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Carer Eligibility and Needs Assessment
for the National Respite for Carers
Program: Consultation Paper

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CARER ELIGIBILITY AND NEEDS ASSESSMENT FOR THE NATIONAL RESPITE FOR CARERS PROGRAM: Consultation Paper

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Disclaimer:

This consultation paper has been written by staff from the Centre for Health Service Development at the University of Wollongong. The views expressed in this paper are those of the authors and not necessarily those of the Australian Government Department of Health and Ageing.

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1 The content of this consultation paper

This consultation paper is about the 'Carer Eligibility and Needs Assessment for the National Respite for Carers Program (NRCP)' project. It is being undertaken as part of the agenda for improving access to services under the Australian Government's 2004 policy document, '*The Way Forward – A New Strategy for Community Care*'¹ (referred to from here on as *The Way Forward*).

The aim of the project is to design a national assessment system for the National Respite for Carers Program (NRCP), and potentially all community care services, that explicitly addresses carer eligibility and the assessment of carer needs.

This paper has a number of sections addressing carer need and eligibility for carer specific services in the context of developing a common assessment system for community care. These issues will also be addressed in subsequent field consultations and provide useful background information on the specific questions we are asking.

This paper and its accompanying survey response sheets are a way to focus on the relevant issues and seek additional comment from a wide group of providers and consumers and program-level stakeholders.

We welcome feedback on this consultation paper. To let us know what you think, please complete the Consultation Survey on Carer Assessment Systems that accompanies this paper. Alternately, you can e-mail us (chsd@uow.edu.au) or phone our contact number (02 42214411).

2 Why this project is being undertaken

In 2002 the Australian Government began a review of community care programs to identify strategies that would simplify and streamline current arrangements for the administration and delivery of community care services. The focus of the community care review was to make it easier for people to access the care they need.

The vision of the future put together in the review was expressed in *The Way Forward*. Programs would in future operate in a more consistent and coordinated way, with agreed assessment processes, eligibility criteria, consistent accountability and quality arrangements, and more focused strategies tailored to the needs of specific client groups.

To assist in realising this vision, the Australian Government Department of Health and Ageing (DHA) has funded this project to review current practice around the assessment of carer needs in community care including the NRCP funded Commonwealth Carer Respite Centres (CCRCs) and respite services. It should be noted at the outset that the purpose is not to carry out an audit of activity. Nor is it an evaluation or a review of performance.

3 How the project is being carried out

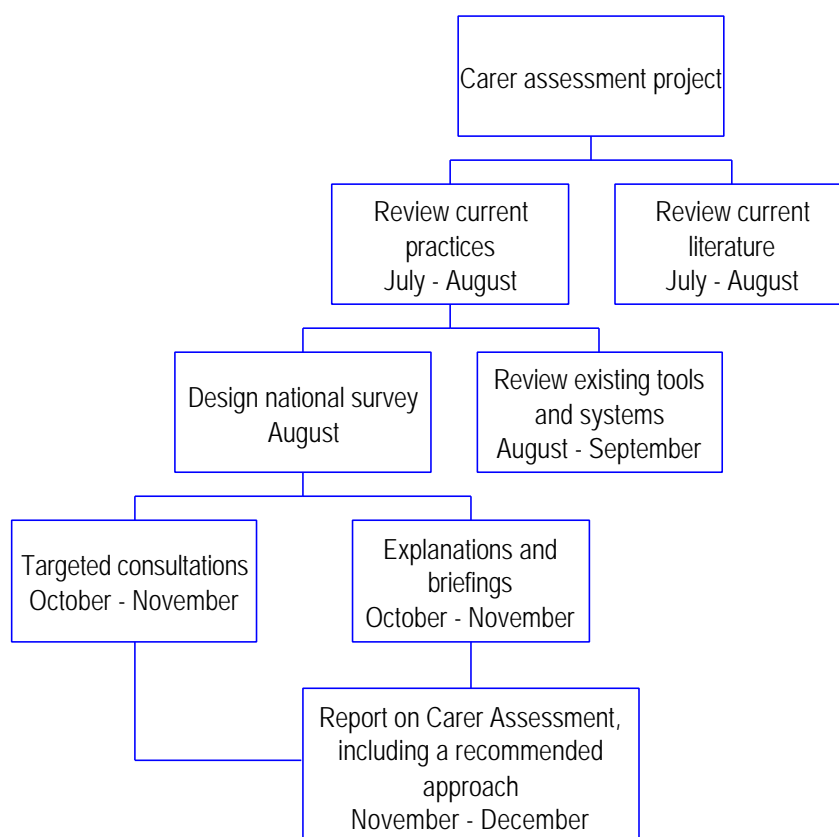
The aim of the carer needs assessment project is to be achieved by moving through a series of logical steps to develop, test and refine a national assessment system that includes the needs of carers and care recipients, and to gather evidence for how such a system could work.

Some of the steps will be taking place together as the projects consult the various experts and decision-makers. The steps are set out in the diagram shown below in Figure 1.

¹ Department of Health and Ageing (2004) *The Way Forward – A New Strategy for Community Care*. DHA, Canberra. ISBN 0 642 82471 1. www.ageing.health.gov.au

The project includes reviews of the literature on carer assessment tools that are in use in Australia and overseas. The purpose of this consultation paper is to assist that review and to recommend a logical set of steps towards implementing a more equitable and standardised approach consistent with *The Way Forward*.

Figure 1 Project timelines and tasks



The first step is a review of existing policies and programs, the local and international literature on carer assessment and priority rating and common practices in related programs. Based on this review, and drawing on their experience, the project team has developed a set of criteria for evaluating existing assessment and priority rating tools and assessing existing tools (see Attachment 2).

The consultation in the project is being conducted between September and November 2005. Consultation with the field is being undertaken by analysing the results of the survey attached to this consultation paper and by field and stakeholder consultations in targeted states and territories. The survey is being followed up by phone interviews with regional or local carer groups, Commonwealth Carer Respite Centres and NRCP respite services, including with providers of multiple types of services. The extent of coverage, while not being comprehensive, is designed to seek a representative sample of current approaches to carer assessment.

The final report on carer needs assessment will be built on the outcomes of the survey, consultations and field visits. The final report will summarise the total project and contain recommendations on the preferred approach to carer needs assessment, the competencies and training implications for providers, and will attempt to identify any resource implications of moving to the new approach. This work will help with the design of a consistent national approach that can be applied in different states and territories, across a mix of locations and service types.

The focus of the project is on the way information on clients and carers is currently used, with the aim of an improved and consistent process for determining eligibility and the assessment of need, as well as determining relative need and priority for service.

