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EXECUTIVE SUMMARY

PURPOSE AND SCOPE

The University of Sydney (the University) was engaged by the Independent Hospital Pricing Authority (IHPA) to identify instruments for assessment of subacute care patients, which address deficiencies in existing tools for each care type.

The project was part of IHPA’s work plan for the development and implementation of nationally consistent data standards, data collection, classification and reporting of subacute and non-acute care required for Activity Based Funding (ABF) purposes.

The specific objectives of the project were to:

a) Identify tools for inclusion in the long-term classification system, which address deficiencies in existing tools for each care type and options to address the lack of suitable instruments for children, ambulatory and GEM patient groups and best explain resource use.

b) Assess the mapping potential of tools identified as suitable for inclusion, and develop mapping (conversion) algorithms from the tools used in the AN-SNAP to any that can be mapped.

c) Describe complementary tools if identified, the areas where the use of components of tools are applicable to increase measurement validity, and interactions between the tools.

The project was informed by the PricewaterhouseCoopers (PwC) report Investigative review of cost drivers and classification systems for subacute care, which was provided to the University of Sydney for the purposes of the project.

In parallel, IHPA had commissioned a separate review of the definitions used in subacute care by the Australian Institute of Health and Welfare (AIHW). IHPA agreed to the exchange of information and discussion between the University and AIHW so that the two projects could be harmonised. IHPA advised the University to consider existing care types, notably the psychogeriatric care type, taking into account the modified definitions (available November 2012).

A separate review by IHPA of the application of Activity Based Funding in mental health care was underway during the project.
CONDUCT OF THE PROJECT

The project commenced in August 2012.

The University had proposed that the World Health Organization’s International Classification of Functioning, Disability and Health (ICF)\(^1\) be used as the underpinning framework for the project. The ICF is a framework and classification for organising and describing information on functioning and disability. It was approved for use by the World Health Assembly in 2001, after extensive worldwide testing involving people with disabilities and people from a range of relevant disciplines.

The ICF conceptualises a person’s level of functioning as a dynamic interaction between their health conditions, environmental factors, and personal factors. The ICF describes functioning using the following dimensions: body functions and structures; activities and participation; and classified environmental factors. The ICF is a framework and classification system on which assessment or measurement tools may be based and to which they can be mapped. The broad framework places assessment in context; it provides the focus for selecting relevant aspects of functioning and disability for assessment.

The capacity of ICF based instruments to predict subacute care expenditure necessarily can be demonstrated only empirically, through the collection and analysis of relevant data. Available evidence to support use of ICF for this purpose is presented.

Potential instruments were identified from the PwC report and an exhaustive literature search was conducted to supplement this list. An initial list of potentially suitable instruments was developed. A survey containing this list was circulated to a wide range of stakeholders in October 2012, seeking comments on the instruments and suggestions of additional instruments. Seventy-four organisations responded (102 individual responses were received from within these organisations), representing a wide variety of stakeholders.

In November 2012, one or more members of the University team visited all jurisdictions for stakeholder consultations. Many of these consultations were attended by subacute care experts within the relevant jurisdiction. A range of additional consultations followed in December 2012 and early 2013. At the 5 December 2012 Subacute Care Advisory Working Group (SCWG) meeting, an interim report was provided for initial feedback. SCWG commented on a further draft on 25 January 2013.

INSTRUMENTS

Existing

The bulk of survey responses and consultation feedback focused on instruments with which respondents were familiar: the Functional Independence Measure (FIM), the Health of the Nation Outcome Scales (HoNOS), the Resource Utilisation Groups – Activities of Daily Living (RUG-ADL), and the other instruments in the Palliative Care Outcomes Collaboration.
Opinions on the FIM varied. Several respondents were satisfied that the FIM domains adequately cover the needs of inpatients, while others considered that the domains were not sufficient for complex rehabilitation care. There was broad agreement on the need for expansion of the range of domains for ambulatory (non-admitted) patients. Critical comments were made on ceiling effects and the adequacy of the cognition domains. The training program was seen as strength and also a burden given its formal structure. There was a strong view that the large investment in the FIM and related systems should not be discarded lightly.

The HoNOS is widely used in mental health assessment. It was seen as useful for assessment of psychogeriatric patients, and it covers a wide range of domains including Behaviour.

The RUG-ADL is used for palliative care and maintenance patients. It covers a narrow range of needs for assistance which do not cover the full scope of palliative care, especially when provided in the home/community.

The Karnofsky Scale, System Assessment Scale (SAS) and Palliative Care Problem Severity Score (PCPSS), as well as the RUG-ADL, are each used in palliative care, although uses varied between users. Only the PCPSS covers psychosocial and spiritual domains.

Additional
A number of other instruments covered a wider range of domains than did the existing instruments. Many were rapidly excluded and a list developed for circulation to stakeholders for consideration during consultations and in the survey.

In light of the literature reviewed and the feedback received, the list was substantially reduced. Remaining instruments were carefully examined against a range of criteria.

Conclusion
No instrument met all the desirable criteria which are developed and explained in Chapter 4: in brief, an instrument should cover the full range of ICF Activities and Participation (A&P) domains, measure needs for assistance, be well validated and be easily completed by staff.

Consideration turned to alternative approaches, recognising that these should be able to be introduced alongside existing instruments such as the FIM and RUG-ADL with as little overlap or duplication as possible.

MAPPING
While an instrument’s coverage of the ICF chapters provides information on which domains are being addressed, consideration of the perspective with which information is collected is essential in order to put this information into context. The key perspectives discussed in the project are ‘disability’, i.e., the severity or extent of a functioning problem in general, and ‘dependency’, i.e., the nature or extent of a person’s dependency (or need for assistance) because of a problem or difficulty.
An in-depth content analysis of each assessment tool was carried out. The content of each instrument was mapped to the ICF following published linking rules\(^2\) as well as their current revision [unpublished work].

A total of 33 assessment tools were eventually mapped to the ICF. The maps have been used to guide the construction of recommendations throughout this report.

**SPECIAL POPULATIONS**

**Children**

Instruments designed to assess the need for subacute care for adults are generally not suitable for use with children. Moreover, there was clear evidence that subacute care types are not widely used for children, and that use is inconsistent across and within jurisdictions. Proposals to improve data collection for children using subacute care are addressed in chapter 9.

The recommendations for rehabilitation and palliative care include discussion of relevant issues for children.

**Aboriginal and Torres Strait Islander peoples**

The current approach to Aboriginal and Torres Strait Islander health problems is to arrange the provision of care in the total context of a person’s life. Care should be continuous between inpatient and outpatient settings, and it is vital that all domains of rehabilitation are addressed in the early stages of rehabilitation planning and care.

During the NT consultation, it was observed that Aboriginal and Torres Strait Islander peoples have specific priorities in relation to their culture. These priorities can have significant resource implications. These matters reinforce the need for a broad range of activities and participation domains to be considered.

Testing of the ability of the ICF to capture the various aspects of Aboriginal life has found a good fit. All Activities and Participation (A&P) chapters are needed for this purpose.

In completing an assessment, it is essential that a culturally competent person, such as an Aboriginal Health Worker, be involved in the process.

**Rural and remote communities**

Inpatients in rural and remote hospitals may have a wide range of rehabilitation goals, or people may be living in the community during rehabilitation when, in other regions, they would be inpatients. This argues for a seamless assessment system across inpatient and non-admitted patient settings.
Training issues are also important in rural and remote areas. There is a relatively high staff turnover, and trainers need to be located and retained. This argues for assessment instruments to be as simple as possible while being fit for purpose.

**GEM patients**
There is a substantial inconsistency in use of the GEM care type across Australia, with 68% of GEM public hospital separations being in Victoria in 2010-11.

The importance of co-morbidities in GEM patients was stressed, highlighting the need to assess these patients separately from other subacute care types, and for activity based funding to take account of the complexity of patients’ needs.

**SETTING**
The increasing movement between inpatient and non-admitted settings highlighted the need for assessments to cover the needs of both settings wherever possible. For non-admitted settings, the targets of a rehabilitation program may be broader than for inpatient settings.

Repeated assessments at change of setting can lead to duplication, and the use of different instruments can lead to adverse patient outcomes.

**RECOMMENDATIONS**
Table 1 summarises the recommendations concerning instruments for each care type. The table should be read in conjunction with the relevant text following.
|
|---|
|**Table 1: Summary of recommendations concerning instruments**|

<table>
<thead>
<tr>
<th>Care Type</th>
<th>Setting of care</th>
<th>Option 1: medium term</th>
<th>Option 2: longer term</th>
</tr>
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<tbody>
<tr>
<td><strong>Rehabilitation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted</td>
<td>ALSAR + FIM. Consider adapted RUDAS for cognition</td>
<td>AusRehab: 18 ICF A&amp;P domains</td>
<td></td>
</tr>
<tr>
<td>Non-admitted</td>
<td>As above</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>Consider adapted CASP + WeeFIM</td>
<td>AusRehab-Child: 15 ICF-CY A&amp;P domains</td>
<td></td>
</tr>
<tr>
<td><strong>GEM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted</td>
<td>ALSAR + FIM. Consider RUDAS for cognition</td>
<td>AusGEM: 17 ICF A&amp;P domains</td>
<td></td>
</tr>
<tr>
<td>Non-admitted</td>
<td>As above</td>
<td>As above</td>
<td>As above</td>
</tr>
<tr>
<td><strong>Palliative care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted</td>
<td>PCOC instruments</td>
<td>AusPallCare: 6 ICF A&amp;P domains</td>
<td></td>
</tr>
<tr>
<td>Non-admitted</td>
<td>PCOC instruments</td>
<td>AusPallCare possibly expanded to include additional domains</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>Nil</td>
<td>Further discussion needed; play to be taken into account</td>
<td></td>
</tr>
<tr>
<td><strong>Psychogeriatric</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Admitted</td>
<td>Retain HoNOS</td>
<td>AusPG: 7 ICF A&amp;P domains</td>
<td></td>
</tr>
<tr>
<td>Non-admitted</td>
<td>As above</td>
<td>As above</td>
<td></td>
</tr>
<tr>
<td><strong>Maintenance</strong></td>
<td></td>
<td>No change: RUG-ADL</td>
<td>No change: RUG-ADL</td>
</tr>
</tbody>
</table>

**Rehabilitation**

It was concluded that there were strong arguments for a broader based assessment of the need for assistance of rehabilitation care patients than is provided using the FIM. All domains of the ICF’s Activities and Participation chapters should be covered.

Two options are proposed. Option 1, which could be introduced in the medium term, and possibly during 2014-15, would involve a combination of instruments. The FIM would be retained, and a second instrument would be added, to assess need for assistance in relation to the range of ICF A&P domains not covered by the FIM. The Assessment of Living Skills and Resources (ALSAR) is proposed as the additional instrument. The clinician could have the option of not using the ALSAR, with the minimum ALSAR score being assigned. An additional instrument, the Rowland Universal Dementia Assessment Scale (RUDAS), could be included to improve assessment of cognition.

Option 1 could also be applied to non-admitted patients. As the FIM is subject to ceiling effect issues for non-admitted patients, the ALSAR could be tested for its capability to predict non-admitted patient rehabilitation expenditure on its own account as well as in conjunction with the FIM.
Option 2, which would be a longer term option, involves the development of a new instrument, AusRehab, designed to measure need for assistance. AusRehab consists of 18 items covering the full range of ICF A&P domains. Six of the 18 domains can be mapped directly from the FIM items, meaning that FIM users would need to measure 12 additional domains to complete AusRehab.

Table 2 shows the domains of AusRehab, and the ICF A&P domains to which AusRehab domains map.

**Table 2: The AusRehab domains**

<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>ICF Activities and Participation Codes</th>
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<tr>
<td><strong>Learning, management and communication</strong></td>
<td></td>
</tr>
<tr>
<td>1. Learning and applying knowledge</td>
<td>Chapter 1 (d110-d199)</td>
</tr>
<tr>
<td>2. Carrying out tasks and daily routine</td>
<td>d210, d220, d230</td>
</tr>
<tr>
<td>3. Communicating – receiving</td>
<td>d310, d315</td>
</tr>
<tr>
<td>4. Communication – producing</td>
<td>d330, d335</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td>5. Changing and maintaining body position</td>
<td>d410, d415, d420</td>
</tr>
<tr>
<td>6. Walking and moving around with and without equipment</td>
<td>d450, d455, d460, d465</td>
</tr>
<tr>
<td>7. Moving around using transportation</td>
<td>d470, d475, d480</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td></td>
</tr>
<tr>
<td>8. Personal hygiene</td>
<td>d510, d520, d530</td>
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<tr>
<td>9. Dressing</td>
<td>d540</td>
</tr>
<tr>
<td>10. Eating</td>
<td>d550</td>
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<tr>
<td><strong>Getting along with people</strong></td>
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</tr>
<tr>
<td>11. Complex interpersonal interactions</td>
<td>d720</td>
</tr>
<tr>
<td>12. Formal relationships (including service providers)</td>
<td>d740</td>
</tr>
<tr>
<td>13. Family relationships</td>
<td>d760</td>
</tr>
<tr>
<td><strong>Performance in major areas of life</strong></td>
<td></td>
</tr>
<tr>
<td>14. Acquiring necessities</td>
<td>d610, d620, d860</td>
</tr>
<tr>
<td>15. Household tasks</td>
<td>d630, d640</td>
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<td>16. Education</td>
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<td>17. Work and economic life</td>
<td>d840-d865, d865, d870</td>
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<tr>
<td><strong>Community participation</strong></td>
<td></td>
</tr>
<tr>
<td>18. Community, social and civic life</td>
<td>Chapter 9 (d910-d999)</td>
</tr>
</tbody>
</table>

A five-point scale is proposed to measure need for assistance. Verbal descriptors of the scale points for each domain need to be developed.
AusRehab is designed for use with inpatients and non-admitted patients, and would avoid repeated assessments when a patient’s care setting changes.

The impact of behaviours of concern on rehabilitation costs has also been addressed. Testing is proposed to determine whether an additional behaviour item needs to be assessed, in addition to the behaviour related domains included in both options, and the weight that should be given to behaviour assessment.

Option 2 could be modified to become a suitable assessment instrument for children (AusRehab-Child). Option 1 for children is more problematic: the Child and Adolescent Scale of Participation (CASP) is put forward as a useful instrument, but it does not meet some of the criteria proposed for instruments in the project. Further consultation would be needed before pursuing this option.

**Geriatric Evaluation and Management**
It is recommended that a more consistent use of this care type is achieved both across and within jurisdictions.

Two options are put forward for assessment of the need for assistance in GEM care. Option 1: the FIM will be in place for all GEM patients from 1 July 2013, and the ALSAR is proposed to be assessed for additional domains. In addition, in recognition of the need for a cognition assessment instrument for GEM patients, the RUDAS is proposed.

For non-admitted patients, it would be sensible to test the predictive power of the ALSAR alone and in conjunction with the FIM. The impact of addition of the RUDAS should especially be considered for GEM non-admitted patients.

Option 2, which would be a longer term option, involves the development of a new 17-item instrument (AusGEM) for assessment of need for assistance for GEM inpatients and non-admitted patients, covering the broad range of ICF Activities and Participation domains. A five-level scale for need for assistance should be piloted, along with appropriate descriptors.

Independent of which assessment option is pursued, the importance of co-morbidities for GEM patients is recognised. In view of limited data numbers of patients, it is proposed that a small number of co-morbidities which are thought likely to be significant determinants of GEM costs be identified, and that these be tested for their importance as cost predictors.

**Palliative Care**
Stakeholders generally agreed during the consultations that the phases of care are clinically meaningful. Definitions of phases of care are now included in a Data Set Specification, specified by IHPA.

Use of phases of care in AN-SNAP means that casemix groups are being substantially influenced by phase. It is important that phase be determined by the health condition of the
patient, not the care plan in place or changes to it. The existing definitions in part refer to changes in care plans. It is suggested that these be reviewed to ensure there is no circularity in the definitions.

The RUG-ADL, used in the AN-SNAP, does not include any psycho-social or spiritual domains, key parts of the definition of palliative care. A new instrument, AusPallCare, which incorporates RUG-ADL domains and also two relevant Activities and Participation chapters of the ICF, is proposed, for use with inpatients and non-admitted patients. A rating scale, having regard to that used in the RUG-ADL, needs to be developed along with appropriate descriptors. Once this has been done, AusPallCare should be pilot tested, and then a Data Set Specification developed to enable national data collection and analysis.

AusPallCare would be applied to all adult patients receiving palliative care regardless of whether they are palliative care type or acute type.

The proposal made for the AusPallCare has not explicitly considered the needs of children. The Australian and New Zealand Paediatric Palliative Care Reference Group expressed interest in having an opportunity to consider the AusPallCare proposal. The Group considered that, for children, a suitable instrument needs to take account of play for children too young to attend school and educational activities for school age children.

**Psychogeriatric Care**

This small group of patients is also included in the considerations of the Mental Health Working Group, and decisions on assessment should be made in light of the recommendations of that Group.

The HoNOS is currently used in the AN-SNAP for these patients.

An instrument consistent with those proposed for other subacute care types based on ICF A&P domains and incorporating domains now included in the HoNOS or the RUG-ADL has been described, for use with inpatients and non-admitted patients. This instrument should be discussed with stakeholders in light of the outcomes of the Mental Health Working Group.

**Maintenance Care (Non-acute care)**

Need for assistance is currently assessed using the RUG-ADL, for use in the AN-SNAP. No stakeholder proposed any alternative. No change in the clinical assessment tool is proposed for the maintenance episodes of care.

Several stakeholders raised concerns that patients are in maintenance care because more appropriate care is not available. The admitted patient data could be used to conduct an analysis (based on the ICD code Z75.1-) of the reasons for people being in maintenance care.
TRANSITION ARRANGEMENTS

1) Adults

Decision to base assessments on ICF A&P domains
A decision in principle is needed that the proposed wider range of life areas covered by the ICF A&P chapters should be included in assessment for rehabilitation, GEM and palliative care type patients (no recommendation has been made to expand the domains for psychogeriatric and maintenance care).

Decide on Option 1 or Option 2 to expand domains
For rehabilitation and GEM care, two options have been proposed:

1) A medium term option to use a combination of instruments, retaining the FIM and adding the ALSAR, as well as consideration of use of the RUDAS
2) A longer term option to develop a new instrument, AusRehab and AusGEM respectively.

Given the timing differences, it is possible to commence work on both options, recognising that lessons from use of Option 1 will assist in the development of Option 2.

For GEM, there is the additional need for an early decision to move to a consistent national application of the GEM care type.

(For palliative care, no combination option has been proposed. The proposal to develop AusPallCare needs to be considered.)

2) Children

For rehabilitation, an equivalent to Option 1 for adults is more problematic, given the absence of suitable instruments. Possible use of the CASP in conjunction with the WeeFIM is discussed. Development of a new instrument, AusRehab-Child, is discussed.

For palliative care, no specific approach has been recommended. The Australian and New Zealand Paediatric Palliative Care Reference Group is keen to work with IHPA on possible options.
1 INTRODUCTION

1.1 BACKGROUND AND PURPOSE

The purpose of this project was to assess and decide on the functional assessment instruments required for subacute classification, particularly for children and ambulatory care, to inform the development of future classification systems for subacute episodes of care.

1.2 OBJECTIVES

The key objectives of this review were to:

1. Identify tools which address deficiencies in existing tools for each care type, for inclusion in the long-term classification system, and explore options to address the lack of suitable instruments for children, ambulatory and GEM patient groups and best explain resource use
2. Assess the mapping potential of tools identified as suitable for inclusion, and develop mapping (conversion) algorithms from the tools used in the AN-SNAP to any that can be mapped
3. Describe complementary tools if identified; the areas where the use of components of tools are applicable to increase measurement validity; and interactions between the tools.

1.3 METHODS

1.3.1 Literature Review

The literature review followed two streams. The first focused on accessing literature relevant to the psychometric properties and clinical utility of instruments identified via the PwC report, consultations completed in the present project and input from Expert Advisors. Literature and internet searches were conducted in the second stream to locate potentially suitable instruments, not otherwise identified. The searches were iterative and commenced with the terms ‘functional’, ‘assessment’ and ‘resource’ as the principal terms used in conjunction with ‘subacute’, ‘non-acute’ ‘rehabilitation’, ‘geriatric’, ‘psycho-geriatric’, ‘palliative’ and ‘children’. Databases used were Cochrane Library, CINAHL (Cumulative Index to Nursing and Allied Health), PubMed (medicine), MedlinePlus (medicine), PsycINFO (psychology) and Google Scholar.

1.3.2 Consultation

The objectives of the consultations were to:

- Identify potentially suitable assessment instruments, not identified through the literature searches
- Establish stakeholder perceptions of the strengths and weaknesses of instruments, with particular reference to the current use in resource allocation and clinical practice
- Establish the degree of engagement of stakeholders with the current funding methods (the AN-SNAP and CRAFT)
• Identify barriers to the implementation of additional/alternative tools
• Identify facilitators to the implementation of additional/alternative tools.

Two primary groups of stakeholders were consulted. These included:
• State government representatives including IHPA’s Subacute Care Working Group
• Other key stakeholders (Stakeholders, Appendix 4).

Through these consultations a wide range of specialist practitioners was also consulted.

Both state representatives and other stakeholders received letters describing the project and inviting their contribution. Some jurisdictions elected to conduct joint workshops involving state government officials and clinicians. Details of participants are appended (Appendix 5).

On completion of the literature search and initial instrument review (chapter 5), government officials and stakeholders were invited to complete an on-line survey. Necessarily, given the time constraints, this process overlapped the consultations. Respondents were asked to rate and comment on the identified instruments with specific reference to their own field, the instruments’ clinical utility, capacity to profile for relevant complexity factors and relevance to resource allocation.

Respondents were also given the opportunity to comment on the AN-SNAP and/or the CRAFT. Some survey invitees elected to engage others in completion of their survey and nominated appropriate others who were then sent the survey.

Following the analysis, arrangements were made for follow-up consultations where respondents had indicated they were interested in a further discussion.
2 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

2.1 INTRODUCTION TO THE ICF

The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organising information on functioning and disability. It was approved for use by the World Health Assembly in 2001, after extensive worldwide testing involving people with disabilities and people from a range of relevant disciplines. A companion classification for children and youth (ICF-CY) was published in 2007.

The ICF integrates the major models of disability. It recognises the role of environmental factors in the creation of the disability experience and the importance of participation as a desired outcome, as well as the relevance of associated health conditions.

The ICF ‘has been accepted as one of the UN social classifications and...provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation’.¹ (p. 5-6)

2.2 ABOUT THE ICF: A MULTI-DIMENSIONAL INTERACTIVE MODEL

In the ICF, functioning and disability are multi-dimensional concepts, relating to:

- The **body functions and structures** of people (and impairments thereof)
- The **activities** of people and the life areas in which they **participate** (and the activity limitations or participation restrictions they experience)
- The **environmental factors** which affect these experiences (and whether these are facilitators or barriers).

The ICF conceptualises a person's level of functioning as a dynamic interaction between their health conditions, environmental factors, and personal factors (Figure 2-1).
Disability is thus seen as multidimensional and interactive. All dimensions are important and any one may affect any other. Environmental factors are important, affect everything, must be understood and may need to be changed.

2.3 DOMAINS WITHIN THE ICF COMPONENTS

Each component in the ICF is composed of hierarchically arranged domains and categories; ICF has a separate chapter for each of the domains, as listed below.

**Body Function:**
- Mental functions
- Sensory functions and pain
- Voice and speech functions
- Functions of the cardiovascular, haematological, immunological and respiratory systems
- Functions of the digestive, metabolic, endocrine systems
- Genitourinary and reproductive functions
- Neuromusculoskeletal and movement-related functions
- Functions of the skin and related structures

**Activities and Participation**
- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life
Body Structure:
Structure of the nervous system
The eye, ear and related structures
Structures involved in voice and speech
Structure of the cardiovascular, immunological and respiratory Systems
Structures related to the digestive, metabolic and endocrine systems
Structure related to genitourinary and reproductive systems
Structures related to movement
Skin and related structures

Environmental Factors
Products and technology
Natural environment and human-made changes to environment
Support and relationships
Attitudes
Services, systems and policies

2.4 THE SCOPE OF USES OF THE ICF

The ICF is a multipurpose classification system designed to serve various disciplines and sectors across different countries and cultures. People may use the ICF across sectors including health, disability, community care, insurance, social security, employment, education, economics, social policy and legislation, and environmental design and modification.

ICF provides a standard language and framework for the description of human functioning, on a continuum - not just at the extremes - and it is important to remember that it classifies functioning, not people. As the development and testing of the ICF involved people from a broad range of backgrounds and disciplines, including people with disability, the ICF has a wide range of potential applications. Appropriately collecting functional status information across health and other relevant care systems allows the evaluation of outcomes, comparison of treatments, prediction and management of costs, and assessment of eligibility for government programs.

The aims of the ICF\(^1\) (p. 5) are to:

- Provide a scientific basis for understanding and studying health, functioning and disability, outcomes and processes
- Establish a common language to improve communication between different users, including people with disabilities, health and community care workers, researchers, policy-makers and the community generally
- Permit comparison of data across time, services, disciplines and countries
- Provide a systematic coding scheme of health information systems.

The ICF is a framework and classification system on which assessment or measurement tools may be based and to which they can be mapped. The broad framework puts assessment in context; it provides the focus for selecting relevant aspects of functioning and disability for assessment.

