A functioning and related health outcomes module

The development of a data capture tool for health and community services information systems

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Abbreviations

ABI	Acquired Brain Injury
ABS	Australian Bureau of Statistics
ACAIDD	Advisory Committee on Australian and International Disability Data
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
CSTDA	Commonwealth State/Territory Disability Agreement
CVD	Cardiovascular diseases
FRHOM	Functioning and related health outcomes module
HRQOL	Health related quality of life
ICD	International Statistical Classification of Diseases and Related Health Problems
ICF	International Classification of Functioning, Disability and Health
NAMSCAG	National Arthritis and Musculoskeletal Conditions Advisory Group
NHPA	National Health Priority Area
NHPC	National Health Performance Committee
NHPF	National health performance framework
NMDS	National Minimum Data Set
METeOR	Metadata Online Registry
MS	Musculoskeletal diseases
SDAC	Survey of Disability, Ageing and Carers
SIMC	Statistical Information Management Committee
UNECE	United Nations Economic Commission for Europe
WHO	World Health Organization
WHO-FIC	World Health Organization Family of International Classifications

Summary

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 has been supported by the Australian Health Ministers' Advisory Council (AHMAC) through its National Health Information Group.

This report recommends a module or framework of summary information—the Functioning and Related Health Outcomes Module (FRHOM)—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 capture, storage and transmission of data on human functioning in a wide range of human service systems.

As a result of this exploratory work and advice received from a range of sources, including the Statistical Information Management Committee (SIMC), the module has been refined and published together with test materials in a report *A functioning and related health outcomes module: testing and refining a data capture tool for health and community services information systems,* available at <www.aihw.gov.au/publications/index.cfm/title/10196> (AIHW 2005a).

The rest of this summary outlines:

- the work done and the results of the investigations;
- the implications of the work and the logic of the proposed way forward;
- what a module might look like and what it would be used for; and
- the next steps.

The work done

A major element of the work carried out involved a review of existing functional assessment tools, both condition-specific and generic, and both clinical and population based. The purpose of this work was to investigate whether it was feasible to develop a 'meta map' over the top of the existing tools so that a module could be established by 'rolling up' the existing tools.

In carrying out the mapping, the ICF was used as an evaluative and mapping framework. Apart from being the international standard for the conceptualisation of human functioning, it was also found that the ICF 'sat well' with Australian health information and performance monitoring frameworks. A review of existing frameworks for health information and national priority monitoring was conducted to establish this. It was concluded that the ICF offered the best, most feasible framework for the development of any data module. The ICF is envisaged by the World Health Organization to have many applications in the health and human services fields, including for the collection of health outcomes information.

The ICF should be used as a mechanism for understanding the course and consequences of various health conditions[1]. It has the potential to classify and interpret 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, as well as the environmental factors affecting these functional outcomes). Using all the ICF components helps to explain logically the relationship between impairments and everyday activities and participation in all major life areas.

The review of a selection of the literature on functional outcome measures was carried out, to identify commonly used assessment tools. The review focused on cardiovascular diseases (CVD), musculoskeletal diseases, and acquired brain injury (ABI). The first two areas are national health priority areas, and also offered the opportunity of interaction with expert groups and workshops, that were able to advise and/or stimulate the project. ABI is a complex, multidimensional condition that would test our developing ideas and one where there was some existing review work that could be built on. The work on these three condition groups included the following elements:

- the tools found were related to the ICF to see whether there were common domains that could be used in a data module;
- consultation and discussions were held with a range of advisory groups and committees to determine the need for and desired content of a summary measure of functional status; and
- the metrics in the tools were investigated to see whether they could be related to the qualifiers (measures) in the ICF, and whether the ICF could provide a high level framework to calibrate the scores from the many instruments used by clinicians.

Similar mapping work was then carried out with generic measures including health-related quality of life tools, used in both clinical and population survey settings.

Finally, data collections already using the ICF framework were also examined for what they had to offer the potential construction of a summary module—primarily the ABS Survey of Disability, Ageing and Carers, the related question for the 2006 Census, and the support needs question used in the National Minimum Data Set for the Commonwealth State/Territory Disability Agreement.

