



A National Approach to Assessing the Needs of Carers

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Executive Summary

This is the Final Report on the development of Version 1 of the Australian Carer Eligibility and Needs Assessment (CENA) instrument. The Interim Report on the project¹ presented the results at the end of the period of field-testing and before all the data had been collected and analysed. The Interim Report period included the view, consolidated from all levels of field testing, that most of the required changes are minor and that the next version should build on the ability to follow the 'flow' of a conversation by the explicit 'layering' of items at different depths.

The draft recommendations to achieve this set of aims were included in the CENA Interim Report, Part 2². Feedback on the content of earlier reports and further data analyses have informed the discussion in sections 5 to 8 and these sections have been used to refine the recommendations in section 9 and these are also included after this summary.

The conclusion from the findings of field testing the CENA is that a more 'modular' design should improve useability by a split of the pool of data elements into different modules and recommended configurations, each with optional layers of greater depth. With each module having an Action Plan, and containing a mixture of the three types of information: carer and care recipient assessment information; information to guide a service response; and information for the purpose of reporting.

Field-testing the CENA

The CENA was field tested at four levels, with agencies in routine practice, via using database and web versions to give wider access, and by presentations and focus group feedback. The most resource intensive was the technical trial of the data elements and electronic data collection. This covered 16 agencies, half being Carer Respite Centres and half being service providers and resulted in 805 carer assessments for detailed analysis. CDs containing the database version and manuals were mailed to 67 participants and 184 individuals registered on the website, plus some of those organisations and individuals that registered also wrote thoughtful submissions. There were 12 focus group presentations and about the same number of presentations to conferences, meetings and briefing sessions. The exposure of the wider community care sector to the tool was good, the feedback was consistent and a large amount of data was collected that warrants further analysis and will be helpful in designing further trials.

Results on the CENA

The analysis undertaken for this final report has been limited to the testing and refinement of the CENA instrument. The main questions to be answered were about whether it worked and for whom, and how useable and acceptable it was for experienced assessors. The focus was on testing whether the data elements can be routinely collected and then used to guide an action plan and service response.

This analysis suggests that the relationships between the data elements were sufficiently clear to warrant further refinement, and the information collected provided a useful carer profile with relationships between the data elements being able to be interpreted in the expected directions.

There was a practice effect for the assessors; they became quicker as they became more familiar with the data elements and took on average 38 minutes in the CCRCs and 54 minutes for providers. 72% of the assessments were done over the phone, and the providers, who did most assessments face to face, mainly used the paper version and then the data were entered electronically at a subsequent time.

¹ Ramsay L, Samsa P, Owen A, Siminski P, Stevermuer T, Grootemaat P and Eagar K (2006) *The CENA Field Trial Interim Report, Part 1 Results*. Centre for Health Service Development, University of Wollongong

² Ramsay L, Samsa P, Owen A and Eagar K (2006) *The CENA Field Trial Interim Report. Part 2 Recommendations*. Centre for Health Service Development, University of Wollongong.

The profile of carers contained in the database is useful and the sections that were used by assessors varied according to the needs of the carers, and for the service response. Not all sections were expected to be completed, for example the functional screen was used for only 48% of carers because many are functioning well, are mobile and in employment.

The level one data analysis revealed several key findings:

- The majority of assessments were conducted over the telephone
- As expected CCRC's conducted less face to face assessments compared to service providers
- 'Carer emotional stress and strain' was the most common circumstance triggering referrals followed by 'care recipient increasing needs'
- The average completion time was 43 minutes. Assessments were quicker when conducted over the telephone compared to face to face
- Assessors routinely completed the first five sections of the CENA constituting a 'broad and shallow' assessment. The lowest rates of completion were for the 'K10 Mental Health and Wellbeing Scale' and the 'Functional Profile'. Completion by CCRC's was slightly higher for most of the earlier sections and considerably lower for the optional sections
- Service providers were more likely to attempt all sections of the CENA and complete all items within the carer details section compared to CCRC's
- Assessors completed less domains within the carer details section over time with the exception of 'financial, legal and employment' and 'care tasks'
- As 58% of the assessments used the short form of the Zarit tool; the data supports the inclusion of the 4-item Zarit as a screen and the replacement of the 22-item version with the 12-item Zarit. The recommended rule is that the 12 item version be completed only if triggered by a score of 7 or more on the 4 item version
- The K10 Mental Health and Wellbeing Scale should be included as an optional item for carers who are at risk due to high levels of burden &/or stress
- The Functional Profile should be included as an optional item and only completed if the carer has significant health problems as indicated by earlier items
- It is possible to auto-populate 'carer needs and risks' for the priority rating and the automated version produced an even distribution across all priority rating levels.

The conclusion from these results is that the CENA should be a 'modular' design that accommodates the varying needs carers and the range of different agencies that will potentially adopt this tool.

Carer Needs Assessment

The key design feature was that the assessment approach should be able to accommodate a range of users' requirements from simple to complex, and allow for multiple functions. The use of different modules by different types of agencies, allowing for variable depth and breadth, is the logical extension of this approach. The standardised design should support the assessment of formal and informal support to be part of a wider system.

The database collected from the Level 1 sites now has the potential to produce rich information about the needs of different types of carers through further analyses, should they be required. The purpose of field testing was primarily to test the validity of the CENA and not to carry out a detailed survey of carers, but a useful data set was one by-product of the exercise. This could form a practical starting point for further research and development in the sector.

The next version of the CENA could be reframed as a Carer Needs Assessment (CNA) tool that can help to establish eligibility while collecting assessment information on the carer and care recipient, information for guiding a service response, and for reporting. Having the concept of 'eligibility' in the name implies a limited single program view. Eligibility is just one initial point in a

continuous process and the term implies a gate keeping role for one program, rather than a supportive assessment tool. The purpose of the tool is primarily as an assessment for community services, useable by a range of programs.

The field trial also highlighted how the CENA should not be so “big”, but also reinforced its usefulness for the purpose of care planning as well as information gathering, in which case it might be either big or small depending on the information and the planning required to address the problem. There was evidence from the feedback in the trial that some agencies successfully used components of the CENA to assist carers work through difficult issues and in those instances the tool was seen as part of an intervention, the other parts of which are referral pathways to other parts of a bigger system and requests for further assessments.

Developing a flexible role for the re named “CNA” as a tool for the NRCP and the community care sector potentially has wider implications. A culture change that emphasises how assessment can be for more than just one agency’s services implies a type of care planning. It suggests a different way of gathering data, and a use that is not a new idea in community care, but is new for some. Many carer support agencies already provide a service that includes assessment to assist carers to understand their role more clearly and to think about the future.

A program of further design and testing would focus on the interface with the ACCNA, aged care assessment (ACAT) for community care and residential care. The aim is to address the ‘breadth and depth’ issues in each proposed module and the resulting division of responsibilities, roles and capabilities among the service types that could potentially use the tool. The aim would be to encourage a range of providers and assessors to move in a more carer focussed and preventative manner. It potentially assists the carer to think through their strengths and vulnerabilities, their personal goals and the best options for the care recipient depending on the context in which it is used.

Implementation of recommendations

The national roll-out strategy should have an explicit focus on care that addresses the needs of carers as ‘clients’ in their own right and not just as an extension of the person they are caring for. This is to prevent breakdown in carer health, including mental health, thereby putting the care situation at risk. A set of principles in the ‘roll-out’ program can recognise the considerable variation in agencies’ starting points for the national approach. That includes variation in service types and the goal of carer assessment, as well as how comfortable providers are in opening up areas of inquiry about informal carer support. For some agencies this is not new – finding ways for dealing with reported stresses and strains, psychosocial problems, and positive aspects of care-giving are common in the sector, although not done in a standardised way.

A national roll-out strategy should include the following:

- The roll-out strategy should be carried out over three phases in the context of a research and development framework in which each phase can build on lessons learned in the previous stage
- The CENA needs to inter-relate with the ACCNA to avoid duplication of assessment and provide an indication of some of the efficiencies that might be gained
- That some agencies in the field, including many of those that responded to the invitation to test the CENA, have sophisticated systems in place and many have significant investments in assessment systems planned in the near future as part of their agencies’ work programs, while other agencies have still to progress to operating in a sophisticated electronic environment
- The achievement of a consistent national approach will rely on consistent training and, if deemed appropriate, the development of national competency standards
- Successful implementation is dependent on a centrally organised network of trainers and the development of user friendly training materials.

The strategy that is outlined in this Final Report is not modest. However, it is achievable if resources are well deployed, and organisation, training and support needs are fully addressed.

In summary, a key lesson from the project's tool development and the field testing phase was that carer assessment can be used as an instrument to help carers work through issues related to their role in support of a care recipient. A flexible and layered approach is required to support them in that role in the service system in a way that is relevant to their personal context and the purpose of the assessment. It has been primarily developed for use in assessment for community care services. At a system level, any implementation work should be based on recognition that carers are an integral part of a system that blends formal and informal care, with support needs in their own right.

Recommendations

Recommendation 1. Change of name to the Carer Needs Assessment

The CENA should be renamed as the Carer Needs Assessment (CNA) to highlight its overall use as an assessment services tool, with potential to identify factors relating to the carers own health and well being, that may impinge on the care situation. Having the concept of 'eligibility' in the name reflects a single program view, when referral to another service may be an appropriate response. Eligibility is just one initial point in a much longer process and the term implies a gate keeping rather than a supportive approach.

Recommendation 2. Clear Principles

An implementation strategy for the Carer Needs Assessment should be based on a set of key principles derived from the lessons learned in the background research, consultation surveys, design and field testing of the CENA.

Recommendation 3. A Phased Roll-Out

The implementation strategy should be carried out over three phases in the context of a research and development strategy to support the national roll-out. The first phase should use volunteer agencies from the field testing and employed carers projects, the second phase should involve additional agencies nominated by Jurisdictions and the third phase should be the national roll-out.

Recommendation 4. Link between the ACCNA and CENA

The inter-relationship between the Australian Community Care Needs Assessment and the CENA is the first basic step to be taken in achieving a system where data collection does not have to be duplicated.

Recommendation 5. Training and Support

Implementation should pay attention to the larger change management agenda, use a research and development strategy and a centrally organised network of trainers, and use attractive training materials based on principles of adult learning.

Recommendation 6. Credentialing

The implementation strategy should develop a credentialing framework within an agreed set of competencies over the three phases of the roll-out and in the context of a research and development strategy. The development of an agreed set of competencies will help to overcome barriers such as distrust of another agency's assessment information. Standardised training and credentialing will help to foster confidence about the quality of carer assessment between agencies.

Recommendation 7. Role delineation in assessment

Individual assessors and agencies need to recognise their role in assessment as being an active part of a bigger system. This requires agreement on the roles of different agencies and the technical and cultural capacity to share information between agencies.

Recommendation 8. Research dissemination

One of the outcomes from the field trial was a wealth of information from routine assessment practice that had not been collected on such a scale before. Once a degree of standardisation is achieved, many useful comparisons can be made. Timely disseminating of research findings to participating agencies is a practical way to demonstrate the valuable insights to be gained from turning routine data into useful information.

Recommendation 9. Connection with residential respite

As an extension of the inter-relationship between the NRCP and other programs, there is a useful role for the CENA in sharing information with providers of residential respite. This issue arose in feedback from some level one agencies, in the information sessions and some submissions from respite providers.

Aged Care Assessment Teams and Carer Respite Centres book respite admissions in residential aged care facilities and do not always require a comprehensive assessment of the care recipient. But they do need a short term care plan. The CENA is well suited to this purpose. CCRCs will broker services and use top-up funding to purchase short-term places in residential care, and again the CENA in its proposed modular form could be a useful adjunct to these functions.

Information exchange between community support services and residential aged care will become a practical issue in the near future as a result of the review of Australian government subsidies and services.

As part of the field testing, a number of NRCP funded agencies have indicated their willingness to be involved in further testing of the CENA in a 'system' context, and the opportunity to test this level of inter-relationship should be build into planning the next steps.

Recommendation 10. Towards the measurement and analysis of the outcomes of interventions

When used for both assessment and re-assessment, the CENA captured needs, risks and relationship factors that change over time. That is the basis for a continuous record that, in turn, is a pre-condition for measuring the outcomes for carers (and care recipients). Over time, and with good quality data and sensible analysis, it provides useful information about the effectiveness of the interventions that were put in place. The recommended phased roll-out of version 2 of the CENA gives the program an opportunity to move in that direction in a logical and planned way.

1 Status of this report

The purpose of this report is to guide decision-making in the next stage of the Carer Eligibility and Needs Assessment (CENA) project. This report builds on the feedback provided in the CENA Interim Report Part 1 and Part 2 and provides more detailed analysis of the full CENA data set. It does not duplicate what was in those previous reports³.

This Final Report includes additional information on the following components of the field trial:

- A profile (descriptive analysis) of the characteristics of the carers assessed and included in the full field trial data set
- All evaluation sessions and feedback from Level One assessors
- The focus group sessions from Thursday Island and Townsville
- The feedback from NSW Home Care Aboriginal assessors
- Feedback from the information session with the Victorian Carer Services Network

One aim of the data analysis in this report was to show the quality of the information that could be available when the data elements are being used on a routine basis. However, the analysis has been largely limited to the testing and refinement of the CENA instrument. The database collected from the Level 1 sites has the potential to produce rich information about the needs of different types of carers through further analyses, should it be required. This could form a practical starting point for further research and development in the sector. Another aim was to answer the research questions that were addressed in order to improve the usability of the CENA and its reporting capabilities:

- Which items best predict the 'gold standard' reference point of carer needs and risks, care recipient needs and strength of relationship (i.e. the relationship between items and experienced assessor judgements).
- Profile the carers assessed by age, person they are caring for and functional ability.
- How the assessors used the CENA - and whether the 'sections completed' changed over time.
- Examine the effects of missing data on the priority rating.
- How strongly are the components correlated? Should all components be weighted equally for the priority rating?
- Can the number of data items be reduced without adversely affecting the priority rating?
- An examination of the subset of data items for carers who received emergency respite using the action plan item (carer respite – reason) instead of the item in the evaluation form.
- Investigation of correlations between the different versions of the Zarit scale - does the 4-item version provide sufficient information to eliminate the need for the 12-item or the 22-item Zarit?
- Investigation of correlations between the Zarit burden interview and other carer characteristics. - whether the K-10 mental health screen and the Zarit are both necessary for the CENA tool.
- A comparison of initial assessments with any reassessments

The additional aim of the analysis shows the value of investigating the relationships between individual items, the CENA components (carer needs and risks; care recipient needs; sustainability of relationships) and the priority-rating model.

³ Ramsay, L et al (2006) *The CENA Field Trial Interim Report, Part 1 Results*. Centre for Health Service Development, University of Wollongong.
Ramsay, L et al (2006) *The CENA Field Trial Interim Report, Part 2 Recommendations*. Centre for Health Service Development, University of Wollongong.

2 Summary of the CENA model being field-tested

The overall aim of the field trial and the data analysis as part of the project was to explore whether it was practical and possible to build a better (and national) carer assessment system. Improvements were to be based on the recognition that carers are an ‘integral’ part of a wider system that blends formal and informal care.

The feedback in the design phases and once the CENA was taken into the field, was consistent in the message that improvements to carer assessment should move beyond data collection as the primary purpose. The design that was tested was an instrument to help carers to work through issues related to their caring roles and in a context of their service and personal arrangements.

Using the typology shown in Figure 1, the CENA was tested as a combination of a “Type 3 broad and shallow” and “Type 4 broad and deep” assessment of a carer’s needs. It also includes eligibility for the National Respite for Carers Program (NRCP) and priority rating.

Figure 1 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 CENA model includes a number of domains that assess a carer’s need (see Figure 2 below) with these domains being covered at both a shallow and deep level. The CENA was designed to collect other relevant information, such as demographic information, and the information needed for services to respond to the carer’s needs, which are identified in the development of an Action Plan.

Figure 2 Domains in the CENA

Care giving context	Values and preferences
Functional level of care	Positive aspects of care giving
Health	Strengths and risks
Financial, legal and employment	Action Plan
Confidence and competence	Plus: Client registration and contact details and demographic information. (These items are not measures of need - required to help formulate a service response)
Knowledge	
Care tasks and skills	
Social support	
Coping strategies	

The role of the CENA is to help assessors determine eligibility for the NRCP programs, assess the needs of carers as consumers in their own right and stream carers to:

- other assessments as required i.e. aids & equipment or specialist mental health (“Type 5)
- direct to service provision including service-specific assessment (“Type 6”)
- exit / referral to other more appropriate services.

The model for the CENA is included in diagrammatic form in Attachment 1.

3 Methods

3.1 Field testing the CENA model at four levels

The Carer Eligibility and Needs Assessment (CENA) and Australian Community Care Needs Assessment (ACCNA) trials were linked and used in parallel where possible, incorporated a similar methodology in the evaluation design and used similar methods for their useability testing.

The field trials were comprised of four distinct levels.

Level 1

The technical field trial was a high-volume trial with selected service providers in South Australia, New South Wales and Victoria commencing in July 2006 and covering an 8-9 week period. Service providers used an electronic version of the CENA tool for assessment and data collection and a paper based version was also used.

Service Providers in the technical trial of the CENA were selected in conjunction with the CHSD, state government officials in SA and NSW and VIC and local Department of Health and Ageing representatives. They were selected on the basis of their readiness and interest, the potential volume of assessments during the trial period and to achieve a mix of respite services and Commonwealth Carer Respite Centres (CCRCs).

This level of the trial specifically set out to test the functionality and the useability of both these tools in the agencies' information systems. The technical performance of the tools was evaluated using de-identified data from each site.

Level 2

The General Useability Trial was designed to promote an inclusive approach to the trial and to encourage transparency about what had been developed to date and what was being tested. It involved the full version of the trial software, in CD format, developed for the technical field trial of the CENA and/or ACCNA that was provided to interested service providers to test its acceptability and compatibility with their current systems.

Training manuals on using the CENA and ACCNA were provided to the service providers who registered to participate in this aspect of the trial, but on-site and hotline support was not provided. Participating service providers were asked to provide feedback on the tools and how they were used in local systems and how data could be transferred into their information systems.

Level 3

The General Acceptability Trial was a further level to promote an inclusive approach and encourage transparency. Any interested service providers could participate in the field testing on the CHSD web site and provide feedback on the acceptability of the tools. Users at this level had access to the training manuals and relevant documentation.

This version did not enable the tools to be used for assessments or for data collection, but offered the opportunity to provide feedback to improve the tools and get access to the background information on the CHSD website.

Level 4

Focus Groups were conducted 12 times where CHSD met with selected service providers for clients with special needs. These included client groups from culturally or linguistically diverse backgrounds (CALD) in Victoria, service providers with predominantly indigenous clients in the

Northern Territory (Alice Springs and Darwin), Queensland (Townsville and Thursday Island) and in Sydney (regional/rural and metropolitan, and service providers in Canberra, Launceston and Hobart in Tasmania. A consumer focus group was hosted by Hope Healthcare Limited.

The one-day focus group workshops discussed the appropriateness of the CENA and ACCNA tools to assess the different client groups. In some cases both tools were discussed with participants but in most groups the focus was requested by participants to primarily be on one or the other. The State and Territory Program Managers of the National Respite for Carers Program invited the NRCP services to participate, and the ACCNA participants were selected in consultation with the jurisdictions.

3.2 Opportunistic information sessions and conferences

In the course of field testing a number of jurisdictions and organisations took the opportunity to invite the CHSD team to deliver presentations on the background and current status of field testing of the CENA and ACCNA. This presented an opportunity to get less structured feedback as well as being a useful addition to the communication strategy around the field trial. There were presentations and/or meetings of carer groups in Redfern in Sydney, Perth, Adelaide, Brisbane and with the Victorian Carer Services Network in Footscray in Melbourne.