Since 2010, the WHO-FIC network has conducted an annual ICF updating process.
2.5 USING THE ICD AND THE ICF TOGETHER

The basis of our approach has been to recognise that all aspects of an individual’s health can be well described by the use of the ICD and the ICF together. They are the two existing reference classifications in the WHO Family of Health Classifications (WHO-FIC): the third, the International Classification of Health Interventions is under development. The WHO has made it clear that the WHO Family provides a firm base for the description of a person’s health:

- ICD: The WHO Family ‘can be used singularly or jointly to provide information on different aspects of health and the health care system.’\(^4\) (Vol. 2, p.2)
- ICF: ‘The WHO family of international classifications provides a framework to code a wide range of information about health (e.g., diagnosis, functioning and disability, reasons for contact with health services)\(^4\) (p.3)

An approach to prediction of resource use by patients with a range of health conditions and associated functioning difficulties (impairments, activity limitations, participation restrictions), or disabilities, should therefore be through the use of the two classifications together. The ICF, with its clear underpinning model and a broad range of functioning domains, is increasingly used as a base for the development of new functioning assessment instruments and, conversely, existing instruments are mapped to the ICF.

Casemix grouping for acute patients has been driven by diagnoses, both principal condition and additional diagnoses, or complications and co-morbidities, and interventions. So far, little progress has been made in the refinement of acute casemix through the addition of functioning variables, although there is increasing interest in this approach.\(^5,6\)

For subacute patients, Australian casemix, or activity based funding (ABF), systems to date have been built using instruments not based directly on the ICD or the ICF (although of course they bear some relationship to them). The diagnostic information, using the ICD, is collected routinely for all inpatients as part of the admitted patient National Minimum Data Set. However, this information is not used in the AN-SNAP (even though the ‘impairment’ groups used in the AN-SNAP are based on, and are mappable from, the ICD codes).

The proposals made in this report use the ICD and the ICF. For simplicity, only the A&P dimension of the ICF has been used. Most of the instruments examined focus on activities and participation domains.

Appendix 10 discusses possible changes to the ICD-10-AM Australian Coding Standards\(^114\) to improve the alignment between care types and relevant ICD codes.

2.6 APPLICATION OF THE ICF FRAMEWORK IN CLINICAL ASSESSMENT TOOL REVIEW

Given the scope of the classifications to describe a person’s health, the ICF was seen as a suitable framework to underpin the project.
This view is supported by authors of several compendia of health instruments. Tate\textsuperscript{7} uses the ICF as the conceptual framework underlying the structure and organisation of her compendium. McDowell\textsuperscript{8} distinguishes two approaches to construction of clinical assessment tools: theoretical and empirical. He points out the significant limitation of the empirical approach: a tool can be developed for a particular practical purpose, but it does not provide an understanding of what the tool is actually measuring. In discussing the theoretical approach, he refers to the earlier use of the predecessor to the ICF, the International Classification of Impairments, Disabilities and Handicaps (ICIDH), and more recently the ICF, as a widely-used framework for instrument development.

### 2.7 ICF AS PREDICTOR OF SUBACUTE CARE COSTS

Empirical data are needed to describe the capacity of ICF based instruments as predictors of subacute care costs in Australia. Because domains covered by existing instruments are subsets of ICF domains, it would be expected that predictive capacity will be higher if a broader range of domains is assessed. But the number of additional domains that are justified for particular care types and settings, and the consequent predictive power, require data based analysis.

Studies in Germany\textsuperscript{9, 10} have examined the capacity of the ICF to describe the range of nursing interventions for rehabilitation inpatients. These studies are relevant given that nursing costs are a major component of overall inpatient costs. The studies showed that nursing interventions could all be linked to the ICF domains, indicating a capacity for ICF based instruments to cover these important cost drivers.

Use of the ICF domains to describe functioning is reported in various clinical studies. An Australian example is the study by Alviar et al.\textsuperscript{11} on the description of functioning for patients with osteoarthritis. It would be expected that the use of a wider range of functioning limitations in clinical applications of the ICF will, over time, feed through to the content of rehabilitation programs. This will result in better clinical and functioning outcomes and affect modes of care and cost structures. Instruments in the future will need to be able to capture the breadth of these clinical assessments.

The ICF has been shown to assist in defining rehabilitation goals to include those of the patient, as well as those of clinicians.\textsuperscript{12} This result highlights the potential interaction between assessment tools and the scope of subacute care programs.

The application of the ICF framework in assessing instruments is further discussed in chapter 7.
3 FUNDING SUBACUTE CARE

3.1 BACKGROUND

The National Health Reform Agreement (NHRA)\textsuperscript{13} has established Activity Based Funding (ABF) as a key platform for transparency and accountability of efficiency, effectiveness and quality for public hospital services in Australia. Public hospitals are funded by both the Commonwealth and State and Territory Governments. Continually increasing demand for services and advancing technology have increased demands for improved transparency of the services provided by hospitals and the level of efficiency with which they are provided. Demand for increased quality and safety has also reinforced the focus on transparency. ABF is the mechanism nominated in the NHRA to provide the framework for the necessary measurements.\textsuperscript{13}

Transparency and accountability require well-defined and valid units of activity against which to monitor cost efficiency and quality of care. Since the Medicare Agreements of 1989, the Casemix Development Program has developed into a key component for monitoring hospital activity in Australia. Australia has been at the international forefront of monitoring acute admitted or inpatient activity using the DRG (Diagnostic Related Group) classification mechanism.

During the 1990s, rehabilitation and other longer-term hospital care activities were disadvantaged by recording and reporting (and funding in jurisdictions using casemix funding) on an episodic basis in the same way as, or as a component of, other admitted and non-admitted hospital services. Four categories, or ‘care types’, of subacute care were conceptually separated from Acute hospital services by the initial casemix classification projects: Rehabilitation, Palliative Care, Geriatric Evaluation and Management (GEM), and Psychogeriatric. Maintenance care was included as a fifth category in subsequent scoping of the classification coverage. Definition problems persist with each of these categories, and current work is aimed at clarifying the distinctions between them.\textsuperscript{14} Appendix 2 gives definitions of the various care types.

From the decision in the 1990s to separately record, monitor and fund ‘subacute’ episodes of care, the idea of ‘change of care type’ was developed. Unfortunately, neither recording practice nor clinical patient management has rigorously followed this approach in a uniform way across Australia. A notable example is the allocation of the GEM care type in different jurisdictions.

Many subacute episodes are bundled in as part of acute episodes which may then attract ‘outlier payments’, but may also result in the subacute element not being funded. Where sequence of care is split into separate acute and subacute episodes, the point of separation tends to be applied inconsistently by different hospitals and across jurisdictions.

This problem is not unique to Australia. The issues are replicated internationally wherever efforts have been made to isolate rehabilitation and other ‘subacute’ care components into separate products for pricing.\textsuperscript{15,16,17,18}
These differences create serious validity problems in comparing utilization, comparing performance and the setting of prices to reimburse units of activity. Nevertheless, the idea of funding ‘sub and non-acute patients’ separately from the other parts of their health care has persisted in different manifestations across the Australian jurisdictions and also in the private hospital and private health insurance sectors.

The ‘subacute care type’ reporting and funding framework has been locked in as a separate component of the NHRA ABF framework. The AN-SNAP classification was nominated by the Council of Australian Governments’ Health Reform Implementation Group as the ‘proxy classification’ to be used from 1 July 2013 for reporting activity and funding for subacute services. The system is to be further refined by the IHPA as the basis for pricing subacute care.19,20

Figure 3-1 shows diagrammatically how AN-SNAP is structured for inpatients (Version 2 is shown):

**Figure 3-1: AN–SNAP Classification Version 2**
AN-SNAP is a national casemix classification system for subacute and non-acute patients. The system classifies similar types of patients into care types using specified criteria. AN-SNAP is intended to record and classify the episode of care rather than the clinical specialty or unit providing the service.

Episodes are classified into one of five care types which are: palliative care, rehabilitation, psychogeriatric, geriatric evaluation and management (GEM) and maintenance. Within the care types, episodes are further grouped based on specified criteria such as age, phase of care and patient functioning.

(There is a similar structure for non-admitted patients)

A key component of the ABF mechanism set up under the NHRA is the determination of a National Efficient Price (NEP) for each weighted unit of hospital activity. This is a role of the Independent Hospital Pricing Authority (IHPA), and it requires accurate data on the volumes and types of services provided and the expenditures associated with them.13

Under NHRA, the Commonwealth and the States and Territories are jointly responsible for collecting and providing data to support the objectives of comparability and transparency, and to ensure that data are shared between relevant participants in national health care arrangements to promote better health outcomes. This includes specifying the data items that are to be reported to enable classification of units of activity into the categories to which the NEP relates. Commonwealth funding for public hospital services and functions under NHRA is dependent on the provision of data requested by IHPA and other relevant organisations.13

Most of the jurisdictions that have implemented an ABF mechanism to fund subacute activity have relied heavily on an episode component payment within a narrow length of stay (LOS) range, and per-diem payments for cases outside of the core LOS range. This approach, or even pure LOS based approaches, are widely used internationally because it is commonly held in the literature that patient variation is too great for a basic episode payment approach to work for subacute services.13

However, with the increased visibility and familiarity of stakeholders with the ICF, alongside ICD, it is now being proposed that more patient information, including use of information on patient functioning, will greatly improve the LOS prediction and therefore also cost prediction for the subacute care ABF classes. It is also argued that cost prediction for acute casemix classes can be materially improved with the addition of functioning information.6,5

A graphic from a recent presentation to the WHO Family of International Classifications (WHO-FIC) network illustrates this relationship.5

The figure shows the increased reduction in variance resulting from the addition of functioning information.

As part of the initial examination of refinement options for subacute ABF classification, PricewaterhouseCoopers (PwC) was commissioned in 2011 to review cost drivers for subacute hospital episodes of care.21 The report from the PwC review included a recommendation that instruments for assessing functioning be identified and their value for prediction of LOS or cost within the different subacute case types be examined.21 That recommendation is being pursued in this project. It is expected that the functioning measure provided by the instrument would be used in conjunction with other data on the patient such as diagnoses and relevant demographics.

3.2 DATA FOR ACTIVITY BASED FUNDING MODELS

Data required establishing the necessary IHPA functions for determining NEP include services to patients, information identifying the patient to whom the services were provided, the public
or private status of the patient, the nature of the service, and the facility providing the service. Required data also include information on the costs of providing each type of service to allow comparisons to be made of the efficiency, quality and effectiveness of services.

To classify acute patients into useful categories for pricing services, assignment to the relevant pricing category requires details of the patient’s condition, demographic particulars such as sex and age and utilisation of particular services such as intensive care. These are variables that have been demonstrated as both predicting cost and grouping patients into clinically meaningful categories. The variables are set out in a National Minimum Data Set (NMDS) for admitted patients which forms part of the National Health Data Dictionary (NHDD).22

For patients who have been designated as principally requiring rehabilitation, palliative care, geriatric evaluation and management, psychogeriatric care or maintenance care, functioning information is particularly important as both a determinant of their care planning and a predictor of the cost of their care. The ICF provides a useful framework for ensuring the functioning aspects of the patient’s need for subacute care are taken into account in determining their ABF category.

3.3 NATIONAL MINIMUM DATA SETS

A central mechanism in the national specification of healthcare activity monitoring data is the National Health Information Agreement (NHIA), in place since the early 1990s. In December 2011, the Commonwealth and the States renewed and extended the agreement. The NHIA establishes principles, governance and processes for Commonwealth and State health and statistical authorities to work together to improve, maintain and share national health information. Both NHIA and NHRA acknowledge each other’s function and the need for consistency of dataset specification across the collections and co-ordination of process in specifying new reporting requirements.23

NHIA allows for the specification of data in National Minimum Data Sets (NMDS). ‘A National Minimum Data Set (NMDS) is a minimum set of data elements agreed for mandatory collection and reporting at a national level. It may include data elements that are also included in other national minimum data sets. An NMDS is contingent upon a national agreement to collect uniform data and to supply it as part of the national collection, but does not preclude agencies and service providers from collecting additional data to meet their own specific needs.’24

Specifying functioning data items in national data collections involves substantial effort in both collection and dissemination system adjustments. The existing admitted patient NMDS is designed for acute patients, and does not include functioning information.

NHIA also allows for data sets to be specified by a ‘designated authority’ when they have not been accepted as NMDSs, by designating them as Data Set Specifications (DSS). DSSs are metadata sets that are not mandated for collection but are recommended as best practice.24

The data required for the use of AN-SNAP for subacute care ABF from 1 July 2013 have been specified (by IHPA) as DSSs.
For ABF mechanisms, a record of every relevant unit of activity (such as admission, non-admitted service event, outpatient department attendance) must be compiled from the source documentation and transmitted to the national collections. Several such collections exist at both state/territory and national levels. For this reason, new data items need to be considered and agreed across a complex system; then collection accuracy and completeness need to be managed. ABF nomination can facilitate such collection because a payment level can be linked to the collection or non-collection of the data item.

ABF data may also be used as an input into hospital management information reports. Enabling hospital managers to measure the activity and costs of their hospitals compared to industry norms improves service performance and value. ABF is useful in this way as a funding indicator or payment scale. More importantly, it improves the capabilities and drivers for:

- Comparing how different hospitals treat patients in different conditions
- Identifying treatment trends and their cost effectiveness
- Supporting quality improvement activities
- Identifying and prioritising the types of patients hospitals treat
- Stimulating retrospective data analysis for research and planning.

### 3.4 ABF FUNDING MODEL

There are two general infrastructure requirements for effective ABF mechanisms:

- Establishment of initial capability and baseline measures
- Ongoing management and development of the mechanisms that are required to support progressive goal setting, monitoring and incentive payment mechanisms.

At the State/Territory and hospital system level, ABF mechanisms are based on the following structural elements:

- ABF Budget Modelling Infrastructure
- Classifications framework and coding practice
- Clinical costing systems and practice
- Data management system development
- ABF policies, incentives and feedback mechanisms

In concept ABF data mechanisms are based on two parallel analytical processes:

1. Patient data collection and analysis using NMDSs and/or DSSs as just described. This is a comprehensive, accurate collection of complete system data on units of activity defined by nationally uniform coding standards for each of the areas of activity.

2. A costing study that provides a more detailed intensive study of the cost structures and average costs associated with each of the categories of activity produced.

Figure 3-3 is a generic ABF data flow schema that has been applied internationally. It outlines the relationship between the data collection and analysis operations.
Figure 3-3: The two reporting and analytical streams required for Activity Based Funding

Two types of reports are produced:

- Data quality – validity and reliability analyses:
  - Coding standards compliance analysis
  - Cost data quality analysis
- Activity and cost analyses:
  - Weighted Activity Units analysis reports
  - Cost reports

In considering collecting new or additional data such as that on functioning, it is important to recognise that the specified data items only need to be collected for cases that meet specified criteria (e.g., care type is GEM). In the absence of the provision of functioning data, the weight for the case in the pricing model would default to the baseline value for the grouping concerned.
4 INSTRUMENTS: FITNESS FOR PURPOSE

4.1 INTRODUCTION

This chapter addresses the criteria applied, and reason for application, in reviewing instruments. It is important to remember that there is no ‘perfect tool’, and that tool selection needs to be made on the basis of fundamental criteria, with consideration to other criteria and finally balancing competing criteria.

4.2 EXISTING INSTRUMENTS: FLAWS AND OPPORTUNITIES

There is a wide range of instruments for assessment of subacute care. These have been developed through a variety of mechanisms, and have often not had regard to international classification standards. Without such a standard classification base, comparison of instruments is difficult. Some classifications have been developed with reference to the ICF, or its predecessor, the ICIDH. Mapping of instruments to the ICF as the international standard for classification of functioning is addressed in chapter 7.

The purpose of an instrument is often not clearly stated. At least three broad purposes may be distinguished:

- Need for assistance
- Difficulty
- Performance Outcomes

These purposes are not necessarily mutually exclusive. For example, a sufficiently sensitive measure of ‘difficulty’ or ‘need for assistance’ can also act as an outcome measure, and an outcome measure is simply a measure of status (in relation to ‘difficulty’ or ‘need for assistance’) taken at multiple points in time. Some instruments can be argued to contain a mix of both types of measures.

A person may have substantial difficulty in performing a task, but nevertheless do it without assistance. Some therapy services may be designed to relieve difficulty in performing a task when no assistance is required to actually perform it. But in a subacute setting, the therapy is in fact assistance, and the relief of difficulty generates the need for assistance.

Several key existing instruments in use in subacute care focus on need for assistance.

4.3 VALIDITY AND RELIABILITY OF EXISTING INSTRUMENTS

To be judged ‘fit for purpose’ for ABF funding, there must be an acceptable degree of evidence that an instrument measures what it is meant to measure (validity) with an acceptable degree of consistency (reliability). The evidence must be publicly available in a form that provides information on the research design, statistical methods used and findings. There are two forms of publication that meet these criteria: publications in refereed journals and test development manuals from recognised academic publishers.
With instruments lacking basic evidence on validity and reliability discarded, additional considerations were applied to remaining instruments. When evaluating instruments, considerations include the nature of the validity, strength of the evidence of validity and reliability, consideration of the presence of ceiling and floor effects, risks of gaming, instrument sensitivity and clinical utility.

4.4 NATURE OF VALIDITY

There are many aspects to testing validity of instruments, the overriding one being that the instrument measures what it has been designed to measure. Relevant ones for the project have been adapted from Tate\textsuperscript{7} and Portney and Watkins.\textsuperscript{26}

4.4.1 Construct validity
Establishes the ability of an instrument to measure an abstract construct and the degree to which the instrument reflects the theoretical components of the construct.

4.4.2 Content validity
Indicates that the items that make up an instrument cover the full range of content issues that define the construct being measured.

The ICF provides a means by which the content of an instrument can be reviewed (beyond the methods typically adopted) and confidence in coverage examined. Chapter 7 discusses ICF mapping.

4.4.3 Predictive validity
Extent to which a measure obtained using the instrument can be used to predict a specific criterion (such as cost).

Of particular relevance to ABF would be evidence of predictive relationship between function related variables and cost of service. Studies of predictive validity are few. Instrument designers are more interested in patient status at a given point in time than in the resource implications of the patient’s status (an exception to this is the work with the FIM in developing prospective payment systems). Given the limited studies addressing predictive validity the capacity to comment on the strength of likely changes in variance explanation will be limited.

Importantly, variance explanation achieved by additional or substitute instruments will need to be investigated as part of the ongoing development of subacute funding.

4.4.4 Face validity
Indicates that an instrument appears to the users and people being assessed to measure what it is supposed to measure.
4.5 THE TRADE OFF: CEILING AND FLOOR EFFECTS, SENSITIVITY AND CLINICAL UTILITY

Ceiling and floor effects refer to a phenomenon in instruments measuring individual characteristics whereby the instrument does not distinguish within group differences well at either end of the scale. If the patient is performing at the top of the scale before care begins, the instrument is of no value in describing the need for assistance (ceiling effect). Conversely, if the patient's performance under the instrument is not improved by the care program, the instrument cannot describe the need for assistance usefully.

The risk of ceiling and floor effects can be reduced by including additional domains of relevance to the function being measured. This, however, carries a risk of item redundancy and increases the length of the instrument. A longer instrument increases the likelihood that the resultant model will contain more groups with lower within group variance, in turn enhancing a funding formula resulting from such work. This would tend to argue for instruments to be of greater length, with more rather than fewer variables. Clinicians' requests that instruments be clinically informative and more sensitive would also argue in favour of more comprehensive instruments than, for example, the FIM or RUG-ADLs. However, clinicians also want instruments to be as short as possible.

There is a balance to be struck between the competing demands of sensitivity, an absence of ceiling and floor effects, instrument length, clinical utility, time demands and costs of implementation. There is no 'ideal' solution.

4.6 SELF-REPORT

The number of self-report instruments available is increasing and growing in popularity in line with developments in person- or client-centred practice. In this area they fill an essential role, particularly when an intervention is designed to deliver client valued outcomes. For ABF purposes, however, where the purpose of the instrument is to generate resource homogenous groups, a self-report instrument will not provide the required across-group reliability. People's views of similar characteristics will be different simply because they are personal views of one's own circumstances. Distortion of views is a particular risk where people are experiencing depression or anxiety.

As well, the organisation treating the patient must take responsibility for assessment that is to generate funding in respect of the patient. This does not mean that information provided by the patient cannot influence the assessment: the assessors must take patient-provided information into account, but final responsibility for veracity of information rests with the assessing organisation.

Accordingly, self-report instruments have generally been excluded. However, there is the possibility of adapting a self-report instrument to be a valid clinician-rated instrument if there are other compelling reasons for the instrument’s inclusion.
4.7 COSTS AND LICENSING

Many of the instruments reviewed fulfil similar purposes and most are freely available, not subject to licensing fees or restrictions beyond those of fair dealing (e.g., acknowledgement). Where there were comparable freely available instruments, licensed and/or pay for use instruments were excluded.

Important constraints or costs in the use of instruments are mentioned where relevant.

4.8 CONCLUSION

Fitness for purpose for ABF requires consideration of a range of factors, some of which are not mutually exclusive while others are directly in competition with each other. This chapter has described some of the key considerations informing subsequent chapters.
5 INSTRUMENTS: INITIAL SELECTION AND REVIEW

5.1 INTRODUCTION
This chapter describes the results of instrument identification and reviews. As a result of these activities, instruments likely to be relevant to ABF were subject to a review against the ICF and a more comprehensive review as to properties.

5.2 INSTRUMENT REVIEW AND SELECTION

5.2.1 Method
As noted in the Request for Tender (RFT), subacute care is primarily driven by the patient’s functional status. Accordingly, instruments that focused on functional status were sought using the methods earlier described in this report (chapter 1.3). Particular attention was paid to instruments appropriate to children and ambulatory care (chapter 5.8).

Identified instruments were subject to a multi-tier review process using the criteria described in the preceding chapter and this chapter.

5.2.2 Constraints
Before proceeding to discuss the instruments the following is noted:

- It is not possible in an instrument review to assert that there will be a statistically important impact on variance. Opinions on likelihood of variance impact, based on clinical judgement and other statistical properties, can be proffered but real data and modelling is required to demonstrate a reduction in variance (or conversely an increase in variance explanation or explanatory power).
- Suitability for Australian conditions will be as much affected by staff training, the infrastructure that sits behind the administration of an instrument (e.g., capacity for auto-population of documents, web-enabled systems) as by the instrument itself. A definitive position regarding suitability for Australian conditions needs to take these factors into account.
- The groups identified in the RFT are based on different variable constructs e.g., setting of care (e.g., admitted, outpatient), the care (e.g., palliative) and age (children). The presence of non-mutually exclusive groups complicates instrument selection and modelling.
- Judgements on the ease of use and efficiency will vary across environments. For example, an instrument that takes a long time to complete may be regarded as sufficiently efficient in an admitted setting where a patient is staying for an extended time and as too time consuming in an outpatient clinic.
- A balance needs to be struck between the capacity of an instrument to be used in more than one care type, potentially delivering efficiencies while minimising the risk of a loss of sensitivity.
The range of activities required in the review of instruments, the need to accommodate stakeholders’ availability and the time available meant that some activities (notably the survey) had to be initiated before other activities had been completed.

5.3 INSTRUMENTS IDENTIFIED

The instruments identified for review (and the source of identification) are summarised in Table 5-1.

Table 5-1: Instruments identified and source of identification

<table>
<thead>
<tr>
<th>Field of current use and instruments</th>
<th>ABF use</th>
<th>PwC report</th>
<th>Consultations</th>
<th>Searches</th>
<th>Project Team</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ADULTS: GENERAL</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abbreviated Life Skills Profile (LSP)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canadian Frailty Scale (CFS)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact on Participation and Autonomy (IPA)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>InterRAI family of instruments</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nordic ASSESSment Score (NASS)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal-Care Participation and Resource Tool (PC-PART)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident Classification Instrument (RCI)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behaviour Scale</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short-Form 36 Health Survey (SF-36)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ADULTS: REHABILITATION SETTINGS</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Barthel Index (BI)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FIM and Functional Assessment Measure (FIM+FAM)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional Independence Measure (FIM)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leeds Assessment and Scale of Handicap (LASH)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northwick Park Dependency Score (NPDS)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation Complexity Scale V2 (RCS)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spinal Cord Injury Measure (SCIM)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PALLIATIVE CARE</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edmonton Symptom Assessment Scale</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional Assessment of Chronic Illness Therapy-Palliative Scale (FACIT-Pal)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karnofsky Scale</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memorial Symptom Assessment Scale (MSAS)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative Care Problem Severity Scale (PCPSS)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom Assessment Scale</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ADULTS: PSYCHO-GERIATRIC</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Dementia Rating Scale (CDR)</td>
<td>√</td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Formerly Handicap Assessment and Resource Tool (HART)
2 Also referred to as the Symptom Assessment Scale (SAS)
<table>
<thead>
<tr>
<th>Field of current use and instruments</th>
<th>ABF use</th>
<th>PwC report</th>
<th>Consultations</th>
<th>Searches</th>
<th>Project Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health of the Nation Outcome Scales (HoNOS)</td>
<td></td>
<td>√</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mini-Mental State Examination (MMSE)</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Multidimensional Assessment of Neurodegenerative Symptoms (MANS)</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**ADULTS: INSTRUMENTAL ACTIVITIES OF DAILY LIVING**

| Assessment of Living Skills and Resources (ALSAR) |        |            |               |          |              |
| Lawton’s Instrumental Activities in Daily Living (Lawton’s) |        |            |               |          |              |

**ADULTS: ELDERLY, COMMUNITY LIVING, BROAD FUNCTIONAL SKILLS**

| Activities of Daily Living Questionnaire (ADLQ) |        |            |               |          |              |
| Bristol Activities of Daily Living Scale (BADLS) |        |            |               |          |              |
| Frenchay Activities Index (FAI) |        |            |               |          |              |
| Functional Autonomy Measurement System (SMAF) |        | √          |               |          |              |
| Katz Index of Activities of Daily Living (KIADL) |        |            |               |          |              |
| Rivermead Activities of Daily Living (RADL) |        |            |               |          |              |

**ADULTS: PEOPLE WITH DISABILITIES (COVERED UNDER NATIONAL DISABILITY AGREEMENT)**

| Disability Support Training and Resource Tool (D-START) |        |            |               |          |              |
| Inventory for Client and Agency Planning (ICAP) |        |            |               |          |              |

**CHILD AND YOUTH**

| Bayley Scales of Infant Development |        |            |               |          |              |
| Functional Disability Inventory (FDI) |        |            |               |          |              |
| Functional Independence Measure for Children (WeeFIM) |        |            |               |          |              |
| Pediatric Developmental Inventory (PEDI) |        |            |               |          |              |
| Pediatric Outcomes Data Collection Instrument (PODCI) |        |            |               |          |              |

**ADULTS, CHILD AND YOUTH**

| Australian Therapy Outcome Measures (AusTOMs) |        |            |               |          |              |
| Canadian Occupational Performance Measure (COPM) |        |            |               |          |              |
| Participation Objective, Participation Subjective (POPS) |        |            |               |          |              |

Many other instruments were identified in the course of the work. Those that were not carried through to Table 5-1 were *prima facie* unsuitable for reasons including:

- Specificity to a particular function and/or participation and/or group and/or environment (e.g., Nottingham Leisure Questionnaire, Quality of Upper Extremity Skills Test, School Function Assessment, Craig Handicap Assessment and Reporting Technique).7, 31-33
- Lack of sufficient information on a critical functional indicator/s (e.g., the Nottingham Activities of Daily Living Scale, with only one mobility item ‘walk (or use wheelchair) indoors’).7

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3 Originally in French, Système de Mesure de l’Autonomie Fonctionelle
5.4 TIER 1 REVIEW: ADULTS AND CHILDREN

This review took place prior to the selection of instruments for inclusion in the stakeholders’ survey. Instruments excluded at the Tier 1 review are listed in Table 5-2, together with a brief reason for exclusion.