Results of the analysis of condition-specific and generic tools

In brief, it was found that it was not feasible to develop a 'meta map' over the top of the existing tools to develop a module by 'rolling up' the existing tools. This was

[1] 'Health Condition is an umbrella term for disease (acute or chronic), disorder, injury or trauma. A health condition may include other circumstances such as pregnancy, ageing, stress, congenital anomaly, or genetic predisposition. Health conditions are coded using the ICD-10.' (WHO 2001:212)

because there is too much inconsistency and incommensurability among existing tools for this approach 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), and even 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;
- other factors in the person's usual environment that affect functional outcomes and could be changed so as to enhance functioning;
- 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 implications of the work and the logic of the proposed way forward

It was therefore concluded that it was necessary to develop a new, compact outcome module that could co-exist with, but relate to and draw upon, existing tools. The module would thereby be a useful medium for the capture, summary and exchange of standardised information on health outcomes and human functioning. Existing tools currently sometimes omit important ICF domains.

There is a need for greater recognition of the value of including in assessments the everyday activities in which people want to participate—the wider social arena as well as the day to day activities of daily living. Further, the person's environment is increasingly being recognised as crucially affecting their functional performance and health status, is a key new component of the ICF, and must be included in any new data capture tool.

The use of the ICF framework as a data capture framework in health information systems will, therefore, provide a framework into which likely future developments in functional assessment should fit.

As the study progressed and the existing tools reviewed, it became apparent that a module reflecting 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 the draft FRHOM looks like

The report proposes four matrix tables for capturing summary information on:

- Body functioning qualified by extent of impairment.
- Body structure qualified by extent, location and nature.
- Performance in life areas qualified by difficulty and support needed with activities and extent and satisfaction with participation
- Environmental factors qualified by extent of influence.

The FRHOM is based on the standard ICF-related data elements in the National Community Services Data Dictionary and METeOR. The rows of the tables are consistent with the corresponding ICF chapters, and the columns provide indicators of the degree of impact on the person, in the area of functioning. The inclusion of all components of the multidimensional concepts of functioning, disability and health as defined in the ICF (i.e. body structures and functions, activities and participation and environmental factors) ensures a complete description of human functioning.

The tables are constructed so as to be consistent not only with the ICF, but also national data collections, such as the ABS Survey of Ageing, Disability and Carers, CSTDA NMDS collection and, in the future, the Census, and with the main concepts found in the tools and literature reviewed, and with relevant Australian population data measures.

During further development and testing it can be investigated whether a 'drill down' facility is needed, at least in electronic versions of the module, to enable users to access the greater levels of detail available within the ICF classifications.

What the FRHOM would be used for

Such a summary module would be used for data capture and information exchange, to:

- describe health status, outcomes of health interventions, and the need for assistance in areas of human functioning; and
- enable the efficient and effective capture, storage and transmission of data on human functioning in a wide range of human service systems, and among settings within systems; the means of transmission could include electronic health records.

The National Health Performance Framework includes functioning as an indicator of health status (NHPC 2001). A health outcome data module based on functioning could be useful as the indicator within this framework.

The module could also be used in areas such as:

- promoting continuity of care by sharing information and collating information across different sectors;
- considering health outcomes and functional status in the funding of health care;
- evaluating the quality of health care;
- evaluating the efficacy of preventive measures;
- assembling consistent national information across different sectors of the health and wider human service systems;
- comparing clinical and health service data to 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 key purpose of the module is to provide summary information on the level of functioning of an individual, using all components present in the international standards conceptualisation, the ICF. It is envisaged that this data capture instrument would be completed separately and in addition to any functional outcome 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.

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 use in population surveys and measures, community care and clinical settings, thereby facilitating the process of data sharing and communication across disciplines. 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.

The development of the FRHOM may also inform and help structure the current and future development of clinical assessment tools.

Phase two in the development of the FRHOM

A second phase in the development of the data module includes the following elements:

- Develop a draft outcomes data module, based on the examples in this report, in consultation with specialist clinical groups, and including a data capture table for body structures.
- Develop data elements for the FRHOM that are consistent with national data dictionaries.

- Circulate more widely for consultation with potential users.
- Convene a workshop to further refine the data module.
- Develop guides for use and prepare for pilot testing.
- Plan and conduct pilot test protocols.
- Pilot test in the field with a view to testing for validity, reliability and ease of use in clinical settings.
- Review and report on the field test.
- Recommend a final FRHOM.