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ICF: why collaborate?

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Abstract ICF: why collaborate?

It is clear that all people attending the WHO-FIC meeting lead busy lives. Why do we attend international meetings and seek to cooperate internationally?

The ICF implementation strategy has four main elements—briefly:

1. Establish ICF as the official framework for measuring the health and disability in the general population (in censuses and surveys) across member states

2. Establish the ICF as a major health outcome assessment framework at the clinical and service levels

3. Include functional status indicators in health records and information systems including electronic health records

4. Implement ICF in the social policy field

This paper will reflect on our collective progress, from an Australian perspective. What are some factors in successful international collaborations? Should we concentrate on areas where either we can learn from each other, or there are efficiency gains from collaboration, or there are dangers in not collaborating? What can we expect of each other in terms of the nature and amount of work that can be done collaboratively? How can we make best use of the opportunities we have to collaborate?

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1. An Australian perspective on progress in the four strategic areas

To illustrate our perspective in writing this paper, we first reflect on the ACC's work in relation to the four main ICF strategies listed in the abstract.

The ACC's national program is reported on in our annual report (WHO-FIC paper in 2005). As a national statistical organisation our work focuses significantly on ICF-related national data standards, so as to enhance the quality and consistency of disability data in Australia (see eg METeOR poster). We have developed a data capture tool, consistent with the ICF and these national data standards (the FRHOM reported in Sykes et al 2005); this tool is designed to capture summary information in a range of health and community services settings and to underpin heath records and communicate across 'data silos'. A Rasch analysis conducted on Australian disability services data illustrated that information on functioning was spread across all Activities and Participation domains, and that the broad Australian survey measures of need for personal assistance were relatively well behaved statistically (Anderson 2005); these measures could then be used as part of the suite of ICF-related national data standards. As well as such major projects, we are involved with and advise on data development more broadly, comment on and participate in related developments (including international ones) and provide general education on ICF. Next February we are holding a forum on improving disability data, and this will also serve as an ICF User Forum (see AIHW web site for draft program).

How does the ACC work 'stack up' against the four ICF implementation strategies (WHO 2004), and what synergy is there with international work? This is indicated in Table 1. [Some suggestions for WHO-FIC network are included in the third column of the table, and are discussed in section 4 of this paper.]

From the table it can be seen that, in relation to:

Strategy 1: The Australian data standards work is very relevant (see work listed in second column). The WHO-FIC position on the use of ICF in international surveys has been helpful in giving cohesion to ACC views on various projects notably the Washington Group work, and is internationally important when some other projects put the ICF gains at risk. The Washington group is auspiced by the UN, and membership includes individuals and WHO. Are we (WHO-FIC CCs) a coherent community within this group? There are probably greater risks from other groups (see Madden et al 2005), so that cooperation between UN and WHO is important.

Strategy 2: The ACC work on the FRHOM is relevant in this area, as a data capture tool. It is not an assessment tool. The work on FRHOM leads us to think that mapping is interesting and useful, in developing a data capture method. Establishing equivalence on measurement (calibration) is more complex (as outlined in Kostanjsek and Üstün 2004). The ACC is not involved in the development of ICF related assessment tools. Internationally, are the core sets primarily also data capture tools? Is assessment an area of weakness (or threat), a challenge both nationally and internationally? The construction of assessment tools is proceeding apace and not always with reference to the ICF; in Australia at least these

developments pose a threat to the data related work eg surveys, data standards and harmonising data collections. Should we select some strategic areas for new generic (rather than specialist) assessment tool construction eg rehabilitation with full incorporation of environmental factors? Should the development of ICF-consistent assessment tools be undertaken as a joint international project? Is this an area of risk for the WHO-FIC Network if neglected?

Strategy 3: The ACC work also provides infrastructure for people wanting to use ICF in administrative and clinical information systems. More work could be done to educate some of the technical advisers on these projects (some of whom are more software-driven rather than information-driven). Again, there could be further useful work done cooperatively at an international level, especially in terms of informing relevant professional groups about the ICF and its uses.

Strategy 4: The ACC has little role in direct policy formation, although the information we publish is a policy input, and there is engagement on information matters. There seems to be more activity in other countries. WHO liaison with OECD could be helpful in improving their terminology and conceptualisation of functioning and disability.

From an Australian perspective, then, our work plan is quite well aligned with the four strategies. However we have to ask ourselves: have we engaged as effectively as we might hope with international work? There has been some success in promoting the means for sharing information (via a framework) but there is more to be done. For instance, the paper by Nenad Kostanjsek and Bedirhan Üstün at the 2004 meeting on 'operationalising ICF for measurement' outlined useful work that could be done. Why have we not discussed this more? How could we have put it together with the other papers delivered in 2004, to develop some specific joint work in the areas they outlined?

How does the Network's recent experience contrast with our experience with ICF development? This was a good though challenging collaboration - with a successful output! What were the key ingredients in this success?