Table 5-2: Instruments excluded at Tier 1 review and reasons

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Instrument description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bayley</td>
<td>This scale has an upper age limit of 42 months, so that its age range is insufficient.</td>
</tr>
<tr>
<td>CFS</td>
<td>The CFS is an outcome measure that is used to detect change in a client's perception of performance over time in self-care (personal care, functional mobility, community management), productivity (paid/unpaid work, household management, play/school) and leisure (quiet recreation, active recreation and socialisation). The design of the tool reflects the tool's original design purpose of an assessment supporting person-centred planning in mental health services. COPM was designed to facilitate collaborative goal setting and is not primarily a measure of function or informative as to resource allocation.</td>
</tr>
<tr>
<td>COPM</td>
<td>D-START is an individual planning software program designed for use with people with disabilities receiving services under the National Disability Agreement (NDA). While the developers state that the tool is valid and reliable, there is no evidence in the public domain in relation to its psychometric properties (no publications).</td>
</tr>
<tr>
<td>D-START</td>
<td>I-CAN is primarily a planning tool that is quite time consuming (60-90 minutes) for people with disabilities in receipt (or likely to be in receipt) of services funded under the NDA.</td>
</tr>
<tr>
<td>I-CAN</td>
<td>The InterRAI suite of tools are primarily clinical planning tools initially focussed on the elderly and now advised as providing assessment systems for ‘aged care, disability services and mental health’. Publications as to psychometric properties are surprisingly few. In fact, only one article reporting on a psychometric property was located, and no articles addressing the fundamental criterion of validity were located. Efforts to locate articles relevant to validity included contact with the Australian InterRAI group.</td>
</tr>
<tr>
<td>InterRAI</td>
<td>Abbreviated Life Skills Profile is concerned with measuring behaviour domains in people with schizophrenia.</td>
</tr>
<tr>
<td>LSP</td>
<td>PC-PART remains under development.</td>
</tr>
<tr>
<td>PC-PART</td>
<td>MMSE is a very widely used cognitive screening test subject to copyright and purchase requirements. Given the range of other non-restricted instruments available for the assessment of people with dementia, the financial commitment required by stakeholders was judged as not warranted.</td>
</tr>
<tr>
<td>MMSE</td>
<td>SF-36 is a measurement of health status and not relevant to the purposes of the project.</td>
</tr>
<tr>
<td>SF-36</td>
<td>NASS is only one reference (a conference paper) was located.</td>
</tr>
</tbody>
</table>

A clear theme to emerge in the consultations (and raised in the survey comments on instruments) was the need for instruments to be short, easy to complete and to have clinical utility. Given these requirements, the Inventory for Client and Agency Planning and the Impact on Participation and Autonomy (instruments used in the disability sector with people living in the community) were withdrawn from further consideration.

At this point, the instruments in Table 5-3 were retained for further review.
Table 5-3: Instruments retained for further review

<table>
<thead>
<tr>
<th>Field of current use and instruments</th>
<th>Acronym</th>
<th>Development year</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ADULTS: GENERAL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident Classification Instrument Behaviour Scale</td>
<td>RCI</td>
<td>1997</td>
</tr>
<tr>
<td>World Health Organization Disability Assessment Schedule11</td>
<td>WHODAS 2.0</td>
<td>2000</td>
</tr>
<tr>
<td><strong>ADULTS: REHABILITATION SETTINGS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barthel Index</td>
<td>BI</td>
<td>1965</td>
</tr>
<tr>
<td>Functional Independence Measure</td>
<td>FIM</td>
<td>1987</td>
</tr>
<tr>
<td>Functional Independence Measure and Functional Assessment Measure</td>
<td>FIM+FAM</td>
<td>1995</td>
</tr>
<tr>
<td>Leeds Assessment and Scale of Handicap</td>
<td>LASH</td>
<td>2000</td>
</tr>
<tr>
<td>Northwick Park Dependency Score</td>
<td>NPDS</td>
<td>1998</td>
</tr>
<tr>
<td>Rehabilitation Complexity Scale V2</td>
<td>RCS V2</td>
<td>2010</td>
</tr>
<tr>
<td>Spinal Cord Injury Measure</td>
<td>SCIM</td>
<td>2007</td>
</tr>
<tr>
<td><strong>PALLIATIVE CARE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australian Karnofsky Performance Scale</td>
<td>AKPS</td>
<td>2005</td>
</tr>
<tr>
<td>Edmonton Symptom Assessment Scale</td>
<td>Edmont</td>
<td>1991</td>
</tr>
<tr>
<td>Functional Assessment of Chronic Illness Therapy-Palliative Scale</td>
<td>FACT-Pal</td>
<td>2002</td>
</tr>
<tr>
<td>Palliative Care Problem Severity Scale</td>
<td>PCPSS</td>
<td>1994</td>
</tr>
<tr>
<td>Resource Utilisation Groups – Activities of Daily Living</td>
<td>RUG-ADL</td>
<td>2006</td>
</tr>
<tr>
<td>Symptom Assessment Scale (also referred to as MSAS)</td>
<td>MSAS or SAS</td>
<td>1994</td>
</tr>
<tr>
<td><strong>ADULTS: PSYCHO-GERIATRIC</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral Pathology in Alzheimer’s Disease Rating Scale</td>
<td>BEHAVE-AD</td>
<td>1986</td>
</tr>
<tr>
<td>Clinical Dementia Rating Scale</td>
<td>CDR</td>
<td>1984</td>
</tr>
<tr>
<td>Health of the Nation Outcome Scales</td>
<td>HoNOS</td>
<td>1996</td>
</tr>
<tr>
<td>Multidimensional Assessment of Neurodegenerative Symptoms</td>
<td>MANS</td>
<td>2007</td>
</tr>
<tr>
<td><strong>ADULTS: INSTRUMENTAL ACTIVITIES OF DAILY LIVING</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assessment of Living Skills and Resources</td>
<td>ALSAR</td>
<td>2000</td>
</tr>
<tr>
<td>Lawton’s Instrumental Activities in Daily Living</td>
<td>Lawton’s</td>
<td>1969</td>
</tr>
<tr>
<td><strong>ADULTS: ELDERLY, COMMUNITY LIVING, BROAD FUNCTIONAL SKILLS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities of Daily Living Questionnaire</td>
<td>ADLQ</td>
<td>2004</td>
</tr>
<tr>
<td>Bristol Activities of Daily Living Scale</td>
<td>BADLS</td>
<td>1996</td>
</tr>
<tr>
<td>Frenchay Activities Index</td>
<td>FAI</td>
<td>1983</td>
</tr>
<tr>
<td>Functional Autonomy Measurement System</td>
<td>SMAF</td>
<td>1980</td>
</tr>
<tr>
<td>Katz index of Activities of Daily Living</td>
<td>KIADL</td>
<td>1984</td>
</tr>
<tr>
<td>Rivermead Activities of Daily Living</td>
<td>RADL</td>
<td>1990</td>
</tr>
<tr>
<td><strong>CHILD AND YOUTH</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional Disability Inventory</td>
<td>FDI</td>
<td>1991</td>
</tr>
<tr>
<td>Functional Independence Measure for Children</td>
<td>WeeFIM</td>
<td>1993</td>
</tr>
<tr>
<td>Pediatric Outcomes Data Collection Instrument</td>
<td>PODCI</td>
<td>1998</td>
</tr>
<tr>
<td>Pediatric Developmental Inventory</td>
<td>PEDI</td>
<td>1992</td>
</tr>
<tr>
<td><strong>ADULTS, CHILD AND YOUTH</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australian Therapy Outcome Measures</td>
<td>AusTOMs</td>
<td>2004</td>
</tr>
<tr>
<td><strong>OTHER</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation Objective, Participation Subjective</td>
<td>POPS</td>
<td>2004</td>
</tr>
</tbody>
</table>

The above instruments were then reviewed with reference to the project brief, care types and the criteria discussed in chapter 4.

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4 The limited evidence available on the psychometric properties of the original Karnofsky suggested poor inter-rater reliability. The Karnofsky has been re-developed to become the Australian Karnofsky Performance Scale.
5.5 ADULT FUNCTION RELATED MEASURES

5.5.1 Excluded instruments
At this point, the following instruments were excluded from further consideration:

- The RCI has been used in nursing homes and primarily covers issues of relevance to this population (e.g., continence, maintenance of skin integrity, nursing procedures). Coverage of ICF domains is limited.\textsuperscript{46}
- The BI is very widely used with older people; however, it has important coverage limitations and is therefore frequently used alongside other instruments.\textsuperscript{7, 47}
- The FIM+FAM differs from the FIM in that there are 12 additional items developed by clinicians with an interest in brain injury to better address cognitive and psychosocial components. Tate\textsuperscript{7} and McDowell\textsuperscript{8} each reviewed the FIM+FAM literature and noted that, despite the additional items in the Cognitive scale (14 in FIM+FAM compared to 5 in FIM), the FIM+FAM Cognitive scale does not show the responsiveness of the Motor scale. Tate’s review concluded that ‘A number of investigators have concluded that for the TBI population the FIM+FAM does not appreciably add to the FIM’\textsuperscript{7} (p. 441).
- The LASH is purpose designed for people with brain injuries in inpatient rehabilitation settings\textsuperscript{7, 47}. The four domains do not map well to the ICF.
- The NPDS is designed to assess the nursing dependency of people with neurological conditions (principally used with traumatic brain injury and stroke).\textsuperscript{7, 47}
- The RCS (V2) was excluded for reasons of ceiling effects and gaming potential (the number of therapy disciplines involved is an independent variable in the model).\textsuperscript{48}
- The Behave-AD is designed for the assessment of behavioural and mental health effects of Alzheimer’s disease.\textsuperscript{7} There is a strong focus on symptoms with only a single overall rating on impact and that is on the caregiver, rather than the person’s function.
- The CDR is a scale that reports on the clinical stage of dementia.\textsuperscript{7, 47} Some coverage of ICF Activities and Participation domains is provided, but the instrument largely assesses Body Functions.
- The MANS is relevant to neurodegenerative aetiologies.\textsuperscript{49}
- Lawton’s Instrumental Activities of Daily Living Scale, which is included in the AROC Ambulatory dataset, is a widely-used instrument that is used in the assessment of people’s performance of instrumental activities of daily living, that is, community living skills such as shopping, using a telephone, managing money. Its coverage (8 domains) is similar to, but more restricted than, that of the ALSAR (11 domains, adding reading, leisure and home maintenance to the Lawton’s domains).\textsuperscript{50}
- The FAI is an outcome scale with limited coverage of ICF domains.\textsuperscript{7, 51}
- The BADLS, although covering a range of ICF domains well, was excluded as it is designed to be completed via the observations of a relative or friend over a two-week period.\textsuperscript{7}
- The SMAF is a well-developed instrument. Its coverage of the resources available to assist people (e.g., family, aids, volunteers etc.) provides a sensible coverage of some Environmental Factors, and means that the instrument is particularly useful in planning for, and monitoring, community living. Consistent with this, the SMAF is judged to be likely to be too long to be acceptable (approximately 40 minutes for completion).\textsuperscript{7}
The six domains in the KIADL are covered within the FIM\(^7\) and would therefore be redundant when the FIM is used. The FIM is preferred over the KIADL for reasons of its demonstrated statistical power.

- RADL has a number of strengths but the range of ICF domains covered is limited.\(^7\)

- An attractive feature of POPS is its focus on life tasks and community living (this is returned to in chapter 11). However, it is a combination of self-report (‘subjective’) and assessor reporting (‘objective’). Unfortunately, the latter is not a simple scoring system: ‘A possible drawback of the POPS is the scoring format for the PO component, which is complex and involved, and the need for a statistical program to calculate scores may limit the feasibility of using the POPS in a clinical setting’.\(^7\) (p. 526)

### 5.6 AMBULATORY PATIENTS

During the consultations, there was emphasis on the far greater range of activity and participation capacity needed by people living in the community than is required by people living in an inpatient setting or indeed to be discharged from an inpatient setting (e.g., transport competence, handling money, caring for others, interpersonal relations etc.).

In line with the historical (preceding ICF) focus on basic functional activities (ADL), researchers and clinicians have sought to address the gaps in information by developing measures of ‘instrumental activities of daily living’. The Assessment of Living Skills and Resources (ALSAR)\(^52, 53\) is judged to be the best of these by virtue of its psychometric properties and its clinical value as a planning and monitoring tool.\(^7\)

Given the patient population, it was also decided to consider the Activities of Daily Living Questionnaire (ADLQ), as it is designed to track changes over time in people with various forms of dementia attending an outpatient clinic, and the Rowland Universal Dementia Assessment Scale (RUDAS)\(^54\) (identified in the later stages of the project via follow-up conversation with a survey respondent).

### 5.7 PALLIATIVE CARE

The Palliative Care Outcomes Collaboration collects four instruments, these being the Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)\(^55, 56\), Symptom Assessment Scale (SAS)\(^57\), Karnofsky Scale (Karnofsky)\(^58\) and the Palliative Care Problem Severity Score (PCPSS)\(^55, 57\). The consultation findings demonstrated reasonable satisfaction with the current instruments as tools for the purpose of ABF (with the exception of children).

During the consultations, the Play Performance Scale for Children (PPSC, also referred to as the Lansky\(^59, 60\)) was identified as an instrument warranting investigation. The instrument is structurally similar to the Australian Karnofsky Scale and has a number of desirable psychometric properties. While the developers state that the instrument is applicable across age groups, the studies do not report on the ages of the children with whom the studies were conducted and the extent to which adolescents’ ‘play’ has not been addressed. An independent study comparing physicians’ and parents’ ratings on the PPSC for 120 children with cancer found that neither group of raters’ scores discriminated between outpatients...
receiving ongoing therapy from patients who had completed therapy. This finding raises concerns about validity.\textsuperscript{61,62} Given the similarity to the Karnofsky Scale, and the issues identified, the PPSC was excluded from further consideration. However, the work of these various authors suggests that a useful measure would be one based on play for children too young to attend school and another based in educational activities for school age children.

5.8 PAEDIATRIC MEASURES

Findings from the survey (Section 6.3.3.1) regarding a paucity of instruments relevant to children's rehabilitation were confirmed in the review of instruments.

5.8.1 Pediatric Developmental Inventory

The PEDI is a well-developed, widely-used 217 item scale which provides a clinical assessment of key functioning domains (197 items) and caregiver assistance (20 items) among children aged 6 months to 7.5 years. The assessment is completed by an allied health professional by observation and/or interview of a parent. The instrument takes between 45-60 minutes to complete, is subject to copyright and must be purchased. IBM software can be used for the analyses.\textsuperscript{63}

The instrument can be used with children older than 7.5 years provided that the child is developmentally younger. This is an important limitation for ABF purposes as the PEDI is likely to be unsuitable for a proportion of children over the age of 7.5 years.\textsuperscript{64}

5.8.2 WeeFIM

The WeeFIM has developed from the FIM work of the Uniform Data System for Medical Rehabilitation (UDSMR). Like the FIM, it is built to a minimum data set and designed to sample key areas. Like the PEDI it is designed for children aged 6 months to 7 years and is described as able to be used with older children, again provided they are developmentally younger. As noted, this is an important limitation. The psychometric properties of the instrument are judged acceptable.\textsuperscript{65,66,67} The WeeFIM is subject to copyright and credentials are required to use it.

5.8.3 Pediatric Outcomes Data Collection Instrument

The PODCI, predominantly used with children having had interventions to address primary or secondary musculo-skeletal disorders, is an interesting instrument in that it seeks to ensure that outcomes observed in the clinic can be transferred to school/home functioning.\textsuperscript{68} Factor analysis has shown that it has four dimensions: mobility, upper extremity function, comfort and general health, and self-worth. As a self-report instrument, it is not considered appropriate for ABF purposes.\textsuperscript{69,68,70,71,72,73}

5.8.4 Functional Disability Inventory

The FDI is a well-established measure of function with young people with chronic pain.\textsuperscript{74,75} The items are primarily restricted to those activities most likely to be affected by chronic pain (e.g., sleeping, endurance, eating regularly). It is therefore judged as unsuitable.
5.8.5 **Options**

The PEDI and the WeeFIM share a desirable degree of robustness but have an age limitation likely to impede use in ABF. In the absence of the age limitation problem, either instrument could be used. Both carry ‘purchase’ requirements in direct costs or credentialing. The WeeFIM is shorter to complete and may therefore carry the risk of ceiling effects not evident in the PEDI. The time required to complete the PEDI may be a barrier to clinical acceptance.

5.9 **CONCLUSION**

Children and palliative care instruments have been discussed specifically above.

The following instruments (alphabetical order) warrant further review for consideration for inclusion in ABF models:

- Activities of Daily Living Questionnaire
- Assessment of Living Skills and Resources
- Australian Therapy Outcome Measures
- Functional Independence Measure (FIM)
- Health of the Nation Outcome Scales
- Rowland Universal Dementia Assessment Scale
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)
- Spinal Cord Injury Measure
- WHODAS 2.0

Each of these instruments, their general strengths and limitations and their fitness for ABF purposes are discussed in chapter 8.
6 CONSULTATIONS AND SURVEY FINDINGS

6.1 INTRODUCTION

This Chapter provides information regarding the consultations undertaken as described in Section 1.3.2.

6.2 JURISDICTIONS’ PERSPECTIVES

Below are summarised the key findings relating to the various care types and settings from the consultations followed by a brief discussion of the matters of most importance to the various jurisdictions. Summaries of each consultation are contained in Appendices 7-1 to 7-9. Views expressed on specific populations (children, Aboriginal and Torres Strait Islander peoples and people in rural and remote areas) are discussed in chapter 9.

6.2.1 Key findings from jurisdictions: care types and settings

6.2.1.1 Rehabilitation

Very disparate views were expressed, but no particular variation between jurisdictions was noted.

Several rehabilitation specialists strongly supported continuing the use of the FIM. This support was generally associated with the view that the domains covered by the FIM (communication, self-care, mobility) were those most important in inpatient rehabilitation care. However, some respondents stated that these domains did not adequately recognise the extent of the rehabilitation needs for the patients under their care. There was also a general recognition that the FIM is not appropriate for patients in non-admitted settings.

A broader range of domains needed to be addressed in community based (non-admitted) rehabilitation, when patients are dealing with adaptation to their family and community. It is increasingly common for rehabilitation programs to have inpatient and non-admitted components. Also there are hub and spoke models that are used in rural settings. A single plan, supported by an instrument with sufficiently broad domain coverage, is desirable to avoid repetitive and duplicating assessments.

While most respondents believed that FIM data did not have a substantial clinical value, the FIM domains are considered in care planning, and data collection is a manageable burden for clinical staff.

Some respondents expressed the view that the large investment in training on the use of the FIM has resulted in a familiarity with it. Others considered the training requirements inflexible, particularly for hospitals with high staff turnover, and those in rural and remote areas. Also, some regarded the need to maintain accreditation as a burden, again especially in rural and remote areas.

Some respondents argued for the use of specific instruments for certain conditions, such as spinal cord injury, in addition to a generic instrument such as the FIM. It was recognised that
such instruments could have more clinical value, but training and organisational issues and small data numbers could make this approach impractical. A view in some jurisdictions was that because of the substantial investment in FIM-based systems (notably in NSW), further and alternative developments would require substantial justification. Although the Barthel Index is widely known, its use has attracted little support.

6.2.1.2 Palliative care
Five phases of palliative care in Australia have been identified:

- Stable
- Unstable
- Deteriorating
- Terminal
- Bereavement

There was general agreement during the consultations that these phases are clinically meaningful (there were comments that the unstable and deteriorating phases were not mutually exclusive, so some clarification may be necessary around the definitions).

The instruments included in the Palliative Care Outcomes Collection (PCOC) attracted various but generally positive comments. Use for clinical purposes was reported, but the instruments used for this purpose varied.

6.2.1.3 Geriatric evaluation and management (GEM)
The consultations indicated that the GEM care type is not used consistently across the various jurisdictions (and possibly within them).

The most significant comment came from Victorian specialists, who are the major user of the GEM care type. The view was that the FIM does not have much utility (clinical or resource) for this care type. Consequently, AN-SNAP does not explain much variation in cost. The PwC report had explained the issues, particularly around co-morbidities.

This view does not stem from an inherent dislike of the FIM, which is used for some Victorian rehabilitation patients.

The feature of GEM patients is the high level of co-morbidities and multiple types of need for assistance. The impact of co-morbidities is not well measured by existing rehabilitation oriented systems. The GEM patient has multi-dimensional needs that should drive resource intensity in best practice subacute care. Consequently, the use of the full range of ICF A&P domains is needed to describe the patient’s needs for assistance. Omitting domains risks introducing perverse incentives through inadequate pricing.

There is no way to distinguish GEM patients through existing ICD coding (patients receiving rehabilitation or palliative care can be distinguished in this way).
6.2.1.4 Psychogeriatric
Given the separate IHPA review under way on mental health care, there was limited comment on this care type. Subject to review after that review is complete, there was support for continued use of the HoNOS and possible use of the RUG-ADL. There was a strong view that other data items should not be added to these two instruments.

6.2.1.5 Maintenance care
There was limited specific comment on this care type. However, there were several comments about the factors that could extend rehabilitation, GEM and psychogeriatric stays beyond that which is seen to be clinically necessary. It was not clear that patients in these circumstances are currently routinely transferred to maintenance care. There was a strong view that the reason for delayed discharge should be recorded.

6.3 SURVEY FINDINGS

6.3.1 Experience profile
Information about respondent organisations is provided in Appendix 6. In all, 74 organisations responded (102 individual responses from these organisations) but not all organisations answered all questions. Further, as more than one person contributed to most surveys, and organisations could comment on more than one area, the numbers in Table 6-1 exceed the number of organisational respondents. The range of respondents and experience suggests that the sample was an ‘information rich’ sample and therefore appropriate to the task.76 (p. 169).

Where people indicated experience with ‘children’ or ‘other subacute or non-acute care’, they were asked to provide further information regarding their experience. Respondents for children principally cited palliative care (including home delivery) and rehabilitation. One response cited experience in providing health care to children with disabilities (intellectual disability, autism spectrum disorders).

In relation to ‘other subacute or non-acute care’, some people made reference to mental health services (outside the scope of this work). Other responses predominantly related to programs delivered in the community (centre or home) with elderly people to prevent acute admission, support early discharge, assist in transition to home or deliver slow-stream rehabilitation or GEM-related services.
Table 6-1: Experience of survey respondents

<table>
<thead>
<tr>
<th>Patient group or care type</th>
<th>Age Group</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Adults</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Children (16 or &lt;)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inpatient</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Outpatient clinic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community</td>
</tr>
<tr>
<td>Adults</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Children (16 or &lt;)</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Geriatric evaluation and</td>
<td>40</td>
<td>36</td>
</tr>
<tr>
<td>management</td>
<td></td>
<td>17</td>
</tr>
<tr>
<td>Maintenance care</td>
<td>32</td>
<td>26</td>
</tr>
<tr>
<td>Palliative care</td>
<td>37</td>
<td>33</td>
</tr>
<tr>
<td>Psycho-geriatric</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>59</td>
<td>53</td>
</tr>
<tr>
<td>Other subacute or non-acute</td>
<td>29</td>
<td>11</td>
</tr>
</tbody>
</table>

6.3.2 Instruments in use in Australia

Table 6-2 provides information on respondents’ opinions on the use in Australia of instruments identified through the first literature review. Clearly, there is a lack of consensus as to how widely used the various instruments are in Australia. Only the Barthel and Functional Independence Measure might be regarded as widely known. This suggests that any new instruments will need a well-planned introduction program. Comments on the survey regarding instruments and systems were informative, and are discussed below.