4 What this project will deliver

This project is expected to result in a more consistent and reliable (as well as clinically sensible and practical) way to determine eligibility and carry out the assessment of the needs of carers. The project is also expected to recommend a consistent approach to determining relative need and priority for service. Much useful work has already been done in local settings and that experience will be used to develop the recommended approach and examine any potential barriers to implementation found during the project.

The key characteristics of the desired assessment approach for this project are that it:

- Can be used for all NRCP services and centres in a consistent way across the country to assess the needs of clients and carers
- Can potentially be used for carer services funded from other programs
- Is no/low cost and in the public domain
- Is acceptable to carers, service providers and key stakeholders
- Is based on principles of best practice
- Achieves improved equity of resource allocation
- Is consistent with Australian Government and State and Territory policies and
- Takes into account tools and processes already in use.

5 How to have your say

This paper is written for the many different groups and individuals involved in the community care sector as well as to assist in directly surveying the views of the NRCP, CCRCs and respite services. The success and acceptability of the final recommended approach will depend on how well that strategy meets the needs of various stakeholder groups. People with a stake in the program, including community care clients and their carers, clinicians and managers, hold different views about the programs and the issues in the sector, and about what type of information is most useful. It is important that these views are taken into account at this stage and as the project progresses.

As well as the specific response to the survey questions we welcome your comments and suggestions on the issues raised in the rest of this paper.

Key issues have been summarised in Section 10, but note that we do not expect you to respond to every issue raised. Please give us feedback and respond to the issues that are important to you (and skip over the other issues we raise). In particular, people reading this paper have varying levels of interest in, and knowledge about, the technical tasks and decisions that the project must address. If you are not interested in the more technical details, just ignore those sections. The issues are complex and fall broadly into 4 groups:

- Ideas or concepts (for example, priority and risk)
- Value judgements (for example, about what's important to include in a needs assessment)
- Practical issues (for example, about how the assessment is carried out); and

- Technical details (for example, the psychometric properties of various assessment tools and how best to construct a priority rating system).

In particular we are seeking practical suggestions and examples of current practice in the field.

We welcome all ideas and suggestions that will help the project to develop the best possible system for carer assessment and make a useful contribution to building a common approach. Our contact details are on page 1.

6 The assumptions behind this project

The products from this project will form part of a bigger picture of eligibility and needs assessment in community care. The approach to building that bigger picture suggested in *The Way Forward* is to start with a nationally consistent community care assessment tool, by testing the comparability of current practice with the HACCC 9-item functional screen². Beyond functional abilities, this project aims to determine what other information might be common across related programs for the target groups of the frail elderly, people with disabilities and their carers.

This consultation paper describes the project's assumptions, context, practical issues and key ideas. In Section 10 we summarise the issues that are important to cover with the field and these issues are linked to the questions we are using to conduct face to face, written and telephone consultations to build up a picture of current eligibility and carers needs assessment methods and tools.

Each of the assumptions on which this paper is based is identified below.

Assumption One

Carer needs assessment questions are best seen within a workable design for an information system that includes, but is not limited to, the functions performed at the entry point, or during the first contact with services. These functions are multiple in community care. The multiple purposes of needs assessment include 'triaging' people to other types of assessments, to care coordination and planning of interventions and to service provision.

Assumption Two

Assessment is a valuable intervention in its own right, and is not just the entry point into service provision. It provides an opportunity for both the carer and the care recipient to articulate not only their needs, but also their goals and aspirations. It identifies the issues that need to be addressed in any subsequent care plan. It can be used to collect and use outcome data.

Assumption Three

Assessment should not be a one-off event but an ongoing process. The needs of both carers and care recipients will change over time and these changes need to be identified through a periodic reassessment of their needs. Information collected at first contact can and should be used at other points in the ongoing process of assessment and reassessment and in the planning of service interventions.

² Eagar K, Owen A, Green J, Cromwell D, Poulos R, Gordon R, Quinsey K, Adamson L and Fildes D (2002) A National Measure of Functional Dependency for Home and Community Care Services in Australia. *Aged and Community Care Service Development and Evaluation Reports, Number 41*, July 2002. Commonwealth Department of Health and Ageing, Canberra ISBN 0 642 82092 9

Assumption Four

A standard national approach to needs assessment is not going to be simply the result of adding up the sum of the parts of the various Minimum Data Sets of the national and state and territory community care programs. Even if common reporting requirements were constructed from data items that were comparable and non-redundant, the result would most likely still be too big to be workable in routine practice.

Assumption Five

A common and consistent way of measuring need at the entry point or first contact is complex. However, it is achievable if the new system is derived from evidence. Evidence can be used to inform a shared understanding of the basic concepts of measuring need and determining service responses and assigning priority. So this consultation paper is designed to focus on those ideas as clearly as we can at the outset.

Assumption Six

An improved system has to be workable in the field and this means that it is neither too complex nor too simple, and there should be not too much of a burden involved in collecting any common information from community care clients and their carers. This final point acknowledges that while there are many technical issues that need to be resolved, the implementation of recommendations arising from this project will require some culture change and end-user acceptance to ultimately succeed.

7 Carer assessment systems in context

The Australian Government has developed policies and programs that have expanded the range and availability of community care services, and this has resulted in a community care system that allows many frail aged people and people with disabilities to continue living independently. This has been done with the considerable contribution of family carers and is assisted by funding through State and Territory governments. However, as the need for community care has grown, so has the number of separately funded government programs.

The Australian Government currently funds 17 community care programs through the Department of Health and Ageing. Of these 17 programs, 4 major programs are the National Respite for Carers Program (NRCP), Community Aged Care Packages (CACP), Extended Aged Care at Home Packages (EACH) and the Home and Community Care (HACC) Program. The HACC Program is funded jointly by the Australian Government and the State and Territory governments.

As a result of this growth and service development, community care is delivered in an increasingly complex environment. While considerable progress has been made in expanding the range and level of community care services, the complexity and diversity of the system can make it difficult for consumers to find and access the care they need, particularly as individual care needs change over time. The drive towards independent living for frail aged and people with disabilities has potentially increased the burden on informal and family carers.

The reforms required to improve access to community care are considerable, but the result is expected to be a simpler, streamlined and better-coordinated community care system. That system should be better able to meet the needs of older people and people with disabilities, and their carers, who require assistance. The aim is to meet those needs in a more consistent way across different regions and across the range of agencies in community care, resulting in improved equity of access.

The Way Forward sets the scene for the current project by articulating key policies around consistent eligibility criteria and the linkages of community care across other systems. This therefore applies to the development of any carer assessment system.