It was, therefore, with the need for contemplation and some self criticism, that this paper has been undertaken.

2. What kinds of collaboration could we consider?

Several types of collaboration are identified by Butler and Coleman (2003) including:

- *Library and solicitation* – involving storing shared information in an easily retrievable way, with a possible added facility that enables participants to pose questions and share information in response;
- *Team activities* – involving shared objectives, defined projects, defined and small membership, interactivity, content and project management features present in the collaboration;

- *Community* – members have common interests or goals, seek to share information (community of practice, community of interest), membership is loosely controlled and numerous.

All these types of collaboration are present in the WHO-FIC Network and are currently or potentially useful.

- A 'library' approach could be supported by the collaborative workspace as well as the 'framework for sharing what we know' now established on this space.
- A 'team' approach is one that is in existence within the Network. In relation to the ICF development, very effective team work over several years, some quite challenging, resulted in the ICF.
- A 'community' approach can enable potential members of the WHO-FIC Network to gain knowledge about the classifications themselves and the Network and its operations. What communities are already present within the Network (geographic, committee-based, skill-based etc)? What other communities are working in ICF-related areas?

This paper will:

- suggest that the 'library' and 'community' varieties of collaboration are in existence in the WHO-FIC Network and quite well served by the annual meetings;
- make some simple suggestions for improving our effectiveness in relation to team collaboration.

A 'collaboration rubric' (Cabrillo Tidepool Study Page) suggest three key dimensions of action when considering what makes an 'exemplary' collaboration:

- *Contribute* – includes: research, gather and share information – an exemplary collaboration involves gathering a great deal of relevant information, sharing it and being on time with the sharing.
- *Take responsibility* – includes: fulfil role/duties, participate, and share equally.
- *Value others' viewpoints* – includes: listen and speak, cooperate without argument, make fair decisions.

Again, this rubric seems to provide a useful aide-memoire for evaluating our own performance in collaboration. Some ideas from this rubric have been used in the suggestions made in the paper (section 5).

3. What are some factors in successful international collaborations?

If the development of the ICF itself can be taken as an example of ultimately successful 'teamwork' collaboration, what were the ingredients in its success, in relation to the above and other factors?

There were generally agreed or compatible goals, and there were agreed and realistic plans to achieve them. That is, a planning element was needed; not only was the

work planned, the meetings integrated with the work. Key players' roles were defined. WHO leadership became increasingly important as the project progressed, in terms of finalisation.

As well as this teamwork, the other types of collaboration were also occurring – sharing of information in a 'community' defined by common goals and work. [It is notable that other 'soft' factors as well were at work as people got to know each other.]

Using the 'rubric' outlined above, as well as our collective experience of the ICF development, there are some key factors that can be pointed to in successful international collaboration.

Contribute

Expertise: It is essential that participants know the subject (or at least part of it) and understand the context.

Synergy with a national work program: this contributes to expertise in the subject and understanding its context. It also provides support and drivers and 'local' people with whom to collaborate. Efficiencies are created as participants are able to work on national and international work programs simultaneously.

Take responsibility

Clarity of roles, responsibilities and 'territory' is important; leadership is a key role. A clear international position or ownership of the project group's territory is needed (eg provided by WHO), and the ability to establish working relations and common programs with other collaborations. For instance, in the survey sphere, working with UN's Washington group requires knowing 'our' territory, its limits, and what lies beyond.

Value others' viewpoints

Time and communication are often recognised as key pre-requisites to successful collaboration. Certainly they are essential, to create opportunities to 'listen and speak' and 'make fair decisions'.

4. Which areas of ICF implementation should we concentrate on, and why?

Table 1 summarises some suggested priority areas within the four WHO ICF strategies, from an Australian perspective. This is work within the four areas that appears, based on what ACC is working on (as discussed briefly in section 1), where there may be synergies with international work, where there are gains to be made from international collaboration and/or where there may be risks in failing to collaborate.

5. How can we best work together?

A modest and achievable work plan

Table 1 also outlines (lower in the first column) some of the tasks we set ourselves in 2004, many of which we have not done. Do we need to be more realistic about our desire and ability to undertake international collaboration? Should we develop a more modest and achievable work plan, in a few priority areas selected from those identified in Table 1 (either lower in the 1st column, from 2004, or in the 3rd column).

Methodology improvements

Based on a consideration of the kinds of collaboration we are doing, and some of the criteria very briefly explored in Sections 2 and 3, the following suggestions are made for increasing our chances of success with any tasks we may agree in 2005.

If we are chiefly sharing information (that is, the 'community' and 'library' type of collaboration) the annual 'WHO-FIC meeting' appears to work quite well. More could be done with the collaborative workspace and more could be done for new and potential members of WHO-FIC. Specifically we could:

- Improve the collaborative workspace and its use for sharing information and encouraging potential Network members.
- Develop a methodology for storing suggestions for ICF enhancement (starting with those suggested by people working on ICF-CY).