Members of the CHSD team presented to the NSW Aboriginal HACC Gathering executive meeting and the NSW HACC Issues Forum, both convened by the NSW Council of Social Service. Invitations to speak were accepted at State and regional level conferences conducted by the Aged and Community Services Association and its affiliates in Queensland at Noosa and the Gold Coast, in NSW at Wagga and Coffs Harbour, Caulfield in Victoria and Perth WA.

In addition to the formal and informal presentations, the team also made use of opportunities for written communication with articles in State and local newsletters (Aged Care Queensland, Aged and Community Services Association national and NSW and ACT newsletters) and provided drafts and written feedback on letters, articles, fact sheets and website content for the Department of Health and Ageing.

3.3 Profile of the participating agencies and assessors in Level One

There were 16 agencies in Level One of the trial, with half being Commonwealth Carer Respite Centre (CCRCs) and half being providers funded under the NRCP.

Table 1 Participating agencies

Agency	Location	Assessments Completed	Description of IT	Description of Service
NSW Home Care	RAC Parramatta, NSW	8	NSW DADHC new client system in roll-out phase includes basic items and CIARR level CENA running on Local Area Network version	Single Point of Entry – Home Care NSW – assesses for domestic assistance, personal care and respite
http://www.dadhc.nsw.gov.au/dadhc/Older+People/Home+Care+Service.htm				
Central Coast	Gosford ACAT CCRC/Care link Central Coast, NSW	23	Part of Central Coast local information system (4CN) CENA running on Local Area Network version	Co-located CCC/CCRC and ACAT with AHS links and local e-referral network
http://www.4cn.org.au/				
Baptist Community Services	Cumberland Prospect, NSW	95	Information integration agenda well underway, using a web-based system for the trial	CCC/CCRC HACC
http://www.bcs.org.au/				

Agency	Location	Assessments Completed	Description of IT	Description of Service
Community Care Northern Beaches	Mona Vale, Northern Beaches, Sydney, NSW	21	Local service network with plans to integrated, using experience from the trial CENA used on 3 separate PC's	Community Care NRCP/HACC Respite
http://www.ccnb.com.au/				
Calvary Healthcare	Kogarah, Sydney, NSW	31	CENA used on single PC to record paper forms	NRCP/HACC with AHS links
http://www.lcmhealthcare.org.au/index.php?page=/services				
Benevolent Society	Brighton Le Sands, Sydney, NSW	69	CENA running on Local Area Network version	CCC/CCRC with links to HACC and respite providers
http://www.bensoc.org.au/director/whatwedo/olderpeople.cfm				
Hope Healthcare	Greenwich, Sydney, NSW	27	CENA used on single PC to record paper forms	NRCP/HACC with AHS links
http://www.bensoc.org.au/director/whatwedo/olderpeople.cfm				
Metropolitan Domiciliary Care	Metropolitan Access Team, Netley, SA	100	CENA running on distributed CITRIX network to service several sites	Adelaide wide service - Single Point of Entry for access to domiciliary care
http://www.domcare.sa.gov.au/				
Helping Hands	Adelaide, SA	52	CENA running on distributed CITRIX network to service several sites	NGO provides broad range of residential and community services
www.helpinghand.org.au/				
Aged Care & Housing Group	Adelaide, SA	16	CENA used on 5 separate PC's	NGO range of residential and community resources+ DVA
http://www.ach.org.au/				
Resthaven Incorporated	Malvern SA	15	CENA used on 7 separate PC's	NGO provides broad range of residential and community services
http://www.resthaven.asn.au/				
Uniting Care Wesley Adelaide Inc	Adelaide SA	34	CENA used on 3 separate PC's	CCC/CCRC
http://www.ucwesleyadelaide.org.au/				
Uniting Care Wesley Bowden Inc	Bowden SA	103	CENA running on Local Area Network version	CCC/CCRC
http://www.ucwb.org.au/				
Carers SA	Murray Bridge SA	40	CENA used on 9 separate PC's at 2 different sites	CCC/CCRC
http://www.carers-sa.asn.au/				
Carer Support and Respite Centre Inc	Royston Park SA	111	CENA used on 9 separate PC's	CCC/CCRC
http://www.carers-sa.asn.au/respite.htm				
Carers Victoria - National Carer Counselling Program	Melbourne, VIC	60	CENA used on separate PC's	1800 information number plus short term counselling for carers
http://www.carersvic.org.au/CarerOrgs/CarerCounselling.htm				

The 16 agencies in Level One of the field-testing included seven in NSW, eight in SA and one in Victoria. The size and roles of the organisations varied, with service arrangements being a mix of central phone-based systems, face to face assessments, small agencies, and small outlets of multi outlet organisations. Some were integrated multi-program organisations operating as part of established regional networks.

There were 805 de-identified carer assessments received for analysis from agencies using the CENA at Level One of the field trial. The aggregate data and feedback from assessors is covered in the Results (Section 4) below.

In total, the participating CCRCs and provider agencies used about 60 different assessors with a wide range of assessment qualifications, experience and competencies. The high level of cooperation and goodwill within the agencies and by the assessors was a key factor in achieving sufficient quality and quantity of data in the technical level of the field trial.

3.4 List of the participating agencies involved in Levels Two and Three

Level Three of the trial did not offer support beyond the documentary material contained on the website and no training was involved in how the tool should be used. Relatively few agencies that registered responded to the invitation to provide detailed feedback when compared to the number that showed interest.

There were 191 registrations on the web-site to express interest in the CENA. 9 were DOHA officials. A number of organisations had more than 1 person registered. The list of agencies that logged onto the website and registered in Levels Two and Three showed a mix of services and service types and locations, and includes those that also requested a CD version of the database. The list of organisations is presented in Table 2.

Table 2 Organisations that registered for Level 3 trial

Jurisdiction	Organisation	
ACT	ACT Health	Community Connections Inc
	Alzheimer's Australia ACT	Department of Veterans Affairs
	Belconnen Community Service	Handyhelp ACT Inc
	Carers ACT (CCRC)	Villaggio Sant Antonio
NSW	ACAT	LINC
	Anglicare Sydney	Macarthur Community Options
	Ballina District Community Services Association	Marrickville Council Tom Foster Community Care
	Broken Hill City Council	Mercy Care Centre
	Bucketts Way Neighbourhood Group Inc.	Mid North Coast Commonwealth Carer Respite Centre
	Care for Children with Disabilities Inc	MNC CCRC
	Carrington Centennial Care Ltd	Narellan Congregational Community Service s
	CCRC and Carelink Hunter	Narrabri Meals On Wheels Inc
	Central Coast Case Management Services	Northern Community Care
	COAMAS	NovaCare
	Concord Community Options	Orana Commonwealth Carer Respite Centre
	Department of Ageing Disability and Home Care	Pole Depot Neighbourhood Centre
	Eurobodalla Shire Council	Queanbeyan City Council
	Friends of Woodstock Disability Services	Shellharbour City Council
	Greenways	Snowy Respite Service
	Gunnedah Oxley Community Options	SSWAHS

Jurisdiction	Organisation	
	H.N. Mclean Memorial Retirement Village	St Carthages Community Care
	Hills Community Care	St Hedwig Village
	Holbrook Meals On Wheels Service Inc.	Sunnyfield Association
	Illawarra Retirement Trust	Tablelands Community Support Options
	Indochinese Respite Care Service	TOCAN
	Inner West Community Transport	Uniting Care Lithgow
	Inverell Disability Services Inc	UPA
	ISRCSD	University of Sydney
	Kiama Council	Warialda HACC Multi Service Outlet
	Kiama Shellharbour	Wesley Mission
	KinCare Community Services	
NT	Aputula Aged Care	Ingkerreke Outstations Resource Services
	Australian Red Cross	Mutitjulu Community Health Service Inc.(AC)
	Carers NT Inc.	Titjikala women's centre
Qld	Blue Care	GOC Care
	Centacare Community Support Services	Ipswich Hospice Care Inc
	Co.As.It.	Mater Respite Services
	Community Ventures and Alliances	Ozcare
	DAART	RSL Care
	Diversicare	The University of Queensland
SA	Carers SA	Masonic Homes
	CHAP	Port Pirie community Health
	Country Home Advocacy Project	Resthaven
	Eastern Regional Collaboration Project	Riverland Regional Health Service Inc
	ECH Inc	
Tas	Campbell Town Health & Community Service	Launceston General Hospital
	CBS South	Mersey Community Care
	Commonwealth Carer Respite Centre	Oak Lifestyle Options
	Department of Health and Human Services Tas	Polish Welfare Office
	East Side Care	Primary Health Services
	Family Based Care (North)	TASCOSS
	Family Based Care Association North West Inc	South Eastern Community Care
	Glenview	Southern Cross Care Tas
Healthwest		
Vic	Australian Healthcare Associates	Gippsland Lakes Community Health
	Barwon Health	Inner South Community Health Service
	Bayside Community Options	Knowledge Base Systems Pty Ltd
	Best of Care	Latrobe Community Health Service
	Brotherhood of St Laurence	Lincoln Centre for Ageing
	CCRC	Mildura Rural City Council
	Chinese Community Social Services Centre Inc.	Moreland Community Health Centre
	City of Greater Geelong	Northern Health
	Clark Phillips Pty Ltd	Uniting Care Community Options

Jurisdiction	Organisation	
	Department of Human Services	Villa Maria
WA	ACROD	Hills Community Support Group
	Adamas Corporate Solutions	Kimberley Aged & Community Services
	Bethany Community Care	Perth Home Care Services
	Churches of Christ	Pilbara Community and Aged Care Services
	City of Belmont HACC Services	Silver Chain
	City of Canning Multicultural Respite	Wachs-Midwest Aged and Community Care
	Coolabah Community Care	

4 Field Trial Results

4.1 Analysis of carer assessments collected at Level One

There were 805 carer assessments completed by about 60 assessors in the CENA database. This was fewer than the numbers who were assessed, and the estimates given by agencies during the design of the trial. This was due to the higher than expected number of clients who did not agree to give consent to the evaluation component of the trial assessment. There is no exact figure available for the number of client refusals, which varied between agencies, but based on the evaluation feedback sessions with assessors a 25% refusal rate is a reasonable anecdotal estimate.

4.1.1 Summary of responses by agency

The analysis in this report is based on the responses of 805 carers who consented to having their assessment conducted at Level One of the trial included in the database for the purpose of the evaluation, as reported by sixteen agencies.

These agencies are grouped into two service types: Commonwealth Care Respite Centres (CCRCs) and service providers. The numbers of responses by agency are included in Table 3.

Table 3 *Number of responses by agency*

Provider	Responses
NSW BCS	95
NSW Benevolent Society	69
SA Carers SA	40
SA Carers Support and Respite	111
SA Uniting Bowen	103
SA Uniting Care Adelaide	34
CCRCs	452
NSW Calvary	31
NSW CC ACAT	23
NSW Home Care	8
NSW Hope Healthcare	27
NSW Northern Beaches	21
SA Aged Care Housing	16
SA Helping Hands	52
SA Metro Dom Care	100
SA Resthaven	15
Service providers	293
NCCP Carers Vic	60
Total	805

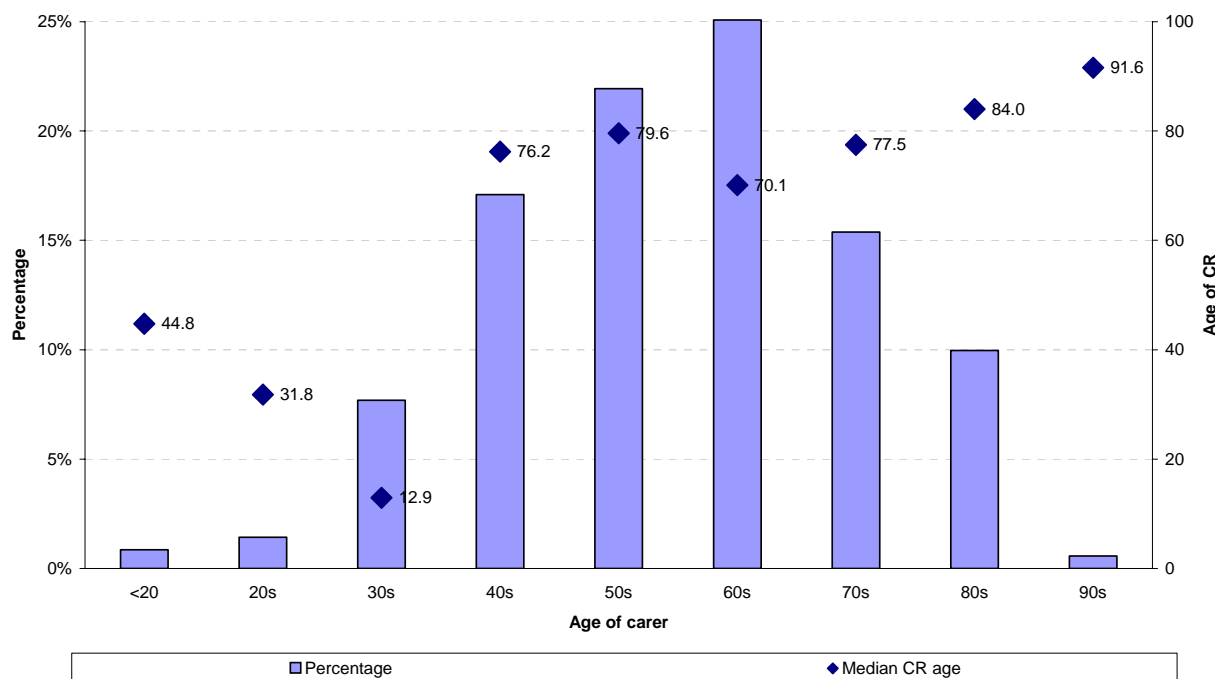
4.1.2 Profile of carers

The following carer profile is based on the assessment data collected in the field trial.

Figure 3 shows the age profile of carers and the people that they care for. This figure is based on 351 carers for whom age was recorded⁴.

One in four carers were in their 60s and a further 22% were in their 50s. For these two groups, the average age of the person they were caring for was 70 and 80 years respectively. Ten percent of carers were aged less than 40, with one percent being aged less than 20. These groups were caring for younger people, with carers in their 30s typically caring for children and young adults. One in four (26%) carers were 70 years or older and they were typically caring for someone of a similar age.

Figure 3 Age of carers and the person they care for



This same information is presented in Figure 4 but this time the figure is based on the age group of the care recipient (CR). It will be seen that, as the age of the CR increases, the more likely it is that they are cared for by an older carer. This is most pronounced for CRs in their 70s, the majority of whom are cared for by their partners.

This is consistent with the carer relationships shown in Figure 5. Nearly half (43%) were caring for their partner while 29% were caring for a parent. Fourteen percent were caring for their child. Only 2% of carers were friends/neighbours of the person they were caring for. In total, 85% of carers were women and 15% were men.

⁴ The low number with age reported is because age was inadvertently deleted in the process of de-identifying the data. Sites were able to subsequently provide age details for 351 carers.

Figure 4 Age of care recipient by age group of carer

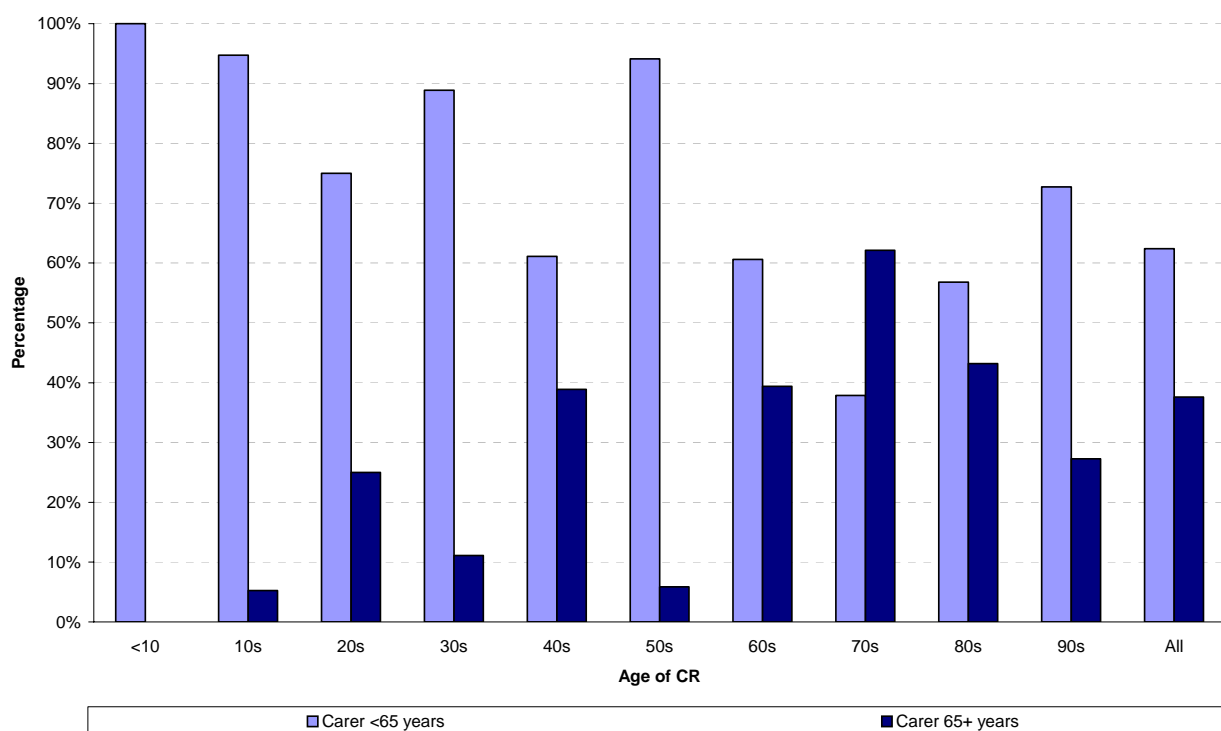
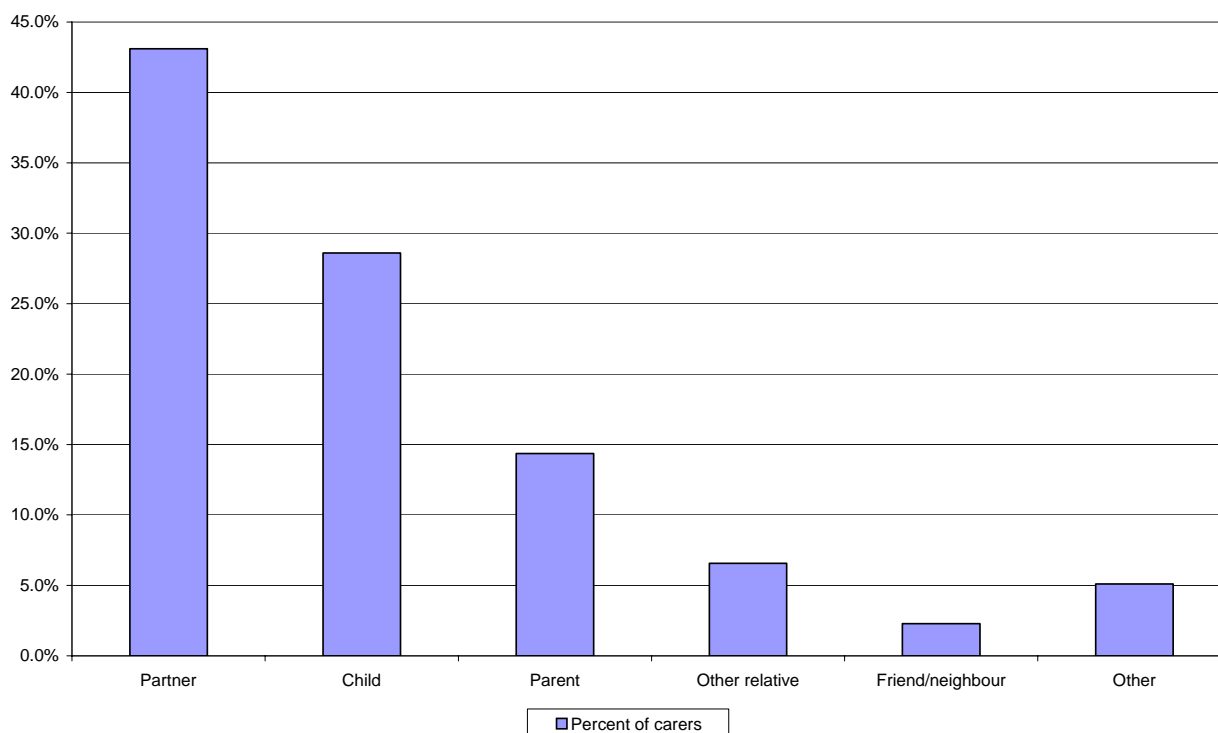


Figure 5 Relationship of carer to CR



Summary data on country of birth is shown in

Table 4. Australia was reported as the country of birth in 71% of cases. Two thirds of those born in Australia were aged less than 65 years. This contrasts with those carers who were born in other countries. Carers born in other countries were much older, with over half being 65 years or more.

