

1 Introduction

1.1 Purpose

This report describes work that set out to explore the value of a module of information on functional status as a health outcome measure and to develop a framework for the development of such a module. The project commenced in November 2003 and is supported by the Australian Health Ministers' Advisory Council (AHMAC) and the National Health Information Group. As the study progressed it became clear that a module guiding recording methods in the community care sector as well as the health sector would promote a better integrated information system spanning both sectors and underpinning whole-of-government approaches to human services.

What this report now recommends is a module or framework of summary information, that:

- can be used to describe health status, outcomes of health interventions, and the need for assistance in areas of human functioning, and
- enables the efficient and effective storage and transmission of data on human functioning in a wide range of human service systems.

It is suggested that the following name best captures what the module can do in the health and community services field, and this name will be used throughout the summary – the Functioning and Related Health Outcomes Module (FRHOM). Other key words and ideas considered for inclusion in the short title to indicate the content and purposes of the module included 'health status', 'human functioning', 'summary information', and 'data module.' The term 'outcomes' has been chosen to signify changes in a person's health status over time as indicated by level of functioning. It is acknowledged that health outcomes are an extensively researched field. Nonetheless, the International Classification of Functioning, Disability and Health (ICF) was developed with the focus of providing a framework for the development of health outcome indicators relating to human functioning.

Such a module could be used in electronic health records and would enable transmission of information among a range of health, clinical and community services.

The National Health Performance Framework includes functioning as an indicator of health status (NHPC 2001). A functioning and related health outcomes module could be useful as the indicator in the framework. In addition, the module could provide benefit to areas such as:

- funding of health care;
- quality of health care;
- continuity of care;

- efficacy of preventive measures;
- consistent national information across different sectors of the health and community services systems;
- comparing health service data with population data;
- summarising patient or client information at key times including at the point of transfer between services or settings; and
- for possible use in the electronic health record.

The proposed module must align with relevant population data collected in Australia as well as with international standards. To date, functioning (and disability) has been measured on a population basis through the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers. In future, a measure of functioning and disability will be included in the population Census. The Census, and relevant AIHW data development work, align with the relevant international standards, in this case, the International Classification of Functioning, Disability and Health (WHO 2001).

The purpose of a functioning and related health outcomes module would be to provide person centred summary information on the level of an individual's function. The module should include the minimum number of domains to be practical to complete and yet be sufficiently comprehensive to describe the person's level of functioning at a particular point in time. Repeated use of the same module of information at different points in the process of care and in different health care settings will enable outcome measurements. The selected domains would be generic across varying health conditions.

1.2 'Health' as broadly defined

Health has been defined as 'a state of complete physical, mental, and social well being and not merely the absence of disease or infirmity' (WHO 1946). Health status is a universal concept in which the profile of each person can be described on a continuum. Health or state of health can only be defined in terms of an individual and that person's goals and expectations. For example a professional gymnast with a need to be extremely flexible, will feel unhealthy at a level most people would consider healthy; or a person born with cystic fibrosis may never know the level of energy most people associate with health. The individual defines when a change in their state of health generates a health problem either by accessing or seeking access to the health system.

1.3 Why is assessment of functional status important?

Change in the way a person functions may be affected by a health condition, and also the intended consequence of health interventions. An individual's health includes

their ability to carry out the full range of activities required to engage in all aspects of human life. The outcomes of health interventions can be evaluated by measuring performance of tasks and activities in the individual's real-life environment.

Functional status information complements information on diseases. Often functional status information is collected for care provision purposes; however it is rarely included in administrative data collections. The inclusion of functional status information in the administrative record would give a fuller picture of the health of the individual or a population. It could promote consistency of records in the health and community care sectors. Community care services and rehabilitation services are much more likely to focus on functional performance and its maintenance or improvement and hence to record it.

Sometimes a disease cannot be diagnosed, for example in an emergency situation where a patient is unconscious and not breathing, treatment is aimed at restoring impaired respiratory function, whether the cause is head injury or asthma. Information about the disease may be of limited value in the management of many chronic diseases as the diagnosis, for example osteoarthritis, will not change over time and yet the level of functioning, and consequent management of the condition may vary markedly.

Two people with the same disease may have profoundly different levels of functioning that determines their actual health status. There may be many in the general population diagnosed with a particular health condition, however only a small proportion of them will seek access to health services. It is often a change in functioning that prompts a person to seek access to the health system. Medical diagnosis alone fails to predict health service needs and utilisation (Beatty et al. 2003; Üstün et al. 1998; Hoepfer et al. 1980) length of hospitalisation (McCrone & Phelan 1994), level of care, health outcomes (Von Korff et al. 1992), receipt of benefits (Hoepfer et al. 1980; Segal & Choi 1991), work capacity, or social integration (Massel et al. 1990).

However, disease diagnosis and functioning together can inform health service utilization (Rabinowitz et al. 1994), length of hospitalisation, improvement in functioning after hospitalisation, return to work (Hlatky et al. 1986), work performance, recovery of social integration and level of need for assistance with self-care (Gatchel et al. 1994).

The benefits that may be realised from functional status information go beyond health system administration. The functional status of the population may inform social policies such as social security, pensions, retirement and long-term care of older people and education, employment, housing and transport policies for younger people.

The World Health Organization Classification of Functioning, Disability and Health (ICF) (WHO 2001) now provides a framework for the development of health outcome indicators relating to human functioning that may be applied across the full spectrum of health conditions. There is increasing recognition that collection of functional status information will fill a gap in health records (NCVHS 2001). The benefits of routinely collecting functional status information across the health system

include evaluating outcomes, comparing treatments and predicting and managing costs associated with health care delivery, establishing eligibility for government programs as well as serving the needs of policy makers, clinicians, researchers and health administrators (Casiano et al. 2002).

Level of human functioning is inextricably linked with environmental factors, either as risk factors or as facilitators or barriers to full participation in society. The ICF has a component to code environmental factors.

As the international standard for the definition, classification and recording of functional status the ICF provides the basis for functional outcome data modules. The ICF is framed in neutral terms and may record the neutral or positive as well as negative aspects of health.

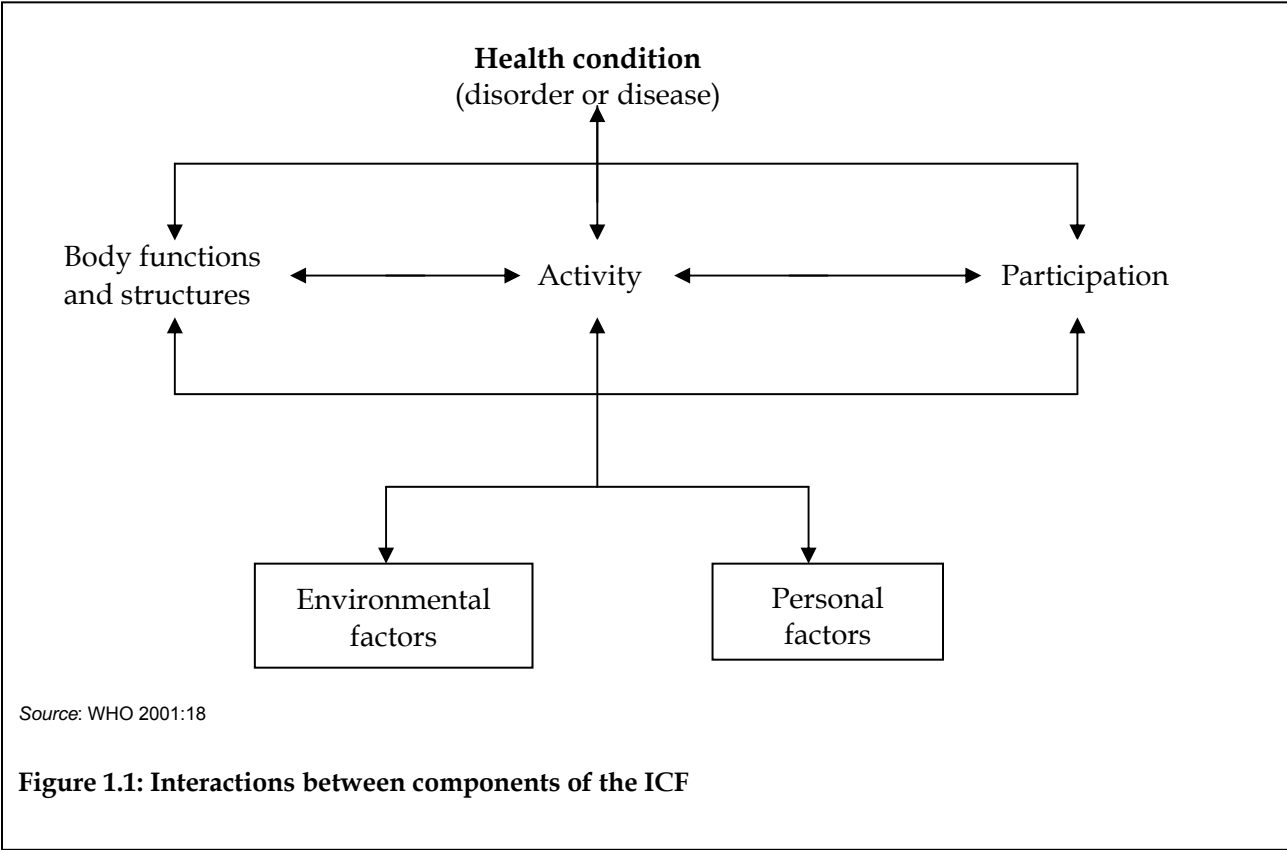
1.4 What is the ICF?

The ICF was endorsed by the World Health Assembly in 2001. It 'provides a unified and standard language and framework for the description for health and health related states'. As stated in the classification the, 'ICF has universal application, with human functioning described on a continuum not just at the extremes. The ICF does not classify people; it describes the situation of each person with a range of domains of functioning, within the context of environmental and personal factors' (WHO 2001:3).

The ICF aims to:

- provide a scientific basis for classifying consequences of health conditions;
- establish a common language to improve communications;
- permit comparison of data across countries, health care disciplines, services and time; and
- provide a systematic coding scheme for health information systems.

Figure 1.1 shows the ICF model of functioning and disability and health. The dynamic interactions between the components of the ICF are in both directions, so for example, the presence of a disability may modify the health condition. It is important to collect data on each of the components to be able to explore the associations between them. The Environmental factors interact with the individual with a health condition and influence the level and extent of the individual's functioning.



The model includes personal factors however these are not classified in the ICF. The classification has three components; Body functions and structures, Activities and Participation, and Environmental factors. Each component consists of various domains, or separate sets of related physiological functions, anatomical structures, actions, tasks, areas of life, and external influences. The components and related domains are below (Table 1.1).

Table 1.1: Components, definitions and domains of ICF

| Component & definition | Domains |
|--|--|
| Body functions are the physiological functions of the body systems (including psychological functions). | Mental Functions Sensory functions and pain Voice and speech functions Functions of the cardiovascular, haematological, immunological and respiratory systems Functions of digestive, metabolic and endocrine systems Genitourinary and reproductive functions Neuromusculoskeletal and movement-related functions Functions of the skin and related structures |

Table 2.1 (continued): Components, definitions and domains of ICF

| | |
|---|---|
| <p>Body structures are anatomical parts of the body such as organs, limbs and their components.</p> <p>Impairments are problems in body function and structures such as significant deviation or loss.</p> | <p>Structures of the nervous system</p> <p>The eye, ear and related structures</p> <p>Structures involved in voice and speech</p> <p>Structures of the cardiovascular, immunological and respiratory systems</p> <p>Structures related to digestive, metabolic and endocrine systems</p> <p>Structures related to the genitourinary and reproductive systems</p> <p>Structures related to movement</p> <p>Skin and related structures</p> |
| <p>Activity is the execution of a task or action by an individual.</p> <p>Participation is involvement in a life situation.</p> <p>Activity limitations are difficulties an individual may have in executing activities.</p> <p>Participation restrictions are problems an individual may experience in involvement in life situations.</p> | <p>Learning and applying knowledge</p> <p>General tasks and demands</p> <p>Communication</p> <p>Mobility</p> <p>Self-care</p> <p>Domestic life</p> <p>Interpersonal interactions and relationships</p> <p>Major life areas, such as education, work and employment and economic life</p> <p>Community, social and civic life</p> |
| <p>Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These are either <i>barriers</i> to or <i>facilitators</i> of the person's functioning.</p> | <p>Products and technology</p> <p>Natural environment and human-made changes to the environment</p> <p>Support and relationships</p> <p>Attitudes</p> <p>Services, systems and policies</p> |

Source: WHO 2001.

Qualifiers

Qualifiers are measures coded after the relevant domain. These qualifiers are essential to meaningful use of the classification because of the neutral terms of the domains. All domains are coded using a uniform or 'generic' qualifier to record the extent of the 'problem' (none, mild, moderate, severe, complete) in relation to impairment, activity limitation or participation restriction. Environmental factors may be coded as either barriers or facilitators. In addition to the generic qualifier, qualifiers for specific components have been proposed.

Further information on the ICF is provided in Appendix 1.

1.5 Use of the ICF in Australian national data collections

Increasingly the ICF is being used to improve the quality and consistency of national data. This leads to the possibility of relating data from different sources to provide new information as in the studies on unmet need for disability services (AIHW 1997, AIHW 2002). The concepts in the ICF are used in the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC). So there is potential for relating population data to National Minimum Data Sets (NMDS) using the same concepts. Consistency across administrative and population data is crucial for the development of meaningful policy and appropriate service delivery which meets consumers needs.

ABS population data

Population data about people with disabilities, older Australians and their carers is collected in the ABS SDAC every five years. It is important that data captured in data modules on human functioning are compatible or relatable to population-based information. As the SDAC is a comprehensive survey, the range of ICF concepts covered is extensive.

The core and non-core activities and tasks included in the SDAC are summarised in Box 1.1. The ABS uses the concepts of mild, moderate, severe and profound disability in the SDAC. The definition of these terms is made in relation to the difficulty and assistance a person may have with performing core activities. Further detail is provided in Chapter 4.

Box 1.1: ABS 1998 Survey of Disability, Ageing and Carers: activity restrictions and their severity

Specific restrictions are:

- Core activity restrictions
- Schooling or employment restrictions.

Core activities are:

- Self-care—bathing or showering, dressing, eating, using the toilet and managing incontinence
- Mobility—moving around at home and away from home, getting into or out of a bed or chair, and using public transport
- Communication—understanding and being understood by others: strangers, family and friends.

A core activity restriction may be:

- Profound—unable to perform a core activity or always needing assistance
- Severe—sometimes needing assistance to perform a core activity
- Moderate—not needing assistance, but having difficulty performing a core activity
- Mild—having no difficulty performing a core activity but using aids or equipment because of a disability.

Source: ABS 1999.

Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS)

A generic measure of functioning is in use in Australia in the disability services field. The CSTDA NMDS support needs question (below) was developed in consultation with service providers and data users and has been used for the last 12 months in a continuous collection (AIHW 2004a). Data linkage methodology has enabled data from different service providers on the same client to be identified. Preliminary analysis has shown that generally the items were consistently recorded by different service providers and that there was no apparent bias relating to service type (AIHW 2000a:135 and additional unpublished analyses).

The domains of functioning selected were those that are relevant to a range of services provided under the CSTDA, including accommodation support, community support, community access, respite and employment. The 'measures' relate to those used in the population survey.

The CSTDA question provides a summary statement about many individual domains of functioning. Thus, it provides a means to collect data from a range of assessment tools that have a variety of items. Further discussion of population measures of functioning is included in Chapter 4.

Aged care data and the ICF

The management of ageing and aged care continues to be a high health information priority as the Australian population ages. Australian 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 HACC and ACAT assessments. The framework of the ICF was used to illustrate the similarities and differences between data items in the Home and Community Care (HACC), Aged Care Assessment Program (ACAP), and Community Aged Care Packages (CACP) collections (AIHW 2004b). As these collections are reviewed, there is the potential to bring them more into harmony with each other. Where the same domain of functioning is being used in different collections the definitions used can be brought in line through the ICF, thus enabling comparisons between collections and between data collected in the aged care services sector and the population.

The ICF based FRHOM, as a portable (electronic) folder of information on functioning, could be common to all programs. It 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.

Numerous other projects in Australia are using the ICF either as the framework for developing new collections, or for a variety of other purposes (AIHW 2003a).

1.6 International applications

The United Nations Washington Group has expressed a commitment to using the ICF as the model for understanding the multidimensional components of functioning and disability in its recent work on the development of an internationally comparable general census measure (Madans et al. 2004).

A major theme of the WHO Family of International Classifications (WHO-FIC) network meeting in Reykjavik in 2004 was the relating and harmonising of health and disability statistics. Traditional health statistics are concerned with deaths and disease and traditional disability statistics with the number of people with disabilities. The way of the future views health and disability on a continuum and the components of health and disability used together in health surveys. The meeting reported that 'using the ICF as an outcome measure can demonstrate the linkage between health and productivity gains' (WHO 2004).