“A New Strategy for Community Care proposed a two level approach to assessment to link people to the services they need, depending on whether people need basic support (the Basic Care Tier) or a more comprehensive package of support for higher care needs (the Packaged Care Tier). With the community care system continuing to expand, the need for consistent and effective assessment is essential.

Access to the Basic Care Tier will be through an easily administered intake assessment, while those with more intensive needs, necessitating Packaged Care services, will require a more rigorous comprehensive assessment. In this way, access to care will be based on assessed need and level of dependency that is determined consistently across the country.

The assessment system will be based on existing infrastructure and services. While there will be many identified entry points for assessing eligibility for Basic Care, there will be fewer agencies assessing for Packaged Care and potentially there will be some agencies assessing for both. The provision of intake assessment does not override the need for assessment by service providers to determine the precise level of service needed. This function will be retained by service providers.”³

Action Item 2.1 states:

“The Australian Government will work with State and Territory governments to collaboratively develop intake assessment for HACC services within the national framework that also encompasses other community care programs. The Australian Government will fund the development of a nationally consistent intake assessment tool⁴, encompassing the HACC nine-item dependency tool. The tool will, at a minimum, incorporate eligibility assessment for the HACC Program, the National Respite for Carers Program and the Day Therapy Centres Program.

Appropriate pilot testing will be a key feature of this development work.”⁵

Under the current system of community care, each program has its own unique set of eligibility criteria and client assessment systems. These have been developed with the specific aims and priorities of each program in mind, and are designed to ensure that limited resources are targeted to specific target groups. Currently, this may result in a new client contacting several agencies to request the service they believe they require, providing their personal details, explaining their circumstances and be assessed for multiple programs.

However, at a systemic level, it has contributed to widespread duplication of client assessment and the development of a complex system of community care services that is difficult for clients (people who are frail aged and/or have disabilities) and their carers to navigate.

Aspects of assessment processes, and other common arrangements in community care, are currently being considered by the states, and territories and the Australian government through a series of working groups.

³ *The Way Forward*, 2004, page 29.

⁴ The “intake assessment tool” has been renamed as Australian Community Care Needs Assessment (ACCNA).

⁵ *The Way Forward* 2004, page 30.

8 Issues that impact on the way that the carer assessment tools should be designed

8.1 What is need?

If the goal is to assess the needs of carers, the first step is to agree on what constitutes 'need'. In this section, we discuss the idea of 'need' in general, rather than the specific need for particular programs (for example, the NRCP). In order to focus on the specific needs of clients and carers, it is helpful to first consider some definitions that 'unpack' the concept of need.

Need, or the ability to benefit from health and community care, should be distinguished from both use and demand. Individuals may use community care services and may or may not benefit from them. Individuals may demand or seek services to assist them with their care, but may not benefit if the service is actually provided. Alternately, a person may need care but not seek it or receive it.

Bradshaw first developed a useful description of different types of need in 1972.⁶ This has been widely used in the health sector over the last 30 years and distinguishes between four different ways of thinking about 'need':

Normative need is defined by *expert opinion* regarding appropriate standards, required levels of service and what constitutes an acceptable health status level for a community. Normative needs are based on standards laid down on the basis of experience and consultation. Providers are authorised to allocate specific classes of resources on the basis of their special expertise and base their prescriptions on normative need. **At the individual level, normative needs are often assessed by the use of standard assessment tools.**

Comparative need defines need objectively, by considering matches (or mismatches) between levels of health and morbidity and the availability of health services. Unless there is an objective standard that can be applied, there is no basis for comparisons to be made. Comparative need is assessed via methods that compare the health status of different communities or population groups or individuals and the health services that are available to those communities, population groups or individuals. A region, population group or person is considered to be in 'need' if they have more health problems, or less access to health services, than other regions, population groups or individuals. At the population level, the programs' service components form part of the overall distribution of resources and is based on comparative need. **At the individual level, comparative needs are also assessed by the use of standard assessment tools.**

Expressed need defines need in terms of what services people use. It is based on what you can infer about a person or a community through observing their use of services. A community or person who uses a lot of services is assumed to have high need. A community or person who does not is assumed to have low needs. However, expressed need is influenced by the availability of services - if one community has many, well distributed resources, its population is likely to use more services than a community with few services. Expressed need can be seen to vary by area, and by the number of services received by individuals.

Felt need recognises that there are subjective elements to the notion of 'need' and defines it in terms of what individuals state their needs to be or say they want. The range of felt needs are identified at the local, state and national levels by having a mix of consumer and carer representatives on the relevant advisory structures. **Getting input to programs through using the direct experience of people who can articulate felt needs is an accepted way to balance other inputs from experts** and comparative data on (dis)advantage, and utilisation data on who currently gets what.

The idea that 'needs' can be defined differently for different purposes is helpful because it does not give primacy to any one type of need. This project is premised on the assumption that achieving equity is the key goal and that this is best done through an objective assessment of comparative need. As such, it is designed to complement (and not replace) other ways of assessing the need

⁶ Bradshaw, J. (1972) The concept of social need. *New Society*, 3, 640-643

for particular types of assistance. The strongest evidence of 'need' is when these four perspectives coincide.

8.2 Eligibility is not the same as need

There is a lot of room for confusion in most programs between assessing for need and assessing for eligibility, compounded by a focus on the specific service types that are being offered. Determination of eligibility and needs assessment are best seen as different issues, although they may be assessed at the one time. There is no point in assessing the needs of the ineligible unless it is done for the purposes of channelling the person to another service for which they are eligible. The sophisticated characteristics of a tool or scale are not necessary to determine eligibility because the first questions asked are not an assessment; they are about the application of a set of defined criteria for entry to a program.

The related policies in other Australian Government programs and in the States and Territories are similar but not always consistent. For example, the HACC Program includes carer residency status, whether a person has a permanent or long-term disability and/or is frail aged, and whether a person requires respite on a permanent or long-term basis. So, at this level, the judgement is not on the basis of a rounded picture of need, but is a statement that the person has a condition amenable to assistance by the program.

Various exclusions come next, based on eligibility for other benefits (DVA, residential aged care, third party payers, inpatients). Other entitlements, as well as broad target group characteristics, are applied to determine eligibility. When other entitlements run out, then eligibility can be revisited and may change, independent of any change in the person's needs.

This project is to develop an eligibility and assessment approach for all applicants, not only those who have already met, for example, the NRCP eligibility criteria. These applicants have already demonstrated that they have a care recipient with a disability of a permanent or indefinite nature. Given the discussion above on the different types of need, there is no overall right answer to the question of how to assess their relative need for assistance.