However, the tasks identified in Table 1 (either from 2004 or in the third column) require more than the sharing of information – sharing information is necessary but not sufficient. 'Team' collaboration is also needed. If we are a collaborating 'team' then each work plan should involve using the annual meeting better. The following annual cycle would more closely reflect the pattern of many within-country collaborations, and also the collaboration that led to the development of ICF:

1. Meet in Year 1
2. Agree work plan, actions and responsibilities at the annual meeting
3. Do the agreed actions in following months
4. Continue discussion by e-mail, in collaborative work space and via occasional teleconference (planned in advance)
5. Prepare update(s) two months before annual meeting, and plan time use at the annual meeting, in detail.
6. Meet again in Year 2 to discuss and review work and plan the following year.

Another method that we could use more often is to develop and agree WHO-FIC views or positions on key aspects of our work. Network members could then refer to and represent these views, especially when involved with other international collaborations. This was begun in 2004 with the development of a WHO-FIC position

on international survey development, and has been effective in promoting clearer conversations with other international projects.

Table 1: Suggestions for WHO-FIC collaboration on ICF: Australian perspective

ICF key strategies (WHO 2004)	ACC work 2004–5	Suggestions for WHO-FIC collaboration
1. Establish ICF as the official framework for measuring the health and disability in the general population (in censuses and surveys) across member states, so as to improve the quality and comparability of health and disability statistics for national and international purposes. Global initiatives like the UN Washington Group on Disability Statistics should be supported in order to carry ICF to its full potential use with proper scientific tests.	• Work on national data standards for use in population surveys, clinical records and administrative data sets. • Provision and development of advice on measurement and qualifiers. Products include metadata standards, data capture modules, national minimum data sets. • Work and advice on national and international census and survey design.	• Develop, promote and represent WHO-FIC position on appropriate (best practice) use of ICF in international survey design and standards (eg with Washington Group and UNECE). Involve WHO and Planning Committee for high level communication. • Common work on metadata? Adopt ISO11179 for metadata standards. • CCs to promote use of ICF by national statistical agencies.
2. Establish the ICF as a major health outcome assessment framework at the clinical and service levels, in order to quantify health gains of treatment programs and understand how health gains translate into productivity gains at the individual and population levels. Particular emphasis should be given to major public health burden such as HIV/AIDS, tuberculosis, malaria or obesity. Identify or develop ICF-related instruments suitable for outcome assessment of effectiveness of interventions within the global health intervention	• Data capture tool based on ICF (Functional and Related Health Outcome Module), for use in wide range of applications.	• Negotiate with journal editors, clinical colleges, expert groups etc to ensure that ICF is considered in the development of new outcome measures and assessment tools. • Data capture – consider the FRHOM and the core sets as data capture tools for communicating among data silos (see Kostanjsek and Üstün 2004) • Mapping and calibration – develop an achievable action plan based on the ideas in Kostanjsek and Üstün 2004. • Assessment and measurement: select key

		areas for development of ICF-related assessment tools (eg new generic assessment tool construction, such as rehabilitation with full incorporation of environmental factors; aged care; functioning components of quality of life measures)
3. Streamline ICF in administrative and clinical information systems including functional status indicators in health records and information systems including electronic health records and terminologies.	• See 1 and 2. • Work with clinical information committees on adoption of ICF to frame outcome indicators. • Work with people developing electronic health records and systems developers to ensure that information on functioning is included in ICF terms.	• Market ICF among people and organisations who need it. • Increase awareness, among professionals and educators, of all ICF-related work and the benefits of its use in systems. • Work with international bodies setting standards for health records and terminologies to ensure that ICF is used for recording functioning.
4. Implement ICF in the social policy field by focusing on: aligning the disability certification process with the ICF framework; developing applications and in the areas of education, labour market and law.	• Some work in labour market and children's services.	• Liaison with OECD to encourage use of ICF in international policy discussion (eg re labour market) and in information gathering (eg health costs) - WHO and Planning Committee?
Within the above priority areas the following general principles should be applied (2004). • Knowledge network: Share information about research, implementation, uses and educational materials and efforts. • Mainstream key policy aspects of ICF including the 'new' dimensions of		

Participation and Environment; use evidence-based thresholds of functioning difficulties at the point of data analysis instead of defining disability a priori with impairment categories. • Improve the level and quality of data in terms of accuracy, reliability and comparability.		
Related tasks (2004): • Development of various implementation strategies for the four strategic directions stated above i.e. statistical use, health outcomes, health records, social policy. • Identify, facilitate and or develop demonstration projects relating to the four strategic directions • Develop platform for the information sharing framework • Develop and implement a work agenda on instrument and qualifier mapping and further development of application tool • Develop methods for systematic recording and analysing of experiences (best practice & difficulties) in using the ICF in practice • Collect information on A&P and E domains for measurement		

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