1.7 Structure of the report and methods used

The purpose of this study was to establish the need for and possible content of a module that provides a profile of level of functioning, to be used at key points in the process of care of an individual in the health system. The report is structured as follows.

Chapter 2 reviews existing national frameworks for health information to establish where information on functioning fits most appropriately and whether the ICF is the most appropriate framework for the development of the FRHOM.

A review of a selection of the literature on functional outcome measures to identify commonly used assessment tools was undertaken. The review focused on cardiovascular diseases (CVD), musculoskeletal diseases (MS) and acquired brain injury (ABI). Chapter 3 presents the results of the exercise to relate the clinical assessment tools to the ICF to see whether there were common domains that could be used in a data module (the mappings are in Appendices 2-5). This 'bottom up' approach is balanced by a review of commonly used generic outcomes assessment tools taking a 'top down' approach in Chapter 4.

The project team consulted with a range of advisory groups and committees to determine the need for and desired content of a summary measure of functional status.

Chapter 5 considers issues of measurement and whether the metrics in the tools could be related to the qualifier in the ICF. Possible areas of application of a functioning and related health outcomes module are discussed to see whether the ICF could provide a high level framework to calibrate the scores from the many instruments used by clinicians. Chapter 6 presents conclusions and recommendations.

2 National health frameworks considered

This section considers existing national frameworks for health and related information, and whether the ICF can be used to describe important elements of these broader frameworks.

2.1 Examination of frameworks used in the Australian health system

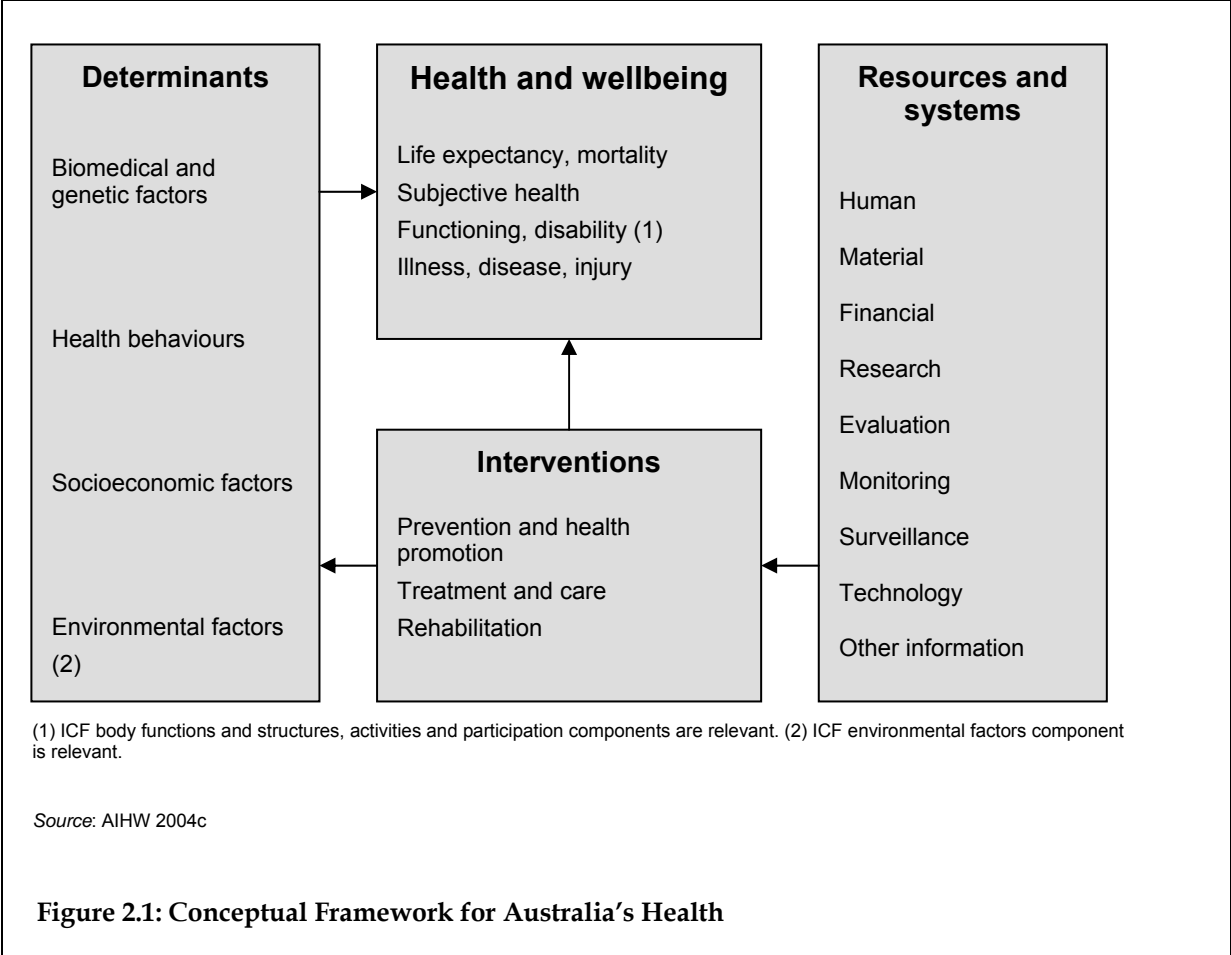
A number of frameworks are used to describe health information and the Australian health system. The health system includes 'all activities whose primary purpose is to promote, restore or maintain health' (WHO 2000). The health system, especially in this broad WHO definition, is complex. There are many types and providers of health care services, some institutionally based and others in the community. Administration of health care differs between the States and Territories. The frameworks aim to organise information for specific purposes. The frameworks were examined to see whether the ICF could support elements of the broader frameworks where information on functioning, disability and health is required. If so, the ICF may be a means to underpin the development of outcome data modules based on human functioning.

2.2 A conceptual framework for health

A conceptual framework for health (Figure 2.1) has been used since 2000 to illustrate the complex relationships between components of the Australian health system (AIHW 2004c). This framework is based on the Canadian Roadmap developed to guide health information developments in that country (CIHI 2000). The framework in turn is essentially consistent with the United States 21st Century Vision for Health Statistics (NCVHS 2002) and the WHO's World Health Report 2000 view of health which places people at the centre of health services (WHO 2000).

It is apparent that the ICF supplies important elements of this broader framework—those relating to functional status. In this framework, the ICF may be used as a classification and coding system to describe information on health and well being (1) as well as for environmental factors (2). Some resources also may be viewed in terms of the Environmental Factors component of the ICF, for example some of the material resources may be grouped under the domains of ICF Chapter 1 (Products and technology) and the human resources under the domains of Chapter 3 (Support and relationships). It is important to note that the health care sector views environmental factors as determinants of health and are often considered in relation to disease

prevention. Environmental factors, as used in the ICF, are considered in relation to human functioning; through their absence or presence they may be either barriers to or facilitators of human functioning. Sometimes the same environmental factor/determinant, for example air, can be used in subtly different ways, although the two interpretations almost merge when talking about, for example, asthma.



2.3 Australian Family of Health and Related Classifications

In August 2002 the National Health Information Management Group (now the Statistical Information Management Committee) endorsed the concept of the Australian Family of Health and Related Classifications. The Family provides a 'conceptual framework of information domains for which classifications are, or are likely to be required for purposes related to health and health management' (NHIMG Secretariat 2002). The scope of the Family is described using a matrix (Figure 2.2), one axis of which is based on the conceptual framework for health (Figure 2.1).

The other axis of the matrix is 'areas of application' which covers, in broad terms, the range of areas of applications of classification systems across the country. This axis

includes a combination of settings, measurement methods, target group, methods of data collection and data informants.

The ICF is the nationally endorsed classification for functioning and disability and the areas of application for which it may be used are comprehensive. The Environmental component of the ICF supports data collection on the environmental factors influencing health and well being across a range of applications in Australia's health system.

| Area of Application | Factors influencing health and wellbeing ¹ | | Health and wellbeing | | Interventions / Services | Resources |
|---|---|--|------------------------------------|----------------------------|---|--|
| | Environmental | Personal | Health condition/ Disease /problem | Functioning and Disability | Prevention ³ Assessment/ Diagnostic Therapeutic Maintenance ⁴ | Research, Evaluation Monitoring, Other information, Financial, Material, Human |
| <u>Mortality</u> (cause of death) | | Data items in the National Data Dictionaries and METeOR are to be used, for example for demographic information. Some personal factors affecting health and well being have not been defined and classified, for example genetic profile or coping styles. Where variables such as Occupation, Industry, and Geography etc are collected, Australian standards, maintained by the ABS, should be used. | ICD-10 | | | The Australian Bureau of Statistics maintains a range of classifications of relevant variables including: Industry (ANZSIC), Occupation (ANZSCO), Qualifications, Research Purpose Expenditure, and Economic Sector etc. Australian standards are generally based on international standards. These standard classifications, or classifications which are compatible with them, are to be used in health data collection. |
| <u>Self report</u> , eg. Population health surveys and reason for encounter | ICF | | ICPC-2 | ICF | | |
| <u>Population and Environmental health</u> | ICF | | ICD-10-AM | ICF | | |
| <u>Primary Care</u> ⁵ | ICF | | | | | |
| General practice | - | | - ICPC-2 | - | - ICPC-2 | |
| Emergency | - | | - | - | - | |
| Other | - | - | - | - | | |
| <u>Acute hospital admissions</u> | ICF | | ICD-10-AM | ICF | ICD-10-AM ATC/DDD | |
| <u>Specialised care</u> ² (residential or non-residential) | ICF | | | ICF | | |

(1) Factors influencing health and well being are defined here as including risk factors, determinants and external causes, but not health services and interventions.

(2) Specialised care includes care in consultant rooms, palliative care, rehabilitation, services for older people, disability services and other forms of non-acute care.

(3) The term prevention is used for interventions that occur before a specific health event occurs. Prevention aims to reduce the occurrence of new cases, decrease risk and/ or increase protective factors that can be documented, delay onset of illness, reduce length of time that early symptoms continue, and halt/delay a progression of severity.

(4) Maintenance interventions are supportive, educational, and/or pharmacological in nature, and are provided on a long-term basis to individuals with continuing impairment. Maintenance interventions involve the provision of support and after-care services to the patient.

(5) Primary care is defined here as the care provided at the first point of contact with health services and relates to the function, not the person delivering the care.

Figure 2.2 Schematic representation of the Australian Family of Health and Related Classifications

2.4 National Health Performance Framework

The National Health Performance Committee (NHPC) has developed a framework for indicators to report on the performance of the health system (NHPC 2001). This National Health Performance Framework (NHPF) was adapted from the Canadian Roadmap (CIHI 2000) and is designed to provide structure to an appraisal of how well the health system is performing. The NHPF was developed from a previous framework that focused on the performance of the acute care hospital sector. It has been expanded to reflect a broader view of the Australian health system.

The framework consists of three tiers; health outcomes, determinants of health and health system performance. The tiers reflect the fact that health system performance and determinants of health influence health outcomes (McCrone & Phelan 1994). This parallels the ICF expression that ‘an individual’s functioning in a specific domain is an interaction or complex relationship between the health condition and contextual factors (i.e. environmental and personal factors)’ (WHO 2001:19). As can be seen from the shaded areas in Figure 2.3 the ICF classification supports several areas of the NHPF; another of the WHO Family of International Classifications, the ICD, supports other areas.

| | | | | |
|---|---|--------------------------------------|------------------------|------------------------|
| Health status and outcomes | | | | |
| Health conditions <i>ICD-10</i> | <u>Human function</u> ICF (B, A, P) | Life expectancy and wellbeing | Deaths <i>ICD10</i> | |
| Determinants of health | | | | |
| <u>Environmental factors</u> ICF (E) | <u>Socioeconomic factors</u> ICF (E) | <u>Community capacity</u> ICF (E) | Health behaviours | Person-related factors |
| Health system performance | | | | |
| <u>Effective</u> ICF (B,A,P) | Appropriate | | Efficient | |
| Responsive | <u>Accessible</u> ICF (E) | | Safe | |
| Continuous | Capable | | Sustainable | |

Figure 2.3: Simplified form of the NHPF with relevant WHO classifications indicated

2.5 The strategic framework for preventing chronic disease

In October 2001 the National Public Health Partnership published a background paper describing a strategic framework for preventing chronic disease (NPHP 2001). The framework is premised on the same basis as the ICF, namely, the context of a health condition, a life course perspective, a multifaceted response, involving action outside the health system as well as within it, and a strong emphasis on the role of environmental factors. Figure 2.4 is a simplified version of the schema published by the National Public Health Partnership. The italics indicate relevant WHO classifications which may be used to develop data collections under this framework.

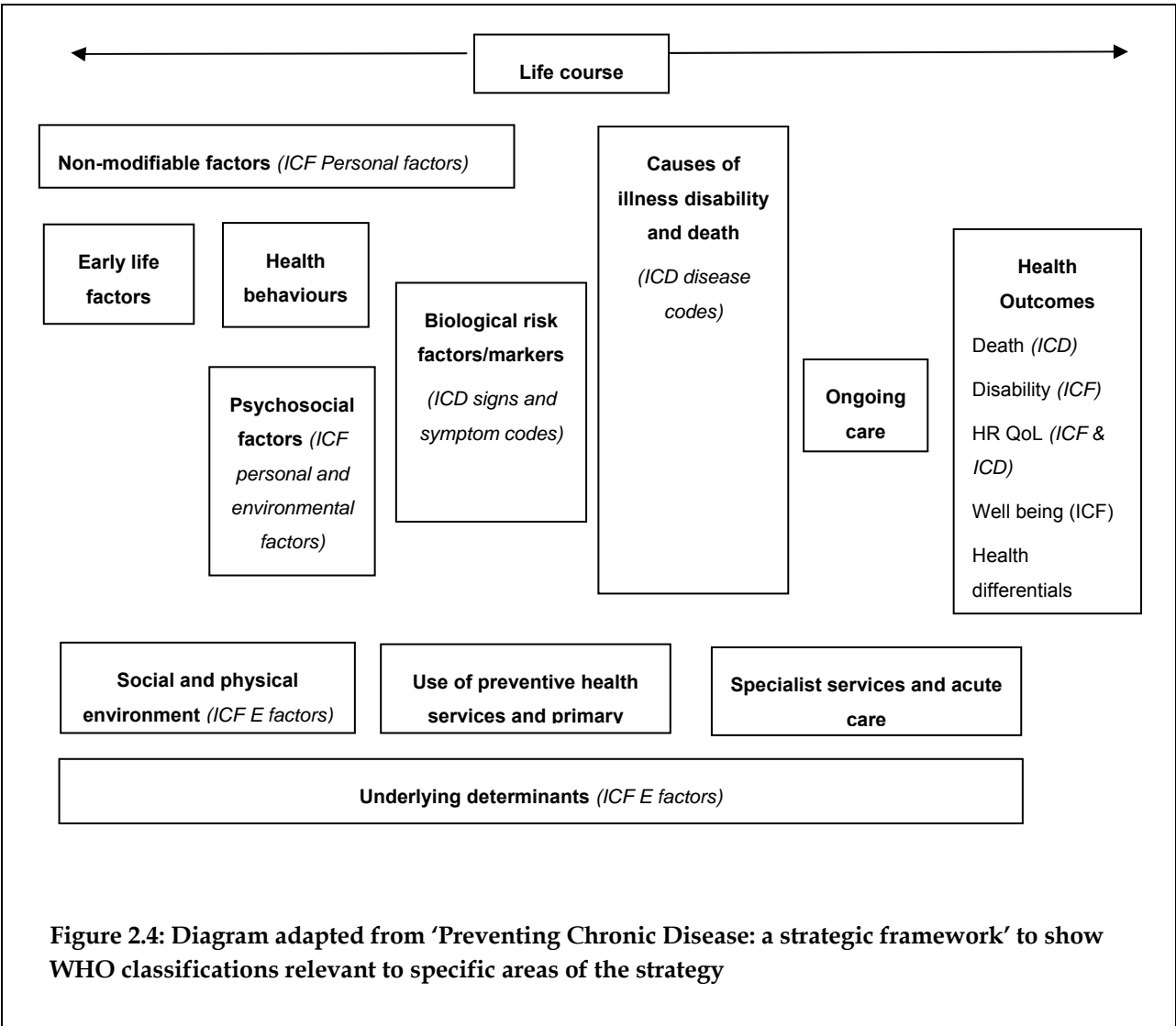


Figure 2.4: Diagram adapted from 'Preventing Chronic Disease: a strategic framework' to show WHO classifications relevant to specific areas of the strategy

2.6 Conclusion

In each of these frameworks human functioning is identified as an important component of the information needed to get a comprehensive picture of the health of Australians and the efficacy of the Australian health system. The ICF features in each of the models and is an appropriate framework for developing functioning and related health outcomes module for use in a range of applications indicated in these frameworks.