Table 4 Country of birth of carer by age group of carer

Country of birth	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers with COB reported	
	N	%	N	%	N	%
Australia	164	78.1%	79	61.2%	524	71.3%
Other	46	21.9%	50	38.8%	211	28.7%
Total	219	100.0%	132	100.0%	735	100.0%

Country of birth	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers with age reported	
	N	%	N	%	N	%
Australia	164	67.5%	79	32.5%	243	100.0%
Other	46	47.9%	50	52.1%	96	100.0%
Total	219	62.4%	132	37.6%	351	100.0%

Figure 6 shows carer residency arrangements. Older carers are more likely to live with the person they are caring for. This is consistent with the data on carer relationships, with older carers more likely to be caring for a partner and younger carers more likely to be caring for a parent or a child.

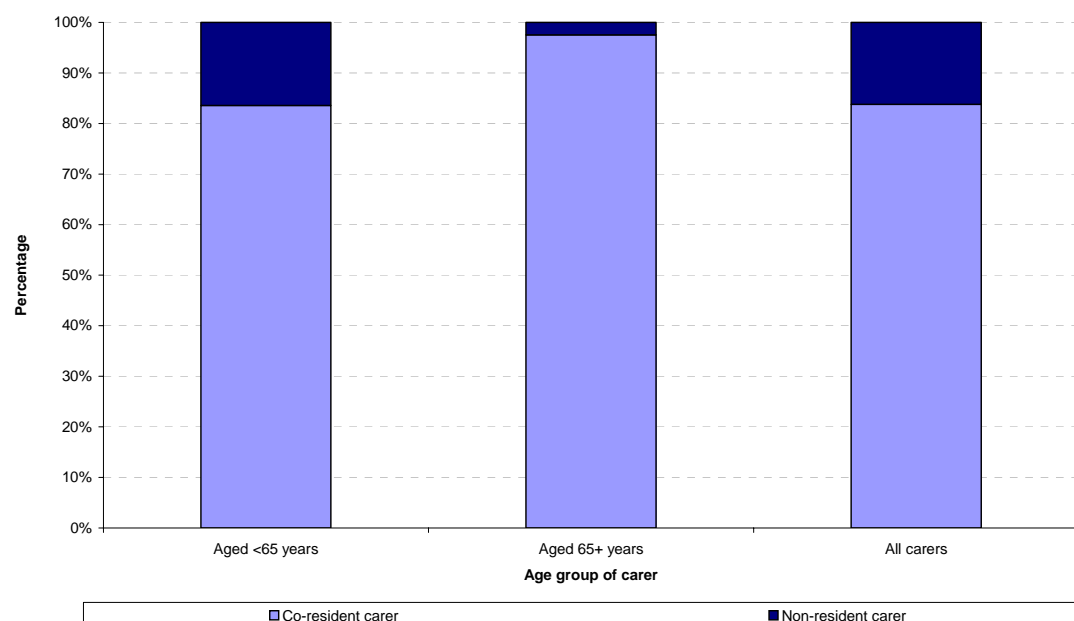
Figure 6 Carer residency status by age group

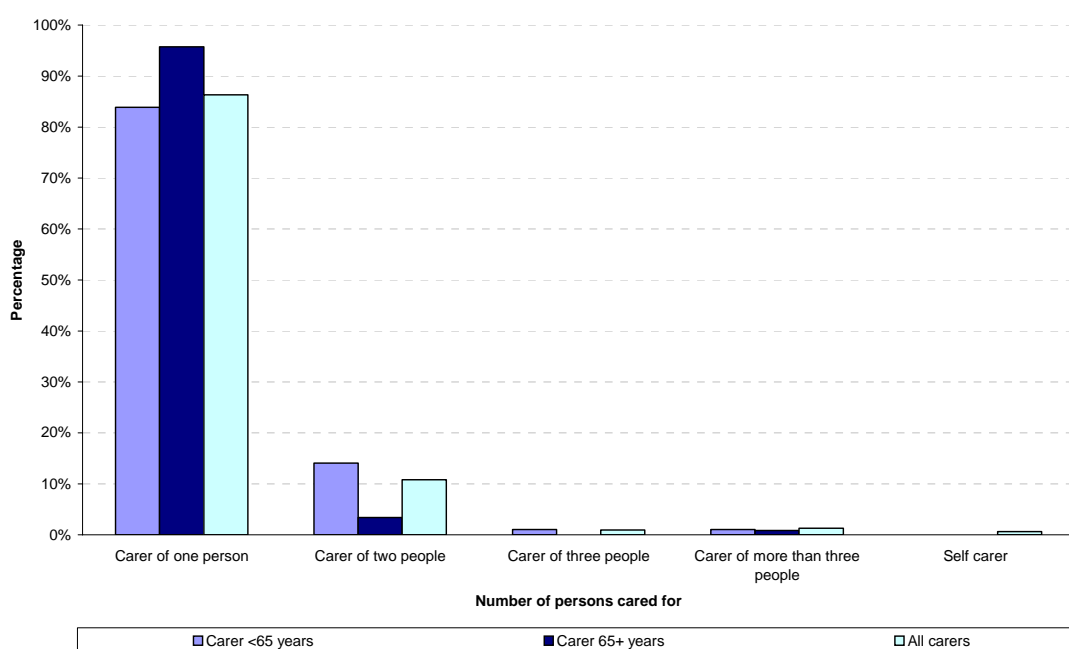
Table 5 shows how long carers have been in the carer role. Consistent with national policy, the great majority had been caring for more than 6 months.

Table 5 Duration of caring

Caring for more than 6 months?	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers	
	N	%	N	%	N	%
Yes	191	97.0%	120	97.6%	582	95.7%
No	6	3.0%	3	2.4%	26	4.3%
Not reported	22		9		197	
Total	219	100.0%	132	100.0%	805	100.0%

Figure 7 shows that the majority of carers are caring for one person. But 16% of younger carers were caring for more than one other person.

Figure 7 Number of persons cared for by age group



The source of income for carers is shown in Figure 8. Three in ten carers were in receipt of an aged pension while a further 30% were receiving carer support (15.7% carer payment and 13.2% carer allowance). Most of the 21% of carers who were receiving no government pension or benefit were less than 65 years old.

Figure 9 summarised the data in terms of access to a government concession card. In total, 53% of carers had a concession card while 47% did not. Older carers were significantly more likely to have a concession card (78% compared to 40% of younger carers).

Figure 8 Income support by carer age group

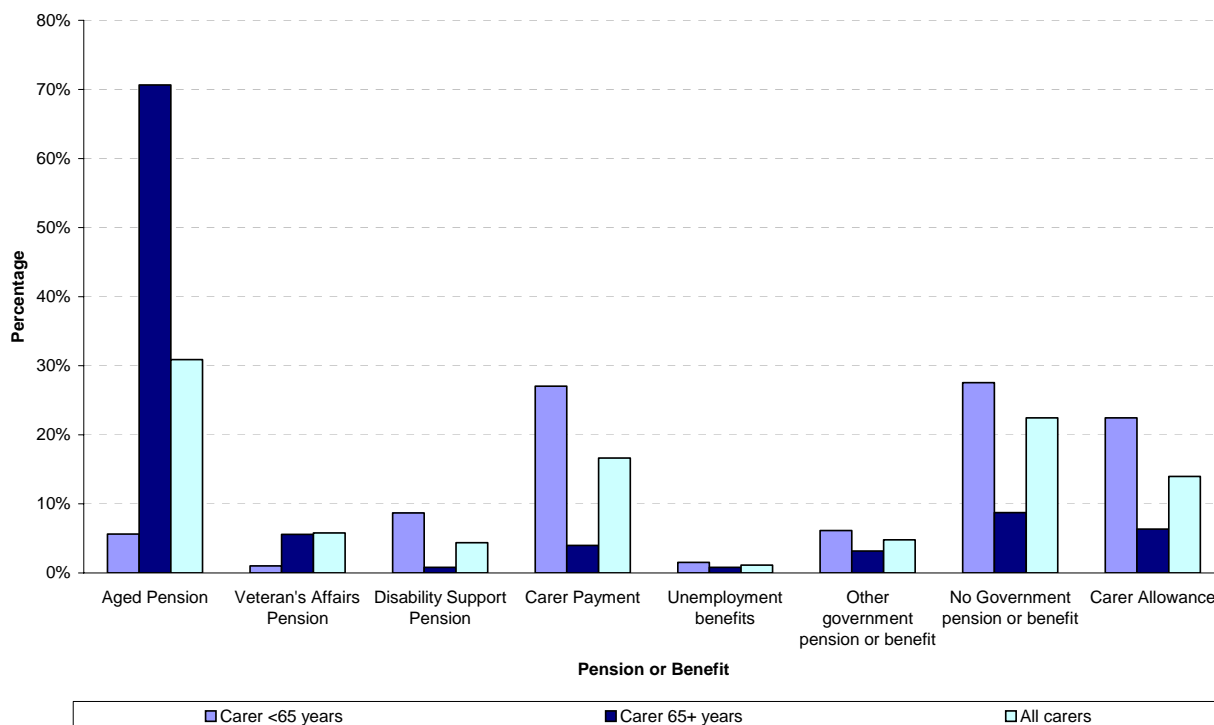
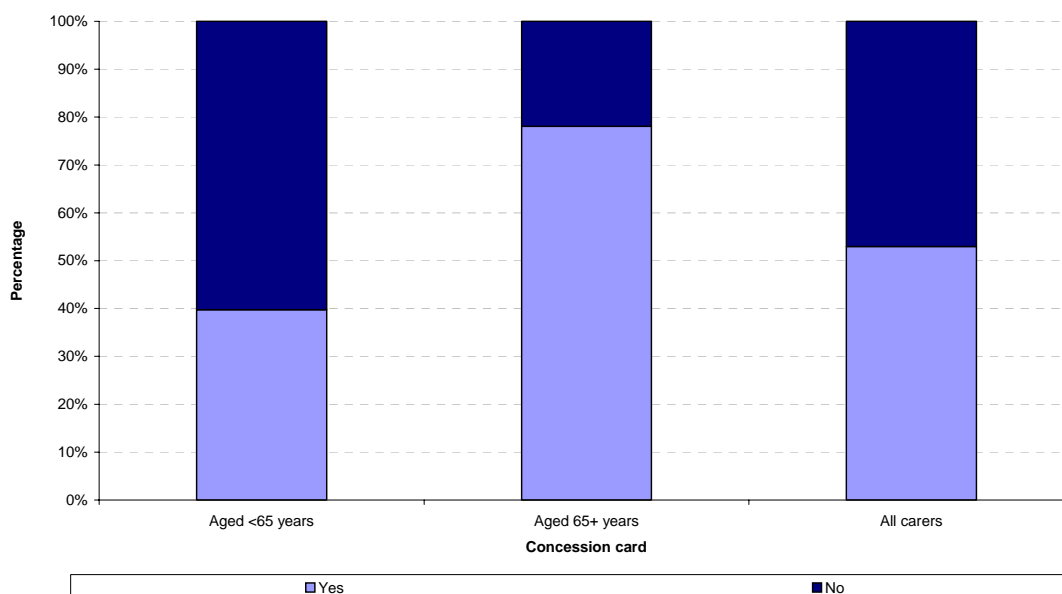


Figure 9 Concession card status



The employment status of carers is summarised in Table 6. The majority (74%) of carers were not in paid employment, with 11% working full time and a further 10% part time. But the rate of paid employment varied by age. For those over 65 years, only 2.5% were in paid employment. For those 65 years or younger, 30.1% were in paid employment, with the majority of those in full-time employment.

Table 6 Carer employment status

Employment status	Age group of carer					
	Aged <65 years		Aged 65+ years		All carers	
	N	%	N	%	N	%
Not in paid employment	127	62.9%	117	97.5%	483	74.2%
Full time	36	17.8%	0	0.0%	70	10.8%
Part time	28	13.9%	2	1.7%	65	10.0%
Casual	8	4.0%	1	0.8%	14	2.2%
Seasonal	1	0.5%	0	0.0%	1	0.2%
Not stated/inadequately described	2	1.0%	0	0.0%	18	2.8%
Not reported	17		12		154	
Total	219	100.0%	132	100.0%	805	100.0%

4.1.3 Assessments by agency and mode of contact

Some assessments were conducted over the telephone, while others were face-to-face. Mode of contact was recorded for 73% of cases. Of these, the majority (72%) were over the telephone, 23% were face-to-face, while the remainder (5%) were both face to face and over the telephone. However, amongst service providers, there were more face-to-face assessments than telephone assessments (Table 7).

Table 7 Number of responses by agency and mode of contact

Agency	Face to face	Over the telephone	Both	(missing)	Total
NSW BCS	4	81	0	10	95
NSW Benevolent Society	1	58	0	10	69
SA Carers SA	2	38	0	0	40
SA Carers Support and Respite	1	75	0	35	111
SA Uniting Bowen	1	71	0	31	103
SA Uniting Care Adelaide	16	10	2	6	34
CCRCs	25	333	2	92	452
NSW Calvary	13	9	1	8	31
NSW CC ACAT	1	15	0	7	23
NSW Home Care	0	2	1	5	8
NSW Hope Healthcare	12	11	2	2	27
NSW Northern Beaches	10	4	6	1	21
SA Aged Care Housing	0	14	0	2	16
SA Helping Hands	21	7	13	11	52
SA Metro Dom Care	52	12	2	34	100
SA Resthaven	1	6	3	5	15
Service providers	110	80	28	75	293
Carers Victoria	0	6	0	54	60
Total	135	419	30	221	805

4.1.4 Circumstances that triggered the CENA

As shown in Table 8, 69% of assessments were conducted as an initial assessment and 31% were reassessments.

Table 8 Assessment type

Assessment type	Age of carer					
	Aged <65 years		Aged 65+ years		All carers	
	N	%	N	%	N	%
Initial assessment	142	70.3%	81	67.5%	496	68.6%
Re-assessment	60	29.7%	39	32.5%	227	31.4%
Not reported	17		12		82	
Total	219	100.0%	132	100.0%	805	100.0%

Assessors could choose more than one option in identifying the circumstances that triggered an assessment and did so for 444 carers. 'Carer emotional stress and strain' was the most common circumstance, followed by 'care recipient increasing needs' (see Table 9). The final design of the CENA needs to accommodate for each of the circumstances listed in the table. It is likely that the circumstance triggering the referral will be one of the factors that determine the depth of assessment completed.

Table 9 Circumstances triggering contact/ the assessment

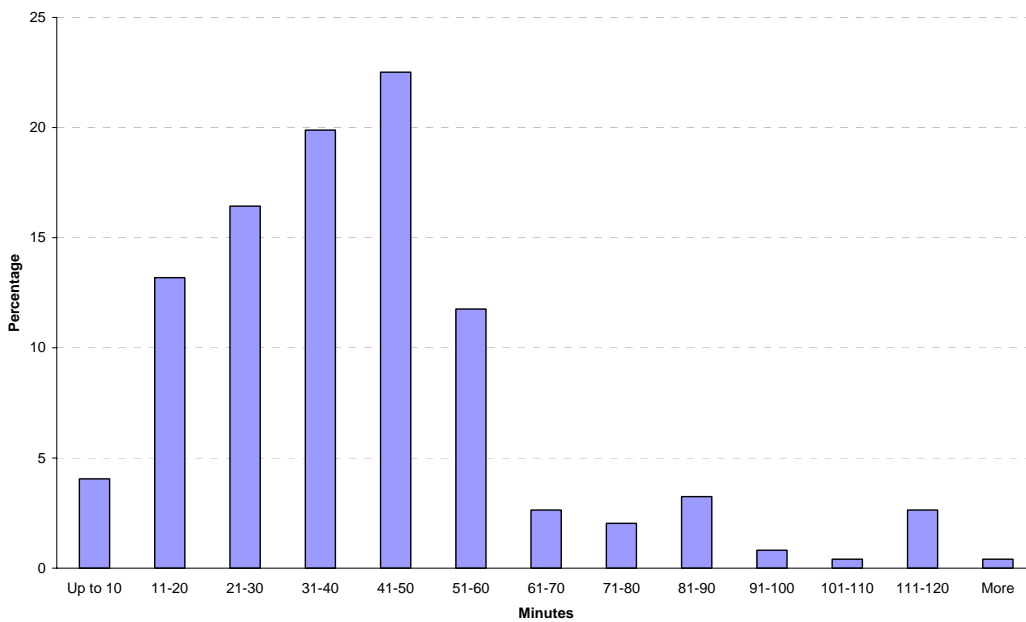
Circumstance	Responses	% of responses
Carer – emotional stress & strain	213	30.5%
Care recipient – increasing needs	149	21.3%
Carer - maintain regular activities	74	10.6%
Carer – acute physical exhaustion/ illness	68	9.7%
Carer – slow physical health deterioration	57	8.2%
One-off event	45	6.4%
Care Recipient – other factors	38	5.4%
Carer - employment issue	24	3.4%
Carer – factors unrelated to care situation	21	3.0%
Carer - return to work/study	9	1.3%
Total	698	100.0%

4.1.5 Time taken and changes in completion over time

There were two sources of data for the time taken to complete a CENA; the estimates given by the assessors and the time recorded automatically in the database. Time recorded in the database is for opening and closing the episode, which may be longer than the assessor estimates as other factors such as breaks or extra phone calls may have influenced the total time.

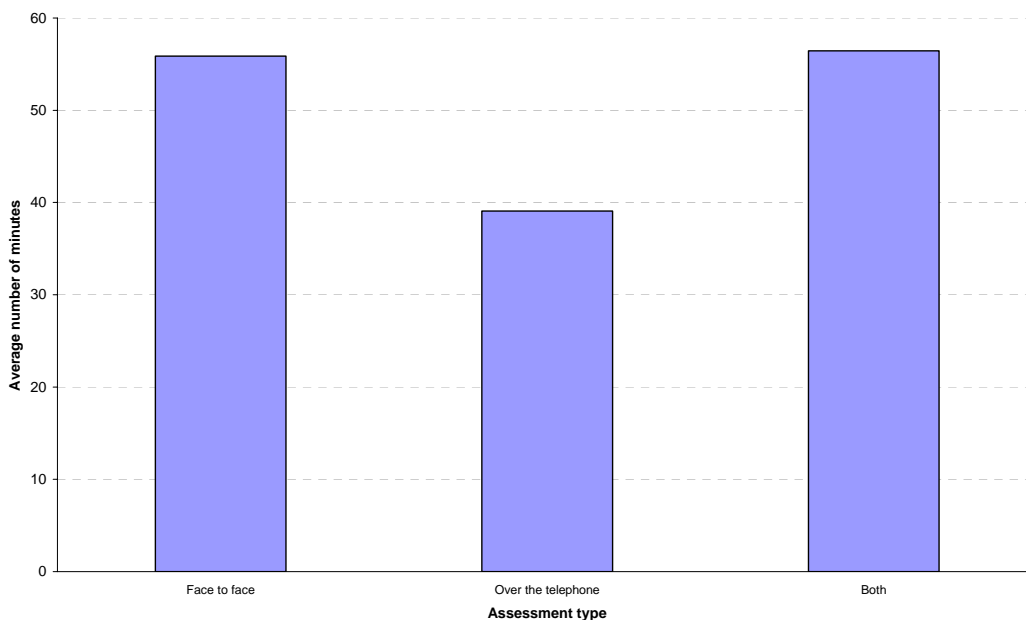
Assessors were asked to estimate the time taken to complete the assessment process. 61% responded to this data item, with an average completion time of 43.4 minutes. The distribution of time taken is shown in Figure 10. Twelve percent of cases took longer than one hour, and 0.4% took longer than two hours.