However, we can look for the best mix of indicators or relevant domains of needs and risks that could be combined to give a sense of relative priority for service for an eligible person. In order to reduce some of the complexity of what is being proposed, it is best to separate thinking about eligibility for carers under the NRCP services from the question of what and how to assess for need.

Given a measure of agreement on the relevant domains of consumer and carer need, we can then evaluate how well the assessment tools currently in use perform in measuring these domains or dimensions of need. Examples of assessment domains that are potentially relevant for assessing carer needs include, but are not limited to, health status and psychosocial issues. Much detailed work has already been done in a variety of programs and projects in most states and territories. These will be summarised at a later stage of the project.

9 Assessment issues

9.1 Assessment domains and systems

An assessment tool is defined as a collection of scales, questions and other information designed to provide a rounded picture of an individual's needs and related circumstances. In the context of the United Kingdom's single assessment process (briefly described below), an assessment tool for overview or comprehensive assessment should cover all the domains and sub-domains of the 'single assessment process'. It is a means of identifying a specific health or care condition such as ability for personal care, mobility, tissue viability, depression and cognitive impairment.

A review of assessment tools in use in Australia is being undertaken, as well as a scientific literature and website search. The results to date indicate some common themes. In the UK, for example, the Department of Health has provided guidelines for a common assessment approach. The UK approach does not use one assessment instrument, but instead, sets guidelines for a recommended 'single assessment process'. It includes a set of different recommended tools for 'contact, overview, specialist and comprehensive assessment', criteria for choosing tools and scales, with the requirement that the tools selected be able to produce core summary information. It also points to examples of integration in 'good practice localities'.

In New Zealand, the requirement in an equipment program is for a common approach that is only generally described, in that the specialised assessor identifies the need for a solution in conjunction with the person. The assessment team includes the person and/or their caregiver and the specialised assessor. The assessment team may also include other medical professionals or technicians and they use a mix of those tools used commonly to carry out functional assessments.

Another model is to develop a weighted checklist for assessors, covering the recommended domains, as part of any assessment tool. If such an approach is pursued, it will need to be resolved whether the included domains are equally weighted or whether some domains are more important than others are. This will inevitably involve value judgements. Possible domains for inclusion in a common system are outlined in Attachment 1.

Many services have to respond to a large number of relatively low cost requests, so it may also be useful to take a separate approach to the assessment of those applicants requesting a simple service or to those who request short term or emergency centre-based or residential care respite. In this approach, there would be a separate instrument that focuses simply on assessing the functional dependency of the care recipient. The assumption is that the level of care recipient need and hence carer priority is directly related to the domains of function, including self care, activities of daily living, cognition and behaviour.

As residential respite care already requires a comprehensive assessment to be completed by an ACAT team, CCRCs would already be familiar with organising this type of assessment for the care recipient. The Centre may book and sometimes contribute to the cost of residential respite as a service for carers. Also in dual eligibility households, a carer will also be assessed, i.e. the carer assessment is part of an overall assessment for the care recipient and carer for services.

Looked at another way, two or more carer applicants may make application for the same service. Currently one carer applicant may be rated as high priority and another as low priority for the same service type, based on the way that the carer's own needs are described. Currently there is not a standardised and consistent way of conducting needs assessment across different agencies and Carer Respite Centres, and equity concerns suggest that more consistency is desirable.

From the literature and practice that have been reviewed to date, the key issue for carers is the ability to sustain and strengthen the *relationship* between the carer and the care recipient by helping either side of that relationship. The next sections explore some ways that the goal of sustaining and strengthening the caring relationship might be achieved by capturing useful information in an assessment tool or process.

9.2 Types of assessment

Consultation to date suggests that a critical issue for the project is the terminology that is used to describe different types of assessments. For example, what is called a 'screen' in one agency may be called an 'assessment' in another. A clear set of definitions and a typology that can logically order the different forms of assessment according to the purposes they serve is the core component of any system that is to be purposely designed. Figure 2 summarises seven different types of assessments that are in current practice. Different jurisdictions, and different agencies

within jurisdictions, use different terms to describe these and so, in Figure 2 below, they are simply referred to by number.

In practice, most assessments in the field consist of a combination of these assessment types (eg, 1, 3 and 7 or 1, 2 and 6) and, in that sense, they are different components of a system of assessment, where the different types have different purposes. Most types of assessment may be provided on their own, except for assigning relative priority (Type 7) which is derived from a combination of responses from other assessments.

Figure 2 Types of assessments and their different purposes and outcomes

Type	Scope	Purpose/outcome
1	Determine eligibility	(1) Eligible or (2) Not eligible (may include referral elsewhere for a more appropriate service) Proceed to another type of assessment
2	Shallow and narrow assessment of need	Determine next steps, including any other assessments required (initial action plan) Prompt further assessment
3	Shallow and broad assessment of need	Determine next steps, including any other assessments required (initial action plan) Prompt further assessment
4	Deep and broad assessment of need	Care planning, potentially including clinical interventions
5	Deep and narrow assessment of need	Care planning, potentially including clinical interventions
6	Assessment of need for a specific service	Agency-specific service plan
7	Determine the relative priority of consumer need(s)	Priority rating derived from other assessments

The schema begins by identifying the process of determining eligibility as an assessment type in its own right. In practice, this is usually done in combination with another assessment type.

This schema then makes distinctions between assessments that are:

- narrow (assessing just one domain such as function, continence or depression) versus broad (more than one domain) and
- shallow (can potentially be undertaken over the phone) versus deep (in depth interview, usually face to face and potentially incorporating an assessment of clinical issues)

This gives rise to 4 combinations, as shown in Figure 3 below.

Figure 3 Depth and breadth of assessment types

Breadth		Depth	
		Shallow	Deep
	Narrow	Type 2	Type 5
Broad	Type 3	Type 4	

Type 6 assessments are those that assess a person's need for a specific service. These assessments have been separately identified as they often occur at first service. For example, a

person may have been assessed as requiring home nursing. The nursing assessment is undertaken on the first occasion that the first day that the nurse provides the service. That assessment results in a service plan as well as an occupational health and safety assessment.

Finally, Type 7 has been included to cover those assessment systems that explicitly assess a person's relative priority for service. A priority rating can be derived from other assessments by combining carefully selected data elements, where the selection of what to include in the rating system is based on what most drives the need for care. The selected sub-set of priority factors might be generic (eg the need for a carer and the sustainability of caring arrangements) or factors more specifically related to the need for a particular service (eg to receive an item of equipment or an emergency respite placement).

A parallel project is underway to develop an Australian Community Care Needs Assessment (ACCNA) for (potential) care recipients.⁷ The ACCNA is best described as Type 3. It is to be a broad, but shallow, assessment of need and will incorporate Type 1 (eligibility assessment) as well. It will need to be appropriate for use by either a service agency or an independent assessor. The ACCNA will include a broad screen of the needs of the person's carer as appropriate, but it will not be an in-depth assessment.