3 Functional status measurement for specific health conditions

3.1 Review of the literature on measurement for specific health conditions

Any data collection instrument must reflect what is happening at the point of data collection. If collection is at the point of health care delivery this must be of relevance to the clinician. Equally, the information must be of relevance to service managers and administrators. Consequently, a first step in this project was to take a 'bottom up' approach and to review of some of the literature on existing work in the area of functional status measurement in the clinical environment. The aim was to identify relevant tests and measures for i) stroke and coronary heart disease (CVD) ii) arthritis and other musculoskeletal diseases (MS) and iii) acquired brain injury (ABI). The reason for starting with these areas of interest was opportunistic:

- There was an identified need for data on functioning and disability in the area of CVD, an established NHPA (AIHW 2003b).
- The inclusion of musculoskeletal conditions in the NHPA initiative and the consequent development of indicators to inform that program provided the incentive for investigating the use of functional status information in that area.
- ABI is an area of interest in the disability services arena and a brief investigation into functional status measurement for people with this condition could be used to enhance previous AIHW work in the area.

The assessment tools identified in the selected literature were then mapped to ICF domains. Some items in the assessment tools did not map to the ICF at all and could be mapped instead to the International Classification of Diseases (ICD) (WHO 1992). The measurement methods and the scoring systems of the assessments and their possible relationship to the ICF qualifier were considered.

The majority of the articles reviewed were from the academic literature pertaining to the relevant specialty areas. There are a huge number of assessment tools, condition specific or specific to particular health professional groups, and the review was by necessity selective. It is recognised that the number and range of tools mapped to the ICF may not include some significant areas of the literature. The quality of the reports was not assessed.

In addition, the assessments reported in the literature were essentially those used in research. Research is generally confined to small numbers of subjects and specific research environments. Thus, the literature may not represent the assessments that are usually used in every day clinical practice (Worrall et al. 2001; Swanson & Bellamy 2004).

3.2 Cardiovascular diseases

The overall aims of cardiac rehabilitation are to optimise patients' functioning, enhance quality of life and to minimise the risk of recurrent cardiac events (Dalal et al. 2004). Cardiac rehabilitation programs have focussed on exercise training, education, advice on lifestyle and risk factors and drugs. In view of the evidence of major depression following myocardial infarction (Dunlop et al. 2004) some programs offer psychological support. Gaps in data to inform the indicators needed for monitoring cardiovascular health relevant to rehabilitation and secondary prevention have been identified (AIHW 2003b).

The indicators recommended by the National Health Priorities Areas and the National Health Performance Committee for monitoring cardiovascular health are:

- Proportion of people with mild/moderate/severe disability at six months following diagnosis of an initial cardiac event, all ages.
- Proportion of people with mild/moderate/severe disability at six months following diagnosis of initial stroke event.

Cardiovascular diseases in brief

The National Health Priorities Area (NHPA) for cardiovascular diseases focus on diseases caused by a damaged blood supply to the heart, brain and legs and includes:

- coronary heart disease;
- stroke;
- heart failure; and
- peripheral vascular disease.

These diseases share a number of preventable risk factors, such as, tobacco smoking, high blood pressure, high blood cholesterol, insufficient physical activity, and overweight and obesity.

Cardiovascular diseases accounted for the greatest health expenditure in Australia in 2000-01 (\$5.4 billion, 11% of total allocated health expenditure) (AIHW 2004d).

Cardiovascular diseases also accounted for 38% of deaths in Australia in the same period (AIHW 2004e). In the 2001 National Health Survey 19.4% of the Australian population reported heart, stroke and vascular conditions; with increasing age-standardised prevalence with increasing age.

Associated with cardiovascular diseases is a high incidence of disability. It is estimated that, of 1.10 million Australians affected by heart stroke and vascular diseases, 59.1% needed assistance or had difficulty with self-care, mobility or communication and around 30.1% had no difficulty with these activities but needed aids and equipment (AIHW 2004e:19).

The signs and symptoms of both coronary heart disease and stroke cited in the AIHW report on secondary prevention (AIHW 2003b) may be found in the ICF body functions chapters (Table 3.1).

Table 3.1: Signs and symptoms of coronary disease and stroke related to ICF

| Signs and symptoms of coronary heart disease | ICF Code |
|---|-----------------|
| Chest pain | b28012 |
| Blood supply to the heart | b4103 |
| Heart functions – rate, rhythm, contraction force | b4100 – 4102 |
| Blood pressure | b420 |
| Exercise tolerance – endurance, aerobic capacity, fatigability | b4550 – 4552 |
| Sensations associated with cardiovascular and respiratory functions | b460 |
| Weight maintenance | b530 |
| Signs and symptoms of Stroke | |
| Mental functions | Ch 1 – b |
| Communication | Ch 3 – b |
| Mobility | Ch 4 – b |
| Swallowing | b5105 |
| Seeing functions | b210 |
| Organisation and planning | b1641 |

All the signs and symptoms of both coronary heart disease and stroke can be coded using the ICF. This illustrates that the ICF provides a framework for human functioning at the body function and structure (impairment) level. The literature was searched to find the most commonly reported assessments used in the management of cardiovascular diseases and stroke to determine whether the other components of the ICF—activities (and limitations), participation (and restrictions) and environmental factors—were routinely assessed and documented in the literature. This search would also establish whether there were items of information, important to the management of the conditions, which could not be coded to the ICF. The domains of the assessment tools were related to the ICF components and domains to determine whether the ICF would be an appropriate framework for relating the clinical data for statistical purposes. See Appendix 2.

Personal factors are recognised in the ICF as contributing to extent of functioning, disability and health, however personal factors are not classified. The personal factors reported to affect the outcomes of cardiovascular disease management are also included in the appendix.

Cardiovascular diseases themselves may be coded using the International Classification of Diseases, Australian Modification (NCCH 2004). Co-morbidities may also be classified in ICD-10-AM. A functional status data module would complement a record of health conditions that are relevant to the functional status. A person's level of mobility may be related to a number of health conditions, such as a stroke and pre-existing osteoarthritis.

Review of CVD-related functional measures

Appendix 2 captures the results of the literature search for CVD related functional assessment tools. The tools included are those found in references accessed through internet and usual library processes and those advised by the National Centre for Monitoring Cardiovascular Disease Advisory Group. Following consultation with the Group an additional table was constructed to address generic health status and quality of life measures. This is discussed in Chapter 4.

Appendix 2 includes information on the findings that may be recorded as a result of the clinical assessment process. These are related to the relevant ICF domain in the next column. The assessment methods and any information on the measurements or scales are recorded in the 3rd and 4th columns. The final columns include comment on issues of reliability, or measurement and reference to the measurement method. At present this table is incomplete (in terms of content and number of tools). As the work progressed it became apparent that it would not be possible to reliably map the assessment domains and measures to a single data capture framework. Consequently the focus of the project moved to the development of questions to fulfil the need for an instrument to provide summary information on functioning.

Observations from the literature

The domains in commonly mentioned clinical assessments of function for people with CVD were related to the components and domains in the ICF (Appendix 2). The main findings from this exercise are:

- Impairments of body function are commonly reported in the sample of the literature surveyed. All ICF chapters are covered to some extent except those for functions of the digestive, metabolic and endocrine systems, genitourinary and reproductive functions, and functions related to skin and related structures. Of those Chapters covered, the most commonly reported domains are those that may affect mobility, for example, the impairments of heart and lung function from ICF Chapter 4.
- Impairments of body structure are not commonly reported. Those that were mentioned in the literature surveyed are not likely to be measured at different points of care provision.
- Domains of the ICF Activities and Participation component are commonly reported. Assessments of these domains in general, are made in the clinical situation and do not take into account the person's individual environmental circumstances. The most common domains to be assessed are those that relate to self-care and mobility/moving around. To a lesser extent activities of daily living in the community are addressed, for example, managing money and shopping. This may reflect the sample of the literature surveyed or may reflect actual clinical practice where the level of functioning in major life areas such as work and education and social and community participation is not considered.

- The environmental factors are rarely reported. Only social support and relationships are reported in the literature. A range of environmental factors is mentioned in a study of barriers to participation in sport by people with disabilities.
- Personal factors are also included in the ICF model, though not classified. The literature sampled frequently referred to personal factors as risk factors for CVD. This was not balanced by reference to environmental factors as risk factors for CVD.
- The sampled literature includes information on diseases and co-morbidities. These can be coded using the ICD codes. A functional outcome data module could be collected alongside summary information on relevant diseases.
- Different assessment tools use domains that relate to different levels of the ICF. For example, the mobility scale for acute stroke patients operates at the 4 digit level of the ICF, where the majority operate at the three digit level. It may be possible to relate the measures to a higher level in the ICF classification and use descriptors to assist with the use of the ICF qualifier to indicate the level of functioning for each component.
- Some assessment tools, such as the Functional Independence Measure, aggregate scores to form rating scales.
- Though similar domains were being assessed by several tools there seems to be no consistency in the way they were being measured. Many areas of functioning are assessed differently by different professionals for example a physician may make an estimation of mobility, where a physiotherapist may do a timed walk test. Without reporting of the environmental factors influencing performance there may be inconsistency between reported results. At the point of care level it seems that it may not be possible to compare measures made with different assessment tools.
- There are many areas of functioning not reported as being assessed:
 - Many areas of learning and applying knowledge.
 - Communication.
 - Interpersonal interactions and relationships.
 - Major life areas such as education, work and employment.
 - Community, social and civic life.
 - Only the products and technology area of environment is covered to any extent. Other environmental factors such as the natural environment, support and relationships, attitudes, services systems and policies are not reported.

As it became apparent that there were many areas of functioning not addressed in the clinical assessments the focus of the project moved to consider the development of questions to inform a data module on functioning.

3.3 Arthritis and other musculoskeletal conditions

In July 2002, Australian Health Ministers recognised the major health and economic burdens of arthritis and musculoskeletal disorders by declaring this a new NHPA. More than six million Australians (323 out of 1,000 persons) are estimated to have arthritis and other musculoskeletal conditions (AIHW 2004c). There were similar rates of occurrence in males and females. Increasing age is a strong risk factor for musculoskeletal conditions. Arthritis and musculoskeletal conditions are associated with more disability than any other health condition. It was estimated, from the 1998 ABS Survey of Disability, Ageing and Carers, that 1.2 million people (34% of all persons with a disability) reported a disability due to a musculoskeletal condition (AIHW 2004c).

The focus of the NHPA is on osteoarthritis, rheumatoid arthritis and osteoporosis, some of the most prevalent forms of musculoskeletal disease within Australia. Common to all these conditions is the diversity of effects for individuals depending on the severity and number of joints affected. As any area of the body may be affected, any of several domains of functioning may be affected. For example, osteoarthritis in a single joint may cause minor limitations in a small number of activities, whereas severe rheumatoid arthritis may affect most of the joints in the body and be related to profound difficulties in most domains of functioning. Osteoporosis may be present, but asymptomatic for many years and yet may cause sudden severe pain and loss of function at a particular point in time when a fracture occurs. Environmental factors may have a significant influence on participation outcomes for people with musculoskeletal conditions.

Each of these conditions is more prevalent with increasing age and level of functioning is likely to be influenced by many factors, including co-existing health conditions, personal and environmental factors.

Arthritis and other musculoskeletal conditions in brief

Osteoarthritis in brief

Osteoarthritis is the most common form of degenerative joint disease. Osteoarthritis affects the cartilage in the joints. Cartilage cushions the ends of bones, where bones meet to form a joint. With age the cartilage changes in structure, becomes less effective as a shock absorber and may become shredded and vulnerable to friction from normal function (Salter 1983). Osteoarthritis is most commonly found in the knees, neck, lower back, hip and fingers; in general, few joints are affected. Associated as it is with ageing, osteoarthritis tends to be both permanent and progressive. The prevalence of osteoarthritis increases with age and is highest in those aged above 65. Women (9.2%) are more often affected with osteoarthritis than men (5.7%) (AIHW 2004c).

Osteoarthritis is characterised by:

- painful joints, that usually worsen with exercise or repetitive use;
- swelling of the affected joint(s);
- pain and stiffness that restrict movement;
- weakened muscles surrounding the affected joint; and
- joint deformity.

These symptoms are associated with difficulty or need for assistance in accomplishing usual activities such as caring for oneself and others, decreased productivity at work and restrictions in the way a person manages and enjoys their daily life. A person may change what they do or the way they do their usual activities in terms of the speed, frequency or the discomfort experienced. For example, a person may change the number of hours worked, take more frequent breaks, change the tasks performed or the order in which tasks are performed.

Risk factors for osteoarthritis include a history of joint trauma, repetitive use of joints, overweight and bony deformities causing malalignment of joints.

Rheumatoid arthritis in brief

Rheumatoid arthritis is the most common form of inflammatory arthritis. Inflammatory arthritis is characterised by swelling and destruction of joint structures. In rheumatoid arthritis the immune system attacks the tissues lining the joints. The resulting inflammation causes pain, heat and swelling. The disease can also cause inflammation of connective tissue, blood vessels and organs. Generally many joints are affected.

The most common symptoms of rheumatoid arthritis include:

- general feeling of ill-health;
- pain in the affected joints;
- swelling of the joints; and
- stiffness, which restricts movement.

Symptoms are associated with diverse effects on activity and participation in society depending on the severity and number of joints involved. The destructive nature of the disease may mean that functional limitations are life long. The range of domains of functioning affected may be extensive and include impairment of multiple body systems, many areas of difficulty or need for assistance in accomplishing usual activities such as caring for oneself and others, decreased productivity at work and restrictions in the way a person manages and enjoys their daily life.

Rheumatoid arthritis most commonly develops between the ages of 25 and 50 but can begin at any age. The disease affects more women (2.7%) than men (2.0%) (AIHW 2004c). There is also a form of the disease that affects children.

Osteoporosis in brief

Osteoporosis is not a form of arthritis but a disease where bone density and structural quality deteriorate, leading to an increased risk of deformity and fracture. The most common sites of fracture are the bones of the spine, the hip and the wrist. Other bones commonly affected, include the shoulder, ribs and the pelvis.

Lifestyle, exercise, hormonal activity and nutrition all affect bone strength. Peak bone mass development occurs during childhood and adolescence; building stronger bones at this time means greater protection against fractures in later life.

People are often unaware they are suffering from osteoporosis; by the time symptoms occur the bone density can be significantly reduced. Fractures resulting from minor trauma are a consequence of osteoporosis. They are often painful and can lead to serious complications, particularly in the elderly. Common symptoms of osteoporosis include:

- a fracture, commonly of the wrist, hip or spine;
- curvature of the spine; or
- loss of height.

Osteoporosis is more common in women because, for five to ten years following menopause, there is a sharp decline in the female hormone oestrogen, which plays a central role in maintaining bone mass balance. This decrease in production of oestrogen accelerates calcium loss in bones.

Indicators for osteoarthritis and other musculoskeletal diseases

The Data Working Group of the National Arthritis and Musculoskeletal Conditions Advisory Group (NAMSCAG) has proposed a list of indicators for this NHPA. The indicators cover all areas of the National Health Performance Framework and include a number of aspects of human functioning and the environment. The proposed list of indicators was discussed by stakeholders at a workshop in July 2004. Some of the indicators are generic across the conditions of interest and others are condition specific. Table 3.2 relates the proposed indicators for functioning, disability and health to the ICF.

Following discussion at the workshop it was decided to reject the three human function indicators and include the concepts of pain and activity limitation in a musculoskeletal disease specific indicator of health related quality of life. The items suggested in the health related quality of life indicator are a mixture of ICF concepts including health conditions (anxiety and depression) and body functions. No domains from the activities and participation component are considered, though it was anticipated that this indicator would need work.

The workshop participants recognised the importance of environmental factors and recommended that development of an indicator should be a high priority; no indicator was suggested (AIHW 2004f).

Table 3.2: Proposed indicators for musculoskeletal conditions related to the ICF

| ICF domain | Indicator | NHPA dimension |
|---|---|-------------------------------|
| b280-b289 Pain | Pain | Human Function |
| | Disability days | |
| Chapter 5 Self-care | Activity limitation (self-care, ambulation, physical, work related) | |
| d450-d469 Walking and moving | | |
| d430-d449 Carrying, moving & handling objects | | |
| d840-d859 Work & employment | | |
| b280-b289 Pain, Chapter 1 Mental functions | Health related quality of life (including pain, mental health, emotional function, self-image, fatigue, sexuality, anxiety, depression) | Life expectancy and wellbeing |
| b152 Emotional functions | | |
| b1644 Insight | | |
| b130 Energy &drive functions | | |
| b640 Sexual functions | | |
| (Anxiety and depression are health conditions and would be coded using the ICD) | | |
| Environmental factors component | High priority for indicator development | Environmental factors |
| d840-859 Work and employment | Lost productivity/exit from workforce | Socio-economic factors |
| Chapter 3 Support and relationships | Carer burden | Community capacity |
| Chapter 5 Self-care | People with condition are confident/able to effectively self care | |

Observations from the literature

An outcome data module based on human functioning should then provide a component to cover activity limitations for a musculoskeletal diseases indicator set, and a summary of information on the environment.

Appendix 3 Table A3.1 captures the results of the literature search for clinical assessment tools and methods used in the assessment of musculoskeletal diseases and relates them to the ICF. These tools may be used by a range of health care providers including physicians, surgeons, physiotherapists, occupational therapists and orthotists. The measures included are those found in references accessed through internet and usual library processes.