Figure 10 Estimated time taken to complete the CENA



The mode of contact was obviously a factor in the time taken. The average time to complete the assessment was longer when face to face than over the phone. The average completion time by mode of contact is shown in Figure 11. Assessments were quicker when conducted over the telephone (39 minutes) than face-to-face (56 minutes) or in both modes (56 minutes). To illustrate this further, NSW Calvary did all assessments in the home and, as shown in Figure 13 below, this agency took longest to complete the CENA.

Figure 11 Average completion time by mode of contact (minutes)



The average completion time is shown by agency type in Figure 12. The lighter bars represent the average time amongst all CCRCs and the darker bars represent service providers. The average completion time was 38 minutes for CCRCs and 54 minutes for service providers. This finding was not unexpected because service providers completed a higher proportion of face to face assessments.

Figure 12 Estimated time taken to complete the CENA by CCRCs and providers

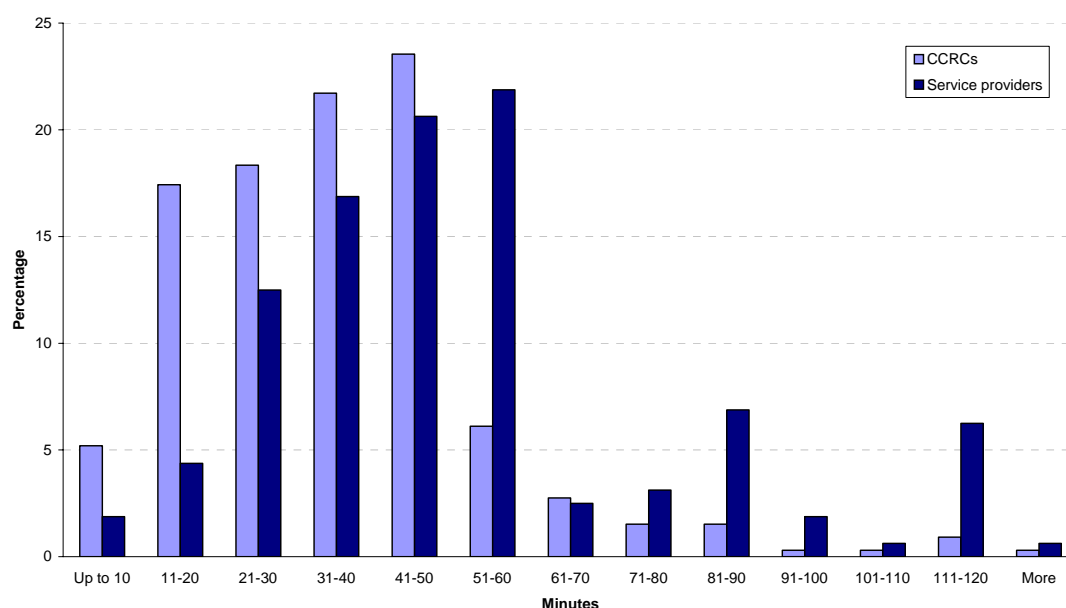
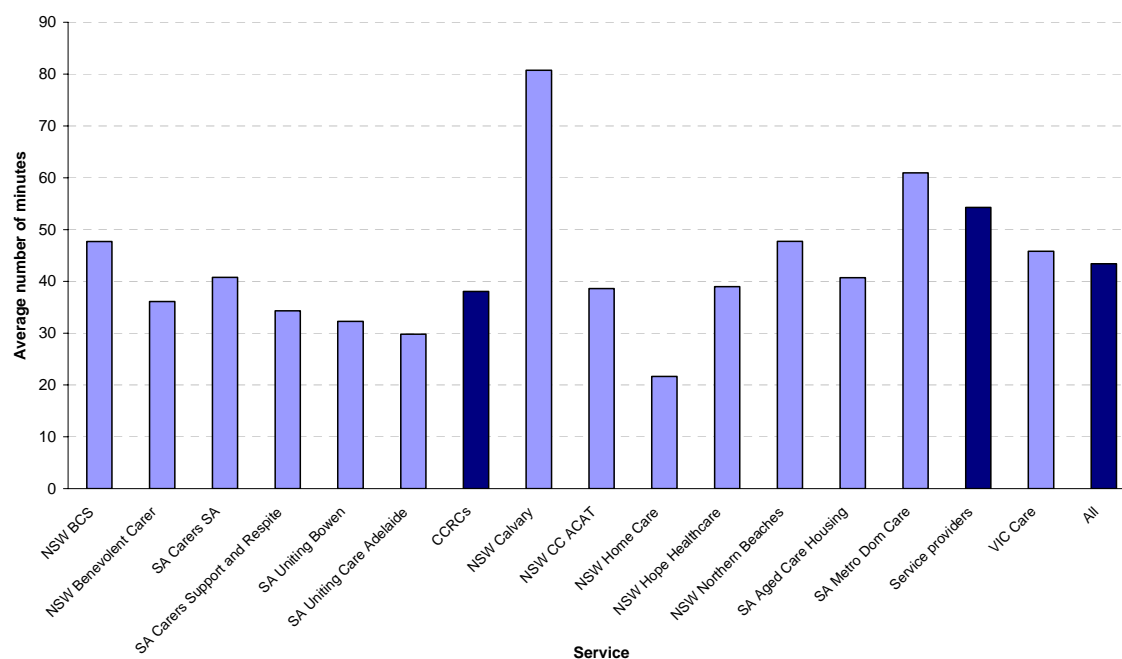
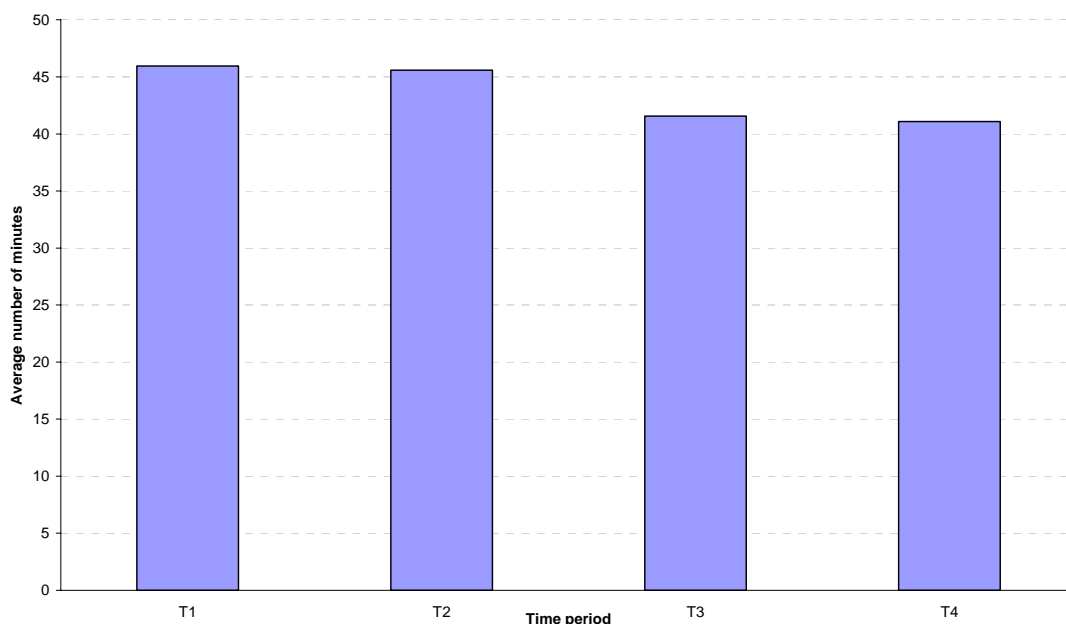


Figure 13 Average completion time by service (minutes)



It was expected that the time taken would decrease as the trial progressed. The data were split into four time periods (Time 1 [T1], Time 2 and so on) in order to investigate if this was the case. The amount of time taken was related to the practice effect of increasing familiarity with using the CENA and this was also confirmed by the feedback sessions with the assessors. This is shown in Figure 14.

Figure 14 Completion time by agency over 4 time periods



4.1.6 Who are you calling on behalf of?

In the initial contact, people were asked whether they were calling on behalf of themselves, a relative/friend, or an organisation calling on behalf of a carer or client. The purpose of this item was to give the assessor an opportunity to check that consent had been given to disclose personal information. Feedback suggested the item appeared redundant in the course of the conversation and the data concept overlapped with both the Source of Referral item in the NRCP MDS and the item on the circumstances triggering the contact, which may explain why it was missing for 96% of records. Out of the twenty nine non-missing responses 10 carers initiated contact themselves, 17 contacts were initiated by an agency, and 2 by a relative/friend. This item will need to be revisited in future versions of the instrument in an attempt to clarify its purpose to either improve the response or delete it.

4.1.7 Source of referral

The source of referral is an MDS item with 22 codes. Less than half of respondents completed this item. Table 10 shows that 47% of assessments were self-referred and a further 6.6% stated ‘Family, significant other, friend’. Community based agencies were the next most common with ‘Other government community-based services agency’ and ‘Other non-government community-based services’ at 7% each and there were 2.8% from ‘Other community-based medical/health’ sources and 2.6% were from GPs. Public hospitals were 6% and 4.8% were from specialist aged or disability assessment teams and 1.8% from a ‘Comprehensive HACC assessment authority’.

Nine sources of referral categories each accounted for 1% or less of the total contacts. The 22 referral source codes are inconsistent with the 15 categories in the HACC MDS and could usefully be reviewed and the number of codes reduced overall.

Table 10 Source of referral

Referral Source	Count	Percentage
Self	184	47.1%
Other government community-based services agency	29	7.4%
Other non-government community-based services	28	7.2%
Family, significant other, friend	26	6.6%
Hospital (public)	23	5.9%

Referral Source	Count	Percentage
Specialist aged or disability assessment team / service	19	4.9%
Other referral sources	82	18.5%

4.1.8 Completion of sections and items

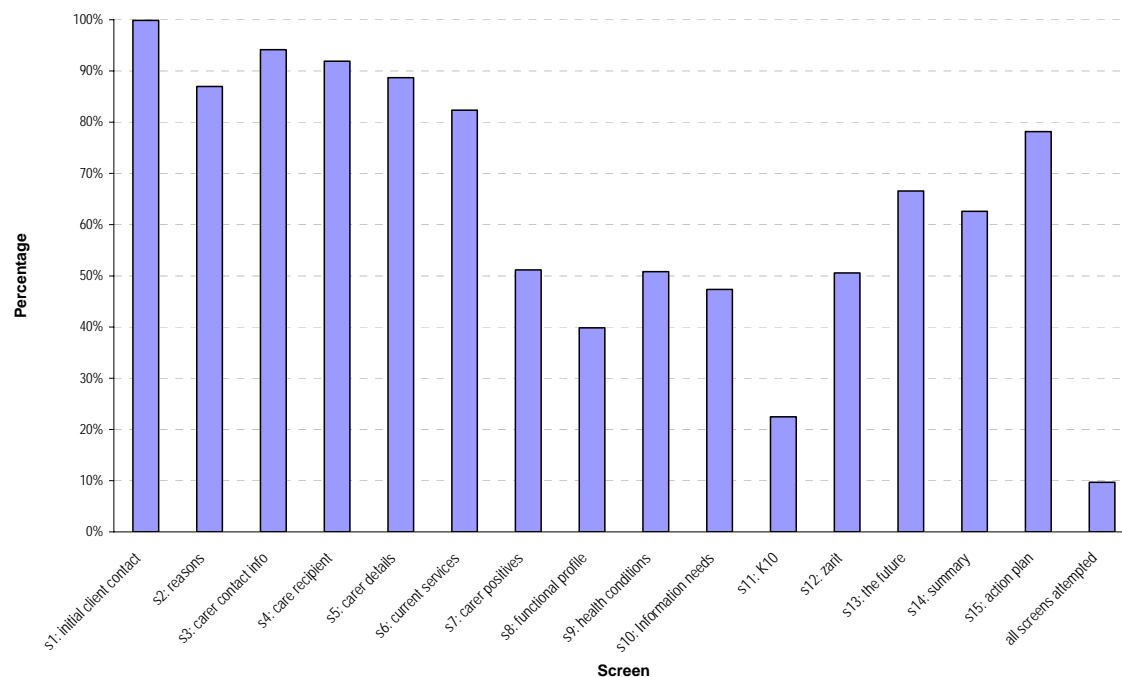
This section describes the completion of sections and individual items within the CENA tool.

Completion of sections

Figure 15 shows the completion rates for each subsection of the tool. A section was deemed to have been attempted if one or more items were completed. Completion was high for the sections constituting a 'broad and shallow' assessment with greater than 85% of items completed in each of the first five sections.

The lowest rates of completion were for the optional K10 (23%) and Functional Profile (40%) sections. When compared to the early results presented in the CENA Interim Report, Part 1, two sections are notably higher, 10 % of people completed all sections and 51% completed the Zarit scale.

Figure 15 Completion of sections of CENA



These same data are presented by provider in Table 11, by service type in

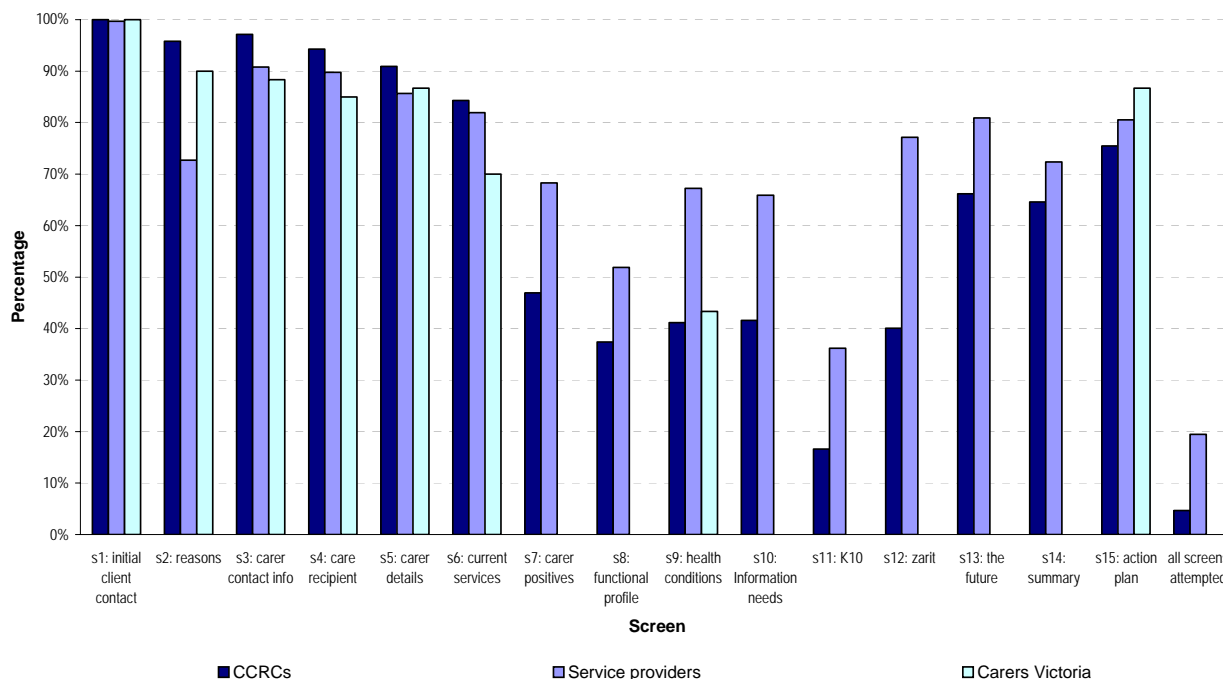
Figure 16 and by mode of assessment in Figure 17.

Table 11 Completion of sections by provider (% of records by provider)

Screens completed	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	All
NSW BCS	100	96	98	97	97	95	97	56	83	85	53	56	96	83	84	17
NSW Benevolent Carer	100	99	97	99	90	91	54	49	36	45	23	35	67	67	74	4
SA Carers SA	100	100	100	98	88	93	18	25	28	15	0	5	38	83	90	0
SA Carers Support and Respite	100	96	96	94	93	79	19	19	25	23	0	21	49	63	72	0
SA Uniting Bowen	100	91	95	86	83	70	40	45	23	27	4	56	62	40	60	2

Screens completed	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	All
SA Uniting Care Adelaide	100	97	100	100	100	91	41	15	56	47	15	62	85	68	94	0
CCRCs	100	96	97	94	91	84	47	37	41	42	17	40	66	65	75	5
NSW Calvary	100	100	94	94	94	90	77	74	90	90	81	90	94	81	87	48
NSW CC ACAT	100	65	91	87	83	74	61	39	61	65	52	78	74	52	70	30
NSW Home Care	100	100	88	88	88	38	25	75	50	13	25	50	63	63	75	13
NSW Hope Healthcare	100	70	93	93	93	89	89	59	85	89	85	89	89	93	89	44
NSW Northern Beaches	100	86	100	100	100	90	76	81	71	86	14	81	86	81	95	5
SA Aged Care Housing	100	88	88	88	88	88	88	88	88	88	75	88	88	69	88	63
SA Helping Hands	98	83	98	98	85	85	60	23	48	42	21	81	81	67	79	8
SA Metro Dom Care	100	64	88	86	82	81	68	52	67	63	17	69	78	72	78	7
SA Resthaven	100	7	67	67	67	67	47	20	47	53	7	67	67	67	67	0
Service providers	100	73	91	90	86	82	68	52	67	66	36	77	81	72	81	19
VIC Carers Vic	100	90	88	85	87	70	0	0	43	0	0	0	0	0	87	0
All services	100	87	94	92	89	82	51	40	51	47	22	51	67	63	78	10

Figure 16 Completion of sections by service type



Completion by CCRC's was slightly higher for most of the earlier sections (1-6), but considerably lower for the optional sections (7-12). Carers Victoria only completed the first 6 sections and the action plan. While some agencies attempted all sections of the CENA, most were selective. Those agencies that had a higher tendency to complete all sections included SA Aged Care Housing Group, NSW Calvary, NSW Hope Healthcare, Central Coast ACAT and NSW Baptist Community Services.