The type of carer assessment tool to be developed in this project is discussed in Section 9.5.

9.3 Definition of a carer

'Primary carer' includes a family member or friend who is the person primarily responsible for providing support or care to a person, other than completely or substantially on a commercial basis. The primary carer role may in some instances be shared among a group of family members or a community, in which case a more detailed assessment may (or may not) be able to determine who is the "primary" carer for the person.

State and territory legislation is consistent with the various definitions of a carer or caregiver under national programs. As was proposed above, there are essentially three key ideas in both eligibility and assessment, and these are the definition of the carer role, the key indicators of the needs of the care recipient, and any indicators about the relationship between the two (or more) parties to the care relationship.

(1) Carer role

The key questions to ask are 'does the care recipient need a carer?' and 'is there a carer?' An informal care relationship exists between 2 persons if a person is dependent on another person (a carer) to assist them in an activity of daily living (personal care activity).

Examples of personal care activities a carer may perform include:

- Dressing or other personal grooming of the person.
- Preparing the person's meals or helping the person with eating meals.
- Shopping for the person's groceries.
- Telephoning a specialist to make a medical appointment for the person.

⁷ For more information, see Owen A, et al (2005) *The Australian Community Care Needs Assessment Project: Consultation Paper*. Centre for Health Service Development, University of Wollongong

(2) The disabilities, incapacities and needs of the care recipient

The threshold question again is ‘does the care recipient need a carer?’ and ‘are their care needs being met?’ Assistance with a personal care activity must be required, because the care recipient has a disability, illness or impairment. Usually the concept of a moderate to severe functional disability is used to determine eligibility. If eligible, there is a resulting incapacity and functional burden, and the resulting needs are being met by the carer.

(3) The relationship between the carer and care recipient

The relationship between a carer and a care recipient we are interested in is an informal care relationship, in which the personal care activity is provided in a context where a fee is not paid for the care. A carer allowance is not considered to be a fee, but is financial assistance to the carer to support their informal role.

9.4 Priority rating of carer needs

A specific task in the carer needs assessment project is to develop a nationally standard approach to establishing priority for service, as that is the logical next step after policies determine suitable thresholds for eligibility.

Combining a series of structured professional judgements in a generic or specialist/service specific way will involve judgements about how to assign a suitable weighting system for different client need or carer risk or relationship factors. Key design elements in a system for rating priority could build in screening questions with prompts for the types of support to consider.

For example a high score on the care recipient’s functional disabilities and behaviour might indicate a need for specialised care workers, a specialised service, home modification and frequent respite. Or a high score for carer health and stress indicators might prompt a request for home cleaning or laundry services on a temporary basis, residential respite until the carer’s health improves, stress management sessions, a carer support group or counselling, depending on the results of an individual assessment. A high score on relationship factors might indicate a need for a social worker, carer education, involvement of an independent advocate or mediator, carer counselling, carer mentoring by an experienced carer, as well as some respite

The design of any new system will inevitably become more technical as it moves towards trials and implementation, but the resulting system needs to not be too complex for the end user. There are different approaches we are considering in how the assessment system for carers might look.

Approach One

One option within programs that specifically target the needs of carers is to do this by *only* taking into account the needs of the carer (see Figure 4 below). All carers assessed as having high needs would be classified as priority one, irrespective of the needs of the person they care for. Likewise, a carer assessed as being low need would be classified as a low priority, even if the person they care for has high needs.

Figure 4 The relationship between carer and care recipient need - focus on carer need

CARER NEED	CARE RECIPIENT NEED		
	High need	Medium need	Low need
High need	Priority 1		
Medium need	Priority 2		
Low need	Priority 3		

There are some obvious limitations in taking this approach. One carer applicant may make multiple requests for assistance of different types and it might be that they are high priority for some services but low priority for others. Further, in some relationships there is not one carer and one care recipient. These relationships, in which both parties have needs and each supports the other, are better defined as co-dependent carers.

Approach Two

An alternate approach is to take account of the needs of both the carer and the care recipient. This approach thus focuses on assessing the relationship, rather than the needs of the carer in isolation from the person they care for.

There are complex factors to be taken into account in designing a needs assessment approach that specifically, but not only, addresses carer issues. The complexity in designing assessment tools for carer support arises because the needs of the carers and their care recipients are often compounded and the service aim is to support the relationship as well as the carer.

Other complex factors to consider are that the types of respite services used can be different in terms of cost and the expected volumes of different service types used. On top of this, the types of consumer needs that are being met are also many and various.

If we choose to base the allocation of resources and priority on the relationship, then the priority for service will be different than if the only concern is the needs of the carer. To illustrate the idea, Figure 5 is an example of how priorities might be assessed when the needs of both the carer and the care recipient are taken into account.

The ranking of priorities in this figure is illustrative only and is included to illustrate the concept of rating the carer's priority for service by taking into account both their needs and the needs of the person they care for.

In this option, the needs of the carer are understood in terms of the various levels of needs of both the carer and the care recipient. These include the medical conditions, functional ability, cognitive impairment and other factors of both parties.

Figure 5 *The relationship between carer and care recipient need - focus on the needs of both the carer and the care recipient*

CARER NEED	CARE RECIPIENT NEED		
	High need	Medium need	Low need
High need	Priority 1	Priority 2	Priority 5
Medium need	Priority 3	Priority 4	Priority 7
Low need	Priority 6	Priority 8	Priority 9

As we implied in our overall discussion of the aims of the projects, it is unclear at this stage whether the outcome will be a recommended assessment tool, or a set of mappable data elements. It is also not certain whether it will also be possible to establish thresholds that can be used to determine a priority rating for each client and their carer, or both, in some form of combination.

In practice, establishing a priority rating system involves value judgements for which it may be difficult to gain a universal consensus as each service will have its own views of what the factors are that drive the need for their particular type of service. As one example, Figure 5 identifies 9 carer priority ratings. It is likely that most stakeholders would agree with the ratings at the extremes. That is, that the highest priority should be given to providing services to support relationships in which both the carer and the care recipient have high needs. Likewise, that the

lowest priority should be given to supporting relationships in which both the carer and the care recipient have low needs.

However, we expect that there would be less agreement about the priority ratings in the middle. For example, should the carer with medium needs caring for a high need care recipient be rated a higher priority for service than a high needs carer caring for someone who has medium needs? It may be that the history and quality of the caring relationship (including any alerts or evidence of abuse) are necessary to take into account in making these judgements of relative priority.

