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Use of ICF in health information systems and surveys

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Abstract The ICF offers an array of components, domains, classifications and measurement ideas relevant to the description of functioning and disability, and health outcomes. Further international collaborative work is needed to ensure that the classification achieves its aim of improving the quality and comparability of information on functioning, disability and health. The WHO-FIC network should lead the establishment of more broadly based mechanisms for discussion of health status measurement.

Introduction

The infrastructure developed to promote quality, relevance and comparability of information systems and surveys include:

- Frameworks for organising data
- Indicator sets and related frameworks defining key measures
- International classifications which provide the world standards (WHO-FIC including ICF & ICD)
- Metadata specifications, such as data dictionaries and registries (METeOR)

There are a growing number of ICF applications around the world, such as in health information systems and surveys. In Australia, the ICF is increasingly being used as the framework in major national information systems, including:

- Population surveys (ICIDH and ICF since 1981)
- Administrative data collections (disability services, children's services, medical indemnity)
- National data standards (data dictionaries and FRHOM)
- Research and clinical applications
- ICF User Guide and 2006 Forum

In order to improve the quality and comparability of information on functioning and disability, new ICF applications in health information systems and survey should be evaluated in the light of:

- The purpose of information collected
- The selection of components and domains 'fit for purpose'
- Operationalisation of qualifiers including the 'constructs' of capacity and performance
- Relationship to existing applications and data sources

Four case studies are discussed in relation to the above criteria:

- The Australian Survey of Disability, Ageing and Carers (SDAC)
- The Joint Canada/United States Survey of Health (JCUSH) and the Nutrition Examination Survey (NHANES)
- The Washington Group
- The Geneva meeting & 'Health state'

Case studies

The SDAC

It measures prevalence of disability and related need for assistance and provides a profile of people and carers. It includes the 'core' activities and participation domains of self care, mobility and communication as well as some information on other domains. Impairment was used in screening questions. 'Main disabling condition' was collected and coded to ICD. Information on performance, not capacity, is sought.

The JCUSH and NHANES

JCUSH aimed at gathering comparable health data for Canada and the US using a common survey instrument. It covered some, but not all body functions and body structures, as well as a broad range of activities and participation. Information on performance, not capacity, is sought. NHANES uses interviews plus clinical assessment of a subsample. It provides an approach to the ascertainment of capacity as conceptualised in the ICF.

The Washington Group

It aims at guiding the development of disability questions for censuses, recommending 'extended sets' for surveys. Selecting the general (core) set has involved consultation and negotiation, and has implications for all countries. Information on performance, not capacity, is sought.

The Geneva meeting & 'health state' (UNECE)

At this meeting, it was agreed that health status includes diseases, injury, 'health state' and mortality risks. On the other hand, 'health state', a term not defined, relates to capacity (it does not change with environment), it includes impairments and activity limitations and 'should be linked to ICF'.
This implies that the 'health status' of the population is described only in terms of indicators of functioning and disability that specifically exclude participation and performance.

Results

The four examples discussed

- The SDAC–provides information widely used for policy purpose and it allows for comparison over time.
- JCUSH and NHANES–JCUSH provides a comparison across two close countries. NHANES provides an approach to 'capacity'.
- The Washington Group–involves more countries and compromises, it deals with general and extended sets and entails consultation.
- The Geneva meeting & 'health state' –'health state' is not defined; there is limited use of ICF concepts and domains; the proposal needs much broader debate before agreement.

Conclusions

There can be no standard subset of ICF domains:

- Disability information is spread across all domains, specially for heterogeneous groups
- Omission of any domain involves omission of disability information
- Subsets for specific purposes must be justified for the purpose

Measure the environment rather than capacity:

- Performance can vary across many environments – it is hard to define one as 'standard' and one as 'current'
- The challenge is thus to measure environments and their effects
- If an application needs 'capacity' does NHANES provide a model?

More discussion, so that survey applications preserve the ICF model:

- Discussion among and between groups designing surveys
- WHO-FIC should get involved

The ICF framework is coherent, not a menu of items to co-opt into pre-existing frameworks.

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