Figure 17 Completion of sections by mode of contact

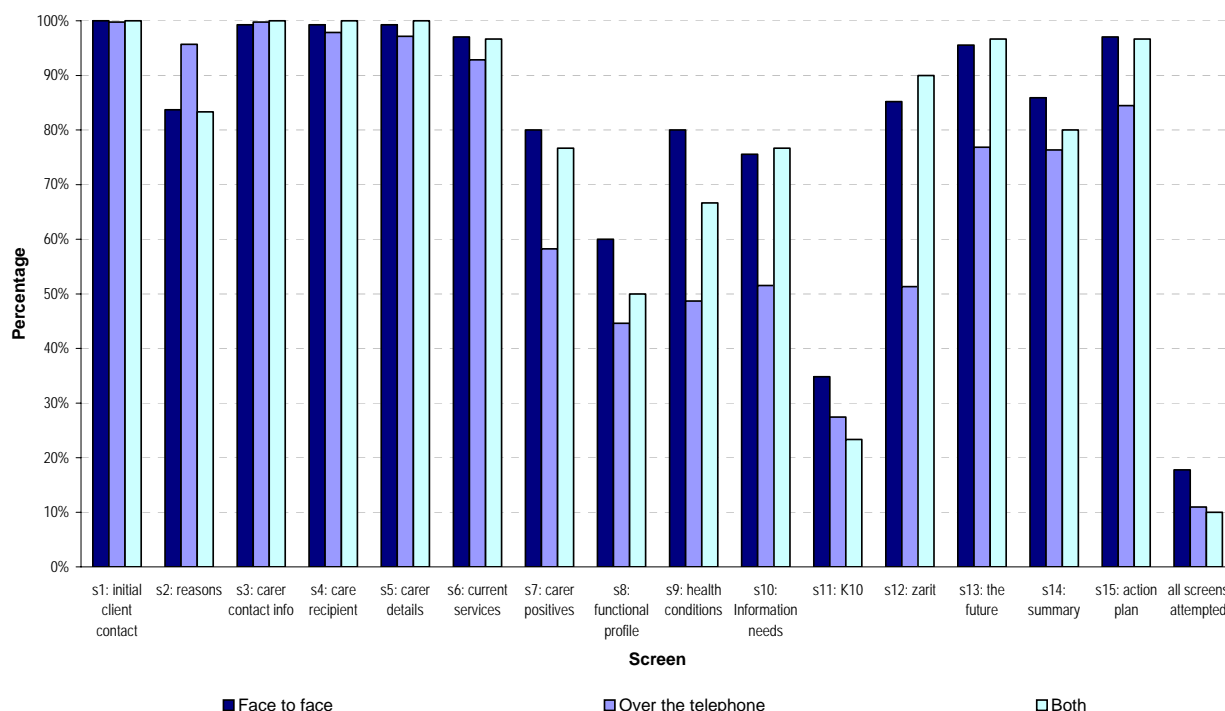


Figure 18 shows that the question on behaviour management (47%) and the 4-item Zarit Burden Interview (57%) were the least likely to be collected. The financial, legal and employment (98%) section and care task question (92%) were most likely to be collected.

Figure 18 Completion of sub-sections within the carer details section

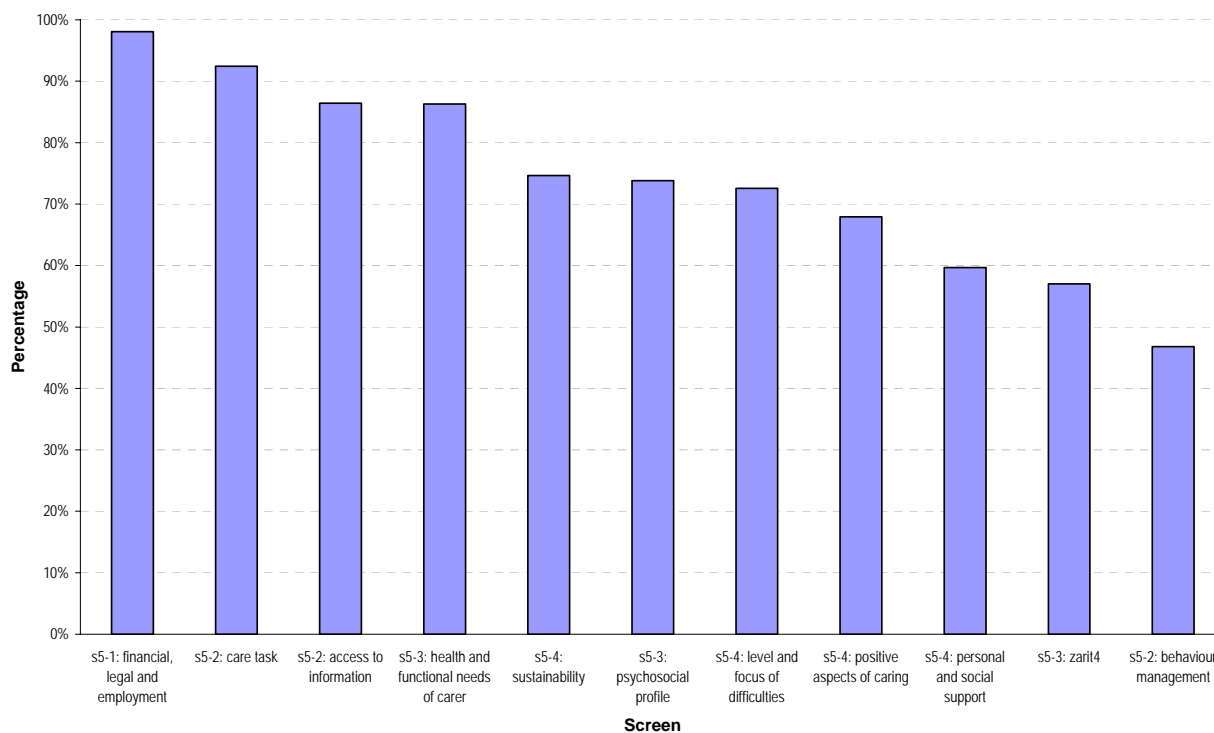


Figure 19 shows that service providers were more likely to complete all items in the carer details section compared to CCRC's, whilst Carers Victoria only completed the financial, legal and employment section and care tasks.

Figure 19 Completion of sub sections within the carer details section by service type

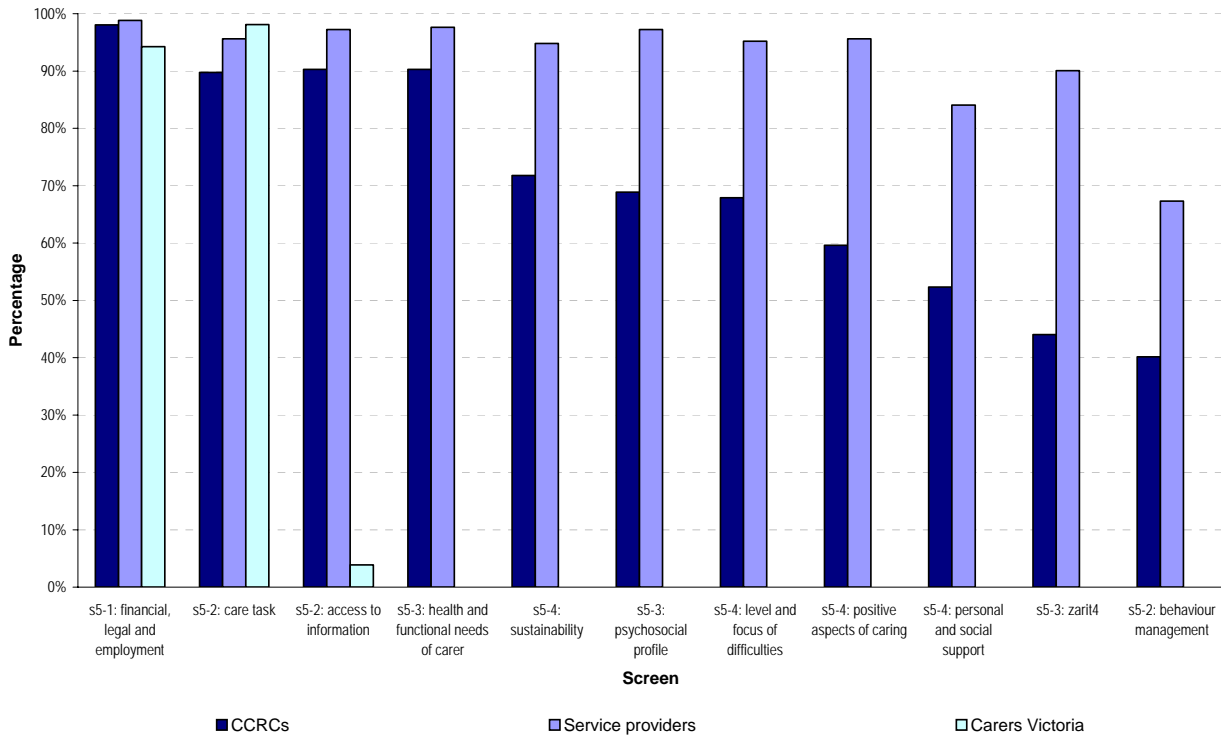


Figure 20 shows that within ‘The Future’ section concerns were most likely to be completed. Service providers were more likely to complete all sections as were those assessments done face to face.

Figure 20 Completion of sub-sections with ‘The Future’

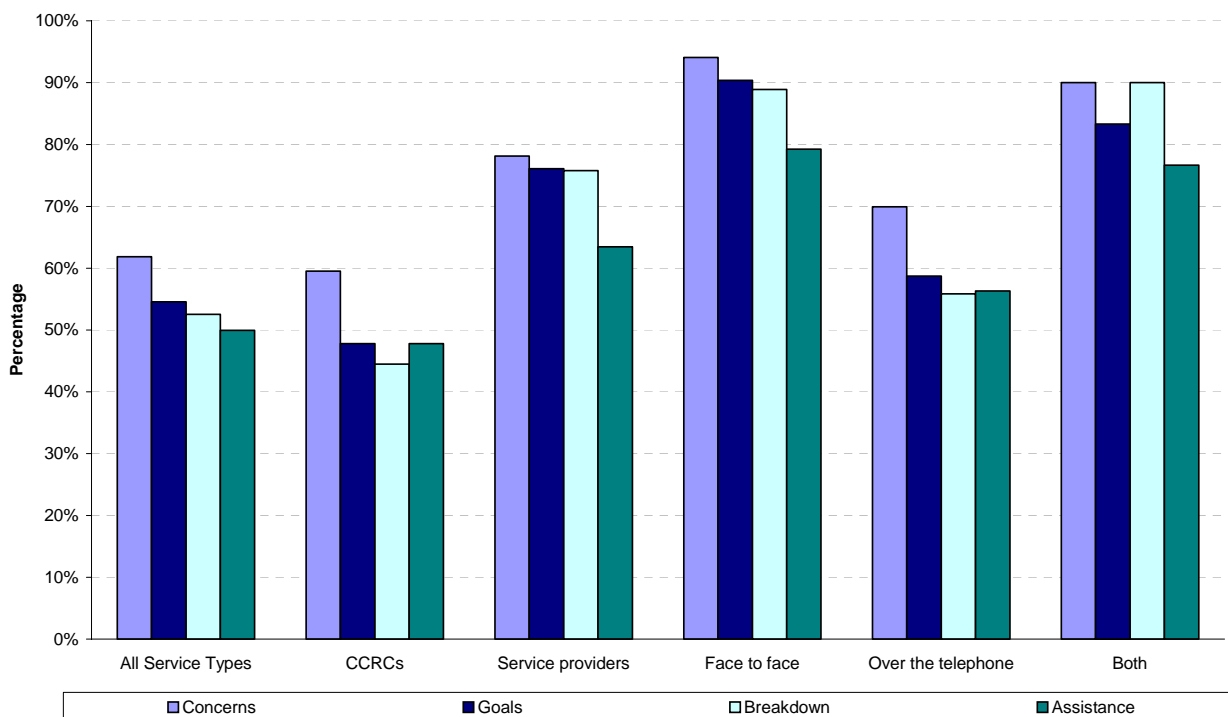
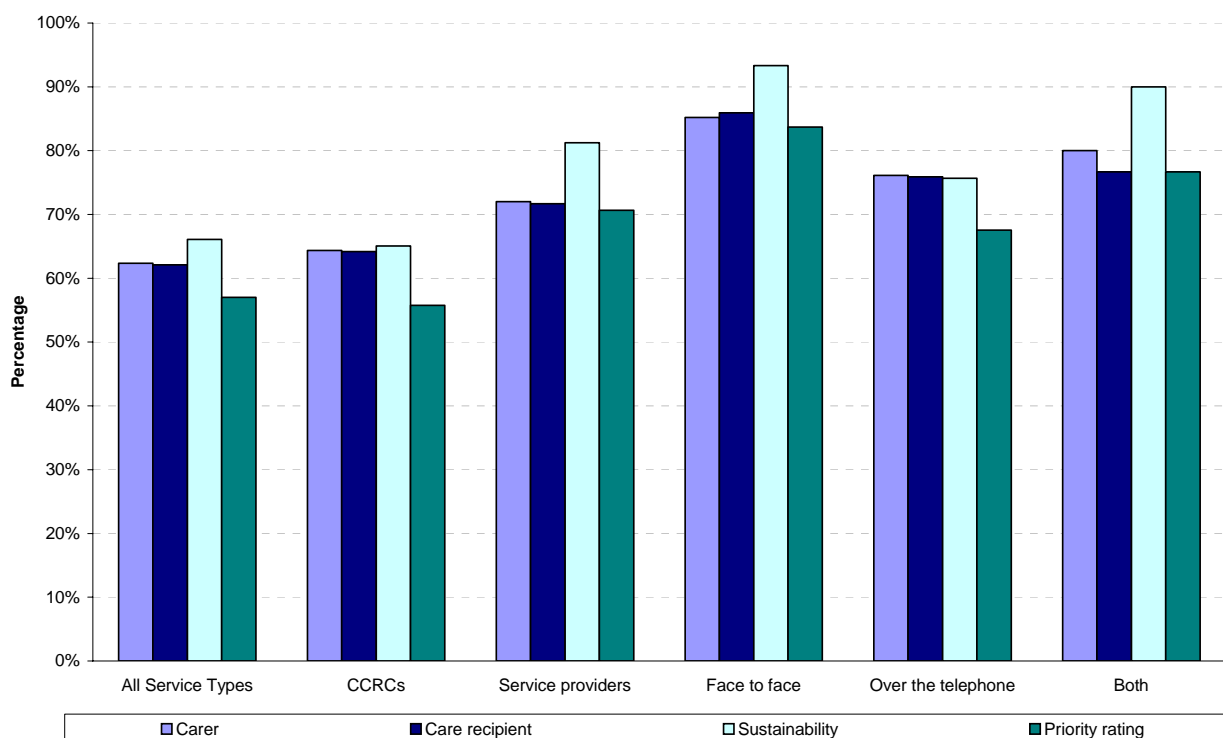


Figure 21 shows the completion of the priority rating items. The question on the sustainability of the relationship between the carer and care recipient was completed the most, especially by service providers. There were little differences between service type and mode of assessment with respect to completion of items within this section.

Figure 21 Completion of priority rating items



The carer positives section was completed almost all of the time (greater than 90%) by both CCRC’s and service providers with the exception of the question related to ‘confidence dealing with others’ (service providers only completed 41% of the time).

The following three figures highlight changes in completion over time. The data were divided equally into four quarters based on the number of assessments completed within each service, with Time 1 (T1) representing the earliest assessments completed in the trial through to T4 representing the last 25% of assessments completed.

Figure 22 shows the first and last time periods data broken into the total number of screens completed. This shows some more of the practice effects. Total number of screens completed decreased over time with less screens being completed in the fourth time quarter. In the first quarter it was more common to complete 10 or more screens (65%) than in the fourth quarter (53%), in which it was more common to complete between 6 and 8 screens (28% and 18%, respectively). This may be due to assessors being more familiar with the CENA and consequently completing only what was necessary.

Figure 23 shows the completion of individual screens over time. The only screen that was completed more frequently was the action plan and to a lesser extent the carer contact information and care recipient details. All other sections were completed less frequently when comparing time period 1 with time period 4.

Figure 24 shows similar results with all domains within the carer details section being completed less frequently over time with the exception of ‘financial, legal and employment’ and ‘care tasks’.