Table 6-2 Views of instrument use in Australia

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Clinical use in Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High</td>
</tr>
<tr>
<td>Activities of Daily Living Questionnaire</td>
<td>3</td>
</tr>
<tr>
<td>Assessment of Living Skills and Resources</td>
<td>-</td>
</tr>
<tr>
<td>Australian Karnofsky Performance Scale</td>
<td>5</td>
</tr>
<tr>
<td>Australian Therapy Outcome Measures</td>
<td>1</td>
</tr>
<tr>
<td>Barthel Index</td>
<td>19</td>
</tr>
<tr>
<td>Behavioral Pathology in Alzheimer’s Disease Rating Scale</td>
<td>1</td>
</tr>
<tr>
<td>Bristol Activities of Daily Living Scale</td>
<td>1</td>
</tr>
<tr>
<td>Clinical Dementia Rating Scale</td>
<td>2</td>
</tr>
<tr>
<td>Edmonton Symptom Assessment Scale</td>
<td>-</td>
</tr>
<tr>
<td>Frenchay Activities Index</td>
<td>-</td>
</tr>
<tr>
<td>Functional Assessment of Chronic Illness Therapy-Palliative Scale</td>
<td>-</td>
</tr>
<tr>
<td>Functional Autonomy Measurement System</td>
<td>-</td>
</tr>
<tr>
<td>Functional Disability Inventory</td>
<td>-</td>
</tr>
<tr>
<td>Functional Independence Measure</td>
<td>30</td>
</tr>
<tr>
<td>Functional Independence Measure for Children</td>
<td>7</td>
</tr>
<tr>
<td>Health of the Nation Outcome Score</td>
<td>2</td>
</tr>
<tr>
<td>Impact on Participation and Autonomy</td>
<td>-</td>
</tr>
<tr>
<td>InterRAI Scales (one or more of the scales)</td>
<td>2</td>
</tr>
</tbody>
</table>
### Table: Clinical use in Australia

<table>
<thead>
<tr>
<th>Instrument</th>
<th>High</th>
<th>Moderate</th>
<th>Low/None</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Katz Index of Activities of Daily Living</td>
<td>3</td>
<td>1</td>
<td>13</td>
<td>29</td>
</tr>
<tr>
<td>Lawton’s Instrumental Activities in Daily Living</td>
<td>7</td>
<td>8</td>
<td>12</td>
<td>19</td>
</tr>
<tr>
<td>Leeds Assessment and Scale of Handicap</td>
<td>-</td>
<td>-</td>
<td>7</td>
<td>39</td>
</tr>
<tr>
<td>London Handicap Scale</td>
<td>-</td>
<td>-</td>
<td>13</td>
<td>33</td>
</tr>
<tr>
<td>Lawton’s Instrumental Activities in Daily Living</td>
<td>3</td>
<td>1</td>
<td>7</td>
<td>38</td>
</tr>
<tr>
<td>Northwick Park Dependency Score</td>
<td>-</td>
<td>1</td>
<td>7</td>
<td>37</td>
</tr>
<tr>
<td>Palliative Care Problem Severity Scale</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>32</td>
</tr>
<tr>
<td>Pediatric Outcomes Data Collection Instrument</td>
<td>1</td>
<td>-</td>
<td>4</td>
<td>41</td>
</tr>
<tr>
<td>Personal-Care Participation and Resource Tool</td>
<td>-</td>
<td>1</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Resident Classification Instrument Behaviour Scale</td>
<td>-</td>
<td>2</td>
<td>5</td>
<td>40</td>
</tr>
<tr>
<td>Resource Utilisation Groups – Activities of Daily Living</td>
<td>5</td>
<td>8</td>
<td>12</td>
<td>24</td>
</tr>
<tr>
<td>Rivermead Activities of Daily Living</td>
<td>8</td>
<td>11</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td>Self-administered Gerocognitive Examination</td>
<td>-</td>
<td>-</td>
<td>5</td>
<td>41</td>
</tr>
<tr>
<td>World Health Organization Disability Assessment Schedule</td>
<td>2</td>
<td>2</td>
<td>11</td>
<td>26</td>
</tr>
</tbody>
</table>

6.3.2.1 **Functional Independence Measure (FIM)**

Unsurprisingly the FIM attracted most comment with its particular strengths identified as being:

- Its widespread use
- The validity of the instrument for rehabilitation inpatients
- Its capacity to reflect functional skills (conversely burden of care or need for human assistance) and activity/activity limitations.

Limitations particularly noted were:

- The lack of validity and/or limited sensitivity for certain groups, in particular, people with psychogeriatric disorders, ambulatory/outpatients and people living in the community
- The presence of ceiling and floor effects (see Chapter 8 for a more detailed discussion)
- Training costs.

6.3.2.2 **Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)**

The RUG-ADL attracted positive comment in relation to its brevity, ease of use and perceived reliability. Floor and ceiling effects and a lack of sensitivity were described as being limitations.

6.3.2.3 **Functional Impairment Category of AN-SNAP**

Positive and negative aspects primarily linked to those already cited for the FIM. Of more specific interest were comments relating to the failure to capture the complexities of dual diagnosis and co-morbidities.
6.3.2.4 Health of the Nation Outcome Scale (HoNOS)
The HoNOS attracted few comments and some of these were contradictory (e.g., clear guidelines versus difficult to follow).

6.3.2.5 Symptom Assessment Scale (SAS)
The SAS also attracted few comments. It was the only instrument mentioned as being clinically informative; however the absence of psychosocial domains (or coverage of symptoms alone) were noted as limitations.

6.3.2.6 Palliative Care Problem Severity Score (PCPSS)
Again, few comments and concerns were expressed regarding various psychometric properties. The particular value of the instrument was cited as being its consideration of the family. As one respondent noted: The family is considered the unit of care and this is the only tool that recognises them in formal assessment.

6.3.3 Specific groups
At various points in the survey comments were made that are of relevance to specific groups. These comments are discussed below.

6.3.3.1 Children
Comment was made on the paucity of instruments suitable for the paediatric group with one survey respondent noting: Paediatric outcome measures to evaluate rehabilitation outcomes are VERY limited and those that are available are the ones that are used but remain limited in completeness and ability to reflect the real picture.

Note was also made that palliative care for children is very different from that for adults, and that different tools are required.

6.3.3.2 GEM
One commentator well captured the views regarding AN-SNAP, associated tools and GEM when commenting: AN-SNAP … is of limited value in GEM with very broad and meaningless categories - this is evidenced by the fact that AN-SNAP is a poor way to determine costs in GEM (explains less than 20% of clinical costs). Other factors need to be added to AN-SNAP for assessment of clinical costs including assessments of co-morbidity, presence of carers, socio-economic information and participation restriction.

6.3.3.3 Maintenance care
This area did not attract any comments.

6.3.3.4 Palliative care
Support for the current palliative care phases was expressed together with positive comment on the Karnofsky (Australian Karnofsky Performance Scale), and comment that there was…very little appetite for change. The absence of suitable tools for people receiving palliative care in the community was seen as a problem.
6.3.3.5 Psychogeriatric care
One comment noted that: AN-SNAP for psychogeriatrics is effectively a subset of the measures used for MH auspice psychogeriatric services under MHNOCC. Another noted the desirability of bringing psychogeriatrics in under the mental health data systems and instruments, given the commonality of instruments in use.

6.3.3.6 Rehabilitation
Comments in this area are reported with those for the FIM (Section 6.3.2.1) and the AN-SNAP (6.3.4).

6.3.3.7 Ambulatory
There were a number of comments relating to the limitations of current tools in the community environment and/or with outpatients (ambulatory patients).

6.3.4 AN-SNAP
The AN-SNAP was seen as being broadly acceptable for rehabilitation, but some respondents noted that it is not adequate for complex neurological conditions (e.g., severe stroke) and spinal cord injury. What was not clear from the comments was whether or not the perceived deficiencies were in the AN-SNAP itself or the actual funding received under the AN-SNAP.

Comment was made regarding the high investment in current systems and past and current research. These comments in turn led to views on the need for gradual change (if any), a compelling case for change (if change is proposed) and support for ‘add-on’ instruments rather than replacement of current instruments.

6.3.5 CRAFT
CRAFT attracted far fewer comments than did the AN-SNAP, with four of the nine comments expressing a preference for, or greater confidence in, the AN-SNAP over and above CRAFT.

6.3.6 Other instruments
Fifty-four instruments additional to those circulated were identified by participants as warranting consideration. A number of these had been identified through the literature and discounted for the reasons described in chapter 4; others offered no particular benefit over and above those already identified; and some were not consistent with the need to inform variance explanation. One instrument was considered warranting further review as it does address on the group of rehabilitation clients with more complex needs; this instrument is the Spinal Cord Injury Measure (SCIM). Accordingly, it has been added in the subsequent instrument reviews.
6.3.7 What would people like to have?

There was consensus that where elderly people are the patients, regardless of setting/care type, there was a need to have co-morbidities recognised as increasing resource requirements, and comment on the low likelihood of a single principal diagnosis. One respondent noted: *For example in a patient with dementia who has fallen and fractured her hip, which is the primary diagnosis? Is it the dementia, unsafe gait pattern, apraxia, and limited ability to follow instructions and to learn to use the gait aid, or is it the hip fracture?*

There was agreement on the appropriateness of an ‘add-on’ approach, rather than replacement of current instruments/systems.

There were conflicting opinions on whether single or multiple instruments are needed. Some respondents wanted to have instruments that go across all care settings, others argued for more specific instruments for people with complex or specific needs.

There was an interesting tension over the length/time demands of instruments. Alongside a preference that instruments be as short as possible, there was a request that instruments consider more areas (e.g., carers, participation restrictions, socio-economic factors) and demonstrate sensitivity. At present, these requirements cannot be delivered simultaneously.

6.4 CONCLUSIONS: OVERVIEW OF VIEWS FROM SURVEY AND CONSULTATIONS

From the preceding material, the following conclusions may be drawn:

- There is support for the FIM for rehabilitation inpatients; however, ceiling and floor effects are recognised as a problem, in particular, in relation to people with complex/high needs
- There is little/no appetite for the FIM being used with other care types
- There is a need to better describe and manage the problem of multiple diagnoses/co-morbidities
- There is a dearth of instruments suitable for children generally and in palliative care in particular
- There was support for an ‘add-on’ approach that builds on current instruments/systems
- Any new instruments will need a well-planned training program that is short and flexible in mode of delivery, and inexpensive.
7 MAPPING INSTRUMENTS TO THE ICF

7.1 OBJECTIVE

The International Classification of Functioning Disability and Health (ICF) is a member of the WHO’s family of international classifications, and provides a classification of health and health-related dimensions of human functioning. The ICF contains an exhaustive and mutually exclusive set of categories of information, which constitute a unified and consistent standard language of human functioning suitable for serving as a reference for both health and health-related information.

The first level of the ICF hierarchy and the first frame of reference for collecting health and health-related information is made up of chapters or domains. Each chapter consists of second-level categories followed by third-level categories. There are also fourth-level categories. The second-, third-, and fourth-level categories represent increasingly more detailed frames of reference for collecting and organizing information.

The ICF has been used extensively as a framework for comparing different assessment tools across settings and health conditions. In the present work, a qualitative content analysis of assessment tools previously identified in a systematic literature review was performed by mapping them to the International Classification of Functioning, Disability and Health (ICF).

7.2 METHODOLOGY

The content of the selected assessment tools identified in a previous systematic review was linked to the ICF using standardized linking rules as well as their current revision [unpublished work].

In a first step, data was extracted in order to provide an overview of the information that can be gathered by using the selected assessment tools. In this step, content analyses focused on ‘what’ is being measured by the tools, i.e., the coverage of Body Functions, Activities and Participation, and Environmental factors at the chapter level, as well as on ‘how’ it is being measured, considering the perspective and response options used.

While the coverage of ICF chapters provides information on which domains are being addressed, consideration of the perspective with which information is collected is essential in order to put this information into context. The most prominent perspectives include:

- Disability, i.e., the severity or extent of a functioning problem in general
- Impact, i.e., the impact of an individual’s disability on their immediate or more distal, social environment
- Needs, i.e., the kind and levels of needs an individual has as a consequence of the problem or difficulty
- Dependency, i.e., the nature or extent of a person’s dependency (or need for assistance) because of a problem or difficulty
- Satisfaction, i.e., the level of satisfaction with a problem or difficulty.
The operationalisation of perspectives when collecting data is eventually reflected in both the wording of questions as well as in the response options used. The most prominent response options target:

- The presence of a problem, i.e., “yes/no”
- The frequency of a functioning problem in general, i.e., “most days - 2-3 times - 4 or more times” or “rarely - occasionally - frequently - almost constantly”
- The intensity of an individual’s disability, i.e., “slight - moderate - severe - very severe” or “not at all - a little bit - somewhat - quite a bit - very much”.

In a second step, an in-depth content analysis of each assessment tool was carried out. Following published linking rules\(^2\) as well as their current revision [unpublished work], the content of each instrument was mapped to the ICF by:

- Identifying the concepts to be linked by answering the questions “What is this piece of health or health-related information about?”, “What is the information about?”, and “What is this item about?” for each single item
- Documenting information about the perspective of each single item
- Documenting the operationalisation of perspectives of each single item.

Two health professionals who were experts on the ICF and on the application of the linkage rules translated the concepts into corresponding ICF categories, which represented them most precisely. In this step, second-, third-, and even fourth-level categories were considered in order to increase precision. Each relevant concept was linked separately by the two health professionals. The two independent mapping results were then compared and, in case of disagreement, the opinion of a third linker was considered in order to reach consensus on which ICF category to use.

If a concept pertained to a specific chapter or domain of the ICF but the information was not sufficient to select a specific category, the ICF codes ‘unspecified’ or ‘other specified’ were used. If a concept was too general to be mapped to a specific ICF chapter, domain or category, the concept was considered as ‘not defined’ (nd). If a concept pertained to personal factors, which are not coded yet in the ICF, the abbreviation ‘personal factor’ (pf) was used.

7.3 RESULTS

A total of 33 assessment tools were selected to be linked to the ICF. For one instrument, the questionnaire was, however, not available: Personal-Care Participation and Resource Tool (PC-PART). An extra suggested tool, the Participation Objective Participation Subjective (POPS), was mapped to the ICF.

The data extracted to provide the overview of the information that can be gathered by using the selected assessment tools is presented in Table 7-1. Table 7-2 presents a comparison of ICF chapters addressed across assessment tools regarding Activities and Participation.
7.4 DISCUSSION

In the present work, a qualitative content analysis of assessment tools previously identified in a systematic literature review was performed by mapping them to the International Classification of Functioning, Disability and Health (ICF).

Considering the ultimate goal of identifying suitable clinical assessment instruments for subacute and non-acute care classification development, special attention should be paid to two key issues: the perspective used by assessment tools to address functioning and their coverage of ICF chapters.

Considering the perspective, we show that 12 assessment tools address functioning from the perspective of dependency and 12 from the perspective of disability. Two tools address both perspectives. These assessment tools usually measure the extent to which patients are dependent on personal assistance (dependency perspective) or the severity or extent of a functioning problem (disability perspective). Few selected assessment tools address functioning considering either the impact of disability on the social environment, the kind and levels of needs an individual has or the level of satisfaction with functioning.

Regarding the coverage of ICF chapters by the selected tools, we observed that 11 assessment tools do not assess any Body Functions. Out of the remaining assessment tools, the vast majority address mental functions. The Memorial Symptom Assessment Scale is the tool addressing the highest number of chapters of the ICF component Body Functions.

Most of the assessment tools assess at least one chapter of the ICF component, namely Activities and Participation. The domains Mobility and Self-care are the most frequently addressed ones, followed by Domestic Life (mostly questions on household tasks) and major life areas (items addressing work). The assessment tools addressing the highest number of Activities and Participation domains (at least 6 domains) are the WHODAS; Impact on Participation and Autonomy Questionnaire (IPA); the Functional Independence Measure (FIM), the Assessment of Living Skills and Resources (ALSAR); the Lawton & Brody instrumental activities of daily living scale; the Activities of Daily Living Questionnaire; the Bristol Activities of Daily Living Scale; and the Functional Disability Inventory.

A total of 19 assessment tools target environmental factors, the majority of which concern personal support received or needed from health professionals or family members. The WHODAS, the Health of the Nation Outcome Score, the Inventory for Client and Agency Planning (ICAP) and the Pediatric Outcomes Data Collection Instrument are the ones addressing the highest number of chapters of the environmental factors component.
It is important to note that some assessment tools such as the London Handicap Scale and the Leeds Assessment and Scale of Handicap were developed based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH). In 2001, the WHO substantially revised the ICIDH and replaced it with the ICF. The appropriateness of selecting tools based on a classification model (ICIDH) that has been revised and replaced by the ICF should therefore be carefully considered.
**Table 7-1: Overview of the information that can be gathered by using the selected assessment tools.**
Cells in grey mean scale is not available.

<table>
<thead>
<tr>
<th>Name of the Instrument</th>
<th>Aim of the instrument</th>
<th>Perspective</th>
<th>Response options</th>
<th>Coverage of Body Functions (chapter level)</th>
<th>Coverage of Activities &amp; Participation (chapter level)</th>
<th>Coverage of Environmental factors (chapter level)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ADULTS GENERAL</strong></td>
<td></td>
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<tr>
<td>Impact on Participation and Autonomy Questionnaire</td>
<td>Assess participation and autonomy</td>
<td>self-determination</td>
<td>intensity</td>
<td>na</td>
<td>d3, d4, d5, d6, d7, d8, d9</td>
<td>e3</td>
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<tr>
<td>London Handicap Scale</td>
<td>Impact of a health condition on functioning</td>
<td>disability</td>
<td>intensity</td>
<td>na</td>
<td>d4, d7, d8, d9</td>
<td>na</td>
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<tr>
<td>Personal-Care Participation and Resource Tool</td>
<td>person’s participation restriction in the area of personal care</td>
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<td>Excluded from mapping exercise (not available)</td>
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<td>Resident Classification Instrument Behaviour Scale</td>
<td>patient dependency measure in nursing homes, cover types of behaviours important in determining resource use</td>
<td>dependency</td>
<td>frequency</td>
<td>b1</td>
<td>d7</td>
<td>e3</td>
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<tr>
<td>WHODAS 2.0</td>
<td>Difficulties due to health conditions</td>
<td>disability / impact</td>
<td>intensity / frequency (impact)</td>
<td>b1</td>
<td>d1, d2, d3, d4, d5, d6, d7, d8, d9</td>
<td>e1, e3, e4</td>
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<tr>
<td><strong>ADULTS: REHABILITATION SETTINGS</strong></td>
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<tr>
<td>Barthel Index</td>
<td>level of assistance required to perform activities of daily living</td>
<td>dependency</td>
<td>intensity</td>
<td>b5, b6</td>
<td>d4, d5</td>
<td>e3</td>
</tr>
<tr>
<td>Functional Independence Measure (FIM)</td>
<td>level of assistance required to perform activities of daily living</td>
<td>dependency</td>
<td>intensity</td>
<td>b1, b5, b6</td>
<td>d1, d2, d3, d4, d5, d6, d7</td>
<td>e1, e3</td>
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<tr>
<td>Name of the Instrument</td>
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<td>Perspective</td>
<td>Response options</td>
<td>Coverage of Body Functions (chapter level)</td>
<td>Coverage of Activities &amp; Participation (chapter level)</td>
<td>Coverage of Environmental factors (chapter level)</td>
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<td>Leeds Assessment and Scale of Handicap</td>
<td>Difficulties in mobility, physical independence, orientation and social integration</td>
<td>disability / dependency</td>
<td>intensity</td>
<td>b1</td>
<td>d4, d9</td>
<td>e3</td>
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<tr>
<td>Northwick Park Dependency Scale</td>
<td>quantify an individual’s needs for nursing care and support</td>
<td>dependency</td>
<td>Intensity / frequency / statements</td>
<td>b1, b5, b6, b8</td>
<td>d3, d4, d5, d6</td>
<td>e1, e3</td>
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<td>Karnofsky performance status</td>
<td>disability level</td>
<td>dependency</td>
<td>intensity</td>
<td>na</td>
<td>d8</td>
<td>e3</td>
</tr>
<tr>
<td>Edmonton Symptom Assessment Scale (ESAS)</td>
<td>symptoms of patients receiving palliative care</td>
<td>disability</td>
<td>intensity</td>
<td>b1, b2, b4, b5</td>
<td>na</td>
<td>na</td>
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<tr>
<td>Functional Assessment of Chronic Illness Therapy</td>
<td>multidimensional measure of health-related quality of life</td>
<td>disability/satisfaction</td>
<td>intensity</td>
<td>b1, b2, b5</td>
<td>d1, d6, d7, d8, d9</td>
<td>e3, e4</td>
</tr>
<tr>
<td>Memorial Symptom Assessment Scale</td>
<td>Evaluation of symptom prevalence, characteristics and distress</td>
<td>disability/impact</td>
<td>presence of problem / frequency / intensity</td>
<td>b1, b2, b4, b5, b6, b8</td>
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<td>na</td>
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<tr>
<td>Palliative Care Problem Severity Scale</td>
<td>severity of physical and psychological problems</td>
<td>disability</td>
<td>intensity</td>
<td>b1, b2, b4, b5, b8</td>
<td>na</td>
<td>e3, e4</td>
</tr>
<tr>
<td>Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-)</td>
<td>Behavioral disturbances and psychiatric disorders in Alzheimer’s disease</td>
<td>disability</td>
<td>intensity</td>
<td>b1</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>Name of the Instrument</td>
<td>Aim of the instrument</td>
<td>Perspective</td>
<td>Response options</td>
<td>Coverage of Body Functions (chapter level)</td>
<td>Coverage of Activities &amp; Participation (chapter level)</td>
<td>Coverage of Environmental factors (chapter level)</td>
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<tr>
<td>Clinical Dementia Rating</td>
<td>Diagnostic and staging scale for Dementia</td>
<td>disability</td>
<td>presence of problem / frequency / intensity</td>
<td>b1</td>
<td>d1, d5, d6, d7, d8, d9</td>
<td>na</td>
</tr>
<tr>
<td>Health of the Nation Outcome Score</td>
<td>measure consumer outcomes in inpatient and ambulatory mental health services</td>
<td>disability</td>
<td>intensity</td>
<td>b1</td>
<td>d5, d7</td>
<td>e1, e3, e4</td>
</tr>
<tr>
<td>Multidimensional Assessment of Neurodegenerative Symptoms</td>
<td>changes in daily habits, personality and motor functioning</td>
<td>disability</td>
<td>presence of problem / frequency</td>
<td>b1, b6, b7</td>
<td>d1, d2, d3, d4, d6, d7, d8</td>
<td>na</td>
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<tr>
<td>Self-administered Gerocognitive Examination</td>
<td>cognitive function</td>
<td>disability</td>
<td>test format</td>
<td>b1</td>
<td>na</td>
<td>na</td>
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**ADULTS: INSTRUMENTAL ACTIVITIES OF DAILY LIVING**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Aim of the instrument</th>
<th>Perspective</th>
<th>Response options</th>
<th>Coverage of Body Functions (chapter level)</th>
<th>Coverage of Activities &amp; Participation (chapter level)</th>
<th>Coverage of Environmental factors (chapter level)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment of Living Skills and Resources (ALSAR)</td>
<td>instrumental activities of daily living (IADL)</td>
<td>dependency</td>
<td>intensity</td>
<td>na</td>
<td>d1, d3, d4, d5, d6, d8, d9</td>
<td>e1, e5</td>
</tr>
<tr>
<td>Lawton &amp; Brody Instrumental activities of daily living</td>
<td>measure of instrumental activities of daily living</td>
<td>dependency</td>
<td>intensity</td>
<td>na</td>
<td>d2, d3, d4, d5, d6, d8</td>
<td>na</td>
</tr>
</tbody>
</table>

**ADULTS: ELDERLY, COMMUNITY LIVING, BROAD FUNCTIONAL SKILLS**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Aim of the instrument</th>
<th>Perspective</th>
<th>Response options</th>
<th>Coverage of Body Functions (chapter level)</th>
<th>Coverage of Activities &amp; Participation (chapter level)</th>
<th>Coverage of Environmental factors (chapter level)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities of Daily Living Questionnaire</td>
<td>assessment of functional abilities, in patients with probable Alzheimer disease and</td>
<td>disability</td>
<td>intensity</td>
<td>na</td>
<td>d1, d3, d4, d5, d6, d8, d9</td>
<td>na</td>
</tr>
<tr>
<td>Name of the Instrument</td>
<td>Aim of the instrument</td>
<td>Perspective</td>
<td>Response options</td>
<td>Coverage of Body Functions (chapter level)</td>
<td>Coverage of Activities &amp; Participation (chapter level)</td>
<td>Coverage of Environmental factors (chapter level)</td>
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<tr>
<td>Bristol Activities of Daily Living Scale</td>
<td>ability to perform activities of daily living</td>
<td>disability</td>
<td>intensity</td>
<td>b1, b5, b6</td>
<td>d3, d4, d5, d6, d8, d9</td>
<td>e1</td>
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<tr>
<td>Frenchay Activities Index (FAI)</td>
<td>measure of instrumental activities of daily living</td>
<td>disability</td>
<td>frequency</td>
<td>na</td>
<td>d1, d4, d6, d8, d9</td>
<td>na</td>
</tr>
<tr>
<td>Functional Autonomy Measurement System</td>
<td>disabilities and whether available physical and social resources are adequate</td>
<td>dependency</td>
<td>intensity</td>
<td>b1, b2, b5, b6</td>
<td>d3, d4, d5, d6, d8</td>
<td>e1, e3</td>
</tr>
<tr>
<td>Katz Index of Independence in Activities of Daily Living (ADL)</td>
<td>ability to perform activities of daily living independently</td>
<td>dependency</td>
<td>intensity</td>
<td>b5, b6</td>
<td>d4, d5</td>
<td>e1</td>
</tr>
<tr>
<td>Rivermead ADL</td>
<td>measure instrumental activities of daily living (IADL)</td>
<td>dependency</td>
<td>statements</td>
<td>na</td>
<td>d4, d5, d6, d8</td>
<td>e3</td>
</tr>
</tbody>
</table>

