to clinicians be found in the FRHOM;
J. Feasibility—is the module easy to use, quick, is it clinically useful;
K. Can the information for the FRHOM be drawn from what is already collected;
L. Do users see the benefit of including information on the environment;
M. Can information in the FRHOM be interpreted across settings;
N. testing the feasibility in terms of the time taken to complete;
O. identifying gaps in information collected during the process of care.

Method

A guide including information on the project to date, the purpose of the FRHOM and how to complete it will be provided.

The clinician will perform the usual examination of the person in the clinical setting and record in the usual manner. The FRHOM will be completed based on the information gained during this process.

Reporting format

The same reporting format to that used for coding FRHOM from case records may be used. See pages 32–34.

G Pilot testing in projects that are about to happen

The opportunistic inclusion of the module in projects that have been established for other purposes is a method of testing that can be used. Methods will need to be considered on a case-by-case basis.

H Testing the FRHOM with existing data

Tests of FRHOM with existing data will be developed when availability of data has been established. Possible data may be:

- Acquired brain injury data from Victoria, NSW and Tasmania coded to the FRHOM
- Rehabilitation data collected with Barthel (Victoria) and with Functional Independence Measure (NSW) coded to the FRHOM.

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Appendix 1: Key questions

These questions may be used in a range of tests of the FRHOM described in Chapter 5 including:

- structured discussions during committee meetings;
- key informant interviews; and
- consensus conferences.
- A questionnaire using these questions has been developed for use in key informant surveys.

FRHOM applications

1 Which of the following applications do you envisage for the FRHOM? Please mark with a tick the extent of use in each area.

	Significant use	Moderate use	Some use	No use
Statistical applications				
Research				
Clinical care				
Continuity of care, e.g. case summaries for transmission of files				
Policy				
Data capture in information systems				
Other (please specify)				

Appropriateness

2 Do you envisage that the FRHOM will be useful as a summary report of functional status to (i) capture, (ii) store and (iii) transmit data at:

(a) an individual level

(b) a service delivery level

(c) a population level?

	(i) capture			(ii) store			(iii) transmit		
	Low	Medium	High	Low	Medium	High	Low	Medium	High
Individual level									
Service delivery level									
Population level									

3 Please state what you see as any limitations and provide suggestions to improve the FRHOM.

Coverage of the FRHOM

4 Does the FRHOM include all areas of functioning that will be relevant to your needs or to the needs of your organisation? If not, then what other areas should also be covered?

5 Will the FRHOM relate to assessment protocols in services to which the subject is likely to be transferred thus enabling transfer of information between services?

Responsiveness

6 Do you believe the five point scale of the FRHOM will be sensitive enough to convey summary level information on functional status?

7 Do you believe the FRHOM will be sensitive to changes

(a) within clients over time

(b) within populations over time?

8 If not, please suggest ways in which the sensitivity of the FRHOM can be improved.

9 When should the FRHOM be completed to provide useful health outcomes data?

On admission to a health or community service setting	Yes/No
On transfer between service settings	Yes/No
On discharge from a service setting	Yes/No
On request by individual	Yes/No
On request by health care provider	Yes/No
Other (please specify)	Yes/No

Acceptability

10 Is the FRHOM acceptable to those who are providing information?

Special groups

11 Are there any special groups that we need to consider? (E.g. children, the Indigenous population, people from cultural and/or linguistically diverse backgrounds.)

12 Please provide suggestions as to how the FRHOM might need to be adapted for these populations.

Informant

The FRHOM should reflect the individual's experience of functioning. There may be many informants to provide complete information on all components of functioning.

13 How can the views of the following be combined?

(a) the person as subject of information

(b) family member

(c) health professional

(d) community service provider

14 How may the individual be involved in completion of the FRHOM?

15 How may the carer or other significant person be involved in providing information for completion of the FRHOM?

16 Will it be possible to report against population standards when completing the FRHOM?

Information sources and missing information

Relevant information is derived from multiple sources, the individual subject of information, carers, significant others, other health care providers (letters of referral), clinical assessments, test results.

17 What information sources are most relevant and should be available as evidence for completion of the FRHOM?

18 Should all these sources be available prior to completion of the FRHOM?

19 Is there a minimum information requirement for satisfactory completion of the FRHOM?

20 For a complete picture of human functioning all components of the module should be completed. How might missing information be handled in the FRHOM?

Recording environmental factors

Environmental factors have a significant effect on human functioning and, though recognised, are not commonly recorded in clinical and administrative records.

21 Was the information to complete the environmental factors component readily available?

22 What were the sources for information on the environment?

23 How confident were you when completing the environmental factors component? Can you suggest ways of improving the FRHOM tables?

24 If you had difficulty in completing the environmental factors table would it be useful to have a tick box format to indicate whether the factor is present as a facilitator or barrier?

Ease of administration

25 Will the information needed to complete the FRHOM be easily drawn from what is already collected?

26 Do you envisage that additional resources will be required to complete the FRHOM? Please state any resources you think will be required.

27 Do you envisage the FRHOM will be quick and easy to complete?

Interpretability

28 Are the questions easily understood?

29 Please make suggestions to improve the questions

Level of detail in the application

Ideally the module could have a 'drill down' capacity, much like the ICF, that allows use of the module at the level of detail suitable for the purpose.

29 Is the high level structure of the module, as it is, meaningful?

30 Would a drill down facility improve the FRHOM's usefulness?

Summary scores

31 Do we need to develop a summary score from the scores for each component? If yes, then what would be the best way to do this?

32 Options for summarising the existing information could be:

- to record number of domains affected on a present/absent basis
- to record number of domains affected as well as the level of functioning and develop an algorithm to explain or summarise
- to record the number of domains are 'severe' level

More information would be required to create new measures such as;

- to use only the principal or most significant domain for each component of functioning to form the profile or
- to weight the domains according to level of importance to the person.

33 Would any of these be a useful addition to the FRHOM? Please provide comments and suggestions.

Mode of delivery (administration)

34 What do you envisage will be the most efficient mode of delivery of the FRHOM?

(a) paper based record transmission

(b) electronic record transmission

35 If the FRHOM was to be electronically administered, do you/ your organisation have a) the relevant technology b) the expertise for this mode of delivery?

Title of the module

36 Is the 'Functioning and Related Health Outcomes Module (FRHOM)' an appropriate title for the module?

Questions about the respondent(s)

Please indicate the group to which you belong

Group	
State or territory health authority	
Other state or territory government department	
Australian Government Department of Health and Ageing	
Australian Government Department of Veterans Affairs	
Other Australian Government department	
Australian Institute of Health and Welfare	
Health care consumer	
Community services consumer	
Carer or family member of a health care consumer	
Carer or family member of a community services consumer	
Clinician	
Public hospital	
Private hospital	
Other health service provider	
University or other research organisation	
Interest group	
Other, please specify _____	

37 Please provide some general information about your current information needs/practices relating to functional status.

38 Please indicate the importance and usefulness of the FRHOM overall and for each individual component. When assessing usefulness consider whether the FRHOM and each component is relevant to your requirements. Will the FRHOM provide useful information to you or your organisation?

39 Please provide any additional comments or suggestions that may assist with the development of the FRHOM.