Figure 22 Total number of screens completed in first and last time periods

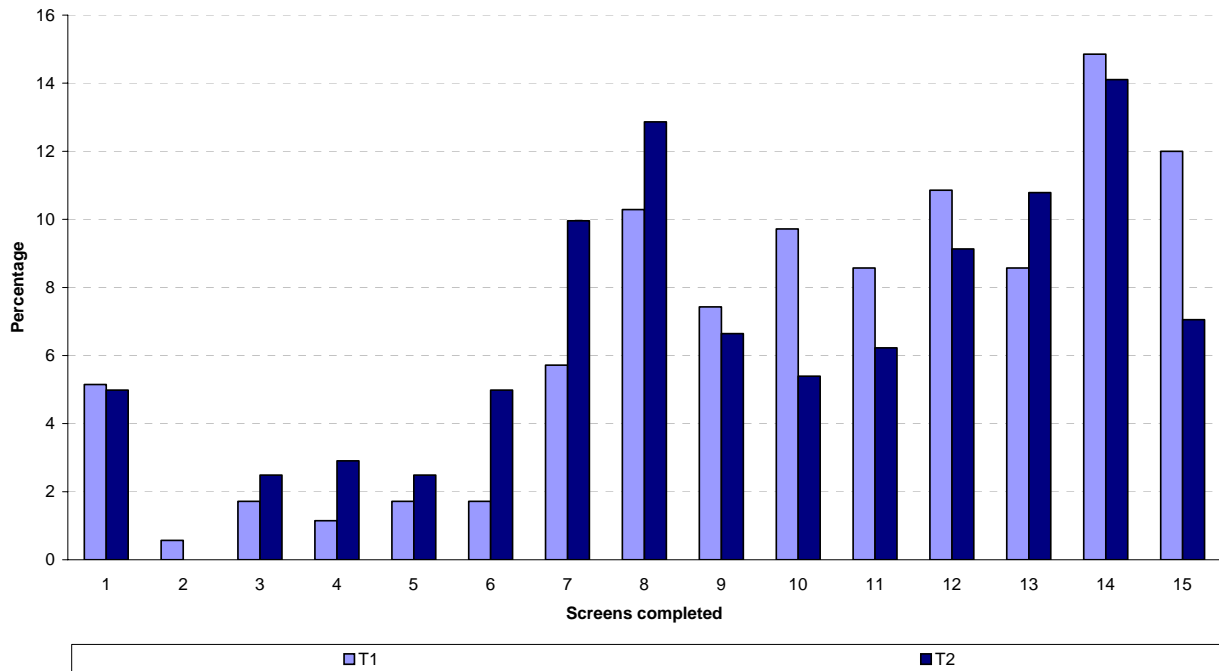


Figure 23 Completion of individual screens over time

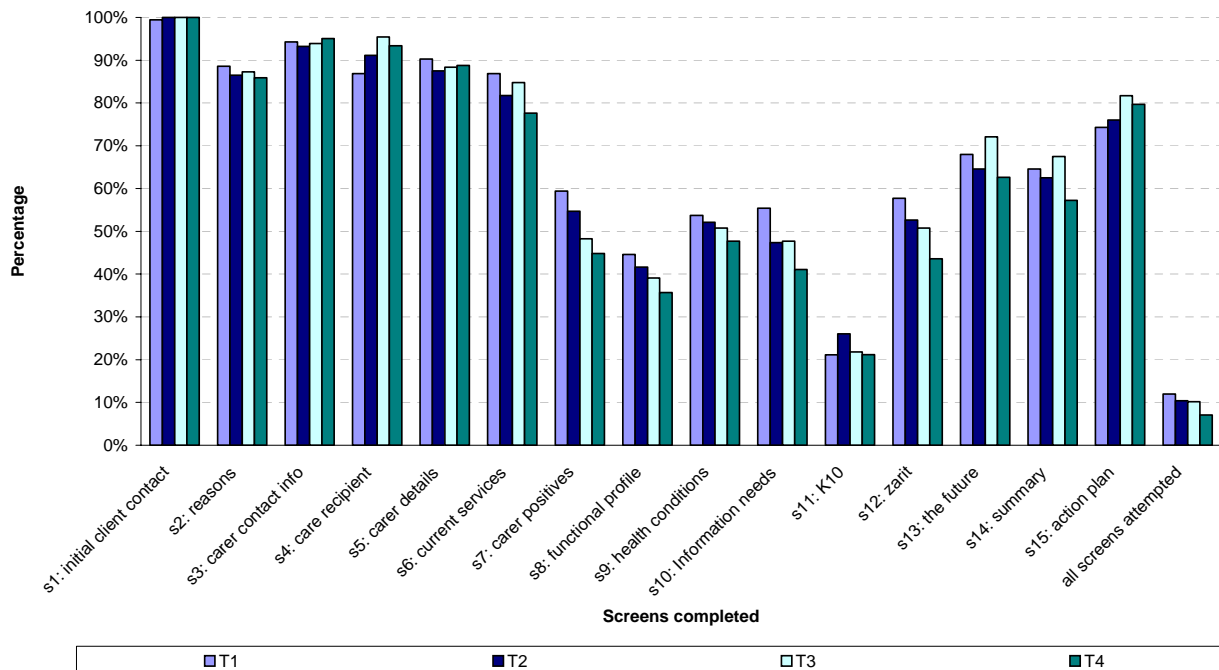


Figure 24 Completion of domains in carer details section over time

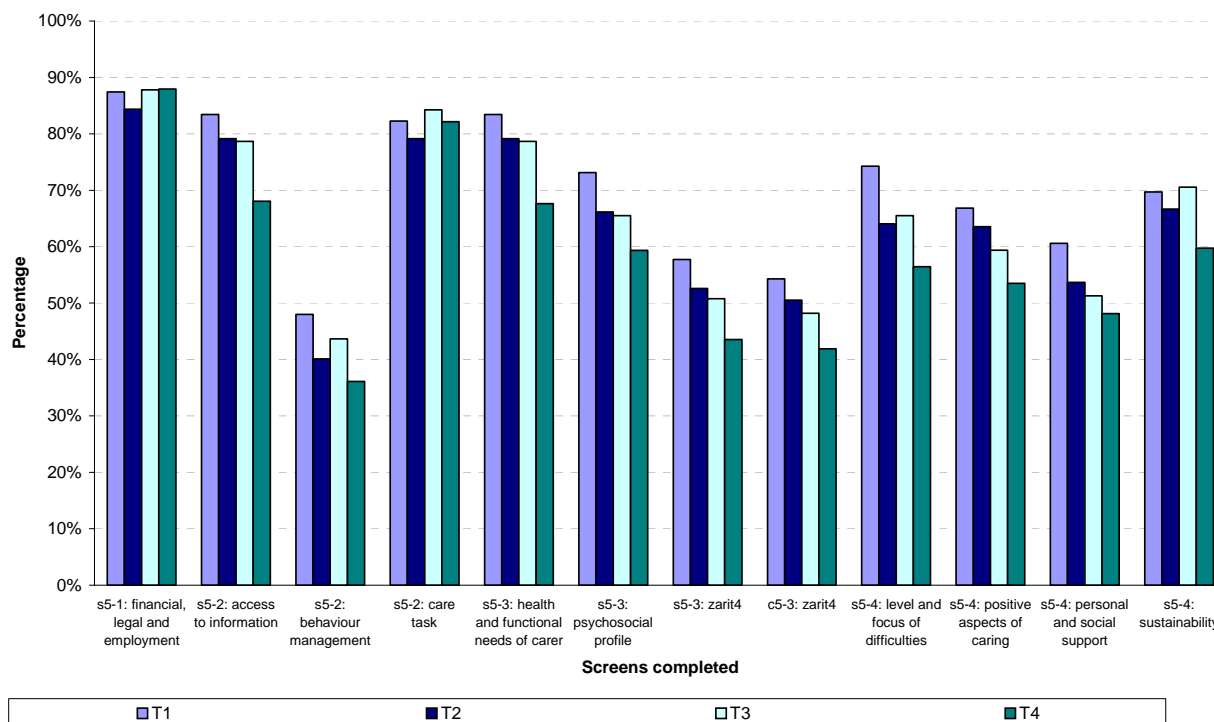


Table 12 shows completion rates for individual items over the full course of the trial. They varied from 81% for employment to just 5% on the item within ‘carer positives’ on companionship.

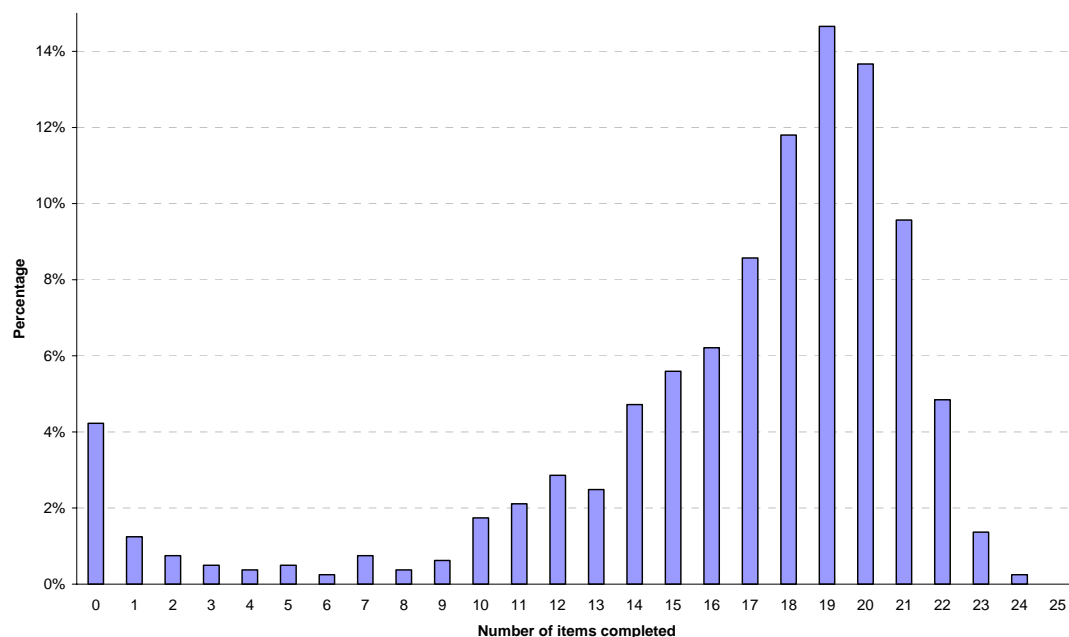
Table 12 Completion rates for individual items

Item	% answered
Employment Participation	80.9%
Care Hours	80.5%
Information Access	76.0%
General Health	76.0%
Financial Strain	73.5%
Health Interfere	70.3%
Sleep Difficulties	66.2%
Sustainable	66.1%
Quit Work	66.0%
Work Interfere	64.3%
Fit things in	64.3%
Help Needed	61.2%
Face Challenges	60.9%
Caused Strain	60.7%
Behaviour Manage Hours	55.8%
Cost Living Decisions	54.9%
Greatest Challenge	51.2%
Positive Help CR	47.6%
Specify Problems	37.3%
Positive Caring	30.6%
Positive Appreciated	25.8%

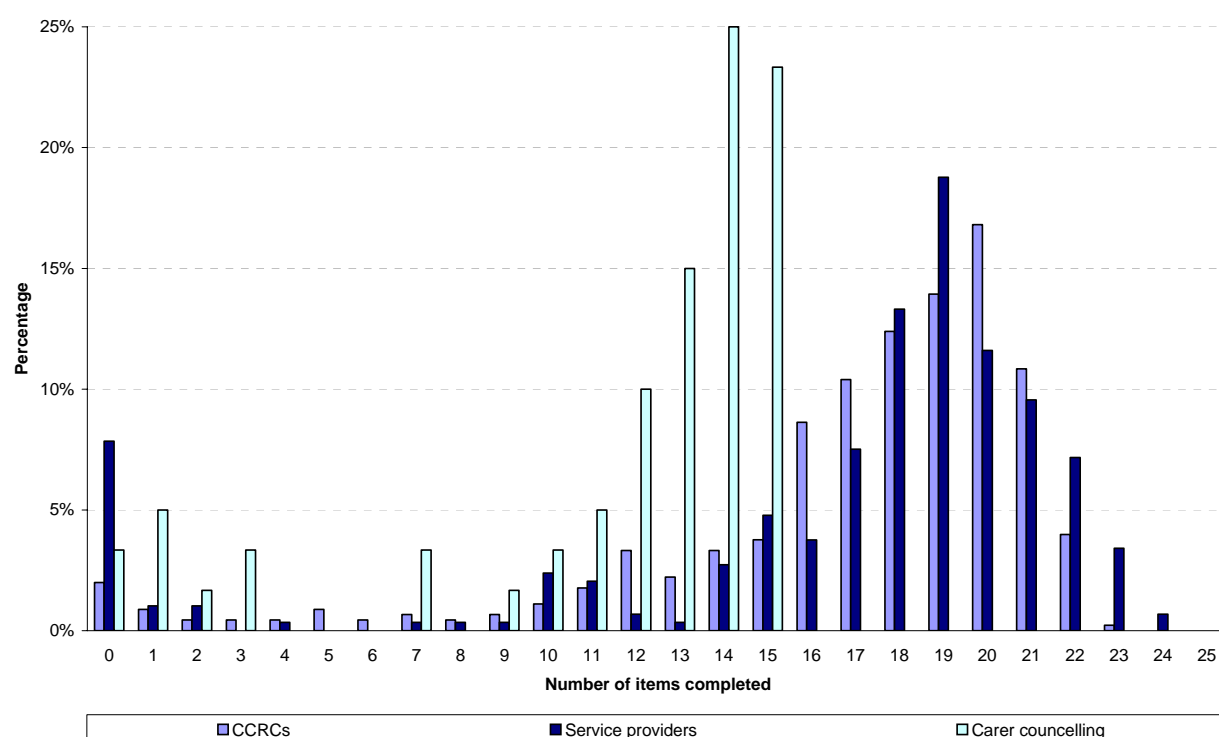
Item	% answered
Positive Accomplishment	24.0%
Problem with Family	15.8%
Positive Help Other Family	14.2%
Problem with CR	9.3%
Positive Companionship	5.2%

4.1.9 MDS Items

Figure 25 Number of MDS items completed



There were 25 National Respite for Carers MDS items in the CENA. Figure 25 shows that no one completed all 25 items, with most people completing between 17 and 22. Figure 26 shows that Carers Victoria completed the least number of NRCP MDS items while service providers completed the most. Details by item are shown in Table 13.

Figure 26 Completion of MDS items by CCRCs, Providers and Counselling**Table 13 Completion of MDS items**

MDS ITEM		Completed by...			
		CCRCs	Service providers	Carer counselling	All services
Country of Birth	(Carer)	93.1%	89.4%	86.7%	91.3%
Main language spoken at home	(Carer)	92.5%	84.6%	83.3%	88.9%
Care giving context	(CR)	89.8%	84.6%	85.0%	87.6%
Government pension/benefit status	(Carer)	89.8%	85.7%	76.7%	87.3%
Co-residency of carer and care recipient	(CR)	89.4%	85.0%	75.0%	86.7%
Date of first contact	(Carer)	87.4%	81.2%	83.3%	84.8%
Carer Role	(CR)	85.0%	82.3%	75.0%	83.2%
Paid employment participation	(Carer)	82.1%	78.8%	81.7%	80.9%
Time spent caring	(Carer)	78.8%	82.6%	83.3%	80.5%
Number of care recipients	(Carer)	85.0%	65.9%	86.7%	78.1%
Care recipient's primary care needs	(CR)	82.5%	79.9%	0.0%	75.4%
Dementia	(CR)	81.0%	76.5%	0.0%	73.3%
Challenging behaviour	(CR)	79.4%	77.8%	0.0%	72.9%
Care recipient's primary disability	(CR)	79.6%	75.4%	0.0%	72.2%
Care recipient's level of need	(CR)	73.0%	76.1%	0.0%	68.7%
Date caring role commences	(CR)	70.4%	77.1%	6.7%	68.1%

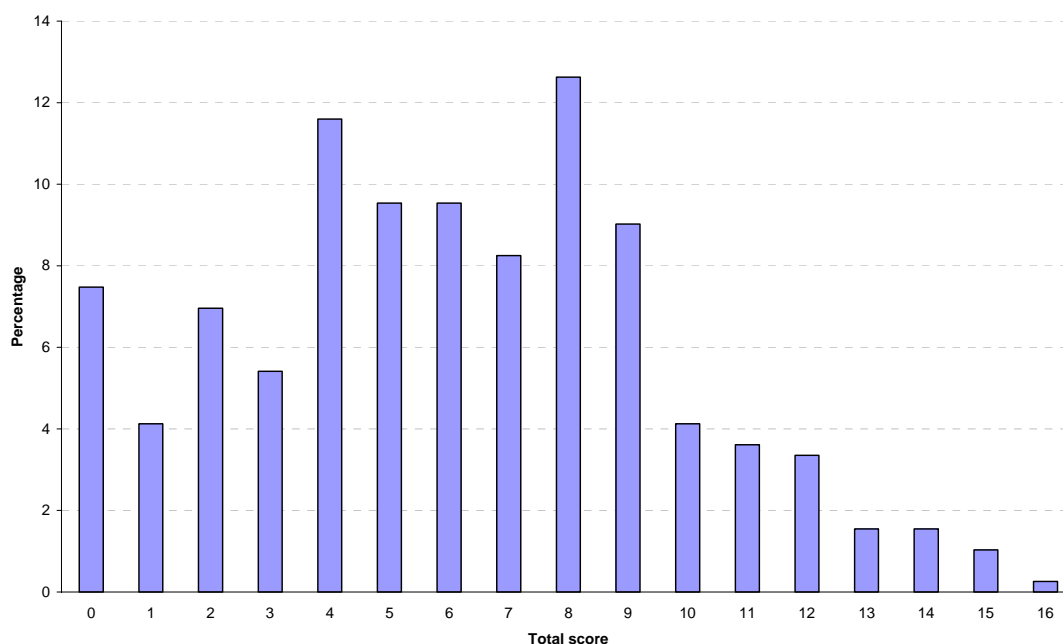
MDS ITEM		Completed by...			
		CCRCs	Service providers	Carer counselling	All services
Indigenous status	(Carer)	64.4%	57.3%	75.0%	62.6%
Referral to service/s	(Carer)	55.1%	67.6%	70.0%	60.7%
Current use of formal services	(Carer)	61.7%	66.6%	10.0%	59.6%
DVA Card holder status	(Carer)	64.6%	45.4%	70.0%	58.0%
Source of referral	(Carer)	56.0%	33.1%	70.0%	48.7%
Informal support	(Carer)	37.8%	60.1%	41.7%	46.2%
Assistance – reason not provided	(Carer)	9.1%	6.5%	0.0%	7.5%

The ‘Carer counselling’ column represents the National Carer Counselling Program (NCCP) section of the trial, which was designed to assess the suitability of the CENA for a counselling context. The NCCP team including Carelink and the counselling team consulted internally and agreed to develop a CENA short form that would be suitable to trial in the context of the NCCP. The short form did not include particular MDS items, the K10 or the Zarit Burden Interview.

4.1.10 Zarit Burden Interview

The 4-item Zarit was attempted on 58% of carers. Of these, 95% answered all four questions. The full Zarit was attempted on 50% of carers, of whom 40% answered all 22 items. The 12-Item Zarit is a subset of the 22 items and is reported here to test whether it is possible to reduce the number of questions in the CENA. The scores on the 4-item Zarit ranged from 0-16, with most carers scoring between 4 and 9 (Figure 27). The lower the score the lower the level of burden indicated. For the 12-Item Zarit there were a large number of carers who scored 16 (10%) while most other scores ranged between 2% and 4% (Figure 28). Five carers scored 35 or more on the 12-Item Zarit (indicating a level of ‘severe stress’). Figure 29 shows the distribution of scores for the 22 Item Zarit. Most carers were found to have ‘mild to moderate stress’ (53%), 1 in 5 (18%) had ‘moderate to severe stress’ whilst 4% were assessed as having ‘severe stress’.

Figure 27 4-Item Zarit distribution of scores



The relationships between the 3 versions (4-item, 12-item and 22-item) were examined to test whether the 4-item Zarit or 12-item Zarit could be used instead of the 22-item Zarit. This was done using Spearman’s correlation for ordinal data. All correlations were statistically significant and very

close to 1. The strongest relationship was between the 12-item Zarit and the 22-item Zarit ($r=0.935$), the weakest between the 4-item Zarit and 22-item Zarit ($r=0.832$).

This supports the use of the 12-item version instead of the 22-item version. It also supports the use of the 4-item version as a screen. The 12-item Zarit should be recommended for completion if a carer scores 7 or more on the 4-item version. This would result in 40.2% of those assessed with the 12-item version being identified having Moderate or Severe Stress while 2.8% of those who would have been found to have Moderate or Severe Stress (if administered the 12-item version) will be missed.

The relationship between the 3 Zarit scales and the K10 scale was also examined. There was a statistically significant relationship between all three Zarit scales and the K10, with the 12-item and the 22-item have the strongest relationship ($r=0.649$ and $r=0.691$ respectively). While this is a strong statistical relationship, the K10 is capturing different types of information. This supports retaining the K10 as an optional item for carers who are at risk due to high levels of burden &/or stress. It should not be routinely included in an initial assessment for carers but rather used if triggered by early indicators in the assessment process or judged to be appropriate by an experienced and appropriately trained assessor.