**ADULTS: RESOURCE ALLOCATION**

| Resource Utilisation Groups – Activities of Daily Living | classification of long-term care residents | dependency | intensity | na | d4, d5 | e3 |

**ADULTS: PEOPLE WITH DISABILITIES (COVERED UNDER NATIONAL DISABILITY AGREEMENT CHILD & YOUTH)**

<p>| Inventory for Client and Agency Planning (ICAP) | level of support required based on: a) level of functioning, and b) the presence/absence of maladaptive behaviours | disability | intensity | b1, b2, b5, b6 | d1, d2, d3, d4, d5, d6, d7, d8, d9 | e1, e3, e5 |</p>
<table>
<thead>
<tr>
<th>Name of the Instrument</th>
<th>Aim of the instrument</th>
<th>Perspective</th>
<th>Response options</th>
<th>Coverage of Body Functions (chapter level)</th>
<th>Coverage of Activities &amp; Participation (chapter level)</th>
<th>Coverage of Environmental factors (chapter level)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Disability Inventory</td>
<td>degree to which children experience difficulty in physical and psychosocial functioning due to their physical health status</td>
<td>disability</td>
<td>intensity</td>
<td>b1</td>
<td>d1, d4, d5, d6, d8, d9</td>
<td>na</td>
</tr>
<tr>
<td>Functional Independence Measure (WeeFIM)</td>
<td>level of assistance required in self-care, mobility, and cognition</td>
<td>dependency</td>
<td>intensity</td>
<td>b1, b5, b6</td>
<td>d1, d3, d4, d5, d9</td>
<td>e3</td>
</tr>
<tr>
<td>Pediatric Outcomes Data Collection Instrument</td>
<td>measure functional outcomes in pediatric orthopaedics</td>
<td>disability/satisfaction/ needs</td>
<td>intensity / frequency</td>
<td>b1, b2</td>
<td>d4, d5, d7, d8, d9</td>
<td>e1, e3, e4</td>
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<tr>
<td><strong>ADULTS &amp; CHILD &amp; YOUTH</strong></td>
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<tr>
<td>Australian Therapy Outcome Measures</td>
<td>changes in clients’ Impairments, Activity (Limitations) and Participation (Restrictions), Wellbeing/Distress</td>
<td>disability / dependency</td>
<td>intensity</td>
<td>b1</td>
<td>d1, d2, d4, d5, d6, d7, d8, d9</td>
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<tr>
<td><strong>EXTRA TOOL</strong></td>
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<tr>
<td>Participation Objective Participation Subjective (POPS)</td>
<td>Address participation</td>
<td>information / satisfaction</td>
<td>intensity</td>
<td>na</td>
<td>d2, d4, d6, d7, d8, d9</td>
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Table 7-2: Comparison of ICF chapters addressed across assessment tools regarding Activities and Participation

<table>
<thead>
<tr>
<th>ADULTS GENERAL</th>
<th>Chapter 1 Learning and applying knowledge</th>
<th>Chapter 2 General tasks and demands</th>
<th>Chapter 3 Communication</th>
<th>Chapter 4 Mobility</th>
<th>Chapter 5 Self-care</th>
<th>Chapter 6 Domestic life</th>
<th>Chapter 7 Interpersonal interactions and relationships</th>
<th>Chapter 8 Major life areas</th>
<th>Chapter 9 Community, social and civic life</th>
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<tbody>
<tr>
<td>Impact on Participation and Autonomy Questionnaire</td>
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<td>Personal-Care Participation and Resource Tool</td>
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<td>Excluded from mapping exercise (not available)</td>
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<td>Resident Classification Instrument Behaviour Scale</td>
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<td>ADULTS: REHABILITATION SETTINGS</td>
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<td>Leeds Assessment and Scale of Handicap</td>
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<td>Memorial Symptom Assessment Scale</td>
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<tr>
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<td>Chapter 1 Learning and applying knowledge</td>
<td>Chapter 2 General tasks and demands</td>
<td>Chapter 3 Communication</td>
<td>Chapter 4 Mobility</td>
<td>Chapter 5 Self-care</td>
<td>Chapter 6 Domestic life</td>
<td>Chapter 7 Interpersonal interactions and relationships</td>
<td>Chapter 8 Major life areas</td>
<td>Chapter 9 Community, social and civic life</td>
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<tr>
<td><strong>ADULTS: PSYCHO-GERIATRIC</strong></td>
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<td>Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD)</td>
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<td>Clinical Dementia Rating</td>
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<tr>
<td>Health of the Nation Outcome Score</td>
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<tr>
<td>Multidimensional Assessment of Neurodegenerative Symptoms</td>
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<td>Self-administered Gerocognitive Examination</td>
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</tr>
<tr>
<td><strong>ADULTS: INSTRUMENTAL ACTIVITIES OF DAILY LIVING</strong></td>
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8 ASSESSMENT INSTRUMENTS FOR CONSIDERATION

8.1 INTRODUCTION
This chapter discusses the complementary tools to the FIM and the RUG-ADL. Given the consultation findings in relation to the palliative care instruments, the SAS, Karnofsky Scale and PCPSS are not discussed. The extent to which instruments assess whether patients have a need for assistance (dependency perspective) or difficulty (disability perspective) is also discussed in this chapter.

8.2 FUNCTIONAL INDEPENDENCE MEASURE

8.2.1 Background
In 1984, the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation convened a joint task force with Dr Carl Granger as co-chairman and project director, and Dr Hamilton as principal investigator to design a patient data set and an assessment instrument that could be used universally among all rehabilitation units.\(^7\) The designers of the FIM sought to create an instrument to support the development of a medical rehabilitation minimum uniform data set which reflected the cost of disability in social and economic terms and the \textit{burden of care}, which is the type and amount of assistance required for a person with disabilities to perform basic life activities effectively. The FIM is not a comprehensive measure of disability or participation; rather, it measures a selected minimum of key activities that are informative as to a person’s need for human assistance.\(^7,9,77,90,81,82\)

Since its inception in 1983, the FIM instrument has been widely regarded and adopted by clinicians and researchers globally for its brevity and reliability in measuring medical rehabilitation outcomes. Over the past 25 years, a sizeable library of supporting research and study has been published that sustains the FIM instrument’s reliability and validity.

8.2.2 Structure
The FIM samples functional skills in the categories: Self Care (six items), Sphincter Control (two items), Mobility (three items); Locomotion (two items); Communication (two items); Psychosocial Adjustment (one item); and Cognitive Function (two items). It is an 18-item, ordinal, seven-point scale with the first decision being whether or not the assistance of another person is required, with finer gradations within each of these gross measures creating the seven points. Total FIM scores lie between 18 (totally dependent) and 126 (completely independent).\(^7\)

The FIM has two underlying constructs, motor and cognitive. The 13 \textit{motor FIM items} characterise physical disabilities and somatic disorders, including limitations in self-care, sphincter control, mobility, and locomotion functions. The five \textit{cognitive FIM} items describe disabilities in communication and social cognitive functions.\(^7\) (p. 636).

Substantial dissatisfaction with the cognitive component of the FIM was reported during the consultation process. Cohen et al.\(^8\) reported in a review article a lower summary rating for the cognitive component than the motor component, with specific reference to spinal cord injured...
and amputee patients, and also reports on many studies dealing with good performance of the FIM motor component.

Several stakeholders raised the limited range of FIM domains to assess need for assistance for patients with complex rehabilitation needs, either because of their condition (e.g., spinal cord injury, traumatic brain injury) or because of their complex social needs.

8.2.3 Ceiling effect

The issue of floor and ceiling effects was raised on several occasions during the consultations.

The FIM has been demonstrated to have ceiling effects in various settings. The cognitive scale has notable ceiling effects (note earlier comments regarding ceiling and floor effects in the FIM, section 4.5) in patients admitted for rehabilitation with multiple sclerosis or stroke, and spinal cord injury. For patients following Traumatic Brain Injury, 49% of the sample showed a ceiling effect (average score 6 to 7) on discharge from inpatient rehabilitation and by one year 84% had an average score of 6 to 7. Schepers et al. looked at the standard deviations for motor, cognitive and total FIM scores of a group of patients six months post stroke. Based on the small standard deviations, they concluded that there was little variance, suggesting a large ceiling effect of the FIM in this population.

As discussed in chapter 4.5, the problems with a ceiling (or floor) effect can be addressed by adding appropriate domains to an instrument (directly or by adding a complementary instrument).

8.2.4 Predictive validity

As well as its role in the AN-SNAP, the FIM forms the basis for the US Centers for Medicare & Medicaid Services Prospective Payment System for patients admitted to an inpatient rehabilitation unit or hospital.

8.2.5 Setting

The inpatient rehabilitation period is primarily targeted at increasing an individual’s functioning skills and reducing disability during the most intense period of recovery, and there is substantial support for the use of the FIM to assess change in a person’s functioning status or abilities during an inpatient stay.

Some functional improvement can occur over the long term following discharge from rehabilitation but the relevant domains may be broader than during an inpatient stay. The FIM is not necessarily sensitive to such changes, particularly where people have very few or very high needs for human assistance.

A common view from the stakeholder consultations was that a broader range of domains than in the FIM is required to describe the need for assistance in non-admitted rehabilitation programs, as well as for patients being treated in smaller rural and remote hospitals.
8.3 RESOURCE UTILISATION GROUPS – ACTIVITIES OF DAILY LIVING

The RUG-ADL is a four-item, clinician completed test.\textsuperscript{55} The four items cover bed mobility, toileting, eating and transfer. It is specifically designed to predict resource use. Consumers are rated on their current poorest performance on these items, receive a score for each item, and a total score is calculated.

The predictive validity of this test is high in terms of costs of nursing and therapy as explained with these four items alone. Nevertheless, given the nature of the target population and the reasons (incontinence, difficulties with eating) that people usually enter this level of care, the large amount of variance explained by the items included is not surprising.

There is no information on either reliability or sensitivity to change for this test. The lack of information on sensitivity is of concern given that ability to carry out these tasks can change rapidly in these populations.

8.4 WHODAS 2.0

The WHODAS 2.0 is particularly relevant to rehabilitation, psychogeriatric and GEM as these care types share a focus on improving functional activities.

8.4.1 Properties

The WHODAS 2.0 is a 36-item scale over six broad domains.\textsuperscript{90, 91-93} It is designed to a disability perspective with the degree of difficulty described as ‘mild’, ‘moderate’, ‘severe’, ‘extreme/cannot do’.

8.4.1.1 Complementarity

There is some overlap with the FIM and RUG-ADL with coverage of mobility and self-care. The other domains of cognition, domestic life, interpersonal interaction, major life areas and community social and civic life would enhance/complement the FIM and RUG-ADL.

8.4.1.2 Population applicability

The instrument is designed for adults with health conditions, without reference to cause or situation, although some items may be difficult to judge in an inpatient environment.

8.4.1.3 Psychometric properties

The construct and discriminant validity and test-retest reliability have been established.\textsuperscript{92} However, there have been no reported studies assessing the predictive validity of the tool.

8.4.1.4 Ease of use

As a modification to the instrument is proposed (section 8.4.2), the ease of use of the revised tool would need to be confirmed but it is judged to be likely to be easy to use.

8.4.1.5 Cost

Information on the tool’s use is freely available on the web.
8.4.2 Potential applicability

The WHODAS 2.0 was specifically designed to provide coverage of the ICF domains\textsuperscript{93} (see Table 7-1) and therefore has much to commend it across the various care types.

The instrument items take three broad forms:

- In five of the six domains ‘\textit{How much difficulty did you have in xxxx?}’ (e.g., ‘… standing up from sitting down’)
- ‘\textit{How much did these difficulties interfere with your life?’}
- In the sixth domain ‘\textit{How much of a problem did you have with xxxx?’} (e.g., joining in community activities).

The WHODAS 2.0 is designed for self-report. The criteria in the first form of questions are activities observable by others (that is, others can observe and report on the degree of difficulty associated with, for example, standing up from sitting down). Therefore, the instructions for completion of these items could be re-drafted to render the validated items observer- (clinician-) reported items. More extensive modifications to the sixth domain would be required, and the second set of questions would not be relevant to ABF purposes, although they may be clinically relevant.

Testing of the reliability of the instrument as an observer-completed instrument would need to be conducted. However, modification and testing of the instrument in this way would overcome the problems associated with the WHODAS 2.0 being a self-report instrument. Modification would require agreement from WHO.

8.5 AUSTRALIAN THERAPY OUTCOME MEASURES

The AusTOMs, like the WHODAS 2.0, are particularly relevant to rehabilitation, psychogeriatric and GEM as these care types share a focus on improving functional activities.

8.5.1 Properties

The AusTOMs were developed to measure difficulty, with the ICF as a basis for their structure and concepts. Developed for physiotherapists, occupational therapists and speech pathologists, the AusTOMs have the potential to be used in ways other than as therapy outcomes.\textsuperscript{91, 94-101} For example, they can be used to describe a patient’s status in relation to some Body Functions and Activities and Participation.

Clinicians use the AusTOMs to report on changes in clients' Body Functions (Impairments), Activities (Limitations) and Participation (Restrictions). The AusTOMs are designed to a disability perspective with the degree of difficulty reported on a six-point scale, where 0 = most severe and 5 = no difficulty. To improve the sensitivity of the scale, clinicians are able to make half-point ratings (e.g., 1.5) to show that a client is performing somewhere between the defined points (e.g., between 1 and 2).
8.5.1.1 Complementarity
As the AusTOMs have been designed so each scale is independent of the others, selected scales could be used in ABF to complement existing instruments in the various care types, provided they were adapted to measure need for assistance.

8.5.1.2 Population applicability
The AusTOMs are not age-, context- or diagnosis-dependent. They can therefore be used with children and adults across different health conditions, with people from various cultures and in different clinical and community settings.

8.5.1.3 Psychometric properties
The concurrent validity and inter-rater reliability have been demonstrated. However, there have been no studies that have assessed the predictive validity of the tool.

8.5.1.4 Ease of use
The various scales are straightforward and the anchor points well described. A training DVD is available for the Occupational Therapy Scales.

8.5.1.5 Cost
Each discipline rating set is available from La Trobe University for $60.50. The rating sheets are included in the once-off cost and do not need to be re-purchased for subsequent uses.

8.5.2 Potential applicability
The AusTOMs measure difficulty, and so are not directly applicable for the measuring of need for assistance. They demonstrate the potential of using the various dimensions of the ICF to develop a flexible range of instruments, based around a construct. The scaling processes for the AusTOMs are further discussed in chapter 11.

8.6 HEALTH OF A NATION OUTCOME SCALES
The HoNOS is relevant to both psycho-geriatric and GEM care types.

8.6.1 Properties
The HoNOS is a widely-used 12-item clinician rating scale. Suitable clinicians are usually psychiatrists or mental health nurses but can include GPs for patients living in the community. A five-point scale is used to rate the most severe episode of behavioural disturbance that occurred during the period rated. The recommended time lapse for this scale is a fortnight. The rating scale ranges from ‘0 – no problem of this kind during the rating period’ to ‘4 – at least one serious attack on others or on animals, destruction of property, serious intimidation or obscene behaviour’.

The HoNOS measures problems, typically in interpersonal relationships, arising from mental health issues. It is not primarily a measure of the patient’s ability to manage activities of daily living; there is only one item regarding such activities. The estimated time required to complete it is about 15 minutes.
8.6.1.1 Complementarity
There is little overlap of content with other scales of impairment except for the Global Assessment of Functioning (GAF).

8.6.1.2 Population applicability
This instrument is intended for patients with mental illness either living in the community or undergoing inpatient hospital treatment.

8.6.1.3 Psychometric properties
Construct and predictive validity have been established. Fair to good measures of both inter-rater and test-retest reliability are reported. The HoNOS is responsive to improvements in clinical condition following treatment.

8.6.1.4 Ease of use
It is designed to be easy though training is available, and this training improves inter-rater reliability.

8.6.1.5 Cost
It is freely available on the web.

8.6.2 Potential applicability
This is a comprehensive and user friendly test of problems in daily living and interpersonal relationships arising from psychiatric illness. It is designed for use by clinicians and therefore places demands on a pressured, expensive resource. If it is used as intended, clinicians would be required to assess each patient at the end of every fortnight.

Its applicability is therefore likely to be low, particularly if a less resource demanding instrument to profile presence and impact of dementia and age-related cognitive decline is found. Potential instruments are discussed below in section 8.7 and 8.8.

8.7 ACTIVITIES OF DAILY LIVING QUESTIONNAIRE

8.7.1 Properties
The ADLQ is a 28-item informant rating scale. Items are concerned with a broad range of activities and each item is rated on a four-point scale from ‘0 – no problem’ to ‘3 – no longer capable of performing that activity’. On some strongly gender-coded household activities (e.g., preparing meals/home repair), the option of a ‘9’ in the rating scale may mean ‘never did this activity’ as well as ‘don’t know’.

8.7.1.1 Complementarity
Given its broad coverage, there is some overlap in content with the RUG-ADL, the ALSAR and the FIM.
8.7.1.2 Population applicability
It is designed for use in outpatient clinic settings, for patients with Alzheimer’s disease and other dementias.

8.7.1.3 Psychometric properties
Criterion, construct and discriminant validity have been established. Test-retest reliability for total score over 8 weeks is good, but there is no information on inter-rater reliability. The ADLQ is a sensitive test and is responsive to deterioration in clinical condition.

8.7.1.4 Ease of use
The ADLQ was designed for use by carers with items that are clear and simple. It is judged likely to be able to be used as a clinician-rated tool (validation would be required). It takes about five to ten minutes to complete.

8.7.1.5 Cost
It is freely available on the web.

8.7.2 Potential applicability
While the ADLQ does not assess challenging behaviours, it assesses changes in ability to perform key ADL activities amongst older patients with dementia. Its sensitivity to change is important given the fact that change in functional ability can be rapid in this population. The design of the rating scale ensures that the activities assessed are relevant to the patient by allowing raters to avoid assessing activities that the patient has never done. The ADLQ is a sound, well-constructed instrument designed to be robust and simple.

The result is calculated as a percentage of the person’s premorbid level of functioning, thus avoiding the need for normative data. Lack of adequate normative data is a very common problem in this field of measurement so that a way to circumvent the need for it is welcome.

This could be a useful scale to assess functioning amongst older patients with dementia.

8.8 ROWLAND UNIVERSAL DEMENTIA ASSESSMENT SCALE

8.8.1 Properties
The RUDAS is a six-item scale which assesses multiple cognitive domains including memory, praxis, language, judgement, drawing and body orientation. It was developed in Australia. It is suitable for use by clinicians to assess dementia. Items are diverse, including a four-item grocery recall list and a request to generate as many animal names as possible within one minute. The choice of problems means that it can be used with patients from a wide range of ethnic backgrounds (unlike the older Mini-mental State Examination [MMSE]). That it has three response formats enables a wide range of clients to respond. It is scored out of 30 with a score
below 23 suggesting dementia. It is the only test reviewed to have included input from a range of population sub-groups in consultation about the design.

8.8.1.1 Complementarity
There is little overlap between the content of the RUDAS and other scales.

8.8.1.2 Population applicability
Older adults (over 65 years) not receiving any formal care for whom a question about dementia has been raised, for example, an older impaired driver.

8.8.1.3 Psychometric properties
Criterion and construct validity have been established. Good reliability is reported.

8.8.1.4 Ease of use
Co-morbid conditions (e.g., depression) must be excluded before testing. A training DVD is available. Although clinician time is required, test administration takes 10 minutes.

8.8.1.5 Cost
It is freely available on the web.

8.8.2 Potential applicability
The RUDAS was designed to assess cognition in people with dementia. Its suitability for a wide range of ethnic groups makes it particularly suitable for a multi-cultural community.

If a diagnosis of dementia is made, planning for the period when people lose their power to give informed consent and to make accurate judgements can be undertaken. It is a useful diagnostic test, although the lack of information on reliability is a concern.

In the psycho-geriatric area, this test might also be a useful alternative to the HoNOS.

8.9 ASSESSMENT OF LIVING SKILLS AND RESOURCES

8.9.1 Properties
The ALSAR is an 11-item clinician rating scale which focuses on the instrumental activities of daily living (e.g., shopping, medication management). The domain focus is on Domestic Life (ICD A&P chapter 6), with only two items applicable to ICF chapters 7, 8 and 9 (see chapter 7).

The ALSAR matches skill deficits with resources available to support the patient with that task. The score on any item is a combination of the patient’s own skills and the availability of resources. This feature bypasses the issue of gender-labelled skills such as cooking. Where the patient is unable to cook/maintain the home, the task may be covered for them by another person, so that it does not pose a problem to independent living.
8.9.1.1 Complementarity
There is some overlap in content between the ALSAR and the ADLQ.

There is little overlap with the FIM. The maps in chapter 7 show that while some domains in the ALSAR and the FIM map to the same ICF A&P chapters, there is no overlap at the finer-grained level in the ICF A&P domains.

8.9.1.2 Population applicability
The ALSAR was designed for adults over 65 living in the community. However, given the nature of the activities, it is not unreasonable to seek to use the ALSAR for adults generally and not only aged people. Clearly testing would be required.

8.9.1.3 Psychometric properties
Content, construct and criterion validity have been shown. Inter-rater and test-retest reliability are both present. The test is responsive to changes in patients’ clinical profiles.

8.9.1.4 Ease of use
Administration requires approximately 20 minutes and scoring requires combining scores for different areas and performing calculations.

8.9.1.5 Cost
The ALSAR is freely available in the public domain. The ALSAR Training Manual is available from the School of Occupational Therapy, La Trobe University.110

8.9.2 Potential applicability
Although administration is complex and demands more time than other instruments reviewed, the ALSAR has good psychometric properties. It can be used to assess maintenance of independent life in the community, identify needs, assess risk, prioritise treatment goals and promote interdisciplinary problem solving7. Useful planning information is captured in the 11 items covered, and this would be a helpful scale in community settings.

8.10 SPINAL CORD INJURY MEASURE

8.10.1 Properties
The SCIM-III is a standardised rating scale of function among patients with spinal cord injuries, a high-cost group. The total score ranges from 0 – 100 and assessment covers the following areas of function: self-care, respiration and sphincter management, and mobility. The test was specifically designed to be more sensitive than the FIM amongst this specialised group and has met this goal.

8.10.1.1 Complementarity
There is overlap with some areas in the FIM (e.g., self-care and locomotion).
8.10.1.2 Population applicability
The SCIM-III is designed for adult patients with paraplegia/quadriplegia (tetraplegia).

8.10.1.3 Psychometric properties
Inter-rater and internal reliability are good. Concurrent and criterion validity have been established. Sensitivity to change is high. Over a period of three months follow-up of rehabilitation, the SCIM-III identified more changes than the FIM.

8.10.1.4 Ease of use
The tasks assessed are clearly described and the scoring is simple so that the scale would be easy to use.

8.10.1.5 Cost
SCIM-III is freely available in the public domain.

8.10.2 Potential applicability
This test has been designed for clinicians to assess the functional abilities of a high-cost group: spinal injury patients. Its psychometric properties are good and its sensitivity to change would make it particularly useful for assessing response to rehabilitation initiatives. It might be useful in measuring the cost-effectiveness of different interventions for people with spinal injuries. Training is not required, completion time is short and the test is freely available: all factors which promote its cost-effectiveness.

8.11 DEVELOPMENT OF A NEW INSTRUMENT BASED ON ICF ACTIVITIES AND PARTICIPATION DOMAINS
As shown in this chapter, each existing instrument has its own limitations and no perfect tool was found.

In the absence of a single existing tool, there are two alternative paths forward:

i) Use more than one instrument to assess the patient

ii) Construct a new instrument

Such an instrument, or combination of instruments, should have the following features:

1. Instrument would be ICF based and used with ICD coded health conditions
2. All Life Areas covered by the Activities and Participation chapters of the ICF would be considered
3. The instrument needs to be clinically credible and useful
4. The instrument would be based on the Need for Assistance as assessed by the user organisation’s staff
5. The instrument should be applicable in ambulatory/community settings as well as inpatient settings
6. The instrument should include all the domains that clinicians consider should be addressed in the provision of care in their care setting
7. Capability to predict expenditure
8. Easy to collect in routine practice

Each of these points is addressed in more detail below.

8.11.1 **Use of the ICD and ICF together**

ICD-10-AM codes are collected for all admitted patients, according to the Australian Coding Standards. For rehabilitation care patients, the code Z50.- must be used as the principal diagnosis. For casemix purposes, this code needs to be disregarded as it is simply a flag for rehabilitation care (The second condition coded (immediately after Z50.-) is referred to here for clarity as the ‘main condition’).

The remaining ICD codes, taken together, provide a full picture of the patient’s health status which requires treatment and care during the admission.

The use of the ICF and ICD together ensures that a full description of health status is obtained and that elements of the instruments are relevant at all stages of the patient journey.

8.11.2 **All A&P domains to be considered**

The ICF Activities and Participation codes provide a complete set of domains covering all life areas relevant to all people.

Clear advice was received in the course of the consultations that the rehabilitation care provided to the full spectrum of patients requires consideration of this full range. For relatively straightforward inpatient care, not all Activities and Participation domains may be relevant. But the patient’s circumstances (economic, social) may mean that many life areas are involved.

Anderson and Madden\(^{113}\) showed that the ICF 'support needs' in one subset of the ICF Activities and Participation domains could not be used to predict values in another subset when dealing with a diverse population.