The main findings from this exercise are:

- Clinical assessment of musculoskeletal diseases as indicated by the sampled literature covers all components of the ICF, with an emphasis on the body structures and functions component of ICF. Compared to the assessment of CVD more emphasis is placed on the body structures.
- The assessment of activities and participation focuses on self-care and mobility. Activities of daily living such as eating, dressing, washing and toileting are

included in several of the assessment tools. Less commonly, participation in life areas is included, for example vocational skills.

- Mobility domains tend to be restricted to changing body position, transferring from one place to another and walking. Carrying moving and handling objects, moving around in ways other than walking, and places other than 'indoors' and 'outdoors' are not generally covered. In the literature sampled, moving around using transportation or equipment was not covered.
- Very few assessment tools make any indication of the environmental factors that affect the level of functioning. Occupational health and safety assessments in the workplace are the only assessments that consistently record environmental factors that may affect the health condition.
- For some of the domains of functioning there are several methods of measurement ranging from those that are based on observation and palpation, (i.e. more qualitative assessment), to quantitative measures using a range of different equipment.
- Different assessment tools use domains that relate to different levels of the ICF classification.
- The range and number of domains assessed varies between assessments, making it difficult to relate the instruments to a common data framework without jeopardising the psychometric properties of the instruments.
- There are many areas of functioning at the level of the person and social functioning not reported as being assessed:
 - Learning and applying knowledge, general tasks and demands, communication, domestic life, interpersonal interactions and relationships, education, economic life, community, social and civic life.
 - Environmental factors other than those related to the workplace.
- The International Core Sets project has identified a short list of ICF domains for Rheumatoid Arthritis and Osteoarthritis. The domains for body functions and structures are essentially consistent with those seen in the literature. However, environmental factors and participation are included to a far greater extent. This suggests that the clinical community may be recognising the contribution of these components of functioning to the monitoring of outcomes. With the inclusion of these components in a core set which is being developed for research purposes it is likely that the literature of the future will include participation and environmental factors more often (for example, Stucki et al. 2004).

3.4 Acquired brain injury

The diversity of functional limitations that may arise as a result of ABI creates particular challenges for achieving consensus on standard approaches to outcome measurement. This diversity of functional limitations also means that a particularly wide variety of environmental factors is likely to be of relevance to people with ABI and their families and carers.

Many different instruments are used for assessing outcome after ABI. These instruments vary in terms of:

- The stage post-injury and setting in which they are intended to be used (e.g. acute; inpatient rehabilitation, community living);
- Method of administration;
- Whether they focus on a specific aspect of functioning or are more global; and
- The particular domains of functioning assessed.

Many instruments have been developed specifically for assessing outcome after brain injury, but some generic tools are also commonly used.

Recently, substantial work has been undertaken in Australia to look at whether it is possible to achieve some consensus around consistent use of a standard set of tools, to promote comparability of data collected, both for clinical and research purposes. However, achieving such consensus seems difficult (Tate 2004; Swanson & Bellamy 2004). This difficulty in achieving consensus may in part reflect the different purposes for which tools are used – for instance:

- measuring recovery after trauma;
- evaluating interventions;
- investigating association between initial severity of injury and severity/nature of resulting disability; and
- assessing need for services and assistance of individuals with ABI and their families, as well as the diversity of affects that ABI has on individuals and their families and carers.

Acquired brain injury in brief

The term ‘acquired brain injury’ (ABI) is widely used as an umbrella term to describe disabilities arising from any damage to the brain acquired after birth, regardless of cause (AIHW: Fortune & Wen 1999). Brain injury acquired at birth or very early in life is sometimes included in the scope of ABI, but more often included within the intellectual disability group.

ABI can result from a number of causes, including head trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological disease and stroke. The term ‘traumatic brain injury’ (TBI) is generally used to refer to acquired brain injury

caused by a traumatic event (e.g. a motor vehicle accident or a fall). Damage to the structure or function of the brain can lead to physical, cognitive, psychosocial, and sensory impairments of varying degrees of severity. The type of damage and parts of the brain affected can vary with the cause. Thus, ABI may lead to restrictions in a broad range of life areas.

ABI is recognised as a disability group in Australia. In 1994 the Commonwealth and State governments agreed on a National Policy on Services for People with Acquired Brain Injury (Department of Human Services and Health 1994). The National Policy on defines ABI as:

‘injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke. These impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment.’
(Department of Human Services and Health 1994)

The National Community Services Data Dictionary Version 3 defines Acquired Brain Injury as being ‘...used to describe multiple disabilities arising from damage to the brain acquired after birth. It can occur as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease etc. Effects include deterioration in cognitive, physical, emotional or independent functioning’ (AIHW 2004g).

The impact of ABI at the community level is substantial. ABI, particularly traumatic brain injury, commonly affects people in early adulthood, and survivors may not have substantially reduced life expectancy. People with ongoing support needs as a result of ABI commonly live for 20 to 40 years after injury (Jennett et al. 1981).

People living with disability resulting from ABI have characteristic support needs that differ from those of people with other types of disability. In particular, because of the acquired nature of ABI and the wide range of impairments that can result, individuals who sustain ABI, and their families and friends, may need to find strategies for coping with changes in lifestyle and expectations.

While people with only one type of impairment (e.g. mental or physical) may be able to develop compensatory adaptations, people with more than one type of impairment are less able to do this (Jennett & Bond 1975). The wide range of types of disability that can result from ABI means that people with ABI have very diverse support needs. In recent years specialised brain injury services have been established around Australia in response to community demand and in recognition of the unique needs of people with ABI.

Incidence and prevalence of ABI in Australia

It is estimated that in 1998, 201,600 people, or 1.1% of the total population, reported that they had an ABI related disabling condition and related activity limitations or participation restrictions (AIHW 2003c). This number includes 150,800 people aged

under 65 years, or 0.9% of the population in that age group. The rate for males (1.3%) was higher than for females (0.9%).

Around 113,300 people (0.6% of the population) had an ABI-related condition and a severe or profound core activity restriction, meaning that they sometimes or always needed help with self-care, mobility or communication. Of these, 75,200 were aged less than 65 years (0.5% of the population in that age group).

Of the 39,200 people who reported an ABI-related main condition, 81% said that this condition was caused by an accident or injury.

It is difficult to obtain reliable estimates of the incidence of ABI. Data on hospitalisations are often used as an indicator. While it must be emphasised that rates of hospitalisation are not incidence rates, incidence is one of the factors that affects rates of hospitalisation.

ICD-10-AM diagnosis codes can be used to identify conditions that may give rise to acquired brain injury, such as traumatic brain injury, stroke and other cerebrovascular disease, anoxic brain injury, brain injury due to alcohol, other drugs and psychoactive substances, brain damage arising before birth, at birth, or during childhood, brain infections, and dementia and organic psychiatric conditions.

In 2000–01 there were 20,563 hospital separations with a diagnosis of traumatic brain injury – a rate of 107 separations per 100,000 population (AIHW 2003c). The male rate (150 per 100,000) was more than double the female rate (65 per 100,000). Males aged 15–19 years had the highest rate of hospital separations (304 per 100,000), especially compared to females of the same age (less than a third the rate, at 99 per 100,000). For females, the highest rate was for those over the age of 65 (122 per 100,000).

Findings from the review of assessment tools relevant to Acquired Brain Injury

The relationship between the ICF and measures used in the assessment of function in ABI is explored in Appendix 4, Table A4.1. The tools covered vary widely in terms of intended use, ICF domains covered, items assessed, measurement scale and method of administration. Below are some general observations from the tables:

- The Glasgow Coma Scale remains the most widely used score to assess severity of traumatic brain injury in clinical research and to compare patient series (Lovasik et al. 2001; McCarthy 2001). This assessment is used as an indication of the severity of injury and relates to the body functions domain of ICF. Some studies have shown correlation of injury severity with outcome, but this is not always clear. For example, Thornhill et al. (2000) found that increased severity on admission was associated with increased likelihood of death or vegetative state, and decreased rate of good recovery, but initial severity of injury was not found to be related to disability a year later.
- Duration of post-traumatic amnesia is also used as a guide to the severity of diffuse brain damage and cognitive deficits, and has been found to correlate well

with late outcome and the interval before patients return to work (McCarthy 2001).

- Computerised tomography (CT) and magnetic resonance imaging (MRI) are used routinely as diagnostic tools and have confirmed that there is often structural brain damage even in people whose injuries appear to be mild (Jenkins et al. 1986). In some studies focusing on the incidence of ABI (particularly traumatic brain injury), results of CT scan and MRI are used to confirm cases of brain injury or to assess severity (e.g. Kraus et al. 1984; Servadei et al. 1988) and could inform the coding of body structures domains in ICF.
- Tate et al. (2002) conducted an extensive literature review to identify assessment tools suitable for the assessment of disability and care needs following traumatic brain injury (TBI), using the ICF as a framework to guide their review (Table A4.2). The authors recommended 25 instruments as providing the most potentially valid evaluation of disability after TBI, though no single instrument encompassed all domains. In particular, few instruments that measured cognitive and behavioural disability were identified. The key domains of mobility and activities of daily living were represented, as well as cognition, behaviour (including social behaviour) and participation in work, recreational activities and community living.
- Another recent study that provides a review of outcome measurement instruments relevant to ABI is the Brain Injury Outcomes Study. Tate et al. (2004) recommended the implementation of a minimum data set, which should include standardised measures of overall level of functioning, impairments, everyday activities and community participation. Use of a common set of core instruments, administered by all units at comparable time points, would enable documentation of level of functioning and monitoring of progress, and assist in ensuring that people's support needs are identified.

Table A4.3 shows the instruments recommended for use at different stages post injury (acute and subacute stages, in-patient rehabilitation, and after discharge). As at May 2004, the Brain Injury Rehabilitation Program Minimum Data Set had been developed to collect information on basic demographics, injury, details of referral and treatment patterns. Decisions have yet to be made on outcome measures to be included in the data set (Tate et al. 2004). The tools covered vary widely in terms of intended use, ICF domains covered, items assessed, measurement scale, and method of administration.

- Instruments used in the assessment of ABI may be grouped by purpose, phase of recovery, setting for administration; however some assessment tools would appear in more than one group. The domains covered by different assessment tools differ between groups, and within groups. Some of the domains of ICF would be needed in each group, for example mobility and self-care domains. Others would become less relevant depending on the criteria for establishing the group. Body structure items would become less relevant as phase of recovery progresses.

- Few assessment tools consider body structures domains of ICF and rather more consider body functions. As ABI can have diffuse effects depending on the site and severity of the trauma, the range of domains covered is broad. Body systems not mentioned in the assessments include voice and speech functions, functions of the cardiovascular, haematological, immunological and respiratory systems, functions of skin and related structures and only the defecation functions of the functions of digestive, metabolic and endocrine systems. In general genital and reproductive functions are not considered. The authors are aware that there are specialised assessment tools for this area of functioning, they have not been considered in this study.
- Of the Activities and participation domains of ICF, mobility and self-care are the most commonly considered assessments of functioning for people with ABI. However, there is considerable variation in level of detail at which information is collected, relative to the ICF. In some of the assessment tools there is significant coverage of domains of cognition.
- In ABI assessment there are many tools designed for assessment of specific functions, for example the Orientation Log for orientation and the Mississippi Aphasia Screening Test for impaired communication skills. The level of detail included in these specific tests would need to be summarised in a data module. The module may need to consider how a domain such as impairment in speech functions relates to activities such as communication and participation in interpersonal interactions and relations. At the clinical level it is important to know whether a treatment is focussed at the voice and speech functions, however at the outcomes measurement level it is important to know whether the person can communicate better. The attribution of the change for outcomes measurement requires that the interventions be recorded as the change may be due to the provision of a communication board, an environmental factor, rather than speech and language training.
- In general, participation and environment are considered more in the management of ABI than in either of the other conditions reviewed. This may be because the effects of ABI are prolonged, due to the fact that injury tends to occur early in adult life, where the chronic diseases tend to occur later in adult life.

3.5 Conclusion

There are similarities and differences between the assessment tools used in each of the specific health conditions reviewed. In general, the impairment domains for each health condition relate to the body system(s) most affected and may not consider the broader effects on other body systems or the effects of co-morbidities on the level of functioning.

The most consistent activity domains across the different health conditions are those for self-care and mobility. However the methods of measurement vary considerably depending on the assessment tool and the mix of items in any particular tool also varies. The influence of environmental factors on level of functioning is

acknowledged in some assessments through the recording of assistance needed with a task or activity. In general, other environmental factors are not considered.

The situation for ABI is more complex because of the varied effects and the changing range of assessments carried out at different times in the course of treatment.

There is a set of core domains that is common across health conditions reviewed to which information from more detailed condition specific items can be related. This set of domains also appears in the generic health status measures. These domains are Walking and moving (d450-d469) and Self-care (d510-d570). Of these walking (d450), dressing (d540), eating (d550) and washing (d510) are most commonly reported. The level of detail collected varies between instruments.

The variety of assessments reported in the literature may reflect the needs of clinical trials. It is recognised that the assessments used in clinical trials may not be those that are used in every day health care provision (Douglas et al. 2005).

In developing a summary module of information on functioning that would be useful for outcome measurement, the range of domains will need to reflect all components of the ICF. In specifying the domains the range and complexity of the functional limitations that are possible will need to be considered.

In ABI and some other fields (for example mental health) there is useful work happening in unifying the approach to assessment and measurement and this could feed into the data module.

There is a growing focus in the literature and in clinical circles on the need to focus 'person centred' information on all areas of life, including factors in the environment that affects the individual's ability to function optimally. The summary module will need to reflect those areas of ICF also.

4 Generic summary population measures of functioning and health-related quality of life

This chapter takes a 'top down' approach to measurement of functioning, given the complexities encountered in attempting to find a simple module by working from the 'bottom up', from detailed assessment tools in specific clinical areas.

Meaningful and comprehensive descriptions of health-related quality of life should capture information across all (physical, psychological and social) spheres to maintain content validity in relation to WHO's internationally endorsed definition of health. Domains of functioning which are captured consistently and those particularly underrepresented across tools may all indicate areas of specific interest in constructing a FRHOM.

Table A5.1 relates ICF to the content of five generic outcome tools, the ABS, SDAC and Census question, and the CSTDA NMDS 'support needs' question. Questions and response categories have both been considered in the mapping exercise.

4.1 Review of the literature on generic health status measurement

Five commonly used generic tools which have either been recommended for review by our advisors or are health outcome and quality of life instruments commonly used in Australia were reviewed. These were:

- The London Handicap Scale (LHS)
- The Assessment of Quality of Life (AQoL)
- The World Health Disability Assessment Schedule 2 (WHODAS)
- The Short form 36 (SF-36)
- 15-D Quality of Life Questionnaire

The structure, content, administration and conceptual basis of an outcome measure tool directly relate to its purpose. Generic health-related outcome tools intend to capture broad information about health status across health conditions and do not provide the level of detail, or sensitivity to certain conditions, that condition-specific tools may. Generic measures are sometimes used to measure:

- health related quality of life in clinical trials and outcome measures research;
- efficacy of clinical practice, decisions and treatment;
- resource allocation to health care services;
- performance of health care services; or

- improved health status in an individual.

Variations in design, metrics, administration and content of the tools were identified. A mapping exercise relating the content of the measures to the ICF framework has identified significant variation in the coverage of ICF domains and highlighted commonly represented domains for possible inclusion in a module of information on functional status.

It has been recognised that the more generic ‘quality of life’ tools cover a wide range of information and that this can limit their applicability for some purposes. Cummins et al. (2004) argue that it is, both psychometrically and conceptually, inappropriate to put self-reported symptoms and negative affect together to form a health related quality of life (HRQOL) scale. A person may be medically symptom free yet have a very low subjective well being due to other events happening in their life and conversely someone with severe physical symptoms may report high quality of life because of favourable contextual factors such as wealth, supportive relationships and high self efficacy. The authors suggest that each of the components of HRQOL measures should be assessed separately. The proposed data modules may contribute the functioning and disability component.

These authors are essentially questioning the validity of the traditional HRQOL approach which puts varying health measures – health conditions, functional status and subjective wellbeing – into the one tool to combine into summary measures.

4.2 Coverage of ICF domains—observations from the literature

As generic assessment tools cross numerous health conditions, those domains of functioning which are commonly represented should be considered for inclusion in an outcome module based on human functioning.

Table A5.1 shows that mental functions (thinking and memory) and sensory functions and pain (vision, hearing and pain) are the key body function domains represented. Key Activity and Participation domains are mobility, self-care (dressing, eating and washing), domestic life, interpersonal relationships and major life areas. The majority of the generic tools focus on the Activity and Participation component of ICF; however each instrument varies in the extent to which it captures ICF domains and categories.

Some general observations from Table A5.2 are:

- Many concepts measured in the tools relate to domains of the ICF.
- Items related to Body structures are not reported.
- Body function domains are recorded with varying consistency. Those domains most recorded relate to mental functions (thinking and memory) and sensory functions and pain (vision, hearing and speech).