Figure 28 12-Item Zarit distribution of scores

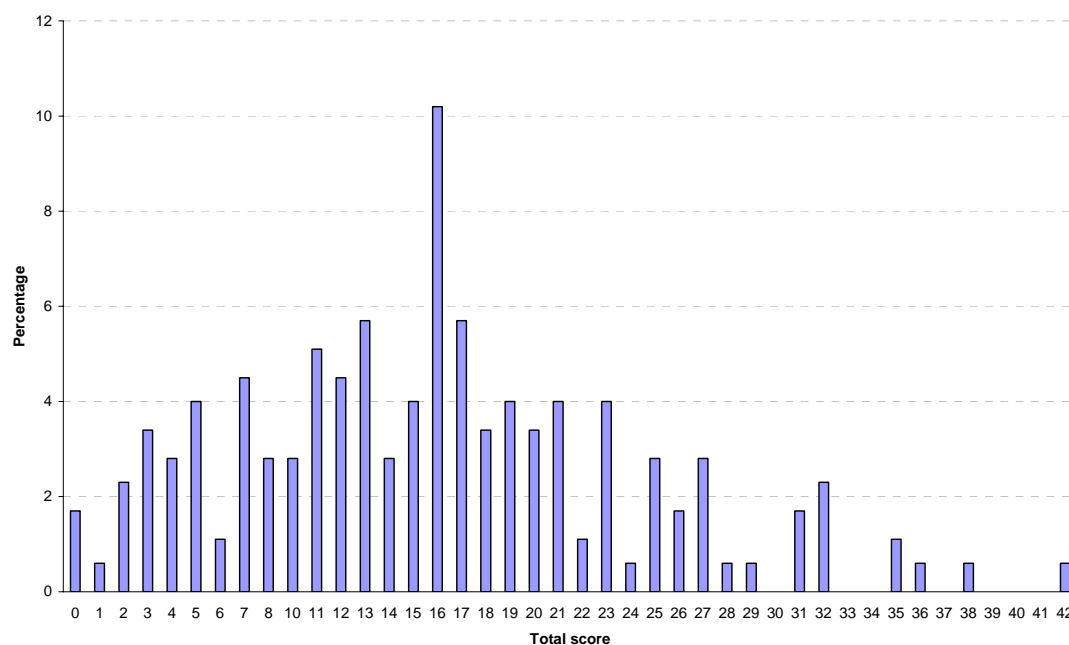


Figure 29 22-Item Zarit distribution of scores

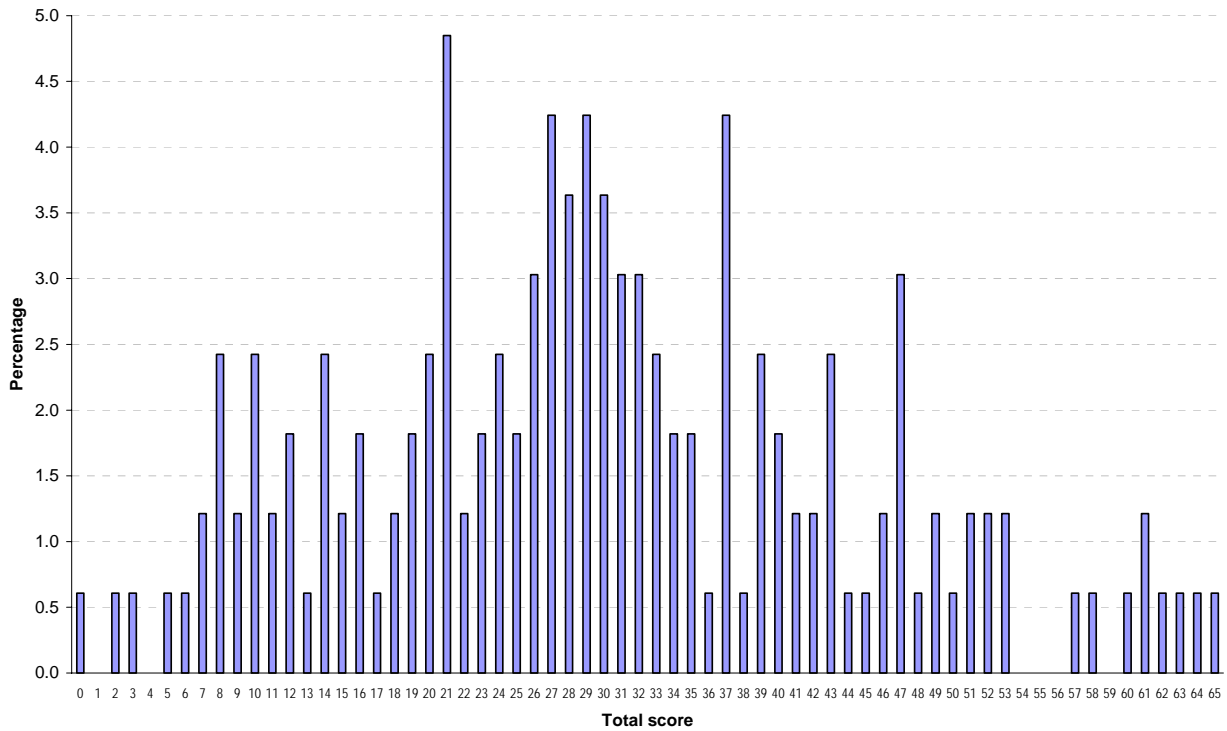
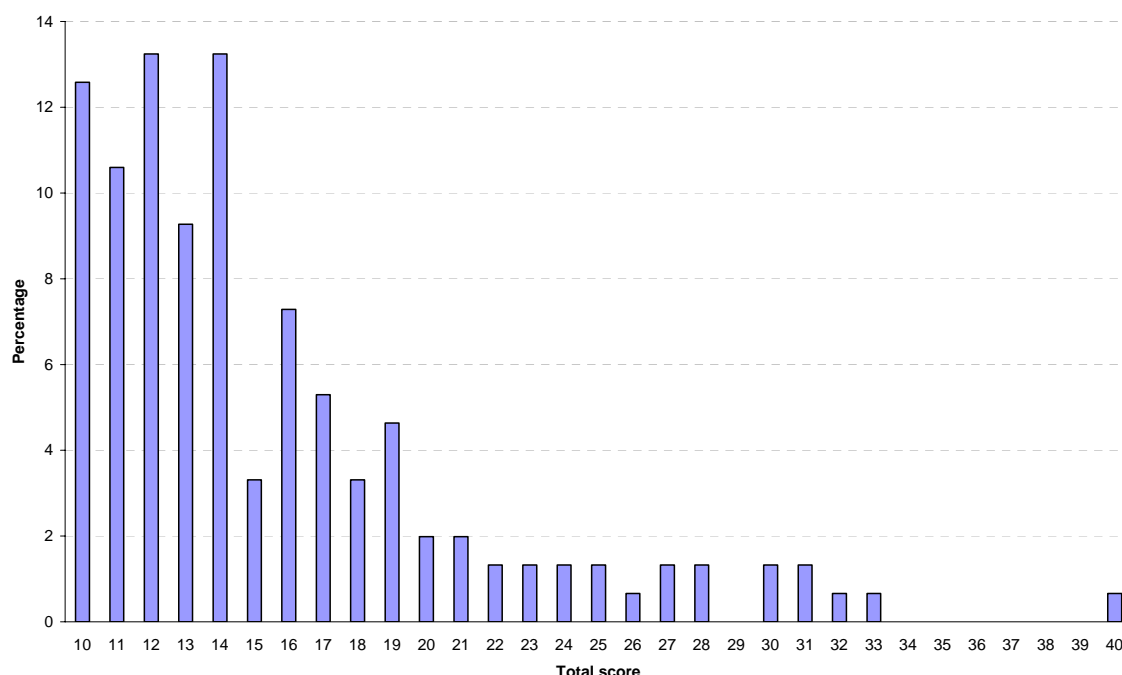


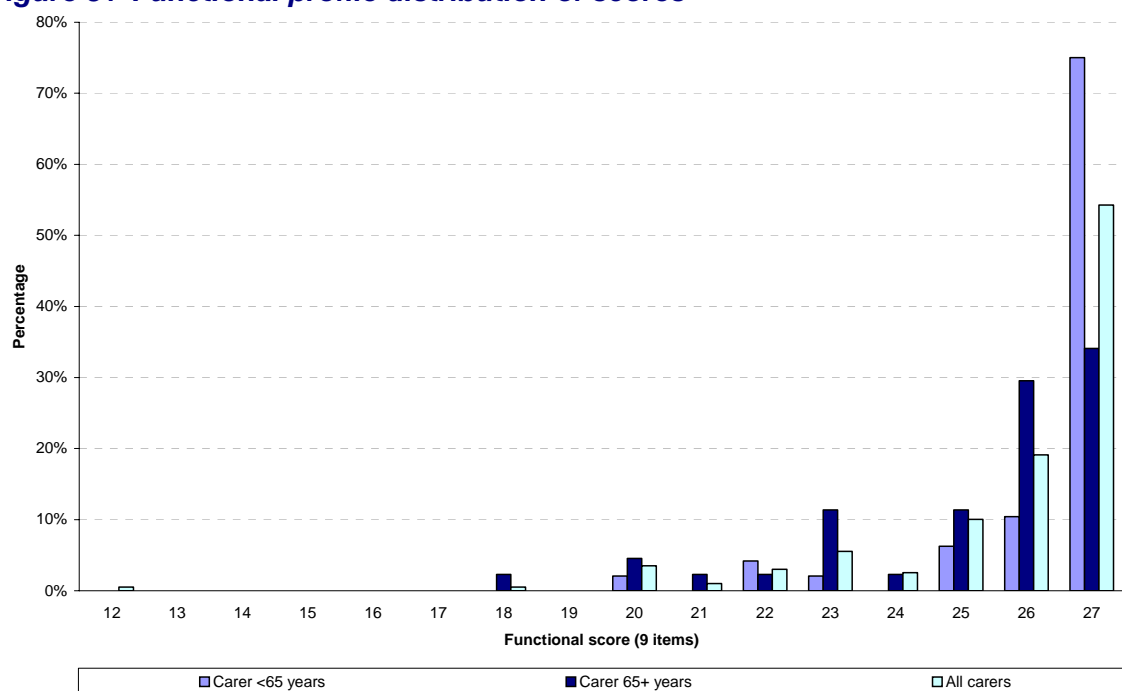
Figure 30 Distribution of K10 scores



4.1.11 Functional Profile

Among those assessors attempting the functional profile, it was completed fully for only half of all carers (48%). The reason for non-completion of the full functional profile is most likely due to the layout of the screens. Overall, the functional profile did not discriminate well between carers, with most scoring a perfect score. Where the age of the carer was considered it was found that most young carers had no functional problems. The functional profile is more useful for use with older carers [see Figure 31].

Figure 31 Functional profile distribution of scores

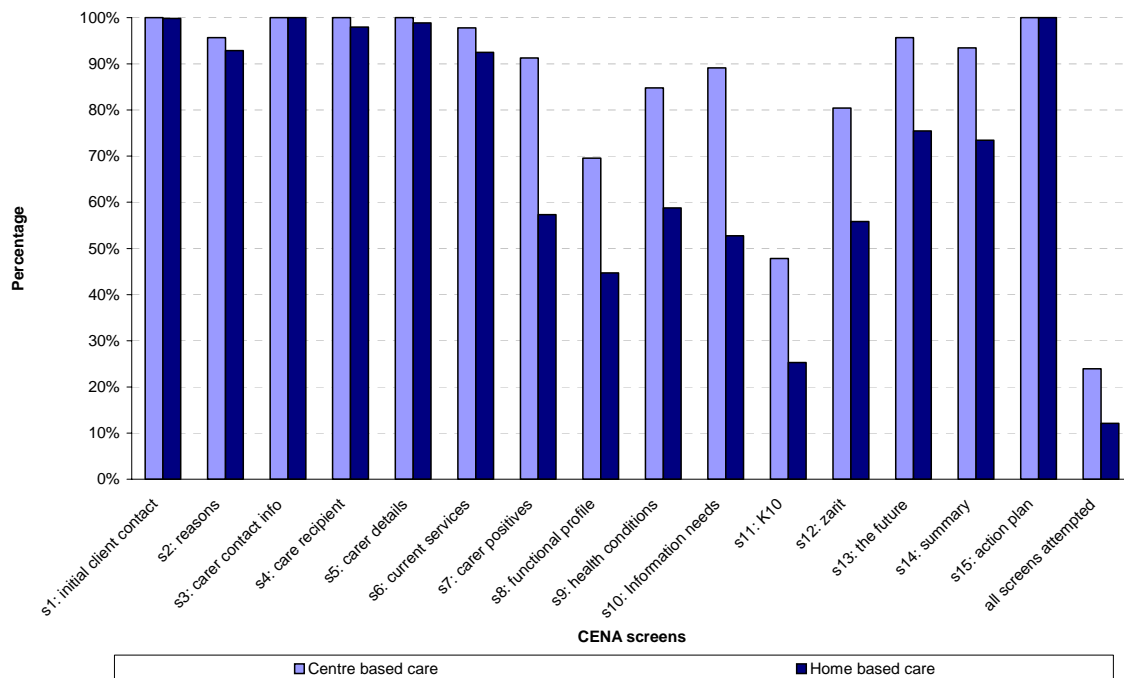


This supports including the functional profile in the CENA but only as an optional item. It should only be completed if a carer has significant health problems. This is identified as a response of 'moderate' or 'quite a lot' to the question about whether their health interferes with daily activities.

4.1.12 Centre versus home-based assessments

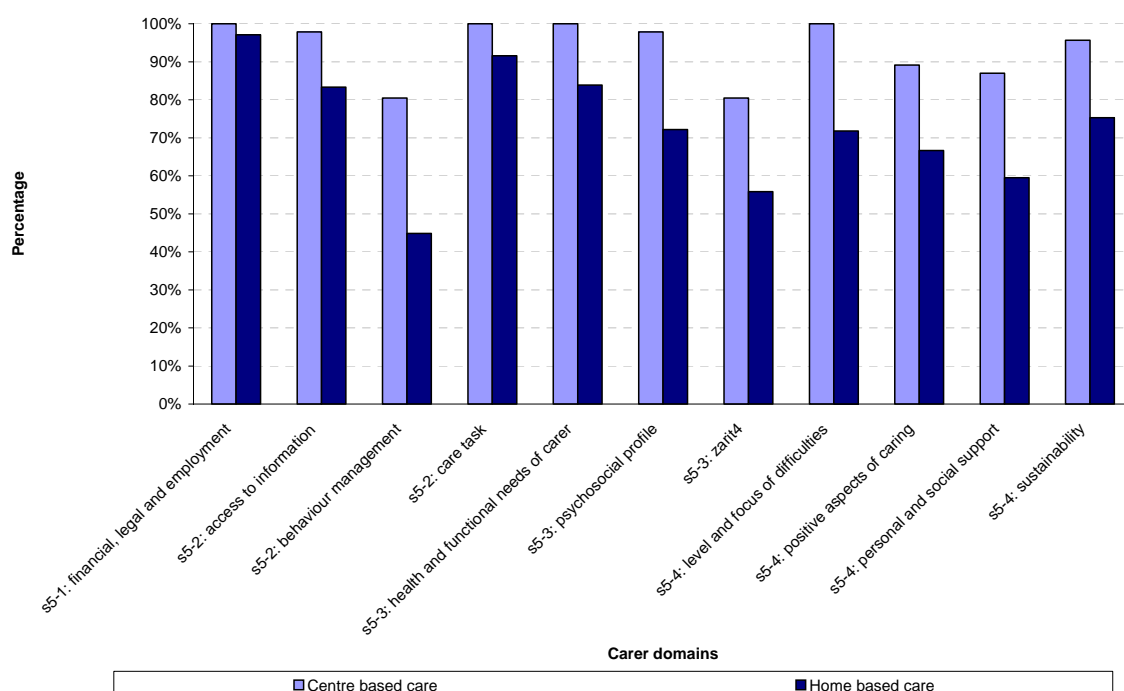
Figure 32 shows the number of CENA sections by place of administration. It will be seen that the percentages are similar for the early sections. Sections 7 to 14 were completed much more frequently during centre-based assessments than during home-based assessments.

Figure 32 CENA sections completed in centre and home-based assessments



These results are consistent with the completion rates for specific carer items shown in Figure 33. Behaviour management was not assessed in over half of home-based assessments compared to 20% of centre-based assessments. There were also large differences in the rate at which questions were asked about psychosocial issues, difficulties, personal support, the positive aspects of caring and sustainability.

Figure 33 Carer items completed in centre and home-based assessments

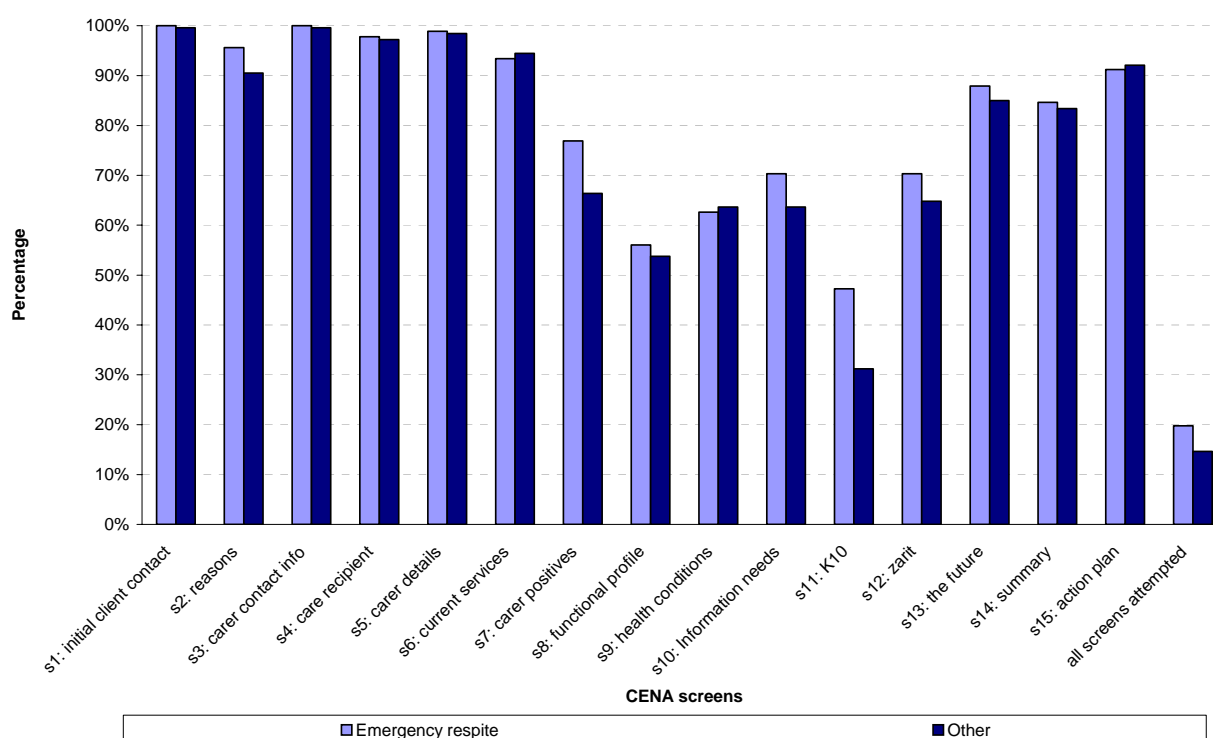


These results were not expected as it had been assumed that more questions would be asked in a home-based assessment than in a centre-based assessment. Further analysis found that this result was in fact due to differences in agency practices and the mix of agencies undertaking home-based and centre-based assessments. When only those agencies that undertook both types of assessments were considered, it was found that more items were completed in home-based assessments. For example, the ‘carer positives’ section was completed in 61% of home-based assessments and only 33% of centre-based assessments in these agencies.

4.1.13 Emergency respite

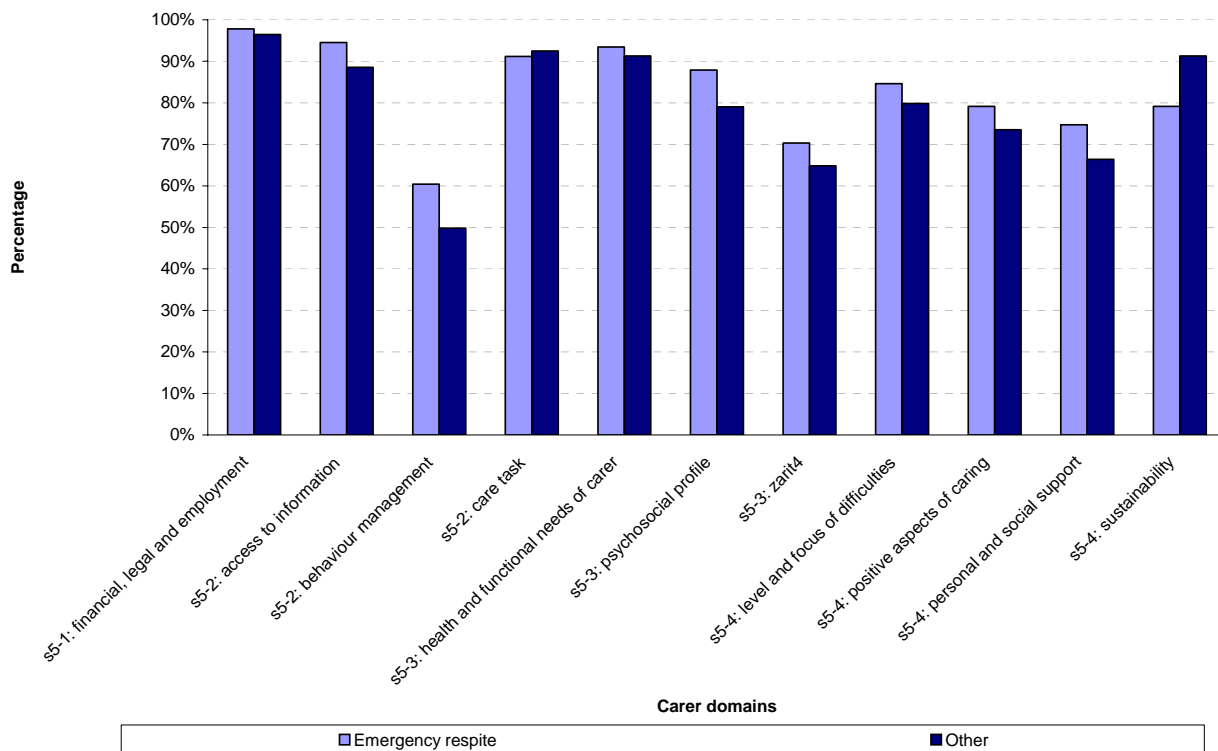
It has been expected that the assessment of those requesting emergency respite would be shorter than for others. As Figure 34 and Figure 35 indicate, this proved not to be case. The one exception was in relation to the sustainability of the relationship. For the other questions and sections, the rate of completion was similar. Where there were differences, emergency respite assessments tended to ask more questions and complete more sections.