The domains assessed for other subacute care types should be broad enough to cover all aspects of care as specified in the care type definition. The counter argument that there is no evidence that covering all the ICF domains will provide the needed improvement in identifying cost drivers for subacute care, needs to be tested (rather than simply asserted). Only by collecting data on the various domains, then testing its predictive power, can such an assertion be tested.
8.11.3 Clinical credibility and utility
Collection of a patient assessment using an instrument requires substantial time from busy clinicians, as well as time for training to learn to use the instrument. Therefore, to justify the time used, and to engage the clinician to correctly apply the instrument, an instrument should be credible and useful to the clinician.

The trade off between instruments designed for a specific health condition or impairment group and generic instruments was repeatedly raised during the consultations. Views about the clinical value of various generic instruments differed across clinicians. It was also pointed out that an instrument could assist in the allocation of resources within an organisation.

8.11.4 Need for Assistance and completion by organisation
Many instruments aim to assess a person’s difficulties in functioning, or their disabilities. While several such instruments cover the full range of ICF Activities and Participation domains, a person’s difficulties in functioning impact on the cost of rehabilitation only where they are addressed as needs in the rehabilitation care plan. While there is some link between difficulties and need for assistance, e.g., a person with extreme difficulty will generally require assistance, the concept of difficulty and need for assistance are distinct.

Several existing instruments are based on need for assistance (e.g., the FIM, Barthel, RUG-ADL). The FIM and RUG-ADL are used for expenditure prediction in the AN-SNAP at present.

Need for Assistance is defined in the National Health Data Dictionary as ‘the level of help and/or supervision a person requires...to perform tasks and actions in a specified life area, as represented by a (ICF) code’. Use of this national definition would be desirable.

If an instrument is to be used for cost prediction, it is important that the assessment be completed by the treating organisation’s staff. The organisation must be responsible for the information used. However, some of the information may be provided by the patient to the organisation’s staff.

8.11.5 Use of instruments in inpatient and community settings
Increasingly, rehabilitation care takes place in a variety of settings. Hub and spoke hospital arrangements, described in chapter 8, and hospital in the home arrangements are being actively developed. There is a strong recognition that rehabilitation is enhanced when a person is at home, so there is a clear incentive (beyond the financial one) to discharge patients from hospital as soon as clinically feasible. Thus assessments must be usable across settings to avoid wasteful duplication and additional response burdens for patients and staff.

8.11.6 Coverage of clinically relevant domains
An instrument needs to cover sufficient domains so that it can assess the needs of the wide variety of patients treated in a particular setting (such as inpatient care). Many patients have relatively clear cut and limited needs in relation to self-care and mobility, and may be admitted
to a facility only addressing these needs. Others will have a broader range of needs, including communication, behaviour and capacity to perform a range of tasks.

Assessment domains not requiring assistance in a particular situation should be coded as ‘no assistance required’, taking minimal time. But the presence of the domain in the instrument could also serve as a check that all domains relevant to the particular patient have been considered in the care plan.

8.11.7 Capability to predict expenditure
To test the capacity of the instrument to predict expenditure it is important that it be collected from the full range of rehabilitation care providers across Australia. This involves:

- Stand alone rehabilitation hospitals and integrated facilities
- Those with complex and more common caseload
- A broad spread across geographic areas
- A good representation of Aboriginal and Torres Strait Islander patients. This can best be achieved by national data collection.

8.12 CONCLUSION
A range of instruments has been examined in this chapter. Instruments in extensive use in the AN-SNAP (the FIM, RUG-ADL and HoNOS) were reviewed to indicate strengths and weaknesses. Then a range of alternative instruments was reviewed. While each had some attractive features, and could overcome some disadvantages of currently used instruments, none were sufficiently attractive to recommend as suitable to replace currently-used instruments.

Some of the attractive features of instruments reviewed here are returned to in later chapters.

Criteria for evaluation of a new instrument have also been described.
9 SPECIFIC POPULATIONS: DISCUSSION OF FINDINGS

9.1 CHILDREN

9.1.1 Instruments
While there are many instruments that address children’s function by examining developmental skills, none have been located that cover the span of childhood (0-16) and meet other ABF requirements. The PEDI and the WeeFIM are only recommended for children up to age 7. These instruments may be used for older children if the child’s skills do not exceed the upper developmental age specified. The PEDI takes about two hours to complete, whereas the WeeFIM is relatively quick.

For paediatric rehabilitation, the WeeFIM is the most commonly-used instrument. The domains covered by the WeeFIM are the 18 FIM domains. Support was expressed for use of another instrument, possibly in conjunction with the WeeFIM, to overcome the limitations of the latter in relation to cognition and psychosocial factors (as earlier observed for the FIM).

An instrument for possible consideration in this regard is the Child and Adolescent Scale of Participation (CASP). This instrument has not been discussed in earlier chapters as its possible applicability was only recognised late in the project. The CASP is discussed in chapter 11.

For palliative care, the various PCOC measures (including the RUG-ADL) are not appropriate, and there are no validated tools for children. As discussed in chapter 5, the Australian New Zealand Paediatric Palliative Care Reference Group is keen to modify the PCOC instruments for use with children.

9.1.2 Use of care types
There was little comment on children during the consultations. An offer during the NSW consultation to have further discussion with paediatric experts was followed up with a meeting at Westmead Children’s Hospital (also attended by an expert from Sydney Children’s Hospital and the project team’s child assessment experts).

The advice received was that subacute care types are not often used for children, with rehabilitation or palliative care being provided in conjunction with acute care, and under the management of a single specialist clinician. The paediatric rehabilitation specialists said rehabilitation generally starts during acute care (sometimes in intensive care), and the treating physician remains the acute specialist, or the rehabilitation specialist is added as a second specialist. There is generally no change of care type. One of the international experts in the project team (Dr Andrea Martinuzzi) participated in this discussion and said the situation described mirrored that in his experience in Italy.

Towards the end of the project, additional valuable feedback on paediatric rehabilitation assessment in other States was received. This indicated that the rehabilitation care type is
used, although the timing of the switch is rather arbitrary because of the mix of care being provided to the patients.

In 2008-09, there were 114 palliative care separations at age 0-14 from Australian hospitals (see Appendix 10); based on feedback during the consultations, it is likely that a significant proportion of these were identified via the ICD code for palliative care (Z51.5), rather than through the care type. One respondent reported the use of the palliative care type as part of a funding condition imposed by the Department of Health and Ageing, and said it was difficult to separate the acute care and palliative care types (a ‘clunky’ process). A meeting with the Australia New Zealand Paediatric Palliative Care Reference Group late in the project to discuss all the issues surrounding assessment of paediatric palliative care patients was most helpful in explaining the present inconsistencies in regard to classification of children receiving palliative care.

9.1.3 Proposed changes to data collections

There is a significant structural problem in the use of ABF for children that should be addressed separately from the adult issues. Subacute care types are inconsistently used for children because care is often provided simultaneously across acute and subacute care. Where rehabilitation or palliative care is provided to an acute care type patient, there is currently no flag to recognise the additional costs of these services, resulting in a fear by stakeholders that NEPs will not properly recognise or resource their work.

A possible way forward is to augment the identification of patients receiving subacute care through the use of appropriate ICD codes:

1) The appropriate ICD code should be used to indicate that subacute care is being provided, whether the relevant care type is used or not:
   - For palliative care, the existing code Z51.5 and the associated Australian Coding Standard 0224114(p. 78) are appropriate.
   - For rehabilitation, code Z50 is currently designated by Australian Coding Standard 2104 to be used as a principal diagnosis code, to apply to admissions for the purpose of rehabilitation. The coding standard would need revision to permit use as an additional diagnosis code (mirroring the palliative care situation). This could be done through the existing ICD-10-AM updating process.

2) Functioning data should be collected for children when rehabilitation or palliative care is provided. Provision of such care should be documented in the patient’s record, and so will in due course be coded using the Z codes.

This changed process would allow an analysis of costs for those acute care type children where rehabilitation or palliative care is also provided. Analysis of the functioning data for these children would identify possible cost predictors for these additional services, separate from the acute care costs.

Practical consequences of these changes in coding practice are addressed in chapter 16.
9.2 ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

There was limited comment on any specific issues for Aboriginal and Torres Strait Islander peoples during the consultations with jurisdictions. No one present identified themselves as being of Aboriginal or Torres Strait Islander origin.

During the NT consultation, it was observed that Aboriginal and Torres Strait Islander peoples have specific priorities in relation to their culture; these impact on their involvement in activities and participation, such as returning to country and attendance at a funeral. These priorities can have significant resource implications. These matters reinforce the need for a broad range of activities and participation domains to be considered.

The current approach to Aboriginal and Torres Strait Islander health problems is to arrange the provision of care in the total context of a person’s life. Care needs to be continuous between inpatient and outpatient settings. In many cases, an assessment in the community will not be possible (especially, but not only, in rural and remote areas). So it is vital that all domains of rehabilitation are addressed in the early stages of rehabilitation planning and care.

There has been some testing of the ability of the ICF to capture the various aspects of Aboriginal life. This found that there was a good fit. All Activities and Participation chapters are needed for this purpose. Senior examined the issue (based on the ICIDH) when the ICF was being developed. She found that ‘when the high levels of unmet need for Aboriginal people with disabilities are considered, there is a role for the ICIDH to be used to document and classify these needs. As a classification tool the ICIDH has been found to be broad enough to be used in the Aboriginal context and the concepts of activity and participation are ones that translate well into people's everyday experience.’

In completing an assessment, it is essential that a culturally-competent person be involved in the process. An Aboriginal Health Worker is well placed to take on this role. The training provided to these people fits them well to deal with the needs and aspirations of Aboriginal and Torres Strait Islander patients, as well as the clinical needs of the rehabilitation care plan. The Aboriginal and Torres Strait Islander Health Workers are critical in the delivery of primary health care to Aboriginal and Torres Strait Islander peoples, whether in the community-controlled or the mainstream health system. Their qualifications consist of competency based education and training and they play a key role in facilitating access to the health system for Aboriginal and Torres Strait Islander peoples.

9.3 RURAL AND REMOTE COMMUNITIES

During the consultations, a hub and spoke model of rehabilitation care was described. This involves initial assessment and care at a regional hospital, followed by transfer to a smaller hospital for later stages of the plan. While there may be community based services to support a patient after discharge from the larger hospital, a patient may not have access to such services in less populated areas, and so have a longer stay as an inpatient in the ‘spoke’ hospital.
Clearly, this model requires the initial assessment to support all stages of the rehabilitation care plan, including those that might be provided in a community setting in urban areas. The instrument used in the hub hospital has to cover the necessary scope of domains applicable to care at the hub and the spoke hospitals.

Training in the use of instruments is a particular concern in rural and remote areas, and is sometimes difficult to arrange for staff in rural and remote areas. Moreover, this staffs have high turnover rates, meaning training has to be provided on a more frequent basis than in urban centres. Instruments that require less training may therefore appear more attractive for use in rural and remote areas. However, during the consultations, it was pointed out that a well organised program, with established train the trainer provisions, and the opportunity for remote learning, may act to offset the more rigorous training requirements of an instrument.

The multidisciplinary team using an assessment instrument in a rural or remote setting may be smaller than in an urban one, and multi-tasking may be common. Instruments that are less specialised would be an advantage in these cases. This argues against the use of instruments designed for specific health conditions and in favour of generic instruments.

9.4 PATIENTS IN DIFFERENT TREATMENT SETTINGS

During the consultations with jurisdictions, some have argued that in the inpatient rehabilitation setting, the main focus is on ‘basic’ activities such as mobility within the home, self-care and communication. An alternative view was that more domains need to be considered when rehabilitation is taking place in a non-admitted setting. These include transport, managing a household, inter-personal relations and economic and social participation. In effect, activities and participation items are part of a continuum which are treated across a range of rehabilitation services (inpatient/day hospital/non-inpatient); the best way to capture the patient journey is to have an assessment tool which can cover the domains relevant to the various stages of this continuum.

Similar comments were made about the broad range of goals that patients receiving palliative care in the community may have.

Modern health care paths, especially in subacute care, emphasise early discharge from hospital and seamless transition to community based care. This argues strongly for an approach where assessment is done once, and repeated only when clinical circumstances require it, not simply a change of setting. In turn, this means the initial inpatient based assessment needs to cover as many domains as feasible at the time. The instrument used should have broad coverage, even though not all domains may be assessable all the time.

The issues discussed above in relation to Aboriginal and Torres Strait Islander peoples and people living in rural and remote areas, highlight the continuity needed between hospital care and community care.
Repeated assessments at change of setting, in the absence of clinical need, may result in assessment duplication. Using different instruments in different settings does not allow comparison or evaluation of progress across settings, with possible adverse outcomes for patients.

9.5 GEM PATIENTS

The consultations indicated that the GEM care type is not used consistently across the various jurisdictions (and possibly within them). The GEM care type is most widely used in Victoria (346,469 separations out of an Australian total of 507,556 separations from public hospitals in 2010-11, or 68%: Australian Hospital Statistics 2010-11, Table S7.5. Offsetting this, the number of rehabilitation care type patients is relatively lower in Victoria (compared to NSW and Queensland)

During the Victorian consultation discussion, it was argued that the FIM does not have much utility (clinical or resource) for this care type. Consequently, the AN-SNAP does not explain much variation in cost. The PwC report had explained the issues, particularly around the importance of co-morbidities. The aims of the patient are crucial to the care provided, and whether these are achievable.

The differences between rehabilitation and GEM were discussed during the Victorian consultation. Active medical and nursing management is a key part of GEM care, with consequent cost impacts relative to rehabilitation care.

In summary, the GEM patient has multi-dimensional needs that should drive resource intensity in best practice subacute care. Consequently, consideration of the full range of ICF A&P domains is needed to describe the patient’s needs for assistance. Omitting key domains risks introducing perverse incentives through inadequate pricing.

It is likely that the long-term use of casemix funding in Victoria has encouraged the identification of GEM care type patients. With national activity based funding, there may be similar moves in other jurisdictions. During the NSW consultation, the view was expressed that a common (but not universal) practice has been to use the rehabilitation care type instead of GEM.
10 DISCUSSION AND THE WAY FORWARD

10.1 INTRODUCTION

In this chapter, the findings from the preceding chapters are brought together to respond to the requirement to:

Identify tools for inclusion in the long-term classification system, which address deficiencies in existing tools for each care type, and options to address the issues raised in relation to children, ambulatory and GEM patient groups, and best explain resource use.

Earlier chapters have evaluated a range of instruments for use in subacute care, including those currently in use. Each of these measures has strengths and limitations. Several enjoy considerable support in Australia, but also attract a range of criticism.

A complete replacement of the current model and instruments in a single step would be expensive, unlikely to be readily accepted by jurisdictions that have invested heavily in IT infrastructure, and may attract significant costs such as staff re-training. Consequently, the options put forward are designed to build on, and evolve from, the instruments already in place.

The approach taken in developing options has sought to avoid licensing and intellectual property issues, but expert advice has not been sought on this matter.
11 REHABILITATION

11.1 DEFINITION

The revised rehabilitation definition (14) is:

Rehabilitation care is care in which the primary clinical purpose or treatment goal is improvement in the functioning of a patient with an impairment, activity limitation or participation restriction due to a health condition. The patient will be capable of actively participating.

Rehabilitation care is always:

• Delivered under the management of, or informed by, a clinician with specialised expertise in rehabilitation; and
• Evidenced by an individualised multidisciplinary management plan, which is documented in the patient’s medical record, that includes negotiated goals within specified time frames and formal assessment of functional ability.

The 2011 WHO/World Bank World Report on Disability considered the definition of rehabilitation. It noted that: ‘the term has described a range of responses … from interventions to improve body function to more comprehensive measures designed to promote inclusion…’119 (p. 95)

The World Report defined rehabilitation as a ‘set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment, using the following broad outcomes:

• Prevention of the loss of function
• Slowing the rate of loss of function
• Improvement or restoration of function
• Compensation for lost function
• Maintenance of current function.’119(p.96-97)

The World Report, on the basis of expert opinion, notes that the ICF provides a framework that can be used for all aspects of rehabilitation, in that rehabilitation measures target body functions and structures, activities and participation, environmental factors, and personal factors.

Both the revised care type definition and the World Report discussion suggest that all ICF Activities and Participation domains should be considered in planning and describing a rehabilitation program. The care included in a program may reflect the setting of care; an inpatient program may focus on different patient needs to a community-based program.

Two options are discussed. The first proposes the use of another instrument alongside the FIM. The second proposes the development of a new instrument based directly on the ICF, with maps from the FIM where possible.
11.2 OPTION 1: USE OF AN ADDITIONAL INSTRUMENT WITH THE FIM

One option is to use a second instrument in addition, and as a complement, to the FIM. This would be based on need for assistance and also would cover ICF A&P domains that are not included, or that are covered only partially, in the FIM.

Table 7-1 shows that instruments in use for ABF purposes measuring need for assistance (FIM, RUG-ADL) do not have good coverage of chapters 6 to 9 of the ICF. These chapters cover Domestic life, Interpersonal interactions and relationships, Major life areas and Community, social and civic life.

Some other instruments cover important domains missing from the FIM, but most would need adaptation to assess need for assistance.

The Assessment of Living Skills and Resources (ALSAR) merits close examination. The ALSAR was designed to assess the skills of older people to carry out a range of tasks, and the resources available to assist in carrying out the tasks. Combining the skills and resources produces an index of risk in relation to each task. The ALSAR focuses on the later ICF A&P chapters. Of 11 domains, 6 map to domains contained in ICF A&P Chapter 6, Domestic Life, and two others map to Chapters 8 and 9. As noted in chapter 5, the 11 ALSAR domains include the 8 domains included in the Lawton’s Instrumental Activities of Daily Living Scale, which is included in the AROC data collection for non-admitted rehabilitation patients.

Table 11-1 shows the maps from FIM and ALSAR to ICF domains, arranged in ICF A&P chapter order (chapter 7 explains the mapping process). It can be seen that no FIM or ALSAR domain map to the same specific ICF A&P domain. Together, the FIM and the ALSAR provide a good coverage of ICF A&P domains.
### Table 11-1: FIM and ALSAR coverage of ICF Activities and Participation domains

<table>
<thead>
<tr>
<th>ICF A&amp;P chapter</th>
<th>FIM items</th>
<th>ALSAR items</th>
</tr>
</thead>
<tbody>
<tr>
<td>No.</td>
<td>Title</td>
<td>No.</td>
</tr>
<tr>
<td>1</td>
<td>Learning and applying knowledge</td>
<td>17</td>
</tr>
<tr>
<td>2</td>
<td>General tasks and demands</td>
<td>18</td>
</tr>
<tr>
<td>3</td>
<td>Communication</td>
<td>14</td>
</tr>
<tr>
<td>4</td>
<td>Mobility</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>Transfers: bed, chair</td>
<td>d4104, d4200, d4201</td>
</tr>
<tr>
<td>11</td>
<td>Transfers: tub to shower</td>
<td>d410, d4104</td>
</tr>
<tr>
<td>12</td>
<td>Walking or using wheelchair</td>
<td>d4600, d4601, d465</td>
</tr>
<tr>
<td>13</td>
<td>Stairs</td>
<td>d4551</td>
</tr>
<tr>
<td>5</td>
<td>Self-care</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Grooming</td>
<td>d5100, d5200, d5201, d5202</td>
</tr>
<tr>
<td>3</td>
<td>Bathing</td>
<td>d5101</td>
</tr>
<tr>
<td>4</td>
<td>Dressing: upper body</td>
<td>d540</td>
</tr>
<tr>
<td>5</td>
<td>Dressing: lower body</td>
<td>d540</td>
</tr>
<tr>
<td>6</td>
<td>Toileting</td>
<td>d5100, d5300, d5301, d530</td>
</tr>
<tr>
<td>10</td>
<td>Transfer: toilet</td>
<td>d530</td>
</tr>
<tr>
<td>6</td>
<td>Domestic life</td>
<td>8</td>
</tr>
<tr>
<td>9</td>
<td>Meal preparation</td>
<td>d630</td>
</tr>
<tr>
<td>10</td>
<td>Laundering</td>
<td>d6400, d6403</td>
</tr>
<tr>
<td>11</td>
<td>Housekeeping</td>
<td>d640</td>
</tr>
<tr>
<td>7</td>
<td>Interpersonal interactions and relationships</td>
<td>16</td>
</tr>
<tr>
<td>8</td>
<td>Major life areas</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Learning and Community, social and civic life</td>
<td>5</td>
</tr>
</tbody>
</table>
The complementarity of the FIM and ALSAR domains raises the possibility of joint use. A strong view expressed during the consultations, and in particular from the Australian Faculty of Rehabilitation Medicine, is that in view of the large investment over many years in introducing the FIM and obtaining the necessary assessment skills, its use should continue in the medium term for inpatients. It is recognised by stakeholders that the FIM has limitations, and that its use is mainly for admitted patients. But it has been made clear that a preferred way to cover domains not included in the FIM would be through the use of a second instrument.

There are two issues to be considered. First, the ALSAR was designed for older people living in the community. Its capacity to add to the FIM's capacity to predict rehabilitation expenditure through the inclusion of additional domains, especially for inpatients, cannot be determined in the absence of evidence, and therefore needs to be tested. Second, the ALSAR measures risk, and it needs to be determined how closely this relates to need for assistance. The ALSAR assesses 'skills' (accomplishment of tasks) and resources available to assist the task accomplishment: in principle, this residual skills gap is akin to need for assistance. Again, the actual utility of the risk measure as a proxy for need for assistance would need to be tested.

Skills and resources are each measured on a three-point scale, and the scores are added to give risk on a five-point scale. The ALSAR has been reviewed by Clemson et al., who proposed an alternate nine-point scale.

Other instruments do not provide as much potential as the ALSAR. The Occupational Therapy section of the Australian Therapy Outcome Measures (AusTOMs) covers domains missing from the FIM. However, the AusTOMs measure difficulty, not need for assistance, and are a set of distinct domains, with no metric specified to combine domain scores. (Some features of the AusTOMs are addressed below).

The FIM+FAM combination was discussed in chapter 5, noting Tate's\(^7\) and McDowell's\(^8\) conclusion that the combination did not appreciably add to the FIM.

The Participation Objective Participation Subjective (POPS, 24 items from ICF chapters 6-9) is based on the ICF and aims to gather information on a range of Life Areas. However, as discussed in chapter 5, POPS was excluded at Phase 1 of the instrument evaluation process.

It was noted that the Community Integration Questionnaire (CIQ, 13 items from the ICF chapters 6-9, one mobility item) also covers domains missing from the FIM. The CIQ had not been included in instruments examined in the report. The CIQ is a self-report outcome measure and was seen as less relevant for purposes of this project than scales with similar coverage, including the ALSAR and Lawton's IADLS (the latter was discussed in chapter 5).

The conclusion is that the ALSAR provides the best option for an instrument to use alongside the FIM. Domains are complementary, and together the domains provide broad coverage of ICF Activities and Participation domains.

However, the concerns about cognition in using the FIM are not explicitly addressed through use of the ALSAR - which does not include any ICF A&P Chapter 1 (Learning and applying...
knowledge) domains; several ALSAR domains require a certain cognition level, and this may be seen as adequate by stakeholders.

To assess cognition directly, an instrument such as the RUDAS could be considered. The RUDAS, developed in Australia, is discussed in chapter 8. It was designed for older people with dementia, and so would need testing for use across a broader age span and range of health conditions. The implications of ‘double counting’ of cognition (through the FIM and the RUDAS) would need to be considered.

If the clinician assessing the patient considers that the FIM domains adequately assess the patient’s need for assistance, it is suggested that the lowest level of risk in the ALSAR domains (and overall) be recorded. This would remove the need for separate assessment if the clinician did not think it necessary.

One limitation that would remain with use of the FIM and the ALSAR (and possibly the RUDAS) is the allowance for Behaviours of Concern. This matter is discussed in section 11.6 below.

11.3 OPTION 2: BUILDING A COMPREHENSIVE INSTRUMENT FOR REHABILITATION ASSESSMENT

11.3.1 Choosing the domains

The domains used for grouping patients in casemix systems for acute patients are diagnoses and interventions. Complexity is allowed for through the use of complications and co-morbidity codes, also based on diagnoses. Instruments are not used to combine these domains to form scores.

A parallel path for grouping subacute patients is to use principal diagnosis based groups, then define sub-groups based on scores in specific functioning domains or groups of domains that are shown to result in sub-groups with similar costs. Diagnoses are drawn from the ICD-10-AM. Functioning domains are drawn from the ICF A&P chapters.

The AN-SNAP for rehabilitation uses some of these features: the ‘impairment’ codes are in fact groups of diagnoses, and functioning is assessed using relatively narrowly defined (fine grained) FIM domains. Functioning scores are combined across a broad range of domains (FIM mobility, FIM cognition, total FIM score).

What functioning domains should be used? Anderson and Madden have shown that it is not possible to use some ICF domains as proxies for others when dealing with diverse populations. So the starting point would be to include all ICF A&P domains. This approach could easily result in an unworkably large model unless a broad level of granularity is generally used.