- Domains of the Activities and Participation component are most commonly reported – mobility, self care and domestic life are included in all five instruments.
- Environmental factors have been largely neglected.
- The coverage of ICF domains differs in each instrument: e.g. the 15 D includes 13 functions and the LHS (Harwood et al. 1994) contains 5. The LHS operates at the chapter level of the ICF summarises a broad range of functioning where the 15D is more detailed and operates at the sub-chapter level of the ICF. Activity and Participation chapters not specifically addressed by the LHS are Learning and applying knowledge, General tasks and demands and communication. The 15D does not include General tasks and demands or Interpersonal relationships.
- Three tools consider environmental factors which relate to the ICF chapters: Products and technology and Support and relationships. There is variability in the way that these concepts are introduced in the measures, i.e. they may be included in the question or the response category.
- ICF domains are represented at different levels of detail (or coding levels), e.g. information on self care is captured in numerous ways: for example the AQoL asks ‘Do I need any help looking after myself’ (ICF domains a 510-a599). The WHODAS 2 focuses on single domains of functioning such as ‘How much difficulty did you have ...getting dressed’ (ICF domain a 540).
- The extent to which an item is divided into discrete domains varies in each assessment tool: e.g. for mobility, the SF-36 captures information on vigorous activities, moderate activities, lifting or carrying groceries, climbing stairs and walking. Whilst the AQoL considers ‘how easily (a person) can get around (their) home and community’.
- Very few concepts relate to the ICF at a four-digit level, e.g. ‘climbing several flights of stairs’ (d4551).
- Even when items map directly to a specific domain, such as ‘walking’ the parameters can be defined differently. WHODAS 2 asks about the level of difficulty experienced by ‘walking a long distance such as a kilometre (or equivalent)’, the SF-36 considers the respondent’s limitations in ‘walking more than a mile’, ‘walking several blocks’ or ‘walking one block’ and the 15-D provides response categories for mobility such as, ‘I am able to walk normally (without difficulty) indoors, outdoors and on stairs’ and does not specify distance.
- Some tools generally use few examples (WHODAS 2, SF-36), and others provide numerous (LHS & AQoL). Examples are often used to clarify concepts which are introduced in a preceding general question, for example, ‘washing’ or ‘dressing’ to clarify what is meant by a term, such as ‘self care’.
- Different tools can use different examples to describe the same domain. The 15D describes walking (indoors, outdoors and on stairs), the LHS describes ‘getting around from one place to another’ (indoors (room to room) and outdoors) and the WHODAS 2 inquires about walking a long distance such as a kilometre.

- Numerous concepts are also interwoven in the same question. The LHS asks, ‘Does your health stop you looking after yourself?’ and provides examples, (housework, shopping, looking after yourself, cooking, laundry, getting dressed, washing, shaving and using the toilet) which map to two ICF domains, Self-care and Domestic life.
- All five tools use ordinal scales, with response categories such as, ‘none’, ‘mild’ and ‘severe’ (WHODAS 2), or brief statements, ‘I am able to perform (an activity) normally, without difficulty’ (AQoL), which maps approximately to these categories.

Table A5.2 illustrates how the response categories of the tools relate to the ICF qualifiers. Responses to outcome measures and assessment tools are not easily related. Table A5.2 does not attempt to relate the response categories with statistical precision, but does demonstrate the variability between instruments. The scales used in the instruments range in sensitivity (from dichotomous to six-level response scales). The SF-36 includes scales with a varying number of response categories depending on the domain being measured.

Response categories can also involve numerous dimensions. In the five tools reviewed, mobility is described by: level of difficulty (WHODAS 2), level of difficulty and level of assistance (AQoL, 15-D) or extent of limitation (SF-36, LHS). For example, a response category in the 15D is, ‘I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others’.

The use of different reference states of health has implications for the comparability of information captured in different measurement tools. Table 4.1 displays the varying reference states of functioning for the five instruments reviewed.

Table 4.1: Reference state of functioning and/or health

| Instrument | Reference state of functioning and/or health |
|-----------------------|--|
| London Handicap Scale | (Think about things you have done over the last week.) Compare what you can do with what someone like you who is in good health can do. |
| SF-36 | Consider your ‘views about your health’ |
| WHODAS-2 | — |
| 15-D | ‘...which best describes your present health status’ |
| AQoL | — |

The recall period can influence how a question is interpreted. Table 4.2 summarises the variability in the reference periods of each of the five instruments.

Table 4.2: Summary of time recall periods for generic measures

| Instrument | Time recall |
|-----------------------|-------------------------------------|
| London Handicap Scale | past week |
| SF-36 | 'an answer that best describes you' |
| WHODAS-2 | month |
| 15-D | 'present health status' |
| AQoL | past week |

4.3 ABS population data

This section provides further detail on the content of the ABS SDAC. Population data about people with disabilities is collected in the SDAC every five years. It is important that data captured in data modules are compatible or relatable to population-based information. Consistency across administrative and population data is crucial for the development of meaningful policy and appropriate service delivery which meets consumers needs.

As the SDAC is a comprehensive survey, the range of ICF concepts covered is extensive. All key chapter headings of the Activities and Participation component of the ICF are represented and a greater number of environmental factors are considered than in the five generic outcome tools reviewed. Table A8 relates the content of the ABS SDAC and the proposed 2006 disability Census question to the ICF.

The core and non-core activities and tasks included in the SDAC are summarised in Tables 4.3 and 4.4.

Table 4.3: Core activities and tasks (ABS 1998 SDAC)

| Self-care | Mobility | Communication |
|------------------------------|--|------------------------------------|
| Assistance | | |
| Showering/bathing | Getting into or out of bed/chair | Understanding family/friends |
| Dressing | Moving about usual place of residence | Being understood by family/friends |
| Eating | Moving about a place away from usual residence | Understanding strangers |
| Toileting | Bending to pick something up off the floor | Being understood by strangers |
| Controlling bladder or bowel | | |
| Difficulty | | |
| | Walking 200 metres | Non-verbal |
| | Walking up and down stairs without a handrail | |

Source: ABS 1999.

(Continued)

Table 4.4: All other non-core activities and tasks (ABS 1998 SDAC)

| Activities domains | Activity tasks |
|---------------------------|--|
| Health care | Foot care Taking medications/administering injections Dressing wounds Using medical machinery Manipulating muscles or limbs |
| Housework | Household chores such as: Washing Vacuuming Dusting |
| Property maintenance | Changing light bulbs, tap washers, car registration stickers Making minor home repairs Mowing lawns, watering, pruning shrubs, light weeding, planting Removing rubbish |
| Paperwork | Reading or writing tasks such as: Checking bills or bank statements Writing letters Filling in forms |
| Meal preparation | Preparing ingredients Cooking food |
| Transport | Going to places away from the usual place of residence |
| Guidance | Interacting, making and maintaining relationships Coping with emotions Making decisions, thinking through problems Managing behaviour (children aged under 15 years, people in cared accommodation) |

Source: ABS 1999.

SDAC question design—length and concepts

Example of questions for core activities:

- Do you ever need help or supervision to shower or bathe?
- Even though you do not need help or supervision with these activities, do you find them difficult?
- Do you always, or only sometimes, need help with showering or bathing?
- How often do you need this help: daily, weekly, monthly, or less than once a month?
- On average, how many times per (day/week/month)?

Example of questions for non-core activities:

- Because of your conditions, do you need help or supervision with any of these types of health care tasks?
- Even though you do not need help with health care tasks, do you find any of them difficult to do?

- How often do you need this help: daily, weekly, monthly, or less than once a month?
- On average, how many times per (day/week/month)?

Response categories

The response categories for most questions are Yes and No. Three types of response categories are used for the three types of questions about frequency of need for help (see above examples): (1) Always and Sometimes; (2) Daily, Weekly, Monthly, Less than once a month; and (3) Numeric entry (1–30).

The 2006 Census question

The new disability question for the 2006 Census focuses on the three core activities—self care, mobility and communication. As in the SDAC, the key qualifying concepts are the ‘need for assistance’ or ‘need for supervision’. There are three response categories relating to these concepts: (1) Yes, always; (2) Yes, sometimes and (3) No. The Census question therefore corresponds to the notion of severe or profound core activity restriction in the SDAC.

4.4 Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS)

A generic measure of functioning is in use in Australia in the disability services field. The CSTDA NMDS support needs question (Figure 4.1) was developed in consultation with service providers and data users and has been used for the last 12 months in a continuous collection (AIHW 2004a). Data linkage methodology has enabled data from different service providers on the same client to be identified. Preliminary investigation has shown that generally the items were consistently recorded by different service providers and that there was no apparent bias relating to service type (AIHW 2000a:135 and additional unpublished analyses).

During the development of the item a survey of assessment tools in use in the disability services field was also undertaken, to investigate the ICF activity domains in use, and the measurement concepts most common—‘difficulty’ and ‘assistance’ being the most common (AIHW 2003e). The ICF domains of functioning selected were those that are relevant to a range of services provided under the CSTDA, including accommodation support, community support, community access, respite and employment. The ‘measures’ relate to those used in the population survey (ABS SDAC)—primarily assistance.

The AIHW therefore aimed for consistency with (and an ability to map to):

- the CSTDA definition of people with disabilities;
- the 1998 (& 2003) ABS Survey of Disability, Ageing and Carers;

- the National Community Services Data Dictionary Version 2.0 (then in draft);
- assessment tools currently in use in jurisdictions;
- the existing CSDA MDS (Version 1); and
- other major data collections, assessment tools, data development activities and concepts of relevance, wherever possible.

The development project focused on clarifying the concepts used to describe people's support needs so that information gathered during assessment could be mapped to a national indicator (or indicators) and used for national comparison. The CSTDA question provides a summary statement about many individual domains of functioning. Thus it provides a means to collect data from a range of assessment tools that have a variety of items. The domains of functioning selected were those that are relevant to a range of services provided under the CSTDA, including accommodation support, community support, community access, respite and employment. The 'measures' relate to those used in the population survey.

11. How often does the service user need personal help or supervision with activities or participation in the following life areas?

See Data Guide page 62

Please indicate the level of help or supervision required for each life area (rows a–i) by ticking only one level of help or supervision (columns 1–5).

| <i>The person can undertake activities or participate 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)</i> | 1) Unable to do or always needs help/ supervision in this life area | 2) Sometimes needs help/ supervision in this life area | 3) Does not need help/ supervision in this life area but uses aids or equipment | 4) Does not need help/ supervision in this life area and does not use aids or equipment | 5) Not applicable |
|--|---|--|---|---|----------------------------|
| LIFE AREA | | | | | |
| a) Self-care e.g. washing oneself, dressing, eating, toileting | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| b) Mobility e.g. 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 | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| c) Communication e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| d) Interpersonal interactions and relationships e.g. actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | |
| NOTE: In the following questions 'not applicable' is a valid response only if the person is 0–4 years old. | | | | | |
| e) Learning, applying knowledge and general tasks and demands e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| f) Education e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| g) Community (civic) and economic life e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| NOTE: In the following questions 'not applicable' is a valid response only if the person is 0–14 years old. | | | | | |
| h) Domestic life e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping, cooking, home maintenance | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| i) Working e.g. actions, behaviours and tasks to obtain and retain paid employment | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

Figure 4.1: Support needs question from the CSTDA NMDS

Participation outcomes

Also during the redevelopment of the CSTDA NMDS, a 'participation outcomes' framework was drafted (Table 4.5). The draft participation outcomes framework was not a proposed question that would appear on a form:

- The framework indicates output and concepts rather than the precise wording that would be used in questions. Separate mechanisms would be used to gather information from consumers and service providers.
- The separate recording for the service provider and person is in line with the established principle that quality of life measures should be based on both 'objective' and 'subjective' measures.
- If adopted, there would need to be user guides. Such guides would explain the ICF framework, including the importance of environmental factors. This could bring in social attitudes, i.e. the 'valued members' aspect of the CSTDA goal.

Thus the participation framework acts as multi-purpose 'participation module' and is proposed for use as a broad outcome indicator meaningful in the CSTDA field. It could be used in the course of service administration when conducting satisfaction surveys, discussing people's overall goals and developing individual service plans (e.g. in case management reviews); and in assessing overall quality of life.

The framework was based on ICF-related data standards included in the National Community Services Data Dictionary (AIHW 2004g).

Table 4.5: Draft ‘participation outcomes framework’

| Life area | Extent of participation (judged by service provider or assessment process) | Satisfaction with participation (judged by consumer, with advocate if necessary) in relation to duration, frequency, manner or outcome |
|--|---|--|
| | <ol style="list-style-type: none"> 1. Full participation 2. Mild participation restriction 3. Moderate participation restriction 4. Severe participation restriction 5. Complete participation restriction | <ol style="list-style-type: none"> 1. High satisfaction with participation 2. Moderate satisfaction with participation 3. Moderate dissatisfaction with participation 4. Extreme dissatisfaction with participation 5. No participation 6. No participation and none desired |
| <p>Participation in communication and conversation (e.g. producing and receiving spoken, nonverbal, formal sign or written messages, involvement in conversation, discussion with or without use of communication devices and techniques)</p> | | |
| <p>Participation in mobility within the home and community environment (e.g. changing and maintaining body position; carrying, moving and handling objects; walking and moving; moving around using transportation)</p> | | |
| <p>Participation in domestic life (e.g. acquiring necessities such as a place to live and goods and services; household tasks such as preparing meals; caring for household objects and assisting others)</p> | | |
| <p>Participation in interpersonal interactions and relationships (e.g. relating with strangers, formal and informal social relationships, family and intimate relationships)</p> | | |
| <p>Participation in education, work and employment (e.g. informal education, preschool, school, vocational and higher education; work preparation such as apprenticeships; acquiring, keeping and terminating a job, remunerative or non-remunerative employment)</p> | | |
| <p>Participation in economic life (e.g. basic and complex economic transactions, economic self-sufficiency)</p> | | |
| <p>Participation in community, social and civic life (e.g. community life, religion and spirituality, recreation and leisure, political life and citizenship, human rights)</p> | | |

Source: AIHW 2004a.

4.5 Conclusion

An analysis of the coverage of ICF domains in each of the five generic instruments shows that the domains of the Activity and Participation component are most commonly recorded and that domains related to the environment are generally overlooked. The coverage and depth (i.e. sub levels) of ICF domains vary between instruments.

Generic measures do, however, apply to many health conditions and can provide a strong indication of domains to be considered for inclusion in a functioning and related health outcomes module. Common body function domains represented in the generic assessment tools and the ABS surveys are mental functions (thinking and memory) and sensory functions and pain (vision, hearing and pain). Key Activity and Participation domains represented are mobility, self care (dressing, eating and washing), domestic life, interpersonal relationships and major life areas. A domain which is not covered in the majority of assessment tools, but present in the ABS SDAC and CSTDA NMDS is communication.

The CSTDA NMDS support needs question focuses exclusively on Activities and Participation, all of the ICF domains being included. Its measurement 'scale' relates to the ABS disability survey (SDAC).

Environmental factors, which may be enabling or disabling to a person's functioning and health status, are widely ignored by the five generic instruments reviewed. Environmental factors (if included) are not considered consistently within instruments (i.e. across all data items) and, there is variability in the way the environment is considered across tools. Environmental factors are considered in the SDAC; products and technology items are fairly well included and some concepts relating to the natural environment and human made changes to the environment and, services, systems and policies (not included in the assessment tools) are represented.

The concepts, terminology and use of examples in questions affect the nature and extent of information captured on domains. There is variability in the content and structure of questions within and between the five generic instruments reviewed. Variability also exists in the concepts and terminology of response categories. Some tools interweave concepts of difficulty and assistance in one response category, whilst others may only measure 'extent' of limitation. The reference state of functioning (e.g. 'compare yourself to someone like you who is in good health') and the reference period for respondents (e.g. one week, one month) also differ between instruments.

There are many generic health-related quality of life outcome tools currently being used in the health and rehabilitation fields. An analysis of five commonly used tools demonstrates the difficulty health professionals and policy makers would have in accurately relating outcomes among these tools. Every outcome measure tells a different story. This chapter and Appendix 5 illustrate the complexities of relating

generic HRQOL instruments which may vary in content, purpose, design, metrics and administration.

The comparability and consistency of information on functioning and health-related quality of life at a population and service level is crucial for the development of effective and meaningful policy and service delivery.

In terms of developing a data capture framework that offers the necessary flexibility to Australian users, the CSTDA support needs question may point the way forward. It enables users to capture data on any of the ICF domains (in one component—Activities and Participation) and uses ‘measures’ that are consistent with the main source of Australian population data on functioning and disability. This possibility is further explored in Chapter 6.

5 Discussion

This chapter discusses factors affecting measurement of functioning and then goes on to discuss possible areas of application for the functioning and related health outcomes module.