If priorities for service are to be established, the next question is how they are used. One approach is that they represent thresholds for service provision. If so, the question is then whether thresholds are absolute or are relative to the level of available service hours. In the 'absolute' approach, a program may only be available to a carer rated as, say, priority one to six.

In the 'relative' approach, all carers would be eligible for services but their likelihood of receiving them would depend on their need compared to other carers also seeking services. If relative, then thresholds could vary from Centre to Centre, across service agencies and from month to month or year to year. Either way, the establishment of sound thresholds would need to be tested in the field trial in a later stage. If thresholds are relative, a process will be required to regularly review the thresholds as the volume of applications and the level of available funding change over time. Despite the inevitable complexities and tensions, such an approach is possible and, many would say, essential.

Risks

The discussion to this point has only been considering needs. There is one other element that may also need to be considered – the concept of risk. The Queensland ONI model⁸ has a priority rating system that is used to determine the priorities of care recipients (not carers) and that can be summarised as:

Priority for service = need x risk

Adapting this to an assessment that only takes account of the carer situation, the priority rating model thus becomes:

Priority for service = carer need x carer risk

In this case, the carer needs assessment instrument would capture items that measure the needs of the carer and also any risks to the carer.

But adapting this to a concurrent assessment of the carer and the care recipient leaves open a set of options:

Priority for service = carer need x client need

OR

Priority for service = carer need x client need x carer risk

OR

Priority for service = carer need x client need x carer risk x client risk

⁸ Owen A, Ramsay L, Holt N and Eagar K, (2004) *Ongoing Needs Identification in Queensland Community Care: Why Use the Tier 1 Screening and Referral Tools - Evidence and Explanations*. Centre for Health Service Development, University of Wollongong and Queensland Health.

In these options, the carer needs assessment would capture items that measure the needs of the carer and the care recipient. Depending on the option selected, any risks to either party would also be considered. Further, and again depending on the approach taken, a separate assessment may be undertaken for the carer and the care recipient for different service types.

Either way, a practical issue to resolve will be to determine whether the needs of both parties would have to be assessed by the same agency. One option is, for example, that a Commonwealth Carer Respite Centre would assess both the needs of the carer and the needs of the care recipient (or at least those needs relevant to determining the priority of the carer). Another is that a different assessor assesses the needs of the care recipient. In this case, agencies would require a protocol so that the required information was made available to the assessor who determines the carer's priority for service.

An alternative approach is simply to develop and implement a common assessment approach, but not a common way of setting priorities for assistance. Each community care agency or Commonwealth Carer Respite Centre would use the common tool but would make their own priority decisions.

9.5 The type of assessment required

As identified in Section 9.2, a key task for this project is to define the type of carer assessment required. Based on consultation to date, this carer assessment project is aiming to develop a broad assessment of carer needs. A question to be resolved is what should trigger such an assessment.

One option is that a carer would be referred for a Carer Needs Assessment as a result of the assessment of the person they care for. Thus, the broad but shallow questions in the ACCNA would be designed to identify those carers with more complex care needs and the answers to these questions would trigger a carer assessment.

The alternative is that a Carer Needs Assessment would be triggered by the type of service requested. Commonly the services requested by a carer might be centre-based respite but some requests are for higher cost in-home respite. An important factor to consider is whether the level and complexity of assessment should be commensurate with the type of respite being sought.

Thus, one possibility is that, applicants requesting in-home and residential respite receive a Type 4 assessment while applicants requesting a lower cost service would not. In the case of the latter, their needs would be captured through the ACCNA.

There is considerable agreement in the literature on how to assess need, as well as agreement that no single tool does the job. An important factor to take into account is the acceptability of assessments, in terms of their logistics of administration, the burden of data collection, the user-friendliness of the process, the fit with professional practice, and whether they are culturally sensitive or age appropriate.

The other (related) issue to resolve is the exact nature of the assessment task. In the broadest terms there are three options on what the assessment task is:

- To assess the carer applicant's needs for each service they apply for, with one assessment for each different service. This is the current system;
- To assess the carer applicant's needs overall, with one assessment per carer applicant regardless of what, or how many separate services they are already receiving, or that they are applying for;

- Something in between which might be one generic section in the tool, with different sections to be completed for carers of people with needs for different services, or different levels of carer support.

An assumption in the policy framework, and the brief for the project, is that one common tool might be used to assess each carer applicant in relation to each service type requested and that the design of that tool could be used to better understand and strengthen the caring relationship. As well as considering ways to capture priority, we are asking those we consult to consider this when responding to the consultation questions. This assumes that the carer knows what type of service they want when they approach the CCRC, which may not always be the case.

9.6 Working carers

Working carers are a significant sub-group of informal carers who have particular needs. Often they are women who need to balance work and family, as well as their care-giving role. Many are said to be “sandwiched-in” between caring for the needs of their young children and the needs of their elderly parents. This added responsibility places emphasis on the need for good communication with partners, good teamwork amongst families, multi-disciplinary service providers offering an array of services, as well as flexibility from employers.

The development of an assessment system for carers may have to take account of the specific issues of working carers:

Are working carers’ issues unique?

Is this a unique sub-group of carers? That is, do their needs differ significantly from those of other carers? Or are their needs an example of common problems, compounded or heightened due to the pressures of a carer’s particular life circumstances or context. For example, having young children, a problem with personal finances or not having access to private transport, may be as important as employment.

Can working carers’ issues be captured?

Can the particular context of an individual carer’s circumstances be adequately described or summarised by an assessment system or is it just too complex? Would a priority rating system look different for working carers compared to other carers?

Answers to these questions will determine whether a common assessment system can be developed for all carers, including working carers.

10 Issues for consultation

The consultation questions attached to this paper are applicable to carer assessment in the context of a national approach to assessment in community care. An important issue is to see how carer assessment systems fit into this larger picture.

10.1 The nature of the assessment and how it is triggered

As discussed in Section 9.5, this carer assessment project is aiming to develop a broad assessment of carer needs and a key issue to be resolved is what should trigger such an assessment. The other (related) issue is whether to assess the carer applicant’s needs for each service they apply for or to assess their needs overall or something in between.

Another design issue is whether to capture the care recipient and carer’s needs separately, plus information on the caring relationship including history and any risk factors or unmet needs,

leaving open how those needs are combined into a priority rating system. Alternately, one tool might be able to capture the key factors that are then combined to determine eligibility first and then priority.

The attached Consultation Survey asks about your system for assessing eligibility (Question 1), carer need (Question 2), care recipient need (Question 3), and how you understand the relationship between the two sets of needs (Question 4). It also asks you to identify the types of assessments you undertake (Question 5) and whether your assessment system contains triggers to other types of assessments (Question 6). If you have a formal system for determining priority of access, we would like to know how this is done in your service, agency or program (Question 7).