There is existing support for the use of a parsimonious set of domains to cover the full breadth of the ICF A&P domains. Kostanjsek et al. discuss the development of a list of ‘functioning properties’ to allow joint use of the ICD and the ICF. This list contains 38 A&P domains.
To select a parsimonious set of domains for a rehabilitation care assessment instrument, the structure of the WHODAS 2.0 model was used. This has six sections to cover all A&P chapters:

- Cognition (A&P chapters 1 and 3)
- Mobility (A&P chapter 4)
- Self-care (A&P chapter 5)
- Getting along (A&P chapter 7)
- Performance in major areas of life (A&P chapters 6 and 8)
- Community participation (A&P chapter 9)

As well, given the inclusion of the FIM in the AN-SNAP and its national use from 2013, attention was given to ensuring that the domains included in the proposed instrument were mappable from FIM items where possible. The proposed instrument that has been developed is referred to as AusRehab and is set out in Table 11-2.
<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>ICF Activities and Participation Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Learning, management and communication</strong></td>
<td></td>
</tr>
<tr>
<td>1. Learning and applying knowledge</td>
<td>Chapter 1 (d110-d199)</td>
</tr>
<tr>
<td>2. Carrying out tasks and daily routine</td>
<td>d210, d220, d230</td>
</tr>
<tr>
<td>3. Communicating – receiving</td>
<td>d310, d315</td>
</tr>
<tr>
<td>4. Communication – producing</td>
<td>d330, d335</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td>5. Changing and maintaining body position</td>
<td>d410, d415, d420</td>
</tr>
<tr>
<td>6. Walking and moving around with and without equipment</td>
<td>d450, d455, d460, d465</td>
</tr>
<tr>
<td>7. Moving around using transportation</td>
<td>d470, d475, d480</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td></td>
</tr>
<tr>
<td>8. Personal hygiene</td>
<td>d510, d520, d530</td>
</tr>
<tr>
<td>9. Dressing</td>
<td>d540</td>
</tr>
<tr>
<td>10. Eating</td>
<td>d550</td>
</tr>
<tr>
<td><strong>Getting along with people</strong></td>
<td></td>
</tr>
<tr>
<td>11. Complex interpersonal interactions</td>
<td>d720</td>
</tr>
<tr>
<td>12. Formal relationships (including service providers)</td>
<td>d740</td>
</tr>
<tr>
<td>13. Family relationships</td>
<td>d760</td>
</tr>
<tr>
<td><strong>Performance in major areas of life</strong></td>
<td></td>
</tr>
<tr>
<td>14. Acquiring necessities</td>
<td>d610, d620, d860</td>
</tr>
<tr>
<td>15. Household tasks</td>
<td>d630, d640</td>
</tr>
<tr>
<td>16. Education</td>
<td>d810-839</td>
</tr>
<tr>
<td>17. Work and economic life</td>
<td>d840-d855, d865, d870</td>
</tr>
<tr>
<td><strong>Community participation</strong></td>
<td></td>
</tr>
<tr>
<td>18. Community, social and civic life</td>
<td>Chapter 9 (d910-d999)</td>
</tr>
</tbody>
</table>

The domains chosen have different levels of granularity. This reflects the construction criteria described above. The domains would need to be kept under review, with the intention over time to remove domains which do not add explanatory power, by combining them with other domains.
11.3.2 MAPS FROM OTHER INSTRUMENTS

11.3.2.1 FIM

There are six domains in AusRehab that can be mapped from the FIM (using the map in Appendix 9-3) as shown in Table 11-3.

Table 11-3: Maps from FIM to AusRehab

<table>
<thead>
<tr>
<th>FIM</th>
<th>AusRehab domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehension</td>
<td>3 Communicating - receiving</td>
</tr>
<tr>
<td>Expression</td>
<td>4 Communication - producing</td>
</tr>
<tr>
<td>Walk/wheelchair</td>
<td>6 Walking and moving around with and without equipment</td>
</tr>
<tr>
<td>Bathing + Grooming + Toileting</td>
<td>8 Personal hygiene</td>
</tr>
<tr>
<td>Dressing</td>
<td>9 Dressing</td>
</tr>
<tr>
<td>Eating</td>
<td>10 Eating</td>
</tr>
</tbody>
</table>

Note that AusRehab domain 8 is mapped from three FIM domains.

This mapping is important because the various FIM domains have been the subject of substantial validation studies, as discussed in chapter 8. The extent to which these items are validated gives confidence that similar validity will apply to the corresponding items included in AusRehab.

The FIM contains ten items in addition to the eight listed above. Of the FIM Mobility items:

- Dressing is one domain in the AusRehab model, two in the FIM: upper body dressing and lower body dressing are not distinguished in the ICF.
- Sphincter control (bladder, bowel) are two FIM items. Toileting in the ICF includes regulation of urination and defecation.
- Transfers are three FIM items (bed to chair, toilet, bath/shower). The ICF uses more generic terms (changing basic body position, maintaining a body position, transferring oneself) within the ‘Changing and maintaining body position’ category (d410-420).
- Climbing stairs is a separate domain in FIM but is included under ‘Moving around’ in the ICF (d455).

The FIM Cognition items are at different levels of granularity, and cannot be mapped to AusRehab:

- Social interaction is a broad term in the FIM and maps to A&P chapter 7.
- Problem solving (d175) is part of Learning and Applying Knowledge.
- Memory, which maps to d159, is also part of Learning and Applying Knowledge.

It is important to note that the fifth and sixth group of items in AusRehab, Performance in major areas of life and Community participation, are not included in the FIM. These groups comprise the following ICF A&P chapters:
• Domestic life: Chapter 6
• Major life areas: Chapter 8
• Community, social and civic life: Chapter 9.

11.3.2.2 AusTOMs
While the AusTOMs measure difficulties with various domains, not need for assistance, the domain structure of several of the AusTOMs is based directly on ICF A&P chapters. The AusTOMs have been the subject of psychometric evaluation.

The comparison with the AusTOMs for Occupational Therapy is set out in Table 11-4.

Table 11-4: Comparison of AusRehab-domains and AusTOMs

<table>
<thead>
<tr>
<th>AusRehab</th>
<th>AusTOMs</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Learning and applying knowledge</td>
<td>1 Learning and applying knowledge</td>
<td>Exact match</td>
</tr>
<tr>
<td>2 Carrying out tasks and daily routine</td>
<td>4 Carrying out daily life tasks and routines</td>
<td>Exact match</td>
</tr>
<tr>
<td>3 Communication – receiving Speech therapy AusTOM 6 (Cognitive-Communication)</td>
<td>Many to one match</td>
<td></td>
</tr>
<tr>
<td>4 Communication – producing As above</td>
<td>As above</td>
<td>As above</td>
</tr>
<tr>
<td>5 Changing and maintaining body position 5 Transfers</td>
<td>Exact match</td>
<td></td>
</tr>
<tr>
<td>6 Walking and moving around with and without equipment 2 Functional walking and mobility</td>
<td>Near match, AusTOMs excludes powered devices</td>
<td></td>
</tr>
<tr>
<td>7 Moving around using transportation 6 Using transport</td>
<td>Exact match</td>
<td></td>
</tr>
<tr>
<td>8 Personal hygiene</td>
<td>7 Self-care</td>
<td>Many to one match</td>
</tr>
<tr>
<td>9 Dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Complex interpersonal interactions 10 Interpersonal interactions and relationships</td>
<td>Aus Rehab has greater granularity; AusTOMs is broader than the 3 AusRehab domains</td>
<td></td>
</tr>
<tr>
<td>12 Formal relationships (including service providers)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Family relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Acquiring necessities 9 Domestic life - managing resources</td>
<td>Exact match</td>
<td></td>
</tr>
<tr>
<td>15 Household tasks 8 Domestic life - home</td>
<td>Part match, AusTOMs broader</td>
<td></td>
</tr>
<tr>
<td>16 Education 11 Work, employment and education</td>
<td>Many to one match, AusTOMs omits economic life</td>
<td></td>
</tr>
<tr>
<td>17 Work and economic life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 Community, social and civic life 12 Community life, recreation, leisure and play</td>
<td>AusTOMs omits human rights and political life and citizenship</td>
<td></td>
</tr>
</tbody>
</table>

The substantial degree of alignment between AusRehab and the AusTOMs is not surprising. The AusTOMs ‘use the concepts of health outlined by the WHO in the ICF’.

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The alignment with AusTOMs is important because AusTOMs assessments are designed to be based on the clinician’s view (rather than self-report) and because a scoring system (relating to difficulty) is in place (see next section).

11.3.3 SCALING
Along with selection of domains, instrument design requires decisions on scaling. As discussed previously, the instrument is designed to measure need for assistance and to be completed by the treating organisation’s staff.

An alternative would be to consider the Need for Assistance data item in the National Health Data Dictionary (NHDD). This includes a four-point scale:

- 0 Does not need help/supervision
- 1 Sometimes needs help/supervision
- 2 Always needs help/supervision
- 3 Unable to do this task or action, even with supervision.

This is based on frequency of assistance, rather than intensity. The two are related but separate constructs.

Anderson and Madden\textsuperscript{113} discuss the value of identifying ‘frequency of support needs’ questions. Such scaling has been used in the ABS Survey of Disability, Ageing and Carers (SDAC) and has been successfully used in the national disability services collection. In the SDAC, the questions are self-report, but in the disability services collection they are used to collect data reported by thousands of service providers and based on records or instruments in use.

The FIM uses a seven-point scale for ‘assistance’ while the AusTOMs use a six-point scale (to assess difficulty). Table 11-5 shows the comparison across these scales and the NHDD four-point scale:

<table>
<thead>
<tr>
<th>Table 11-5: Comparison of Scales</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIM Scale</strong></td>
</tr>
<tr>
<td>Complete independence</td>
</tr>
<tr>
<td>Modified independence (with a device)</td>
</tr>
<tr>
<td>Supervision or set-up required</td>
</tr>
<tr>
<td>Minimal assistance</td>
</tr>
<tr>
<td>Moderate assistance</td>
</tr>
<tr>
<td>Maximum assistance</td>
</tr>
<tr>
<td>Total assistance</td>
</tr>
</tbody>
</table>
A four-point scale may not be sensitive enough for casemix uses. However, successful use demonstrates the value of the concept and its meaningfulness to a range of respondents.

Table 11-6 shows a possible scale (along with a possible FIM scale map) for use with AusRehab. This is an intensity five-point scale. The intensity/frequency issue, as well as the FIM scale map, should be further considered, and then tested, in finalising a scale; both clinical relevance and sensitivity for activity based funding purposes need to be taken into account.

Table 11-6: AusRehab scale and comparison with FIM scale

<table>
<thead>
<tr>
<th>AusRehab Scale</th>
<th>FIM Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>6,7</td>
</tr>
<tr>
<td>4</td>
<td>4,5</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

A description of each scale level for each of the 18 AusRehab domains is required. The AusTOMs provide insight into possible descriptions using details from the relevant ICF chapter (e.g., Learning and applying knowledge, Activity Limitation, level 2: Moderate/severe difficulty in Learning and applying knowledge: ‘Able to apply learning to a simple, familiar or structured activity, often not at a developmentally appropriate level and with constant verbal prompting and direction. Does not transfer learnt steps of activity to another activity by self.’)

11.4 BEHAVIOURS OF CONCERN

Challenging behaviour (behaviours of concern) can have a major impact on rehabilitation programs, interventions and resources. Behaviours of concern can be associated with any disorder/disease that affects cognition, including brain injury, and some neurological conditions characterised by deterioration (including dementia). A recent NSW study has shown the impact of challenging behaviours on rehabilitation of people with traumatic brain injury. A New Zealand study reported on the relevant literature regarding the impact of challenging behaviours. A New Zealand study reported on the relevant literature regarding the impact of challenging behaviours.

Behaviours can be described in relation to:

- Verbal aggression
- Physical aggression against objects
- Physical acts against self
- Physical aggression against other people
- Inappropriate sexual behaviour
- Perseveration/repetitive behaviour
• Wandering/absconding
• Inappropriate social behaviour
• Lack of initiation

The impact of behaviours of concern is of potentially greater importance in the ambulatory environment where a relatively unstructured environment (compared with inpatient rehabilitation) increases the risk and severity of incidents as well as the consequences.

Both Option 1 and Option 2 include some weight for behaviours of concern. In Option 1, the FIM includes the item ‘Social interaction’, which maps to the whole of the ICF A&P chapter 7 Interpersonal interactions and relationships. Option 2 includes AusRehab item 11, ‘Complex Interpersonal Interactions’. This corresponds to ICF A&P domain d720, which is described as ‘Maintaining and managing interactions with other people, in a contextually and socially appropriate manner, such as by regulating emotions and impulses, controlling verbal and physical aggression, acting independently in social interactions, and acting in accordance with social rules and conventions.’

Given the impact of behaviour on the cost of rehabilitation, there is concern that neither Option as constructed applies enough weight to behaviours of concern, given that the domain scores are simply additive. It is suggested that, in developing Option 2, it be investigated whether the weight for item 11 should have a weight other than one; alternatively, as behaviour may affect performance across all other domains, whether it should be multiplicative.

An alternative would be to consider an additional item for testing with either Option. This would involve an item from the HoNOS which specifically addresses behaviour. The HoNOS includes a Behaviour item ‘Overactive, aggressive, disruptive or agitated behaviour’, with a rating scale from 0 (no problems) to 4 (most serious). Again, the investigation should include whether the weight for this additional item should be additive, whether it should have a weight other than one, and whether the item should be multiplicative.

11.5 USE OF ADDITIONAL INSTRUMENTS FOR SPECIFIC CONDITIONS

During the consultations, there was some discussion of the possibility of proposing one or more additional instruments associated with a specific health condition. Clearly, such an approach could give rise to a multiplicity of instruments. A specific proposal was made to use the Spinal Cord Injury Measure (SCIM) for patients with spinal cord injury. It was argued that this instrument could describe the range of functioning outcomes associated with this particular health condition that are not adequately described by a generic instrument, and provide better benchmarking information for a group characterised by a long-term stay.

Both Option 1 and Option 2 provide a broad coverage of ICF A&P domains, so it would seem unlikely that an additional instrument would add substantial explanatory value. However, there may be value in testing this hypothesis in a particular case such as spinal cord injury.
11.6 CHILDREN

As discussed in chapter 9, the rehabilitation care type is inconsistently used for children. The coding standard for Z50.- requires that these codes be used as a principal diagnosis. If acute care is being provided at the same time as rehabilitation, Z50.- would be unlikely to be used as principal diagnosis. So there would be no indication that rehabilitation is being provided. This matter is further addressed in chapter 17.

The adaptation of Option 1 for children needs to be investigated. This would involve use of the WeeFIM in conjunction with another instrument.

Use of the Child and Adolescent Scale of Participation (CASP) was investigated. The CASP measures participation in home, school and the community at an age appropriate level for children and youth. Table 11-7 shows the CASP domains.

Table 11-7: CASP domains

<table>
<thead>
<tr>
<th>CASP DOMAINS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Home participation</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>1. Social, play or leisure activities with family members at home</td>
</tr>
<tr>
<td>2. Social, play or leisure activities with friends at home</td>
</tr>
<tr>
<td>3. Family chores, responsibilities and decisions at home</td>
</tr>
<tr>
<td>4. Self-care activities</td>
</tr>
<tr>
<td>5. Moving about in and around the home</td>
</tr>
<tr>
<td>6. Communicating with other children and adults at home</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Neighbourhood and community participation</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>7. Social, play or leisure activities with friends in the community</td>
</tr>
<tr>
<td>8. Structured events and activities in the community</td>
</tr>
<tr>
<td>9. Moving around the community</td>
</tr>
<tr>
<td>10. Communicating with other children in the community</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>School participation</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>11. Educational activities with other children</td>
</tr>
<tr>
<td>12. Social, play and recreational activities with other children at school</td>
</tr>
<tr>
<td>13. Moving around at school</td>
</tr>
<tr>
<td>14. Using educational materials, possibly modified</td>
</tr>
<tr>
<td>15. Communicating with other children and adults at school</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Home and Community Living activities</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>16. Household activities</td>
</tr>
<tr>
<td>17. Shopping and managing money</td>
</tr>
<tr>
<td>18. Managing daily schedule</td>
</tr>
<tr>
<td>19. Using transportation to get around in the community</td>
</tr>
<tr>
<td>20. Work activities and responsibilities</td>
</tr>
</tbody>
</table>

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It can be seen that a small number of CASP domains are also covered by the WeeFIM (e.g., domains 4, 5, 9 and 13).

The CASP does not meet some of the criteria set out in chapter 8.11.4. It is designed to be completed by a child’s family member or caregiver. The nature of the some of the topics clearly requires input from such a person. Further, the instrument assesses difficulty, not need for assistance (or a possible proxy, as in the case of the ALSAR).

Further consultation is proposed with relevant experts to see whether the CASP can be suitably adapted for use with the WeeFIM, or whether, despite its limitations for the purpose, it should be trialled as a predictor of rehabilitation costs when used with the WeeFIM.

Option 2 could be adapted for children. Given the difficulties just outlined with Option 1 for children, Option 2 could be the only feasible prospect for children.

The ICF-CY, the children and youth version of the ICF, provides alternative language and domains so that the A&P structure can be adapted for children. Items 14, 15, 17 and 18 are not relevant to children, and should be deleted, but a new domain focusing on Play should be added. (The AusTOMs were developed prior to finalisation of the ICF-CY, and the user is instructed to use the AusTOMs for children as well as adults; however, for children, similar adaptation/deletion seems appropriate).

Table 11-8 shows a possible structure for the child version of AusRehab (AusRehab-Child).

Table 11-8: AusRehab-Child

<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>ICF Activities and Participation Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Learning, management and communication</strong></td>
<td></td>
</tr>
<tr>
<td>1. Learning and applying knowledge</td>
<td>Chapter 1 (d110-d199)</td>
</tr>
<tr>
<td>2. Carrying out tasks and daily routine</td>
<td>d210, d220, d230</td>
</tr>
<tr>
<td>3. Communicating – receiving</td>
<td>d310, d315</td>
</tr>
<tr>
<td>4. Communication – producing</td>
<td>d330, d335</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td>5. Changing and maintaining body position</td>
<td>d410, d415, d420</td>
</tr>
<tr>
<td>6. Walking and moving around with and without equipment</td>
<td>d450, d455, d460, d465</td>
</tr>
<tr>
<td>7. Moving around using transportation</td>
<td>d470, d475, d480</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td></td>
</tr>
<tr>
<td>8. Personal hygiene</td>
<td>d510, d520, d530</td>
</tr>
<tr>
<td>9. Dressing</td>
<td>d540</td>
</tr>
<tr>
<td>10. Eating</td>
<td>d550</td>
</tr>
<tr>
<td>ICF Domain</td>
<td>ICF Activities and Participation Codes</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Getting along with people</td>
<td></td>
</tr>
<tr>
<td>11 Complex interpersonal interactions</td>
<td>d720</td>
</tr>
<tr>
<td>12 Formal relationships (including service providers)</td>
<td>d740</td>
</tr>
<tr>
<td>13 Family relationships</td>
<td>d760</td>
</tr>
<tr>
<td>Performance in major life areas</td>
<td></td>
</tr>
<tr>
<td>14 Education</td>
<td>d810-839</td>
</tr>
<tr>
<td>15 Engagement in play</td>
<td>d880</td>
</tr>
</tbody>
</table>

Given the lack of a viable alternative, specification of a child version of AusRehab should be pursued as a priority with relevant multidisciplinary experts.

11.7 NON-ADMITTED PATIENTS

A recurring theme during the consultations was the need for a wider range of domains to be addressed in assessing need for assistance for non-admitted patients. The range of needs of non-admitted patients can be broad, including a focus on the final three groups of domains in AusRehab: Getting along with people, Performance in major areas of life, and Community participation.

Such a focus was also seen as important for inpatients in rural settings, especially where a hub and spoke model exists between a regional hospital and smaller district hospitals.

Both Option 1 and Option 2 provide a broad range of the ICF A&P domains, and so should be suitable for use with non-admitted patients.

Both Option 1 and Option 2’s clinical value and capacity to predict expenditure need to be examined and compared to the performance of the FIM alone. The FIM is subject to ceiling effect issues for non-admitted patients. So the ALSAR should be tested for its capability to predict non-admitted patient rehabilitation expenditure on its own account as well as in conjunction with the FIM.

Note there is a possibility that the rehabilitation cost of some patients may have been artificially lowered because the use of the FIM as the assessing instrument in the past has resulted in under funding for these patients, so care is needed in data interpretation.

11.8 DISCUSSION OF THE OPTIONS

Option 1 could be adopted in the medium term. The ALSAR instrument needs to be tested for its capability to add to the FIM’s power to predict rehabilitation expenditure. If this work is pursued quickly, trial data collection could be undertaken in time for Option 1 to be
implemented during 2014-15. In addition, use of the RUDAS could be considered as an improved measure of cognition.

Option 2 would require the following steps:

1. Confirm the domains in AusRehab
2. Decide on a measurement scale
3. Develop the verbal descriptors of each level of the rating scale for each domain
4. Develop training material for assessors.

A pilot test of data collection for AusRehab would then need to be undertaken. This would need to include training of staff who will undertake the assessments.

The domains, scales and verbal descriptions should be reviewed in light of the results of the pilot test. The outcome would be an instrument custom designed to best predict rehabilitation costs across the health sector.

In summary, development of AusRehab would be a longer-term project.

The two options are not mutually exclusive. Option 1 can be implemented relatively quickly while work commences on Option 2. The use of both instruments in Option 1 would provide a range of learning for design of AusRehab’s domains and scaling system.

Applicability to Aboriginal and Torres Strait Islander peoples requires consideration under both options. The ICF’s ability to capture the various aspects of Aboriginal life was noted in chapter 9. In constructing AusRehab (under Option 2), applicability to Aboriginal and Torres Strait Islander peoples should be explicitly considered, with the goal that AusRehab be applicable to them without adjustment. The predictive power for Option 1 in respect of this group should be explicitly investigated, so that separate allowance can be considered in pricing decisions.

11.9 CONCLUSION

Two options for establishing a more comprehensive approach to rehabilitation assessment have been described.

Option 1 involves use of a second instrument, the ALSAR, in addition to the FIM. Using the two instruments together results in broad coverage of the ICF A&P domains, with minimum additional data collection burden. The use of the two instruments is designed to cover the needs of inpatients and non-admitted patients, and to facilitate the movement of patients between these settings.

The ALSAR has been proposed as a suitable additional instrument, with no overlap with the FIM domains.

Clinicians who do not consider that the additional instrument is needed to fully assess their patients’ needs would not need to use the instrument.
To improve assessment of cognition, an instrument such as the RUDAS could be included in Option 1 (noting overlap with the FIM).

This option could be adopted in the medium term. Data collection could begin during 2014-15.

Option 2 is to build a new instrument, with maximum connection to the FIM and to the AusTOMs. The domains included have similarities to some FIM domains and some AusTOMs domains, and would need further discussion and development to develop a draft.

Both options would meet the assessment needs for non-admitted patients. They would also cover the broader assessment needs for rural and remote patients and for complex rehabilitation patients.

Option 2 could be modified to become a suitable assessment instrument for children. Option 1 is more problematic: the CASP has been put forward as a useful instrument, but it does not meet some of the criteria set out in chapter 8; further consultation would be needed before pursuing this option.
12 GERIATRIC EVALUATION AND MANAGEMENT (GEM)

12.1 DEFINITION
The revised definition\textsuperscript{14} is:

Geriatric evaluation and management is care in which the primary clinical purpose or treatment goal is improvement in the functioning of a patient with multi-dimensional needs associated with medical conditions related to ageing, such as falls, incontinence, reduced mobility, and cognitive impairment. The patient may also have complex psychosocial problems.

Geriatric evaluation and management is always:

- Delivered under the management of, or informed by, a clinician with specialised expertise in geriatric evaluation and management; and
- Evidenced by an individualised multidisciplinary management plan, which is documented in the patient’s medical record, which includes negotiated goals within indicative time frames, and documented assessment of functional ability.

Issues surrounding GEM care have already been discussed in chapter 9.5. In summary, the FIM is not seen as adequately describing the needs for assistance of GEM patients, and GEM patients often have a wide range of health conditions (co-morbidities).

A complicating feature for the GEM care type is inconsistency in its use across jurisdictions. As shown in chapter 9.5, more than two thirds of public hospital GEM inpatient separations are in Victoria. If the GEM care type is to be continued, there needs to be a national effort to achieve consistency in its use.

12.2 OPTION 1: USE OF EXISTING INSTRUMENT(S)
It is recognised that the AN-SNAP is being introduced on an interim basis for subacute patients. This will require the use of the FIM for GEM patients. The comments received (discussed in chapter 9.5) did not favour use of the FIM. Importantly, the PwC report (p xi)\textsuperscript{21} found that the FIM was not a good predictor of inpatient costs for GEM patients. Therefore, it is sensible to look for another instrument which, in combination with the FIM, would be adequate for assessing GEM patients.

The ALSAR has been discussed in the preceding chapter. As discussed in chapter 8, the ALSAR was designed for assessment of older people living in the community. There is no overlap between FIM domains and ALSAR domains, and, together, they cover a broad range of ICF A&P domains. This makes the ALSAR suitable for use with GEM patients.

During the consultations, the need for an instrument to assess cognition in GEM patients was highlighted. The ALSAR does not meet this expressed need. However, the Rowland Universal Dementia Assessment Scale (RUDAS), which is discussed in chapter 8, is designed to assess
cognition in older people. Some RUDAS items assess need for assistance, but it would need review before testing as a measure of cognitive dysfunction, for predictive capacity when used with the FIM and the ALSAR.

In summary, Option 1 for GEM patients would involve use of the FIM, the ALSAR and the RUDAS. Testing of predictive capacity using various combinations of the three instruments should be undertaken to work out the best combination (which could be one, two or all three of these instruments).

12.3 OPTION 2: BUILDING A COMPREHENSIVE INSTRUMENT FOR GEM ASSESSMENT

The arguments for constructing a new instrument to assess GEM patients are at least as strong as for rehabilitation. The lack of satisfaction with the FIM, and the lack of historical use of FIM in most jurisdictions (and notably Victoria) add to the attraction of considering a new instrument.

The suggested starting point is the set of domains proposed for rehabilitation. The Education and Work domains would not appear to be necessary for GEM patients, but other domains are relevant. Table 12-1 sets out possible domains for a new instrument, titled AusGEM.