5.1 Measurement issues

This section contains a brief discussion of some measurement issues that may affect the ability to relate data collected by clinical assessment tools at the point of care to a functioning and related health outcomes module. However, many of the issues are complex and warrant further discussion. A more comprehensive discussion of the issues associated with measurement and how they affect the comparability of information is provided in *Who Measures and How* (forthcoming AIHW publication). “Measurement is the assigning of numbers to things according to rules” (Glass & Stanley 1975). For something to be measured it must be defined. For a definition to be operational it must have sound theoretical assumptions and the ability to be understood and used by all similarly trained individuals. For example, the definition of human strength may be defined in terms of performance of a single maximal contraction, or a number of repeated contractions. The measurement would be different for the same muscle under the different circumstances. To understand the measurement, the operational definition must be known and consistently applied if comparisons are to be made.

Clinical information and its relationship to the ICF

Any development of standardised approaches to capturing functional information should be based on or, at least, heavily informed by assessment tools used and accepted by professionals in the relevant field. Although clinicians routinely collect information on functional status for the care of patients the information may not be included in notes and rarely coded from the hospital records for inclusion in the administrative reports. Inclusion of functional status information in the administrative record has the potential to benefit health care management, research, public health and policy.

Measurement of body structure and body function

Body functions are the ‘physiological functions of body systems (including psychological functions) and body structures are ‘anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function or structure such as a significant deviation or loss. In the health system to measure impairments, biomedical methods are used predominantly. For example, lung function tests give an indication of the extent of function of the respiratory system, or

X-rays to determine bone structure. These measures are compared with the expected population norms to indicate the level of deviation. Significant deviation from this norm would be considered an impairment. The domains of functioning selected for measurement are usually limited to those pertaining to the diagnosed health condition(s).

Measurement of activity and activity limitation

Activity is 'the execution of a task or action by an individual' and activity limitations are 'difficulties an individual may have in executing activities' (WHO 2001). Often activity limitations are measured using performance-based tests undertaken in the 'clinical' environment. (Clinical in this context may be interpreted broadly to include hospital and other institutional or community based facilities where health and community care providers may see the person). Examples include timed walk tests, activities of daily living assessments, and work capacity assessments. The domains of functioning selected for assessment tend to depend on the specialty of the health care provider. For example, an occupational therapist may test self-care activities, the physiotherapist walking and other moving around activities. The speech and language therapist would assess speech and communication. The measure is often made against a previous performance, or compared to the performance of a person of a similar disposition (age, sex and social background), but without the health condition.

Measurement of participation

Participation is 'involvement in life situations' and participation restrictions are 'problems an individual may experience in involvement with life situations'. The concept of participation takes into account what a person actually does in their life, their choice of particular life areas, the duration, frequency, manner and outcome of participation. For example a good participation outcome for a person whose chosen recreational activity is to participate in sport, can do so for as long as they wish (complete 18 holes of golf), as often as they wish, (each weekend), in the way they wish (keeping up with fellow players) and with the desired outcome (social experience without pain or fatigue).

Health status measures and health related quality of life measures sometimes include assessment of participation with questions such as:

'During the past 4 weeks have you had any of the following problems with your work or other regular activities as a result of your physical health?

Accomplished less than you would like to Yes/No,

Were limited in the kind of work or other activities Yes/No.' (SF-36).

Levels of participation are usually self-reported. Sometimes proxy or clinician responses are made. Participation is usually rated in relation to personal goals and expectations. For some life areas there are, and cannot be, norms and standards – for example participation in community, social and civic life.

Measurement of the environment

The environment has a major impact on level of functioning. A person whose health condition would be described as within normal ranges may perform at a sub-optimal level in a different environment. For example, a person who is blind can move around a dark environment without a change in level of functioning, where a sighted person is disadvantaged. Measurement of function, whether at the level of the body, the individual or in society is affected by the prevailing environmental factors; for example, the measurement of blood pressure will be affected by whether the person has driven or walked to the clinic and whether the measure is taken lying down or standing up. The assessment of drinking will be affected by whether the vessel is a teacup or a tankard, whether it is full or part empty and whether the content is hot or cold. In the usual environment, the availability of carers, technical aids or home modifications may affect how well a person can carry out their usual activities (McDonough et al. 1995).

In hospital and other health care settings the environment is more controlled, however the range of settings and the availability of equipment, time or expertise, may influence the way measurements are taken. As an example, muscle function may be tested manually or with a dynamometer and the resulting scores may vary accordingly.

Within the ICF framework it is possible to identify social factors such as education, transport or housing both as determinants of health and social factors influenced by improvements in health (Üstün et al. 2003). With a given level of functioning the impact on different individuals may be different for various reasons related to the environment. Inability to use public transport would have little impact on a person who can use a private vehicle, and inability to perform household tasks would be unimportant to a person with a spouse able and willing to carry out those tasks. A measure of the environment and its impact is essential in functional outcomes measurement.

Measurement of environmental factors has been focused primarily on architectural barriers in the physical environment (Steinfeld 1997). Environmental factors are commonly assessed by occupational therapists, ergonomists and occupational health and safety professionals. See Box 5.1 for an outline of ergonomic assessment.

Box 5.1: Ergonomic assessments – outline

Ergonomics is involved with the design of equipment and work environments that enable the best use of human capabilities without exceeding human limitations. The sorts of factors that are considered in the assessment of an environment include (Grandjean 1988):

- the layout and dimensions of spaces, furniture and equipment;
- the materials, shapes and positions of materials and equipment;
- the frequency and duration and pattern of performing tasks;
- task analysis;
- lighting, temperature, humidity, air quality (pollution, odours, carbon dioxide and water content), air movement, noise, vibration;
- interpersonal relations as facilitators or barriers to a conducive environment;
- presence or absence of protective or assistive devices, such as head or ear protection or document holders or equipment for lifting and carrying; and
- hazards and harmful substances.

Source: CCH Australia Ltd, 1987

The functioning of the individual is assessed in relation to the environmental factors and the environment adjusted to suit the person. The scope of these assessments is similar in a domestic situation where a person with a disability is returning to their usual environment.

There is a small range of assessment tools designed to measure the environment, including:

- Care and Support Needs tool (CANS) (Tate 2004)
- Supervision Rating Scale (SRS) (Boake 1996)
- Craig Hospital Inventory of Environmental Factors (CHIEF) (Whiteneck et al. 2004)
- Mayo-Portland Adaptability Inventory (MPAI) (COMBI 2003)
- Service Obstacles Scale (SOS) (COMBI 2000)

CANS and SRS focus on the amount of time a person needs assistance or supervision with activities of daily living and or for safety.

MPAI includes elements of the environment in the participation component and may provide an assessment of major obstacles to community integration. It is suggested that the “brief 8-item Participation Index may serve as a particularly useful measure of the final common aim – societal participation – of rehabilitation or other intervention efforts” (COMBI 2003). However, MPAI was specifically developed for ABI. Another condition specific assessment; the SOS was developed to evaluate individuals' and caregivers' perceptions of brain injury services in the community with regard to quality and accessibility.

Whiteneck et al. (2004) identified environmental factors that influence outcomes of people with traumatic brain injury. 12 and 25 item assessment tools were developed

with scales that are aligned with and use the language and definitions of the ICF. CHIEF is designed to assess the frequency and magnitude of perceived physical, attitudinal, and policy barriers that keep people with disabilities from doing what they want or need to do. It is designed to be a short inventory of environmental barriers that can be utilized in large-scale surveys and surveillance systems, and be valid for both individuals with and without disabilities. CHIEF is completed by the subject of the assessment and is not valid if completed by a proxy.

In recent studies to develop core sets of ICF domains for 12 chronic diseases (those with high prevalence and high burden, including CVD, stroke and depression amongst others) the following environmental factors were identified as those for which at least 20% of patients with chronic health conditions have a problem (environmental barrier) (Ewert et al. 2004).

- Products for personal indoor and outdoor mobility and transportation (e120)
- Products of design, building and construction for public use (e150)
- Products of design, building and construction for private use (e155)
- Climate (e225)
- Light (e240)
- Sound (e250)
- People in position of authority (e330)
- Individual attitudes of immediate family members (e410)
- Societal attitudes (e460)
- Social norms, practices and ideologies (e465)
- Legal services, systems and policies (e550)
- Social security services, systems and policies (e570)
- Health services, systems and policies (e580)

On first perusal these recent studies seem relevant to the Australian situation, however testing needs to confirm whether these environmental factors are those that are most pertinent. The number of the range of domains will also need to be considered.

Detailed assessment of environmental factors is not usually reported in health information systems. In some social services collections the need for assistance or whether an activity is actually performed with or without personal assistance or assistive devices may be collected.

Though condition specific assessment tools may be able to be generalised the process of validating is both expensive and time consuming. A pragmatic solution would be to develop a data collection module which includes environmental factors that is informed by the content of these environmental factors assessments.

Health related quality of life measures

Quality of life is defined as 'individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns' (Kuyken et al. 1995). This definition encompasses the personal evaluation of several life domains. In ICF terms, the definition includes both environmental factors and participation. According to WHO, quality of life deals with what people feel about their health condition and its consequences where disability refers to the 'objective' and external manifestations (WHO 2001).

A brief review of the quality of life literature in the disability field found four concepts or themes emerging consistently (Madden & Sykes 1999). These concepts are reflected (to various extents) in the five tools reviewed.

Universal and holistic life domains

A principal idea in the literature reviewed is that quality of life measures for people with disabilities should relate to the same areas of life as those relevant to all people; these areas, in total scope, should reflect a holistic life view (Brown et al. 1996; Doyal & Gough 1991; Schalock 1997; Felce 1997). This principle explicitly underpins the Participation dimension of the ICF.

Autonomy and choice

One of the main guiding principles set out for the consideration of quality of life was:

Although basic components of quality of life are the same for all people, the meaning attached to quality of life will differ to varying degrees from one person to another. This is because individuals attach differing relative importance to the basic components of quality of life and have differing opportunities and constraints within their lives (Brown et al. 1996).

Cummins (1993) and Felce (1997) reflect similar ideas, and other authors confirm the importance of individual choice in deciding which areas of life are important (Mittler 1984 cited in Timmons & Brown 1997; Brown et al. 1994 cited in Renwick et al. 1996).

Autonomy and choice are potentially reflected in the ICF. The ICF includes the option of developing qualifiers such as 'a qualifier for involvement or subjective satisfaction' (WHO 2001). A satisfaction with participation qualifier was developed in Australia and tested during the development of ICF. A Satisfaction with Participation data item based on this qualifier has been included in Version 3 of the National Community Services Data Dictionary (AIHW 2004g). The primary role of the individual in 'driving' the coding of their extent of participation is stressed.

Objective measures

Felce (1997) emphasises four key points for quality of life measures:

- that overall well being should be considered;
- the need for objective descriptors;
- the need for subjective evaluations; and

- the importance of weighting according to the person's own set of values.

Cummins (1993) has emphasised the balancing of individual choice and weighting with 'objective measures'. While many people in the disability field have been highly receptive to rating the extent of Participation in relation to the person's own goals, there has nevertheless been frequent discussion about the need to recognise that some people have not had the life experience which enables them to make full and free choices. For these people, advocates or 'experts' of some kind may have a role in gauging the extent of participation against perhaps higher expectations than the person may hold for themselves. The ICF generic qualifier applied to participation allows for this external rating within relevant life domains.

Person-environment interaction

The fourth key factor in the quality of life literature relating to functioning and disability is the interaction between people and their environments (Renwick et al. 1996; Parmenter & Donnelly 1997; Timmons & Brown 1997). The recognition of environmental factors in either facilitating Participation or creating barriers to Participation is an important new aspect of the ICF.

Subjective well being

More recently Cummins et al. (2004) have explored the concept of subjective wellbeing as separate and distinct from health related quality of life. Subjective wellbeing is described as 'patient reported satisfaction either with their life as a whole or the compartments of the life (domains). They argue that it is, both psychometrically and conceptually, inappropriate to put self-reported symptoms and negative affect together to form a HRQOL scale. A person may be medically symptom free yet have a very low subjective well being due to other events happening in their life and conversely someone with severe physical symptoms may report high quality of life because of favourable contextual factors such as wealth, supportive relationships and high self efficacy. The authors suggest that each of the components of HRQOL life measures should be assessed separately. The proposed data modules may contribute the functioning and disability component.

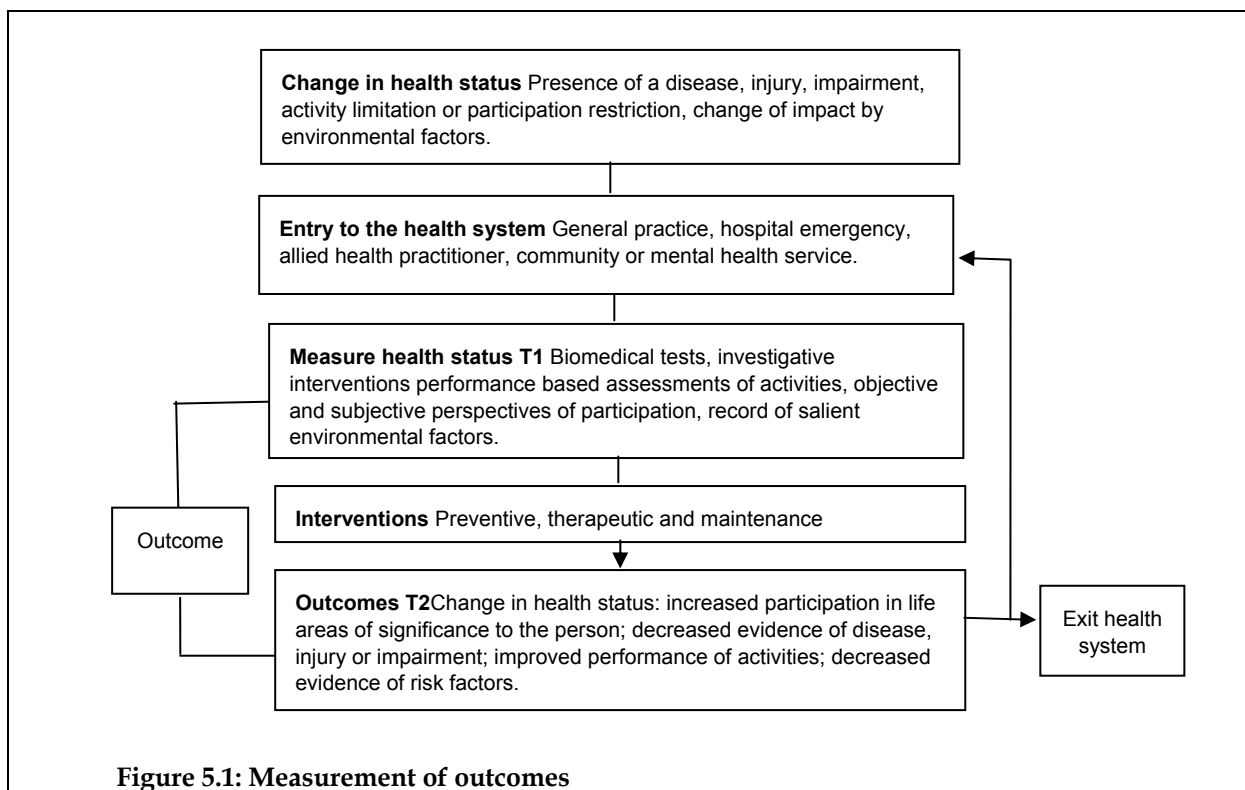
These authors are essentially, questioning the validity of the traditional HRQOL approach which puts varying health measures – health conditions, functional status and subjective wellbeing – into the one tool to combine into summary measures.

Outcomes measurement

A broad definition of an outcome measure is 'an instrument that is used to measure change in patients over at least two time points' (Tennant 2000). AHMAC (1993) defines a health outcome as 'a change in health of an individual, or group of people or population which is attributable to an intervention or series of interventions'. Thus attribution of the outcome to an intervening health intervention(s) is an additional criterion for a health outcome (Figure 5.1). The outcomes measures of mortality and morbidity are used when the focus of health care is on saving lives and curing

diseases. Now that there is an increasing focus on prevention and management of chronic diseases, a more functional approach is needed.

The measurement of outcomes is challenging, as individuals, particularly those with chronic diseases and disabilities may have a complex array of enduring problems that affect their lives in various, often subtle ways. In all conditions reviewed there may be 'hidden' disability, because individuals can appear 'normal' but experience cognitive or emotional disabilities, including aggression, depression, mood swings and disinhibition. Some of the more common sequelae of chronic diseases, such as problems with initiative or motivation, are particularly difficult to assess (Krefting et al. 1992).



There are many approaches to measuring outcome. Some approaches focus primarily on basic functioning at the level of the body, corresponding to the ICF body functions and body structures component. Other approaches look at the person's ability to do more complex activities independently, and to participate in various spheres of community life, corresponding to the Activity and Participation components of the ICF. Some instruments recognise the important role of environmental factors in mediating outcomes.

The primary aim of many people entering the health system is to be able to do, or do more easily, something that they cannot currently do – that is, increasing their level of functioning. The end goal is a participation outcome; however, there may be intermediate steps that may be impairment or activity outcomes.