10.2 How the assessment system is organised

A range of practical issues will influence the successful implementation of any system developed in the course of the project. These implementation issues need to be considered during the consultation and design phase. They include how the carer assessment tool is administered. It might be done by the initial referring agency (such as a hospital), in which case the carer assessment tool would be incorporated as part of the information required of the referral agency. The agency receiving the initial referral might do the assessment, so for carers, this is the role of the CCRC or respite service. Alternately, a separate assessment agency may be involved.

Depending on which tool(s) are used, agencies may vary in the level of skills that are required to do an initial assessment, and this will have implications for the amount of training of staff involved when adopting a standard or common assessment tool. The time taken to undertake the assessment using common tools relative to the time that the current system requires will be part of field testing at a later stage, as this will have cost implications.

The attached Consultation Survey asks about the advantages of your current system (Question 8) and also asks you to tell us about any disadvantages that you find in your current system (Question 9). In particular we want to know about any groups of carers whose needs may not be adequately captured under your current system. We are asking for more than a list and would appreciate a short description of the difficulties in capturing their needs (Question 10).

One of the practical implementation issues that needs to be taken into account is who does the assessment, and here we are focussed mainly on the skills and experience required for initial assessment, are covered in the survey (Question 11).

10.3 Choosing assessment instruments

Earlier in this paper the various issues for carer assessment and some different approaches to how instruments might be applied to client and carer needs assessment, including rating for priority of access, were outlined. Attachment 2 has a list of the criteria we are using to select instruments that may be helpful in designing a common and more equitable and standardised carer assessment system. Question 10 asks for any examples, suggestions or ideas about other tools that may be useful in the carer assessment process. If you have alternate recommendations or can suggest a better way, then we would appreciate your additional comments.

)(X)(X)(X)

We welcome feedback on this consultation paper. To let us know what you think, please complete the Consultation Survey on Carer Assessment Systems that accompanies this paper. Alternately, you can email us (chsd@uow.edu.au) or phone our contact number (02 42214411).

When you complete the attached Consultation Survey, feel free to attach any further comments about the issues raised in this consultation paper at the end of the survey form.

Attachment 1: Examples of domains that could be incorporated into a national assessment tool for carers and care recipients

1. Domains to assess the client or care recipient

Dependency, function or ability to manage activities of daily living

A measure of dependency is a measure that identifies key areas in which a person requires assistance with daily living. It quantifies the extent to which the person has to rely on someone else to help them carry out normal activities of living in their own home and in the community.

Agreement was reached within the HACC Program and with Aged Care Officials in 2000 that four domains would be included in the HACC 9-item 'first tier' functional screening tool:

- Domestic (instrumental) functioning;
- Self-care (motor) functioning;
- Challenging behaviour; and
- Cognitive functioning.

This tool captures whether the person is capable of performing a task (functional ability), rather than what they actually do. For example, in assessing a client's need for shopping assistance, this measure of functional ability assesses the extent to which the person is capable of shopping without taking into account any external factors (such as whether someone else shops for them).

Functional burden (assessment domains of self care, domestic, cognition and behaviour)

This domain attempts to capture the *impact* of the problems a person may have in terms of standardised scales of functional dependency.

Following through with the previous example, this domain takes into account external factors such as the accessibility of public transport and the physical condition and layout of the house. For example, it assesses the need for assistance with shopping, regardless of whether that assistance is required from a carer, friend or a community care agency.

Formal/informal supports

The domain assesses the extent to which other people (including carers and informal supports such as neighbours or friends) are available to meet a person's functional needs. For example, it assesses the extent to which the person's shopping needs are already being met by a carer or a friend.

The need for a carer

The logic is that the tool must first identify if the primary consumer has a need for a carer, and only then go on to collect items on other domains such as availability, residency and the relationship of the carer to the care recipient and so on.

Carer availability, while closely related to both functional capabilities and the need for a carer, is usually captured as a separate data element.

Capacity for improvement

A related domain that could be useful for managing demand is the capacity of a client to improve. It uses a form of structured professional judgement to assess a client's ability to improve his or her functional capacity. In this way, service providers could consider each client's rehabilitation potential and develop short term and cost effective care or treatment options (for example, teaching the client cooking skills). This approach can move away from the traditional maintenance model that has underpinned many community care programs.

Resulting service need

This is the level of assistance specifically required from a community care agency. Continuing the previous example under formal/informal supports, this approach would assess the extent to which the person needs assistance with shopping from a community care agency after taking into account the availability of a carer or friend to assist with the shopping as well as external factors such as accessibility of shops. It could also take account of their capacity to improve.

Impact on the sustainability of carer arrangements

This is a relationship domain assesses whether provision of the service will lessen dependency on family and carers and/or assist the family/carers to support the care recipient in the community. Is the non-provision of a service likely to increase carer burden and/or impact on the sustainability of carer arrangements? This domain assesses whether current carer arrangements are sustainable without additional support, including both respite services and practical aids and appliances that will assist them in their care tasks.

Likelihood of residential care

This domain assesses whether the provision of the respite service will assist in maintaining the applicant in their residence in the community. Is the non-provision of the service type likely to mean that the applicant will require premature residential care?

This includes assessing whether the requested service type is essential and/or likely to benefit the health and safety of the care recipient and/or their carers. Would the safety of the care recipient and/or the sustainability of their carer be endangered by non-provision of the respite service?

If there is a need for a carer, then what supports does the carer need?

There are also items required to identify supports available for the carer, current threats to carer arrangements and whether the carer arrangements are sustainable. That leads on to asking if the carer needs a carer, and flags a dual eligibility household that is also a flag for packaged care.

Living arrangements

The domain captures information on who the person lives with and their accommodation. It also captures information on their legal and financial circumstances, including decision-making capacity. This information has potential implications for a person's ability to give informed consent and is used for care planning and coordination.

Psychosocial functioning

This domain covers issues such as emotional and mental well being, personal and social support, family and personal relationships and relationships with service providers. It captures some common risk factors associated with emotional and/or mental health problems (such as lack of social supports).

Health conditions

This domain covers clinical issues and medical condition. This can include self-rated health, bodily pain, interference with normal activities, vision, hearing, teeth, speech, swallowing, falls, feet, vaccinations, driving, continence, height, weight and blood pressure pulse. Additionally, it can include self-reported health conditions and confirmed medical diagnoses, current medicines and assistance and referral options.