Table 12-1: AusGEM

<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>ICF Activities and Participation Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Learning, management and communication</strong></td>
<td></td>
</tr>
<tr>
<td>1 Learning and applying knowledge</td>
<td>Chapter 1 (d110-d199)</td>
</tr>
<tr>
<td>2 Carrying out tasks and daily routine</td>
<td>d210, d220, d230</td>
</tr>
<tr>
<td>3 Communicating – receiving</td>
<td>d310, d315</td>
</tr>
<tr>
<td>4 Communication – producing</td>
<td>d330, d335</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td>5 Changing and maintaining body position</td>
<td>d410, d415, d420</td>
</tr>
<tr>
<td>6 Walking and moving around with and without equipment</td>
<td>d450, d455, d460, d465</td>
</tr>
<tr>
<td>7 Moving around using transportation</td>
<td>d470, d475, d480</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td></td>
</tr>
<tr>
<td>8 Personal hygiene</td>
<td>d510, d520, d530</td>
</tr>
<tr>
<td>9 Dressing</td>
<td>d540</td>
</tr>
<tr>
<td>10 Eating</td>
<td>d550</td>
</tr>
<tr>
<td><strong>Getting along with people</strong></td>
<td></td>
</tr>
<tr>
<td>11 Complex interpersonal interactions</td>
<td>d720</td>
</tr>
<tr>
<td>12 Formal relationships (including service providers)</td>
<td>d740</td>
</tr>
<tr>
<td>13 Family relationships</td>
<td>d760</td>
</tr>
</tbody>
</table>
### Performance in major life areas

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>Acquiring necessities</td>
<td>d610, d620, d860</td>
</tr>
<tr>
<td>15</td>
<td>Household tasks</td>
<td>d630, d640</td>
</tr>
<tr>
<td>16</td>
<td>Economic life</td>
<td>d865, d870</td>
</tr>
</tbody>
</table>

### Participation

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<tr>
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<tbody>
<tr>
<td>17</td>
<td>Community, social and civic life</td>
<td>Chapter 9 (d910-d999)</td>
</tr>
</tbody>
</table>

These domains should be reviewed by GEM experts. In particular, it may be possible to consolidate some of the Mobility and Self-care domains (three each) to two or one domain each.

Mapping from the FIM has been discussed in the previous chapter.

The five-level need for assistance scale proposed for AusRehab should be the starting point for the AusGEM scale. Descriptors would need to be developed, and then a pilot test of AusGEM should be conducted. Following that, a DSS should be developed for national implementation.

Co-morbidities will be fully described by the ICD codes recorded for the patient. The AR-DRGs already provide a well-established mechanism to incorporate co-morbidities in activity based funding for acute care patients. However the system for assigning complications and co-morbidities to a principal diagnosis is complex and resource intensive.

An alternative approach could be to use an index specifically designed to reflect the impact of co-morbidities. Perhaps the best known such index is the Charlson index. This is designed as an estimate of the probability of death within one year of hospital discharge.

Rather than attempting to calculate a single index, Elixhauser identified 30 co-morbidities that affected length of stay and hospital charges (cost). While this work cannot be directly applied in Australia, and applied to subacute care in particular, the approach is interesting. He provides a generic set of co-morbidities that can be used to analyse the impact of co-morbidities on length of stay and cost.

Elixhauser’s approach could be applied to estimate the impact of co-morbidities on GEM costs. A small set of key co-morbidities which are thought to affect the cost of treating GEM patients could be developed (possibly using Elixhauser’s list as a reference set). These could then be tested with Australian data, along with an assessment of needs for assistance.

### 12.4 NON-ADMITTED PATIENTS

The case for applicability of either Option 1 or Option 2 for non-admitted GEM patients is similar to the arguments in chapter 11 in respect of non-admitted rehabilitation patients. A broad range of domains need to be assessed to measure the need for assistance of these patients.
Again it would be sensible to test the predictive power of the ALSAR alone and in conjunction with the FIM. The impact of addition of the RUDAS should especially be considered for GEM non-admitted patients.

12.5 DISCUSSION

The first priority is to achieve common practice in use of the GEM care type across Australia.

Such a campaign will be greatly assisted by a simple, effective means of assessing GEM patients for ABF purposes. Two options have been proposed. The first is the use of the FIM and the ALSAR, plus possibly the RUDAS, in combination, which could be introduced in the medium term. The second is the development of a new GEM assessment instrument.

Co-morbidities are important in assessing the need for assistance for GEM patients. Recognising that the numbers of GEM patients are small, it is proposed that a small set of co-morbidities be identified as likely to impact on the need for the assistance of GEM patients, and that these then be tested for their importance as cost predictors.

The aim should be a system with a modest number of ABF categories for GEM, so that the reliability available from the actual number of cases is not overstretched.
13 PALLIATIVE CARE

13.1 DEFINITION

The revised palliative care definition is:

Palliative care is care in which the primary clinical purpose or treatment goal is optimisation of the quality of life of a patient with an active and advanced life-limiting illness. The patient will have complex physical, psychosocial and/or spiritual needs.

Palliative care is always:
• Delivered under the management of, or informed by, a clinician with specialised expertise in palliative care; and
• Evidenced by an individualised multidisciplinary assessment and management plan, which is documented in the patient's medical record that covers the physical, psychological, emotional, social and spiritual needs of the patient, and negotiated goals.

13.2 PHASES OF PALLIATIVE CARE

Five phases of palliative care are identified in Australia:

• Stable
• Unstable
• Deteriorating
• Terminal
• Bereavement

There was general agreement during the consultations that these phases are clinically meaningful (there were comments that the unstable and deteriorating phases were not mutually exclusive, so some clarification may be necessary around the definitions).

Phases of care have been used in the AN-SNAP; the use of phases for this purpose was supported during the consultations.

Use of phase in the AN-SNAP means that casemix groups are being substantially influenced by phase. It is important that phase be determined by the health condition of the patient, not the care plan in place or changes to it. The existing definitions in part refer to changes in care plans. It is suggested that these be reviewed to ensure there is no circularity in the definitions.

13.3 INSTRUMENTS

The Palliative Care Outcomes Collection (PCOC) includes four instruments: the RUG-ADL, Symptom Assessment Scale (SAS), the Karnofsky Scale, and the Palliative Care Problem Severity Score (PCPSS).
The RUG-ADL is based on activity domains, and is the instrument used in the AN-SNAP. The domains are:

**Table 13-1: RUG-ADL Domains**

<table>
<thead>
<tr>
<th>RUG-ADL Domain</th>
<th>Scale</th>
<th>ICF Activity and Participation Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed mobility</td>
<td>1,3,4,5</td>
<td>d410-d415</td>
</tr>
<tr>
<td>Toileting</td>
<td>1,3,4,5</td>
<td>d530</td>
</tr>
<tr>
<td>Transfer</td>
<td>1,3,4,5</td>
<td>d420</td>
</tr>
<tr>
<td>Eating</td>
<td>1,2,3</td>
<td>d550</td>
</tr>
</tbody>
</table>

These domains are an important subset of the characteristics of palliative care as set out in the definition. But the psychosocial and spiritual needs domains are not included.

The PCPSS does include psychosocial functions and spirituality in one combined domain.

The instruments are seen as valuable for a range of clinical purposes, with uses varying substantially across palliative care services. The Australian Karnofsky Scale refers to ‘activity’ which, in context, aligns with the broad life areas in the ICF’s chapters 6-9; however, these are not further differentiated. There was some evidence in the consultations that Karnofsky is used to guide resource allocation. The SAS is a symptom based instrument, not based on need for assistance, and so is not a suitable base for resource allocation.

**13.4 PROPOSED PALLIATIVE CARE ASSESSMENT INSTRUMENT**

No medium term option for change in assessment instruments is proposed for palliative care. The current instruments are seen as useful and cover a range of care aspects.

In the longer term, in line with other subacute care types, development of a functioning based instrument based explicitly on relevant ICF A&P domains should be considered.

The domains necessary to describe the need for assistance in palliative care are diverse.

- In terms of resource use, the basic activities covered by the RUG-ADL are clearly important. AusPallCare should therefore cover the RUG-ADL domains. The four RUG-ADL domains can be mapped to these ICF domains.
- Additional ICF domains to encompass psychosocial factors and spirituality. Chapter 7 (Interpersonal interactions and relationships) and chapter 9 (Community, social and civic life, which includes religion and spirituality) have been chosen for this purpose.

Proposed AusPallCare domains are shown in Table 13-2:
### Table 13-2: AusPallCare

<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>ICF Activity and Participation Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Changing and maintaining body position</td>
<td>d410-415</td>
</tr>
<tr>
<td>2 Transferring one's self</td>
<td>d420</td>
</tr>
<tr>
<td>3 Toileting</td>
<td>d530</td>
</tr>
<tr>
<td>4 Eating</td>
<td>d550</td>
</tr>
<tr>
<td>5 Interpersonal interactions and relationships</td>
<td>Chapter 7 (d710-d799)</td>
</tr>
<tr>
<td>6 Community, social and civic life</td>
<td>Chapter 9 (d910-d999)</td>
</tr>
</tbody>
</table>

Consideration should also be given to the possible inclusion of Pain in AusPallCare (Pain is included as a Body Function in ICF, b280).

Scaling will have to also be considered for AusPallCare. A pilot test should be undertaken, to compare the existing NHDD three-point scale and the RUG-ADL scale. If the variability among palliative care patients is limited, the three-point scale may be sufficient. If necessary, a finer scale could be adopted.

Before such a test could take place, verbal descriptors for each scaling level for each AusPallCare domain would need to be developed. The RUG-ADL items are already incorporated in a Data Specification Set (DSS) specified by IHPA, effective from 1 July 2013. Once the AusPallCare data items are finalised, the DSS should be expanded to allow data collection to commence nationally. Data collected can then be analysed for efficacy as cost predictors.

The additional items should result in an instrument that is more useful for assessments in, or for use in, a community (non-admitted patient) setting. Such a setting provides more opportunities than an inpatient setting to pursue a broader range of life areas.

### 13.5 NON-ADMITTED PATIENTS

Because the AusRehab and the AusGEM have been proposed to cover the full range of domains in the ICF A&P chapters, it has been argued that the two instruments could be applied to non-admitted patients. However, the AusPallCare does not have the same broad coverage.

Continuity of care in inpatient and non-admitted care settings is important. As well, during the consultations, the desirability of caring for palliative care patients in the community was recognised as highly valued by many patients and their families. The use of a common instrument for the two settings is therefore desirable to avoid repetitive and duplicating assessments.

During the consultations, however, it was noted that patients have a wide range of goals, which often can best be addressed in home based care. This suggests that a wider range of domains need to be considered in home and community settings to ensure that needs for assistance are fully recognised.
No specific example was raised during the consultation process. But it is suggested that further advice be sought on the need for additional domains relevant to non-admitted care.

13.6 DISCUSSION

There is overall satisfaction among stakeholders with the existing assessment system, which is heavily influenced by the phase of care. It is important that an explicit decision be taken to continue this form of casemix system, where the care being provided (and changes to care) may impact on funding. If there is to be a shift away from the use of phase of care, or to lower the weighting given to phase, as a driver of the casemix payment system, the urgency of developing a new assessment tool increases.

If phases of care are to continue, the phase definitions should be clarified as necessary, and then included in the National Health Data Dictionary.

The revised definition of the palliative care type gives quality of life as the goal of palliative care, and refers specifically to psychosocial and spiritual needs as well as physical needs. The RUG-ADL does not address psychosocial or spiritual needs, and some augmentation is necessary to properly include all aspects of palliative care.

The consequence is that there is no capacity in the AN-SNAP system for these broader goals of palliative care to be addressed, and in turn funded. This is a major drawback and was widely recognised by stakeholders during the consultation process.

The RUG-ADL is used in the AN-SNAP to assess needs for assistance. To better match the broader needs of palliative care as set out in the definition (psycho-social factors and spirituality), a broader instrument (AusPallCare) is proposed, for use in both inpatient and community settings.

Appendix 10 shows that at least 45% of palliative care for inpatients in public hospitals (20,143 out of 44,405 in 2008-09) is not covered by the palliative care type. These patients are identified by the use of the ICD code Z51.5 in the admitted patient data set. PCOC data, including need for assistance (measured by the RUG-ADL) is not collected for these palliative care patients. This group includes almost all children receiving palliative care (see chapter 9). For children, and possibly for many adults as well, palliative care is provided in conjunction with acute care, and the acute care type is assigned to the patients.

In these circumstances, to provide a complete understanding of the provision of palliative care, it is proposed that the AusPallCare data be collected for all patients receiving palliative care. Where the care is not provided by a palliative care team, some training of key staff may be required to allow the data to be collected.

It is important that the provision of palliative care to acute care patients be funded if it is provided. If provision of palliative care is not identified, cost data for relevant ARDRGs will be
inflated by the costs of palliative care provided to patients in the group, and those actually receiving the palliative care will be under-funded. This is a perverse financial incentive and conceivably could lead to denial of palliative care to patients who need it.

AusPallCare data items need to be collected at the time palliative care is provided, but the decision to apply the Z51.5 code may be taken after the patient has died or been discharged. So the code cannot be used directly as a flag for collection of AusPallCare data. A way forward would be to apply AusPallCare whenever palliative care is provided, regardless of care type.

Once collected, the AusPallCare data should be analysed to allow estimation of the additional cost of care for acute patients who receive palliative care. A supplementary price should be considered, in addition to the efficient price for relevant ARDRG groups, for acute care patients who receive palliative care.

The proposal made for the AusPallCare has not explicitly considered the needs of children. The Australian and New Zealand Paediatric Palliative Care Reference Group expressed interest in having an opportunity to consider the proposals discussed in this chapter, but did not have capacity to do so during the project. The Group considered that, for children, a suitable instrument needs to take account of play for children too young to attend school and educational activities for school age children.
14 PSYCHOGERIATRIC CARE

14.1 DEFINITION

The revised psychogeriatric care definition\textsuperscript{14} is:

Psychogeriatric care is care in which the primary clinical purpose or treatment goal is improvement in the functional status, behaviour and/or quality of life for an older patient with significant psychiatric or behavioural disturbance, caused by mental illness, an age-related organic brain impairment or a physical condition.

Psychogeriatric care is always:
- Delivered under the management of, or informed by, a clinician with specialised expertise in psychogeriatric care; and
- Evidenced by an individualised multidisciplinary management plan, which is documented in the patient’s medical record that covers the physical, psychological, emotional and social needs of the patient and includes negotiated goals within indicative time frames and formal assessment of functional ability.

Psychogeriatric care is not applicable if the primary focus of care is acute symptom control.

14.2 INSTRUMENTS

AN-SNAP uses the HoNOS (Health of the Nation Outcome Scales) for assessment of psychogeriatric patients. Two domains in particular are used, as well as the total score.

The first of these domains is Overactive, aggressive, disruptive or agitated behaviour. Behaviour will influence the level of resources needed to provide care for these patients.

The second domain is Problems with Activities of Daily Living. As defined in HoNOS, this is a mix of ‘basic activities of self-care’ (such as eating, washing, dressing, toileting) and ‘complex skills’ (such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development etc). This covers a wide range of ICF A&P domains, and is scaled 0,1,2,3 or 4. The AN-SNAP uses two groups: scores 0 to 3 versus 4 (‘severe disability or incapacity in all or nearly all areas of self-care and complex skills’).

An alternative suggestion arising from consultation with the Mental Health Working Group is to use the RUG-ADL. The limited range of domains covered by this instrument (described above under Palliative Care) contrasts with the wide range of activities and participation domains covered by the HoNOS ‘Problems with Activities of Daily Living’ domain.

There was a strong view that no domains be added beyond those included in the HoNOS and the RUG-ADL.

Medium term (Option 1) and longer term (Option 2) options are discussed below.
14.3 OPTION 1: RETAIN THE HONOS AS THE ASSESSMENT TOOL

The HoNOS is currently widely used across mental health patients; psychogeriatric patients, as well as being subacute patients, are a small subset of the much larger mental health group. Its use in the assessment of subacute patients covers a range of concepts including activities and behaviour.

Psychogeriatric care is being considered currently as part of the University of Queensland definition and cost driver project to develop the mental health classification system. A strong view was expressed during the consultations that final views about changes to the assessment of psychogeriatric patients should await the outcome of this review.

14.4 OPTION 2: PROPOSED PSYCHOGERIATRIC CARE ASSESSMENT INSTRUMENT

In line with other subacute care types, the in principle position would be to propose an instrument based on ICF A&P domains for both inpatients and non-admitted patients. This instrument (AusPG) would include a number of domains to describe the need for assistance of psychogeriatric patients. The precise specification of domains would require further consideration and consultation but the domains mentioned in the two HoNOS domains described above provide a possible starting point.

Using this approach, possible AusPG domains are described in Table 14-1:

<table>
<thead>
<tr>
<th>ICF Domain</th>
<th>ICF Activities and Participation Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mobility</td>
<td>Chapter 4 (d410-d499)</td>
</tr>
<tr>
<td>2. Washing oneself</td>
<td>d510</td>
</tr>
<tr>
<td>3. Toileting</td>
<td>d530</td>
</tr>
<tr>
<td>4. Dressing</td>
<td>d540</td>
</tr>
<tr>
<td>5. Eating</td>
<td>d550</td>
</tr>
<tr>
<td>6. Domestic life</td>
<td>Chapter 6 (d610-d699)</td>
</tr>
<tr>
<td>7. Interpersonal interactions</td>
<td>Chapter 7 (d710-d799)</td>
</tr>
</tbody>
</table>

Scaling and pilot testing would need to be addressed as discussed for other care types. However, in the context described, it would seem wise to continue with the use of the HoNOS pending consideration of the outcomes of the mental health review.
15 NON-ACUTE CARE/MAINTENANCE

15.1 DEFINITION

The revised maintenance definition is:

‘Maintenance (or non-acute) care is care in which the primary clinical purpose or treatment goal is support for a patient with impairment, activity limitation or participation restriction due to a health condition. Following assessment or treatment the patient does not require further complex assessment or stabilisation. Patients with a care type of maintenance care often require care over an indefinite period.’

There was limited comment on maintenance care during the consultations.

Given the circumstances, a hospital provides minimal resources to care for these patients, consistent with safe and humane care provision. But the cost of care may vary depending on the type of care that is being sought for the patient.

Currently, needs for assistance are assessed using the RUG-ADL. The limited scope appears satisfactory for these patients. No stakeholder put a different view. However, there was a strong view that patients in maintenance care were commonly there because of a barrier to move to a more appropriate setting. Barriers include lack of a residential care space, lack of appropriate community care and lack of family support.

It was widely argued that information on these barriers should be collected. In fact, this data is already collected for maintenance patients who are awaiting alternative care, but this is done through the Admitted Patient National Minimum Data Set, not as part of subacute data collection.

ICD-10-AM codes Z75.1- provide useful information on the level of care needed during maintenance. Z75.1 is used for a patient ‘awaiting admission to an adequate facility elsewhere’. The ICD-10-AM provides the following options for additional detail:

Z75.10 Person awaiting admission to acute hospital
Z75.11 Person awaiting admission to residential aged care service (includes nursing home)
Z75.12 Person awaiting admission to psychiatric facility/unit
Z75.13 Person awaiting admission to rehabilitation facility/unit
Z75.14 Person awaiting admission to palliative care facility/unit
Z75.18 Person awaiting admission to other health care facility (includes hostel).
15.2 PROPOSED INSTRUMENT

It is proposed that that RUG-ADL continues to be used as the assessment instrument for maintenance episodes of care. Given that it is recognised that barriers in accessing alternative care are a big factor in maintenance care, an analysis of admitted patient data should be undertaken to better understand barriers for those awaiting alternative care.
16 TRANSITION

16.1 INTRODUCTION

This chapter notes several cross-cutting initiatives which would help the transition from the subacute ABF systems being implemented for 2013-14 to those proposed in this report.

Activity Based Funding systems have been in place in Australia for many years. For acute patients, the system has been widely used, based on well-established casemix groups, largely based on ICD-10-AM codes routinely collected for all inpatient stays. For subacute patients, the AN-SNAP system, based on the FIM, RUG-ADL and HoNOS, is being implemented nationally in 2013-14.

The proposals made in this report have sought to respond to significant gaps in the current subacute casemix systems. However, the proposals have been tailored to use existing data systems (information collected using the FIM and RUG-ADL) as far as possible.

16.2 FIRST STEPS

16.2.1 Decision to base assessments on ICF A&P domains

A decision in principle is needed that the proposed wider range of life areas covered by the ICF A&P chapters should be included in assessment for rehabilitation, GEM and palliative care type patients (no recommendation has been made to expand the domains for psychogeriatric and maintenance care).

16.2.2 Decide on method to expand domains

For rehabilitation and GEM, two options have been identified:

1) A medium-term option to use a combination of instruments, retaining the FIM and adding the ALSAR (as well as consideration of the RUDAS)
2) A longer-term option to develop a new instrument, AusRehab and AusGEM respectively.

A choice between these options is needed, noting that both can be pursued simultaneously.

Given the timing differences, it is possible to commence work on both options, recognising that lessons from use of Option 1 will assist in the development of Option 2.

For GEM, there is the additional early decision to move to a consistent national application of the GEM care type.

For palliative care, no combination approach has been proposed. The decisions to be made are whether to continue to use phase as a base for casemix grouping, and whether to develop AusPallCare.
16.2.3 Development of new instruments

The following steps would be required:

1. Confirm the domains to be assessed in the three care types
2. Decide on a measurement scale
3. Develop the verbal descriptors of each level of the rating scale for each domain
4. Develop training material for assessors.

A pilot test of data collection for AusRehab, AusGEM and AusPallCare should then be undertaken. This would need to include training of staff who will undertake the assessments.

The domains, scales and verbal descriptions should be reviewed in light of the results of the pilot test.

16.3 LATER STEPS

Once the pilot data collection has been completed, a Data Specification Set should be developed for each instrument, for national implementation. Following collection of data nationally for a year, patient characteristics, diagnoses and data items from the relevant instrument should be analysed with patient costs to determine ABF groups.

16.4 ICF EDUCATION

The proposals are based on use of the ICF’s Activities and Participation domains. The consultations revealed a high level of familiarity with the ICF, and widespread enthusiasm for its use in Australian subacute care assessment. However, training would clearly be required for its adaptation as proposed for the various subacute care types. The WHO’s classification network (WHO-FIC) has developed a freely available electronic training tool, and there is expertise in ICF training available in Australia (an expert member of the University’s team has provided training in several overseas countries as well as in Australia).

There is a well-trained coder workforce in Australia to apply ICD-10-AM codes to all inpatients in Australian hospitals. That part of the workforce that codes subacute patients should be provided with training in the structure and use of the ICF. This could be achieved by in-service education akin to what is now done regularly for new editions of the ICD-10-AM system. Involvement of the Health Information Management Association of Australia in this work should be considered.

At the same time, health information management courses in Australian universities should be encouraged to strengthen their educational content on the ICF.
16.5 DATA COLLECTION MECHANISMS

Patient data and diagnoses are already collected through the admitted patient data set.

Functioning data is currently collected and coded by the clinical team. This may be facilitated
in the medium term by the use of electronic collection arrangements within the hospital.

In each jurisdiction, subacute patient information should be collected by the jurisdiction, as is
now done for admitted patient data. This is already done in NSW, although the data collection
system is separate from the admitted patient data collection. These arrangements would allow
State/Territory analysis of subacute patient activity in its jurisdiction as and when required for
policy purposes. It would also form the base for a national collection of data on subacute
patients.

These arrangements should also apply to non-acute (maintenance) patients.

As the use of the instruments becomes commonplace, there may be opportunities for coders
to take on part of the instrument recording. This would be made more likely by improvements
in the patient’s clinical records to include functioning information on the same basis as other
clinical data. Moves to electronic patient records and data acquisition may help in this regard.
More responsibility for coders would reduce any possibility of conflict of interest for clinicians in
completing administrative records which form the base for resource allocation.

Robust audit mechanisms need to be put in place for functioning information collection, as are
already in place for diagnosis coding.
17 OTHER MATTERS

This chapter briefly addresses a number of issues that arose during the project which, while related, do not form part of the project requirements.

17.1 REDEVELOPMENT OF AUSTRALIAN CODING STANDARDS THAT RELATE TO SUBACUTE CARE

Appendix 10 discusses several existing Australian Coding Standards that relate to the provision of subacute care. Already there is evidence of significant provision of palliative care which is not recorded using the palliative care type, and there is substantial anecdotal evidence that rehabilitation is also provided and not recorded under the care type.

Using the existing ICD codes Z51.5 (palliative care) and Z50.- (rehabilitation) as ‘additional diagnoses’ would provide a straightforward means of assessing the extent of this provision, and any related provision of acute care.

These codes (actually the documentation in the patient record that palliative care or rehabilitation are being provided) could then be used as a flag to indicate that relevant functioning information should be collected. The use of this information for casemix purposes would then be possible.

There is also potential for further development of ICD-10-AM coding standards to assist in activity based funding for subacute patients.

17.2 NATIONAL CONSISTENCY IN USE OF CARE TYPES

There is an urgent requirement to achieve national consistency in the use of the subacute care types. A program should be put in place to improve consistency in care type allocation across jurisdictions. This is most urgent for the GEM care type (and potentially for the psychogeriatric care type if it is to continue following the mental health care review).

IHPA should work with jurisdictions and the relevant colleges to ensure a standard set of criteria are in place to distinguish GEM patients from other geriatric patients, and that the care type is used where appropriate. Use of the GEM care type, and the characteristics of GEM patients, should be carefully monitored, perhaps by commissioning the AIHW for this purpose.

17.3 ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

No specific recommendations have been made in relation to Aboriginal and Torres Strait Islander peoples. Relevant issues are discussed in chapters 9 and 11.
Once a decision in principle has been taken to develop new instruments for subacute care, IHPA should undertake a consultative process with Aboriginal and Torres Strait Islander peoples to explore the best arrangements for provision of subacute care, both as inpatients and in the community.
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