Measuring outcomes can be complex. In terms of functioning, outcomes can be measured at the level of the body, the individual tasks and actions or at the level of participation in those life areas that the person deems significant. Outcome measures can be made from different perspectives; that of the provider of health care, the receiver of health care and/or a proxy. For example, the outcome for a medical practitioner may be a lowering of blood pressure as a result of prescribing medication. For the receiver of health care the outcome may be ability to walk further and decreased need for assistance with self-care. It is possible that for a data module using simple 'better', 'same', 'worse' descriptors would enable agreement between the person reporting, and the individual for whom the outcome is being reported. Figure 5.2 suggests a method of recording outcomes at several stages of the intervention process.

| Client – goals of intervention | | | |
|---|--|---|----------------|
| Client specific functional domains as indicator for intervention Clinical record | T1 Entry to health system | T2 transition to a different point of care | T3 → Tn |
| Assessment measures and Interventions | Functioning Impairment Activity Participation Environment | Functioning Impairment Activity Participation Environment Outcome – Functioning has improved, remains the same, has worsened | . |
| Updated goals | | | |
| Assessment measures And Interventions | Functioning - IAPE | Functioning - IAPE Outcome – Functional status has improved, remains the same, has worsened | |

Figure 5.2: Recording outcomes

Measurement design

There is significant variability in the design of the measures reviewed. These differences can relate to the:

- design of the questions;
- content and structure of response categories;
- reference state of health or functioning; and
- temporal context of the question, or reference period.

Design of questions

A person's interpretation of health-related questions is influenced by myriad factors: culture, demographics, socio-economic status, level of education, severity of condition and baseline level of health. The structure, content and length of questions will determine the accuracy of information received.

Questions are understood and interpreted in different ways. For example, people may have different understandings of terms such as 'self-care'. In cognitive testing of some sections of the World Health Survey, the ABS found some respondents said they considered washing clothes and dishes among self-care activities, and one said they thought 'self-care' related to treating a medical problem.

Numerous concepts may also be interwoven in the same question. The London Handicap Scale (Harwood et al. 1994) asks, 'Does your health stop you looking after yourself?' and provides examples, (housework, shopping, looking after yourself, cooking, laundry, getting dressed, washing, shaving and using the toilet) which map to two ICF domains, Self-care and Domestic life.

Even when items map directly to a specific ICF domain, such as 'walking' the parameters can be defined differently. WHODAS 2 (WHO 2001) asks about the level of difficulty experienced by 'walking a long distance such as a kilometre (or equivalent)', the SF-36 (Centre for Functional Assessment Research 1993) considers the respondent's limitations in 'walking more than a mile', 'walking several blocks' or 'walking one block'.

The length of questions may affect the responses given. The inclusion of examples often increases the length of questions. Some tools generally use few examples (WHODAS 2, SF-36), and others provide numerous (LHS & AQoL). Examples are often used to clarify concepts which are introduced in a preceding general question, for example, 'washing' or 'dressing' to clarify what is meant by a term, such as 'self care'. Examples are also used inconsistently within instruments: the AQoL, for example, provides six examples of 'household tasks' but none for 'personal care tasks'.

Content and structure of response categories

The scales used in assessment tools range in sensitivity (from dichotomous to six-level response scales). Many tools use ordinal scales, with response categories such as, 'none', 'mild' and 'severe' (WHODAS 2), or brief statements, 'I am able to perform (an activity) normally, without difficulty' (AQoL). Mapping between assessment tools and the ICF qualifier illustrates the variability between some tools (see Appendix 5).

Individuals can relate questions and response categories differently due to the variation in the way individuals understand and use words, and their expectations for health. Salomon et al. (2004) describe how a categorical response, such as 'mild' can correspond to a range of values on a scale that may vary between individuals. For example, an 80 year old man who struggles walking a block may define himself

as someone with 'mild difficulties' moving around, whereas a 24 year old man with the same mobility restrictions may describe himself as having 'severe difficulties'.

Response categories can also involve numerous dimensions. In the five generic tools reviewed, mobility is described by: level of difficulty (WHODAS 2), level of difficulty and level of assistance (AQoL, 15-D) or extent of limitation (SF-36, LHS). For example, a response category in the 15D is, 'I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others'.

Important qualifier concepts used in existing health status measurement should be captured in an outcome measure based on functioning (e.g. difficulty, assistance, pain).

Reference state of health or functioning

The use of different reference states of health has implications for the comparability of information captured in different measurement tools. The reference state of functioning and/or health is generally stated at the beginning of questionnaires, however sometimes it can be included exclusively in certain data items.

The terminology of reference states of functioning (i.e. 'normal', 'typical', 'someone of your age in good health') all relate to the perceptions, experience and expectations of the individual. The ability to make comparisons between people is difficult when one person's perception of 'normal' is different to another.

Temporal context of the question or reference period

Generic measures are predominately used to present a broad picture of health status over numerous conditions, however, there is also potential for them to assess clinical change when comparisons are being made across conditions (Beaton et al. 1997). The influence of the length of the reference period is much smaller for respondents with chronic health conditions which impact their functioning and health daily.

The recall period can influence how a question is interpreted. For example, a question referring to how much a respondent has been 'emotionally affected by (his/her) health problems' (WHODAS 2) in the past month may be interpreted as referring to a more intense emotional reaction than a question that refers to the past week (Schaeffer & Presser 2003).

Measurement administration

Personal vs professional vs proxy perspectives.

The terms 'objective' and 'subjective' are sometimes used to describe measures where the measurer does not affect the measurement and measures where the measurer does affect the measurement. Often 'objective' is used to describe so called 'clinical' measurement, i.e. measurement by a health professional or proxy and 'subjective' for self-reported measures. It is important to remember that health

professionals bring their own skills and experiences to the task of measurement; also, carers may express a particular view so measurements may be more truly described as having different perspectives. 'Self report measures and objective performance based measures have both proven to be useful indicators of and predictors of subsequent disability.

The five generic health measures were developed as self-administered assessment tools and recognise the importance of the 'patient' perspective and experience in health related quality of life measures. However, in a warranting situation all the tools could be completed with a proxy. Proxies are often used when consumers have cognitive or communication impairments, or for reasons of psychological or emotional distress are unable to complete the questionnaire. Proxies can provide the opportunity for information that may otherwise be un-reported, to be recorded. The level of agreement between respondents and proxies is variable.

The environment

Only three of the five generic tools reviewed consider environmental factors. In all three cases this is either in the context of 'help' (assistance required), aids and equipment (eg. glasses or a hearing aid), or the physical environment (outdoors). Information on the environment is critical for the comparison of functional status and/or health-related quality of life between different people and different environments (natural and unnatural).

Environmental factors (if included) are not considered consistently (i.e. across all data items) throughout instruments. For example, the LHS requires respondents to consider, 'how you get from one place to another, using **any help, aids or means of transport that you normally have available**', but does not qualify other questions relating to domains such as, self care and work and leisure similarly.

The environment is also considered differently across the tools. The AQoL asks people to think about, 'how easily (they) can get around (their) home and community' (with/without difficulty), WHODAS 2 inquires about difficulty experience 'walking a long distance such as a kilometre (or equivalent) and the 15D provides five statements about mobility relating to the ability to walk indoors, outdoors and on stairs (with or without difficulty and with or without help from others). The 15-D question on mobility has one response category which combines the concepts of assistance from aids and equipment and assistance from others, despite not introducing aids and equipment in any of the other four response categories: 'I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others'.

When no environmental factors are stipulated, they may be implied in statements such as 'think about a typical day' or 'regular daily activities' (SF-36). For example, on a typical day respondents may walk around the block (with an aid) without any limitations, but on a non-typical day (without an aid) they may walk the same distance with extreme difficulty. Comparisons between people will also be difficult

in this situation, as what constitutes a 'typical day' can be different for each individual.

In objective clinical measures, which may measure, for example, walking a certain distance. This assessment could be performed on numerous surfaces, with or without special footwear, with or without encouragement, inside, outside, without aids or other environmental factors which may be enabling or disabling to the person's functioning.

Some HRQOL instruments ask respondents to consider their 'present health status' (15-D) when answering questions and the recording of the assessment environment may be particularly relevant in this case. A respondent may not have 'shortness of breath after light activity, e.g. washing or dressing' in a hospital ward as he has oxygen available, whilst he may experience shortness of breath doing the same activity at home. Assessment of functioning and health status can be performed at numerous points across the health care system, e.g. an acute hospital ward or an occupational therapy home visit and the environmental factors which affect an individual's recording of their functioning should be recorded.

Influence of co-morbidities on measurement

A high proportion of people have more than one health condition. For example, a high proportion of people with type 2 diabetes also have cardiovascular diseases or risk factors for CVD. The prevalence of depression in adults with diabetes is also high (Anderson et al. 2001). Many people with CVD also have mental health problems such as depression (Glassman & Shapiro 1998). The relationship between functioning and depression in those with chronic diseases such as arthritis and heart disease is bidirectional, with functional limitation leading to depression and depression having a detrimental effect on level of functioning (Dunlop et al. 2004). Osteoporosis and depression have also been associated (Michelson et al. 1996). Older people may have many separate diagnoses. Measurement of function is independent of aetiology and thus may provide a summary outcome from interventions focussed at more than one specific health condition.

Though a single health care provider may focus on one component of functioning, it is the change in functioning as a result of a total package of care that is important to the individual. For example, the surgeon replaces a joint with a prosthesis, the physiotherapist works with the patient to improve mobility, the occupational therapist provides the necessary technical aids and the social worker co-ordinating appropriate home and community care. The functional outcome for the person should reflect the total package of care. However, the functional outcome may be influenced by factors relating to coexisting health conditions. For these reasons, it would be necessary to design a functional status module that covers all components of functioning.

5.2 Potential uses of an outcomes data module

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, to consider the need for comparisons with other data such as population survey data. With the advent of electronic health records clinical data may well become the source of information for administrative purposes.

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, people with disabilities and older people with multiple health conditions tend to move between different sectors of the health 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.

Pathways Home is a new program under the 2003-08 Australian Health Care Agreements. Over five years, the Australian Government will provide \$253 million to the States and Territories to increase the rehabilitation and 'step down' (convalescent) services provided to patients who are leaving hospital, particularly those patients who are older or who have some form of mental disability (DoHA 2004c). A consistent module of information on functional status may well be of importance to this project. Changes in health status as indicated by level of functioning could indicate the effectiveness of this new program.

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 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.

The National Health Priority Areas, an initiative of Australian Health Ministers, focuses on chronic diseases of significant health burden. The Commonwealth, State and Territory Governments have agreed to work together on seven specific NHPAs, focusing on chronic diseases that:

- have potential for health gains and improved outcomes for consumers;

- pose a significant burden of disease; and
- have the support of all jurisdictions.

The NHPA initiative involves cooperation between governments and other organisations for monitoring, reporting on and developing strategies to improve health outcomes in these areas (DoHA 2004a). The NHPA initiative has taken an indicators approach to monitoring and reporting health outcomes. Sets of indicators have been or are being developed for each of the seven NHPAs; cardiovascular health, cancer control, injury prevention and control, mental health, diabetes mellitus, asthma and musculoskeletal conditions. Some areas have indicators in common as well as condition specific indicators. The indicator sets are aligned with the National Health Performance Framework (NHPC 2001). As indicated earlier, the NHPF is well supported in a number of areas by the ICF.

Two examples of NHPAs explored in this report are cardiovascular diseases and arthritis and other musculoskeletal diseases. It is possible that other NHPAs could benefit from the introduction of data on human functioning into a minimum data set.

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 2004).

Rehabilitation may be considered as primary, secondary and tertiary. Primary rehabilitation involves managing the active stage of pathology or any aberration from the norm at the organ level, that is at the body structure and body function level of the ICF. The goal of rehabilitation is restoration of structure or function of the injured part. Primary rehabilitation is managed in acute care settings. Secondary or medical rehabilitation involves the management of subacute pathology and rehabilitation goals involve restoration of functional limitations predominantly at the individual level. Secondary rehabilitation usually takes place in free-standing medical rehabilitation hospitals or rehabilitation units within larger hospitals. The focus of interventions moves to the activities component of ICF.

Tertiary or vocational rehabilitation is directed towards the process of minimising the impact impairments and activity limitations have on the social and vocational roles of the individual. The rehabilitation goal is to assist the person with impairments and activity limitations to minimise the social disadvantage. Tertiary rehabilitation deals predominantly with the participation and environmental factors components of the ICF. Tertiary rehabilitation is usually conducted in community settings such as the person's own home, locality or workplace.

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 Homme and Community Care (HACC) and Aged Care Assessment Team (ACAT) assessments. The ICF has been used to examine the data collections across some of these programs (AIHE 2004). 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.

Specifically, the Transition Care Program and the New Strategy for Community Care Programs could benefit from a module of information on an individual's functional status for evaluating effectiveness, where a main focus is on functional outcomes.

Transition Care Program

The provision of up to 2,000 new transition care places over three years was announced in the 2004 Federal Budget as one of a set of initiatives titled Investing in Australia's Aged Care: More Places, Better Care (DoHA 2004d). The transition care program targets older people at the conclusion of their hospital episode who need further time and support in a non hospital environment to complete their restorative process, optimise their functional capacity and access longer term care arrangements (AHMAC COAWG 2004).

The Ageing and Aged Care Unit of the AIHW has designed and undertaken national evaluations of pilot aged care services delivered through the Aged Care Innovative Pool (dementia and disability/aged care interface streams) and the Retirement Villages Care Pilot (RVCP) initiatives of the Australian Government Department of Health and Ageing.

The AIHW evaluations measure levels of need for assistance in client groups and the capacity for innovative care to assist older people with special needs to remain in their familiar home environment. Reports of these evaluations will be published in 2006.

Community Care programs

The Department of Health and Ageing currently fund 17 community care programs. Many of these programs have developed and maintain national data collections in isolation from each other. A New Strategy for Community Care – The Way Forward (DoHA 2004e), has identified the need for a national community care minimum data set for all community care programs to improve information sharing across the programs and subsequently coordination and continuity of care between programs.

A module of information on functional status that is consistent with international standards of human functioning, and related to national data collections may well be of importance to the development of a national community care minimum data set.

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 1.1: p10) 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).

Other applications that may inform the development of health outcomes modules based on human function

Choice of validated clinical assessment tools varies with setting, health professional and initial level of functioning. The functional status data module is envisaged as a means of collating the results of clinical assessments into a framework so that it is

possible to compare the profile of one population with others. Varying approaches have been taken by those working on clinically assessed outcomes based on the ICF.

Australian Therapy Outcomes Measures

The Australian Therapy Outcomes Measures (AusTOMs) have been developed as profession-specific scales based of the ICF. The professions for which AusTOMs have been developed are Physiotherapy, Occupational Therapy and Speech and Language Therapy. Each scale focuses on a specific area of clinical practice for the relevant profession (Perry et al. 2004).

The AusTOMs scales are a rating made by the clinician based on their assessment, diagnosis and clinical judgement. Information provided by the person or a proxy may inform the judgement. Environmental factors are limited to the need for personal assistance and appliances.

Core sets

An international project to develop condition-specific subsets of ICF is currently underway. The Core Sets project has the aim of producing a parsimonious list of domains that cover the range of functioning relevant to a particular disease (Stucki et al. 2002). Phase I of the project developed core sets of ICF for 10 conditions by way of consensus conferences. The conditions chosen correspond quite closely to the Australian NHPAs (Table 5.1). Phase II aims to implement and test the core sets developed during phase I in countries around the world including Australia. As with many of the NHPA conditions the conditions chosen for the Core sets project are prevalent in the elderly. It is yet to be seen how the presence of co-existing conditions affects the collection of information using these core sets.

Table 5.1: Health conditions covered by the NHPA and ICF Core Sets project

| National Health Priority Areas | ICF Core Sets |
|---|---|
| Cardiovascular health - Coronary heart disease - Heart failure - Peripheral vascular disease - Stroke | - Chronic ischaemic heart disease - Stroke |
| Cancer control | Breast cancer |
| Mental health | Depression |
| Diabetes Mellitus | Diabetes Mellitus |
| Asthma | Obstructive pulmonary disease |
| Musculoskeletal conditions: - Osteoarthritis - Osteoporosis - Rheumatoid arthritis | Musculoskeletal conditions: Osteoarthritis Osteoporosis Rheumatoid arthritis Low back pain Chronic widespread pain |
| | Obesity |
| Injury prevention and control | |

5.3 Conclusion

The issues of clinical measurement are complex. The complexities outlined briefly in this chapter further illustrate the challenges in attempting a ‘bottom up’ development of a functioning and related health outcomes module. Not only do the ICF domains chosen vary, and the scales not ‘communicate’ with each other, but there is a further layer of measurement issues—those outlined in this chapter. These 3 layers of issues cannot be resolved satisfactorily to enable a summary module of information to be derived from the clinical assessment tools or even from the higher level generic tools. It is apparent that a separate data module, informed by these assessments, must provide a summary of information on the level of functioning of an individual.

There is a wide range of potential uses for a functioning and related health outcomes module, as outlined in this chapter. The proposed functioning and related health outcomes module would need to ensure the focus of the record is the individual whose level of functioning is being monitored if the module is to be useful across service settings and across professions.