Health behaviours

This domain captures information about the person's lifestyle and identifies any opportunities that may be available to improve their health and well being. Risk factors such as smoking, alcohol consumption and physical inactivity are captured in this domain.

Environment

This domain screens for home safety problems and environmental health hazards. It is incorporated into assessments undertaken on-site in the person's house. This domain is not captured through an interview with the consumer.

2. *Domains relevant to the carer's needs*

Carer's needs are very similar to the list of domains outlined above. Carers may have significant disability, functional and quality of life issues to contend with. Carers may have their own needs for a carer, which would be a flag for a dual eligibility household, and working carers will have different issues to those in a carer role full-time. Children may be carers for other children or for adults.

In some communities the carer role will be divided among a wider group of people who may adopt different tasks and activities as part of a care network. Finding ways to assess the resilience of a community or a care network, and the resulting service need, may be possible to consider in designing a carer component as part of the larger assessment system.

Many ongoing needs of a carer are related directly to the level of need of the person for whom they care. The carer assessment may require additional domains like stress levels, coping skills and their own needs for support and training and some indication of whether these needs related to their carer role are being met (see 'resulting service need' above).

The additional third element is the quality and sustainability of the relationship between the client and the carer (see impact on the sustainability of carer arrangements above). This is an important contextual feature and may also include an assessment of the home environment. In this approach, client need, carer need and the relationship between the client and the carer would be examined to give a complete picture of the carer's need.

Some of the important issues to examine in the context of the caring relationship could include:

- whether the primary carer is working or not;
- whether there are any financial constraints on a family;
- whether there are additional caring responsibilities or young children in the family;
- the level of partner support with the informal caring role; and
- whether the carer has access to private transport.

Attachment 2: Criteria for the selection of measures

The process of starting from scratch to develop a new assessment tool in any field is a laborious, time-consuming and expensive one. A large pool of draft items needs to be written. These need to be tested in a pilot study. The best items are then selected on their psychometric performance, the structure of the tool is analysed to ensure it covers the necessary domains, including reliability, validity and norm development.

Where possible, it is best to make use of existing standardised instruments that relate to the domains under investigation. Usually there are a number of standardised instruments available to choose from and the task becomes one of assessing these against standardised criteria for selection.

The proposed criteria for the selection of instruments are as follows:

- Public domain;
- Reliability;
- Validity;
- Applicability;
- Practicability;
- Compatibility; and
- Efficiency.

These criteria are described in more detail below.

Public Domain

The criterion of being in the public domain is that the instrument can be used by all service providers in Australia without the cost of licence fees. Lesser restrictions apply to copyrighted tools where the only requirement is to acknowledge the source of the original work that was involved in the development of the tool or scale.

Reliability

Reliability refers to the capacity for an instrument or measure to give the same result consistently. It is a fundamental way of reflecting the amount of error, including both random and systematic error, inherent in any measurement. There are several different ways of measuring reliability including test-retest reliability (where the same test is administered on two occasions to the same participants by the same assessors), inter-rater reliability (where the same participants are assessed by different assessors and the results compared) and internal consistency where the results of instrument items are compared with each other. Obviously, if an instrument is administered on two occasions close in time to one another, it is desirable for the same results to be obtained for the same individuals. Similarly, it would be unacceptable if different assessors arrived at widely discrepant results for the same individuals while using the same instrument.

Validity

Validity refers to the accuracy of the result and the extent to which the scale or instrument actually measures what it claims to measure. There are different types of validity - content, criterion validity (concurrent and predictive) and construct validity (convergent and discriminant). Criterion validity is where the instrument is correlated with another measure of the domain under study - usually a gold standard measure which has been used and accepted in the field. In clinical contexts, validity is frequently measured by reference to specificity and sensitivity, referring to an instrument's capacity to correctly detect those with the target attribute and to correctly filter out those who do not have it. This is sometimes because there is no readily accessible gold standard criterion against which to determine the instrument accuracy.

Another related aspect is the responsiveness of the instrument or its capacity to detect change in the person over time. In the Australian community care context this may be important, as care recipients may need to be reassessed at periodic intervals. The client or carer's needs may change and there could be a decline in functional status that means that the need for a service may increase.

Applicability

This refers to the ability of the instrument to be applied to the particular target group. For example, a measure of function for adults may not be applicable to children. In the description of many instruments and measures, applicability is poorly specified. In the present context a tool is needed with wide applicability to the full range of applicants requiring a service in the community in a variety of different settings. There are no standardised ways of reporting applicability other than perhaps noting that the psychometric performance of the instrument or measure has been demonstrated to be satisfactory across a range of consumer or clinical groups.

Cultural sensitivity is another side of applicability. A scale or tool should not unfairly discriminate against people either from Aboriginal and Torres Strait Islander, minority ethnic communities or people whose preferred language is not English.

Practicability

This refers to the ability of an instrument to be practically applied in given contexts. For example, if the instrument requires several hours to be administered or expensive equipment then it may not be suitable for a widely dispersed field administration context. Another aspect of practicability is the skills required by staff that must implement the measure. An instrument may be assessed as suitable on most criteria but require extensive training for its use by accredited trainers. In this case an instrument that is easier to administer and requires less training of staff may be chosen in preference. Increasingly, instrument developers are now charging license fees and as a result another practical consideration can be the cost of using the instrument.

A key consideration is that the practicability of an instrument or measure is crucially impacted by who is doing the assessment and for what purpose. A primary care practitioner or a generalist nurse may want quick and somewhat crude measures and for them such measures are highly practical. In contrast, specialist practitioners or researchers may have very different criteria as they will need their instrument to be highly valid and reliable and may be prepared to invest a relatively large amount of time in the measurement process. What is acceptable, a tool's practicability and applicability and level of reliability and validity, are impacted by who is doing the assessment and for what purpose.

Compatibility

This refers to selecting assessment instruments that will be compatible with other assessments the client or carer is likely to undertake for the management of their condition. The client or carer does not want to be assessed with similar items for every different agency or practitioner they are likely to approach. In this respect 'mainstreaming' may be an important consideration that would give priority to selecting tools that are already being used to collect data for another purpose. Many applicants may be assessed for example with the Home and Community Care functional assessment tools and these data elements may already be available for some people. If this is the case, and these tools have sufficient coverage of the domains required for a national approach, then they should be considered a priority for selection.

Efficiency

This refers to the tool's capacity to collect sufficient information to determine relative need and priority in the most parsimonious manner. Assessing need can be time consuming and costly for the agency but it can also place considerable respondent burden on the applicant with a disabling condition. Missing data are likely to increase with increasing respondent burden reducing the quality of the data. Generally, and particularly in field applications, it is considered best to use the shortest tool available that still meets appropriate standards of reliability and validity.