6 Conclusions and recommendations

6.1 Findings from the mappings

In the mapping exercise reported in Chapters 4 and 5 we have examined a range of existing functional assessment tools, both condition-specific and generic, and both clinical and population based, and mapped them to the ICF with a view of determining whether summary information could be derived automatically from such tools.

From this extensive mapping exercise we conclude that we:

- a) could not develop a 'meta map' over the top of the existing tools so that a module could be established by 'rolling up' the existing tools; but
- b) should develop a new compact outcome module that can be used to gather standardised data on functioning to sit alongside (but draw upon) existing tools.

It was found that there is too much inconsistency and incommensurability among existing instruments for the first approach (a) to be practical. Mapping the tools to the ICF has shown that the tools vary in terms of:

- the high-level domains they cover (ICF Chapter level), but they vary much more in terms of the detail of information collected (e.g. Self care may include the single item 'Looking after yourself' or many more specific items such as washing, dressing, toileting and eating);
- the questions used (e.g. for questions on walking, the distance specified varies);
- the response categories and measurement scales used (e.g. five point scale ranging from no problem to extremely limited, Scale from 1 (total assistance) to 7 (complete independence));
- temporal context (e.g. 'over the past week...', 'over the past month...', 'that has lasted six months or more');
- assessment environment - whether environment is specified; whether question refers to functioning with or without aids or assistance;
- who measures (self-report, proxy, clinician); and
- the reference state of functioning (e.g. 'compared with a person of your age in good health...', population norms, status prior to health event).

Because of these many sources of variation, it is concluded that it is not possible to reliably map data collected using a range of existing tools to a single data capture framework based on the ICF.

The second approach, i.e. developing a new compact outcome module to gather standardised data on functioning, is the only practical approach. The module could be used for communication of information between health professionals or clinical areas, and for a range of other purposes (e.g. data to support resource allocation

decisions, electronic health records, etc). It could potentially also be used as a module in surveys to collect information on functioning. Repeated use of the module can indicate change in level of functioning due to interventions, i.e. a health outcome. If the module is constructed to conform to the ICF and Australian population data it should also promote the exchange and collation of data across the health and community services sector.

6.2 Developing the outcome module

The key purpose of the module is to provide summary information on the level of functioning of an individual. All components of the multidimensional concept functioning and disability should be included, i.e. Body functions and structures/impairments, Activities/activity limitations, Participation/participation restriction and the environmental factors affecting level of functioning. With that purpose in mind, we make a number of recommendations about how the module should be developed and used.

It is envisaged that this data capture instrument would be completed separately and in addition to any functional assessment tools routinely used in a given clinical setting and included in the (electronic) health record or administrative data collection. Information gathered using clinical tools would be relevant and thus make completion of the data module faster and easier. The record would be built up over time as different aspects of a person's functioning are addressed by different care providers.

The content of the clinical assessments in the tables in the Appendices 2–4 indicates that the users are 'on the same page' in terms of the domains for which they require information; however there are different emphases and different collection methods.

The ICF should be used as a mechanism for understanding the course and consequences of various health conditions. It has the potential to classify and interpret health and the related functional outcomes in all aspects of life. The ICF framework and coding system organises and reflects the multitude of measures related to the person's health outcomes (body functions and structures, activities and participation). Using all the ICF concepts helps to explain logically the relationship between impairments and everyday activities and participation in all major life areas.

There are a great many information developments underway in the health and welfare information arena. Some are detailed and condition specific, some with a broader generic perspective. The module should provide a summary of important information on functional status for a number of clinical fields across service settings, including community service settings.

The development of the functional outcome data module may also inform and help structure the current and future development of clinical assessment tools. The communications between clinical specialties and professionals may improve with the use of the neutral language of the ICF and framework common across all health care providers (Threats & Worrall 2004).

The draft module, must be tested for validity, reliability and ease of use in clinical settings. The FRHOM and pilot test materials are presented in a separate document, *A functioning and related health outcomes module: testing and refining a data capture tool for health and community services information systems* (AIHW 2005a).

6.3 What the FRHOM might look like

Based on the exploration of existing frameworks for health information and the extensive use of the ICF in existing population and administrative data collections we conclude that the ICF is the appropriate framework for the development of a module of information on functioning (see Chapter 2).

The lessons learned from the development of the ABS Census and survey questions and the CSTDA support needs question and participation framework are beneficial to the development of the data module for functioning (see Chapter 4)

A data module should, then, include each of the components of functioning: body function and structures, activities, participation and environmental factors. (Content validity does not require that every domain of functioning be examined, only that the instrument should include a sample of domains that are representative of the component of interest.) 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 a particular purpose. But the module must have a high level structure that is itself meaningful.

The measures are based on the qualifiers in the ICF (see Appendix 1). The generic qualifier indicates the extent or magnitude of the 'problem'. Other qualifiers have been developed, as permitted in the ICF, to distinguish activities and participation. These are 'Need for assistance with activities' and 'Satisfaction with participation'.

Summary information on impairments

Some impairments can be quantified quite accurately and reliably and have established population norms, for example blood pressure, range of joint motion and vision; however, it remains to be determined whether the assessed ranges can be related to the ICF qualifier percentages in a clinically and statistically meaningful way. WHO acknowledges that until this work is done ICF users will need to use clinical judgement while using the qualifier scale (Kostanjsek & Üstün 2004). The following question based on the ICF qualifier scale indicates a draft item for recording level of impairment of body functions that could be included in a functional outcomes data module.

FRHOM 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 (AIHW 2005a).

Table 6.1: 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 | <input data-bbox="1238 450 1326 495" type="text"/> <input data-bbox="1238 501 1326 546" type="text"/> <input data-bbox="1238 553 1326 598" type="text"/> <input data-bbox="1238 604 1326 649" type="text"/> <input data-bbox="1238 656 1326 701" type="text"/> <input data-bbox="1238 707 1326 752" type="text"/> <input data-bbox="1238 759 1326 804" type="text"/> <input data-bbox="1238 810 1326 855" type="text"/> |

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 following table can be used to record positive or neutral body structure as well as impairment.

FRHOM 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 6.2: Body structures—extent, nature and location of impairment

| | 1 Extent of Impairment | 2 Nature of change | 3 Location of impairment |
|---|--|---|---|
| | 0 – No impairment 1 – Mild impairment 2 – Moderate impairment 3 – Severe impairment 4 – Complete impairment 8 – not specified 9 – not applicable | 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 | 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 | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 2 Eye, ear and related structures | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 3 Structures involved in voice and speech | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 4 Structures of the cardiovascular, immunological and respiratory systems | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 5 Structures related to the digestive, metabolic and endocrine systems | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 6 Structures related to the genitourinary and reproductive systems | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 7 Structures related to movement | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 8 Skin and related structures | <input type="text"/> | <input type="text"/> | <input type="text"/> |

Summary information on activities and participation

Qualifiers for activity

Two possible measures for Activities are considered. The ICF generic qualifier ('difficulty') and the qualifying concept 'Assistance with Activity' can be used in different environments; each could result in different measures depending on which environment is present.

The concept of need for support with activities is well established in the ABS SDAC and the CSTDA. The concept of difficulty in performing activities and participating in life areas is less well established; in the SDAC, it appears to be a less stable measure than the concept of personal assistance. 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.

In 2002 the ABS conducted cognitive testing of the WHO questionnaire for the world health survey (ABS 2002). Respondents were probed on their understanding of the term 'difficulty' and there was some variation in responses including:

- 'something that's hard or harder than what you've been used to'
- 'it's when you're really having trouble'
- 'being harder and taking more energy, needing more effort in doing a function'
- 'it equates with pain'
- 'it's a problem'.

The concept of difficulty was also addressed during the development of the ICF. An analysis performed at the time suggested that performance with difficulty was less severe than performance with assistance of aids, which in turn is less severe than performance with the assistance of another person (van Buuren et al. 1996). During the ABS cognitive testing there did not appear to be a relationship between the level of difficulty reported and the amount of assistance required. For example, one respondent who had severe difficulty stated that they required no assistance. Another respondent who responded with no difficulty reported that they required assistance to shower through the use of a chair and handrails. This highlights the importance of including environmental factors in any summary information on functioning. The reciprocal relationship between personal assistance and other environmental facilitators such as aids and appliances and home modifications also needs consideration.

The ICF includes two measurement constructs, 'capacity' and 'performance'. These constructs indicate the environment in which measurement is taking place. Capacity 'aims to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment'. Capacity assumes a 'standardized' environment to neutralize the varying impact of different environments on the ability of the individual. Performance, on the other hand, describes what an individual does in his or her current environment and includes the environmental factors in the actual context in which the person lives (WHO 2001).

The notion of a standardised environment may be difficult to operationalise consistently across different health care settings. Operationalising performance is more in tune with the ICF and its relationship with the UN Standard Rules on Equalization of Opportunity for Persons with Disabilities. Performance and the actual participation experience of individuals is also accord with Australian policy goals, focusing on people's abilities.

In order to operationalise the concept of 'difficulty with performance' in a functional outcomes data module the degrees of difficulty such as 'mild, moderate, severe and complete' need operational definitions. To capture the level of functioning at the less severe end of the continuum of functioning, further work on the concept of 'difficulty' needs to be undertaken. The relationship between 'difficulty' and 'assistance' may also need to be considered.

What has emerged from discussion in the Advisory Committee on Australian and International Disability Data (ACAIDD) is the need to operationalise more explicitly a concept of 'Assistance with Activity'. This is considered to be an important subset of Environmental factors on which much measurement work has been done, and a major component of disability and aged care services policy in Australia. Work to date conceptualises 'Assistance with Activity' as a multidimensional concept, relating to the duration, frequency and intensity of assistance; information on various scales in use is being assembled. This qualifying concept would be used to describe aspects of the current or standardised or optimum environment, in terms commonly used in measurement and assessment tools – i.e. to record more detail than just 'with or without assistance' as currently envisaged in the ICF. Thus, this concept would be consistent with the ICF and would supplement the information obtained by using the ICF. It is planned to continue work on this idea, as a supplement to data elements based on components of the ICF (AIHW 2003a:40).

Qualifiers for Participation

Work has been carried out in Australia on the measurement of participation, both during the development and since publication of the ICF in May 2001. Two qualifiers were developed for inclusion in the NCSDD V2 on a trial basis – 'Participation extent' and 'Participation – satisfaction level' (AIHW 2000b). A review of measures of participation confirmed these ideas as appropriate templates for the development of new data elements for the NCSDD V3 (AIHW 2004g; Bricknell & Madden 2002).

The qualifier 'Participation extent' corresponds to the ICF generic qualifier and indicates the extent of participation restriction. This corresponds to an externally observable (or 'objective') measure of participation.

The qualifier '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. This corresponds to the qualifier for 'involvement or subjective satisfaction' allowed for in the ICF (Annex 2). Such a qualifier 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 (see also Chapter 6 for a related draft participation framework).

The draft participation framework (Table 4.5) was the starting point for development of the participation component of the FRHOM.

FRHOM 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 6.3: Activities and participation—limitations and restrictions

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

Summary information on the environment

Environmental factors are inextricably linked with the level of performance of activities and the level of participation in life areas. The following table for environmental factors will record the full range of factors at the three digit level of the ICF. It was considered that the level of detail at the chapter level was insufficient to be of use for the care of individuals. It remains to be seen from testing whether the level of detail provided in the FRHOM is appropriate in view of respondent burden versus sufficiency of information.

FRHOM 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 6.4: Environmental factors—facilitators and/or barriers

| The following environmental factors influence the person's functioning either: | | Facilitators | | Barriers | | | |
|--|--------------------------|--------------------------------|--------------------------|--|--------------------------|---------------------------|--------------------------|
| | | | | | | | |
| <ul style="list-style-type: none"> • as facilitators • as barriers | | +0 – No facilitator | | 0 – No barrier | | | |
| | | +1 – Mild facilitator | | 1 – Mild barrier | | | |
| | | +2 – Moderate facilitator | | 2 – Moderate barrier | | | |
| | | +3 – Substantial facilitator | | 3 – Severe barrier | | | |
| | | +4 – Complete facilitator | | 4 – Complete barrier | | | |
| | | +8 – Facilitator not specified | | 8 – Barrier not specified | | | |
| | | 9 – Not applicable | | 9 – Not applicable | | | |
| | | Products and technology | | Natural environment and human made changes to the environment | | Support and relationships | |
| | | Personal consumption | <input type="checkbox"/> | Physical geography | <input type="checkbox"/> | Immediate family | <input type="checkbox"/> |
| Personal use in daily living | <input type="checkbox"/> | Population | <input type="checkbox"/> | Extended family | <input type="checkbox"/> | | |
| Personal indoor and outdoor mobility and transportation | <input type="checkbox"/> | Flora and fauna | <input type="checkbox"/> | Friends | <input type="checkbox"/> | | |
| Communication | <input type="checkbox"/> | Climate | <input type="checkbox"/> | Acquaintances, peers, colleagues, neighbours and community members | <input type="checkbox"/> | | |
| Education | <input type="checkbox"/> | Natural events | <input type="checkbox"/> | People in positions of authority | <input type="checkbox"/> | | |
| Employment | <input type="checkbox"/> | Human-caused events | <input type="checkbox"/> | People in subordinate positions | <input type="checkbox"/> | | |
| Culture, recreation and sport | <input type="checkbox"/> | Light | <input type="checkbox"/> | Personal care providers and personal assistants | <input type="checkbox"/> | | |
| Practice of religion and spirituality | <input type="checkbox"/> | Time-related changes | <input type="checkbox"/> | Strangers | <input type="checkbox"/> | | |
| Design, construction and building for public use | <input type="checkbox"/> | Sound | <input type="checkbox"/> | Domesticated animals | <input type="checkbox"/> | | |
| Design, construction and building for private use | <input type="checkbox"/> | Vibration | <input type="checkbox"/> | Health professionals | <input type="checkbox"/> | | |
| Land development | <input type="checkbox"/> | Air quality | <input type="checkbox"/> | Other professionals | <input type="checkbox"/> | | |
| Assets | <input type="checkbox"/> | | | | | | |

(Continued)

Table 6.4 (continued): Environmental factors—facilitators and/or barriers

| The following environmental factors influence the person's functioning. <ul style="list-style-type: none"> • 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 | <input type="text"/> | Production of consumer goods | <input type="text"/> | Social security | <input type="text"/> |
| Extended family members | <input type="text"/> | Architecture and construction | <input type="text"/> | General social support | <input type="text"/> |
| Friends | <input type="text"/> | Open space planning | <input type="text"/> | Health | <input type="text"/> |
| Acquaintances, peers, colleagues, neighbours and community members | <input type="text"/> | Housing | <input type="text"/> | Education and training | <input type="text"/> |
| People in positions of authority | <input type="text"/> | Utilities | <input type="text"/> | Labour and employment | <input type="text"/> |
| People in subordinate positions | <input type="text"/> | Communication | <input type="text"/> | Political | <input type="text"/> |
| Personal care providers and personal assistants | <input type="text"/> | Transportation | <input type="text"/> | | |
| Strangers | <input type="text"/> | Civil protection | <input type="text"/> | | |
| Health professionals | <input type="text"/> | Legal | <input type="text"/> | | |
| Other professionals | <input type="text"/> | Associations and organisations | <input type="text"/> | | |
| Societal attitudes | <input type="text"/> | Media | <input type="text"/> | | |
| Social norms, practices and ideologies | <input type="text"/> | Economic | <input type="text"/> | | |

This modular approach to summarising information on a complex range of experiences could mean a flexible approach to the use of the tables so that different modules could be used in different service settings and for different purposes. However, to record the complete experience of functioning, disability and health, all components would need to be used.

In some circumstances there may need to be more detailed information on functional status, so it is possible that the data module could actually be a multi-dimensional matrix. The user could then 'drill down' to increasing levels of detail or granularity, which can nevertheless be related to the coarser grained summary information that is suggested in this chapter.

A software product was developed for the 'Australian family' database. This product could possibly be adapted to enable drill-down versions of the outcomes module. The product has a two dimensional surface layer; from each cell in the surface it is possible to drill down to a more detailed layer below. (To view the Australian Family tool see <www.aihw.gov.au/committees/committees/health/nhimg/matrix/index.html>)

6.4 The next steps in the development of the FRHOM

This document provides the background work undertaken to establish the need for a module of information on human functioning and to confirm that the ICF is the appropriate basis for the development. Comments on an early draft of this report provided by the Statistical Information Management Group have been included.

A second phase in the refinement and testing of the FRHOM has started. The work plan for the project includes the following elements:

- Circulate draft outcomes data module widely for consultation with potential users. The report on refining and testing the FRHOM is available on the AIHW website at <http://www.aihw.gov.au/publications/index.cfm/title/10196> (AIHW 2005a).
- Develop guides for use and prepare for pilot testing.
- Plan and conduct pilot test protocols.
- Refine the module with specialist clinical groups.
- Develop data elements consistent with value domains in the national data dictionaries for endorsement by the health and community services data committees.
- Review and report on the field test.
- Recommend a final FRHOM.