Figure 34 CENA sections completed in emergency respite assessments



Further analysis identified that the number of items collected in an emergency respite assessment varied according to how frequently the agency undertook this type of assessment. Agencies that reported only a small number of such assessments collected a significant number of items during each assessment. In some of these cases, every screen of the CENA was collected. In contrast, the three agencies that undertook a high volume of emergency respite assessments collected significantly less items. The results reported here are due to the number of items collected in the low volume agencies, which collectively accounted for one third of all emergency respite.

Figure 35 Carer items completed in emergency respite assessments



4.1.14 Action plan

An action plan was completed for 629 carers. For those whose assessments recorded whether or not referrals made were subsequently accepted, 94% were referred within the agency for service. Details of these are shown in Table 14.

Table 14 Internal referrals recorded in the Action Plan

Accepted	Clients	Percentage
Yes	412	93.8%
No	27	6.2%
Not recorded	366	
Total	805	
Service referred to	Clients	Percentage
Day Respite inhouse	165	40.0%
Direct respite	128	31.1%
Liaison	108	26.2%
Information	98	23.8%
Indirect Respite Domestic	97	23.5%
Indirect Respite Personal Care	90	21.8%
Indirect Respite Social support	74	18.0%
Other 1	59	14.3%
Case Management/Coordination	55	13.3%
Assessment	41	10.0%
Indirect Respite Transport	35	8.5%
Indirect Respite Goods Generic	33	8.0%

Service referred to	Clients	Percentage
Allied Health Care Centre	32	7.8%
Day care centre	25	6.1%
Indirect Respite Day Care	23	5.6%
Indirect Respite Meals	23	5.6%
Indirect Respite Goods Spec	21	5.1%
Overnight Community Respite House	16	3.9%
Overnight Respite in house	15	3.6%
Indirect Respite Home modifications	13	3.2%
Community Access - individual	13	3.2%
Indirect Respite Nursing	12	2.9%
Indirect Respite Home maintenance	12	2.9%
Overnight Other	6	1.5%
Education	4	1.0%
Community Access -group	4	1.0%
Other 2	2	0.5%
Other3	2	0.5%
Host Family Day	1	0.2%
Host Family Overnight	1	0.2%
Indirect Respite Other food	0	0.0%
Indirect Respite Linen	0	0.0%

A little more than a quarter of all carers were also referred to external agencies. Two thirds of these were referred to only one agency, with a further quarter being referred to two.

Table 15 External referrals recorded in the Action Plan

External referrals	Number	Percent
Made	224	27.8%
Not made	581	72.2%
All	805	100.0%
Number of referrals per carer:	Number	Percent
1	146	65.2%
2	52	23.2%
3	16	7.1%
4	9	4.0%
5	1	0.4%
All	224	100.0%

Table 16 shows the external referrals that were recommended based on the electronic prompts built into the CENA and the outcomes of these. Whether or not the assessor made these referrals was not recorded in most cases (see right hand column).

The most common external referral recommended was to a GP and in the 24% of cases (n=13) where the information was recorded, the assessor actually referred 12 carers (92.3%) to the GP. Of these, the GP had accepted 8 (61.5%) of these referrals and this was recorded in the CENA. One carer was recorded as not being referred to a GP when prompted by the software.

In total, 89% of recommended referrals were accepted by the assessor, suggesting that the electronic prompts built into the CENA are appropriate. In over half of these cases the assessor recorded that the referral had been accepted.

Table 16 External referrals recommended

Service type recommended	Referrals recommended	Outcome as % of those recorded				Not recorded
		Sent	Accepted	Rejected	Not made	
GP/medical practitioner – community based	54	30.8%	61.5%	0.0%	7.7%	75.9%
Other government community-based services agency	44	56.8%	35.1%	0.0%	8.1%	15.9%
Carer respite/resource centre	44	36.4%	48.5%	0.0%	15.2%	25.0%
Specialist aged or disability assessment team/service (eg ACAT)	43	32.1%	53.6%	3.6%	10.7%	34.9%
Commonwealth Carelink Centre	38	27.3%	72.7%	0.0%	0.0%	71.1%
Other non-government community-based services	21	61.1%	33.3%	0.0%	5.6%	14.3%
Residential facility (respite house, short term or crisis respite accommodation)	12	50.0%	40.0%	0.0%	10.0%	16.7%
Other1	12	50.0%	25.0%	0.0%	25.0%	66.7%
Community nursing service	11	16.7%	83.3%	0.0%	0.0%	45.5%
Government residential aged care facility (nursing home or aged care hostel)	11	66.7%	16.7%	0.0%	16.7%	45.5%
Other community-based government medical/health service	10	25.0%	25.0%	0.0%	50.0%	60.0%
Comprehensive HACCC assessment authority	8	50.0%	0.0%	0.0%	50.0%	75.0%
Other non government medical/health services	8	40.0%	60.0%	0.0%	0.0%	37.5%
Palliative care facility/hospice	6	25.0%	75.0%	0.0%	0.0%	33.3%
Other2	5	0.0%	100.0%	0.0%	0.0%	80.0%
Other government medical/health service	4	50.0%	50.0%	0.0%	0.0%	50.0%
Non-government residential aged care facility	3	0.0%	0.0%	100.0%	0.0%	66.7%
Other3	2	0.0%	0.0%	0.0%	0.0%	100.0%
Psychiatric/ mental health service or facility	1	0.0%	0.0%	0.0%	0.0%	100.0%
Extended care/rehabilitation facility	1	0.0%	0.0%	0.0%	100.0%	0.0%
Hospital (private)	1	0.0%	0.0%	0.0%	0.0%	100.0%
Acute care hospital	0	0.0%	0.0%	0.0%	0.0%	0.0%
Aboriginal health service	0	0.0%	0.0%	0.0%	0.0%	0.0%
All external referrals	339	41.9%	46.2%	1.1%	10.8%	45.1%

Table 17 shows the reasons why recommended referrals were not made. These reasons are built as codes into the CENA. The assessor judged that the referral was unnecessary in just over half of all cases. The carer declining the referral accounted for another 11% of unmade referrals. Only 5% of unmade referrals were due to the lack of availability of the recommended service.

Table 17 Reasons why external referrals were not made

Service type	Number	%
Advice / information provided. No further action required	30	39.5%
Carer issues resolved. No further action required	13	17.1%
Other	13	17.1%

Service type	Number	%
Carer declines further referral or service	8	10.5%
Referred elsewhere	6	7.9%
Carer will call them	2	2.6%
Service not available	2	2.6%
Requested service not accessible - long waiting time	1	1.3%
Requested service not accessible - other	1	1.3%
All	76	100.0%

4.1.15 Priority rating

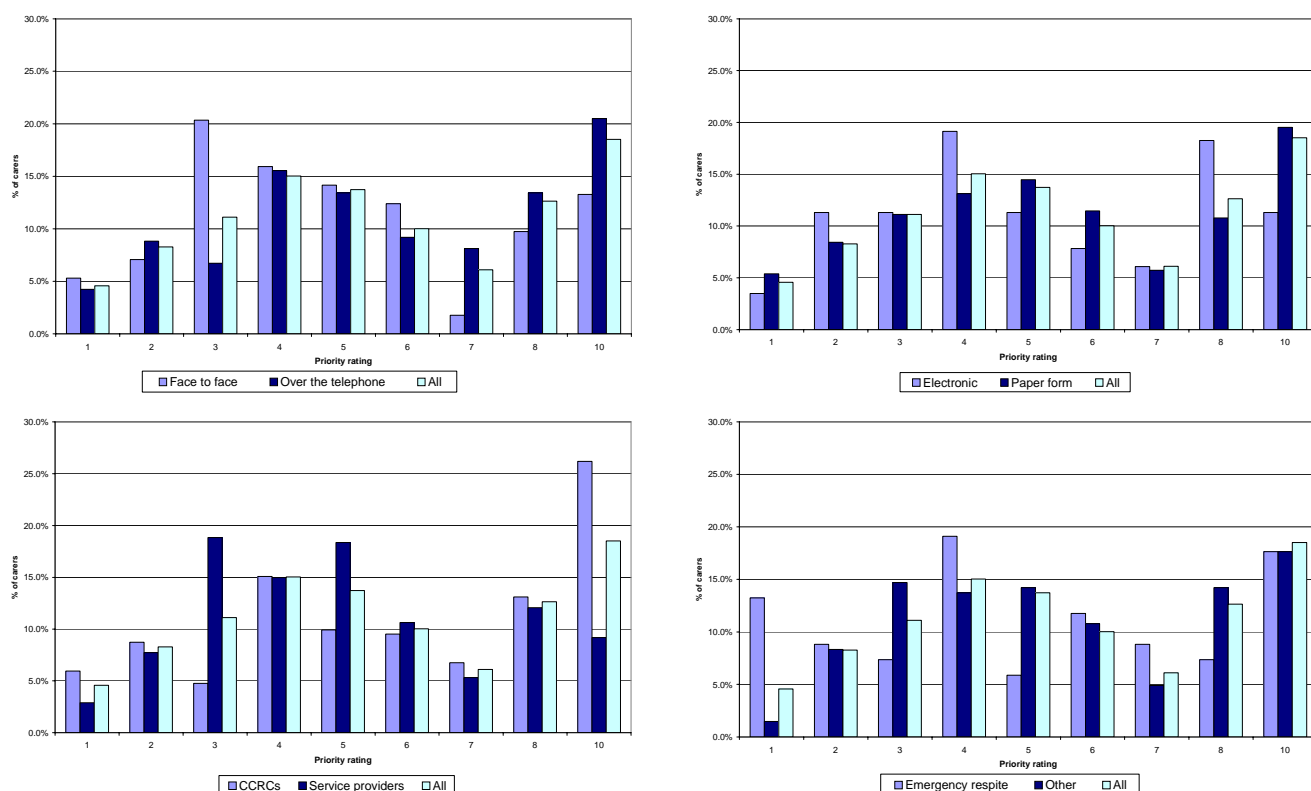
A priority rating system was tested as part of the field trial. The model used is shown in Figure 36.

Figure 36 The priority rating system tested in the trial

Assessor, taking into account all information available to you, record a score for each of the following:				Score
Carer needs and risks	High = 1	Medium = 2	Low = 4	
Care recipient needs	High = 1	Medium = 2	Low = 4	
Sustainability of relationship	Weeks to months = 1	At risk in next year = 2	Sustainable = 4	
Assessor, if relationship has already broken down, treat as a request for emergency respite				<input type="checkbox"/>
Total score				<input type="text"/>
Priority rating = Total score minus 2 =				<input type="text"/>

The highest priority score is 1 and the lowest is 10. There is no rating of 9. The spread of priority ratings using this model is shown in Figure 37.

Figure 37 Spread of priority rating scores



This figure presents the results in four different ways. The top left graph shows the spread of ratings for assessments done over the phone and those conducted face to face. Face to face assessments were rated as a slightly higher priority. The average rating for a face to face assessment was 5.12 compared to 5.96 for telephone assessments.

The top right graph compares electronic versus paper-based assessments. Electronic assessments had an average rating of 5.42 compare to 5.71 for those carers assessed with the paper version.

The bottom left graph shows the ratings for those assessed by CCRCs and those assessed by service providers. The CCRCs assigned the lowest priority overall, with an average rating of 6.19. The average rating for service providers was 5.16.

Finally, the bottom right graph shows the difference in the spread of ratings between emergency respite assessments and others. Emergency respite assessments had an average ratings of 5.26 compared to 5.77 for other assessments.

The model tested in the trial relied on assessor judgements about each of the three components. It is therefore not surprising that the significant majority of assessors (90.1%) agreed with the priority rating that was assigned. Only 2% disagreed. In 8% of cases, assessors indicated that they were not sure. Most of these assessors indicated that they did not have enough information about the care recipient to be confident with the rating.

The views of assessors about the priority rating system were also sought at the feedback sessions and at other levels of the field trial (see next sections). Overall, most people at all levels of the field trial agreed with the model. However, there was some concern that, unlike the electronic ACCNA, it relied too heavily on assessor judgement and that there needed to be flexibility in how it was applied.

The final stage of the analysis of the priority rating system therefore sought to identify whether it would be possible to auto-populate the priority rating system based on items collected during the assessment. This issue is discussed further in Section 5.4.

4.2 Level One Comments and Evaluation Session Feedback

Each assessment form provided the opportunity for assessors to provide feedback on the individual assessment. A total of 805 assessments were received for analysis but feedback was not provided for every assessment. A summary of the feedback received on the evaluation forms is included in the following tables, and any relevant issues are added as comments.

Table 18 How did you find using this tool with this carer?

Satisfaction	Number	%
Satisfied, no further comments	229	48.0%
Too busy to complete evaluation	102	21.4%
Want to provide more details	146	30.6%
All	477	100.0%

About half were satisfied with no extra comments to add. Not all comments expressed negative concerns about the tool.

Table 19 How many contacts did your agency have with the carer for this assessment?

Number of contacts with carer	Number	%
1	378	67.1%
2	121	21.5%
3	43	7.6%

Number of contacts with carer	Number	%
More than 3	21	3.7%
All	563	100.0%

A quarter of all assessments with an attached evaluation form involved more than one contact with the carer to complete the assessment. This result reinforces the need for an assessment model that allows the assessment to be completed over time and not just at initial contact.

Table 20 *How many contacts did you have with other agencies or people to obtain information for this assessment?*

Number of contacts with other agencies	Number	%
1	227	73.5%
2	63	20.4%
3	15	4.9%
More than 3	4	1.3%
All	309	100.0%

A quarter of the assessments involved contact with more than one other agency. Again, this has implications for the design of the assessment system and the need for inter-operability between agencies. This issue is discussed further in Section 5.

Table 21 *Where was the assessment conducted?*

Mode of assessment	Number	%
Face to face	135	23.1%
Over the telephone	419	71.7%
Both	30	5.1%
All	584	100.0%

Three quarters of assessments occurred over the phone. But with one in four assessments conducted face to face, it will be important to develop the next version of the CENA in a range of formats to suit different circumstances. This issue is discussed further in Section 5.7.

Table 22 *Did the order of the questions help the flow of your conversation with this carer?*

Order of Questions	Number	%
Yes	187	52.5%
No	151	42.4%
Not sure	18	5.1%
All	356	100.0%

Just under one half of the assessments were not helped by the order of the questions, which probably reflected the use of the paper-based version that had more limited ability to be used within the flow of a conversation.

Table 23 *Did the form miss any important information?*

Missing Information	Number	%
Yes	91	27.3%
No	242	72.7%
All	333	100.0%

Just over a quarter of the assessments were judged to have missed important information when only the information on the form was being considered. Most of the assessors who felt this reported that they needed more information about the Care Recipient, such as their ADLs, their medical condition, and the care that they required.

Table 24 *Were any of the questions difficult to answer or inappropriate for the carer?*

Difficult or inappropriate questions for carer	Number	%
Yes	201	59.6%
No	136	40.4%
All	337	100.0%

“Carer is 9 years old. Many questions assume carer is an adult.”

“Some of the concepts were difficult for a non-English speaking person. Questions needed re-framing which added to the time spent”

Some of the recurring themes were discussion of a carer’s health, carer’s use of alcohol and medication, and discussion about the future, and that it was too intrusive for first contact.

Table 25 *Did you agree with the priority rating for the carer?*

Priority Rating agreement	Number	%
Agree	234	89.0%
No-higher	2	0.8%
No-lower	1	0.4%
Not sure	26	9.9%
All	263	100.0%

Table 26 *How confident do you feel that the outcomes of the assessment are accurate?*

Confidence in outcomes	Number	%
Very confident	151	60.9%
Somewhat confident	77	31.0%
Not confident	20	8.1%
All	248	100.0%

These results suggest room for improvements to be made in the sequencing and content of the questions, and assessors’ comments in these evaluations covered the types of changes that could help the CENA to suit the type of request:. The 89% agreement with the priority rating, and 92% confidence in the assessment outcomes, indicates that the CENA was broadly acceptable to assessors in the field.

“Made conversation flow somewhat rigid. Forced to ask questions in socio-emotional area where focus of conversation needs only to be establishing eligibility for services and addressing specific question”.

“Opened up a “Pandora’s Box’ with regards to what has gone wrong in life in general. Many many unresolved issues. Not qualified to handle this”.

“Try to find questions out in a discussion, not an order. Becomes too authoritarian. It’s bad enough asking this amount of questions as it is”.

“Made conversation flow somewhat rigid. Forced to ask questions in socio-emotional area where focus of conversation needs only to be establishing eligibility for services and addressing specific question”.

“Unable to complete some information as it wasn't appropriate to ask with CR present”.

“Carer appeared to feel obliged to complete CENA and clearly rushed through it with single answers mainly given. Carer did not wish to expand on anything and gave the impression that completion of CENA was the goal”.

“Some of the concepts were difficult for a non-English speaking person. Questions needed re-framing which added to the time spent”

“Form asks for more information than relevant. This carer has relatively low level of involvement with father in law, who is relatively independent. Purpose of call is merely to register for services in the future”.

“Too much to go into over the phone - re mental health and relationship with care recipient”

“Initial contact with a carer is often when a carer is at breaking point and therefore the priority is around getting respite organised”.

“The Zarit, I feel is more of a professional tool to be used in a professional face to face situation with a professionally trained counsellor or psychologist”.

“Basic questions around role and daily routine are easy to gather by phone. Questions relating to finances, coping etc are often better done face to face and when some form of relationship is already established”.

Comments also covered areas of inquiry for organising respite placements where relevant information was not collected, and where the functional screen was not relevant for younger and more active carers:

“ADLs, emergency contacts, more details about the carer, housing details, GP details”.

“As carer is not an ageing carer, some of the functional profile was irrelevant”

“Carer is 9 years old. Many questions assume carer is an adult.”

The feedback from the Evaluation Sessions highlighted the wide variety of starting points for change and the diversity of practice in the field. Many organisations have already adopted a carer-focused approach, but other agencies are struggling with a lack of clear direction to help them in moving towards this aim.

Information sharing

It was clear from the evaluation sessions that many assessors had limited knowledge about other service agencies in the field. This lack of knowledge meant that referrals into the agency were not generally trusted, and information contained in these referrals was regularly re-asked, wasting the time of the carer, the care recipient and the assessors.

Providing a standardised set of information will increase the ability to share information. However, this will still not be done effectively unless there is a higher level of knowledge of what other agencies do, and greater trust between those who are receiving and sending the information.

Care-coordination

The lack of effective protocols for sharing knowledge of carer issues and information means that service providers are often frustrated in making the best use of limited resources. Assessors

provided anecdotes of carers and care recipients receiving services from several different agencies, none of which knew about the others' provision of services.

In discussion about how a more effective system could be implemented, there was agreement about how it could be done with a central register. One example was the Central Coast 4CN model for how the information can be managed and controlled, which basically came down to a 'mapping' exercise of who does what in the local area. It was clear that wider implementation would need strong trust and respect between service providers, and the use of either electronic information sharing systems or a central register that could be checked by phone or fax.

Technology issues

Implementation of new software into an organisation is always difficult, with the difficulty increasing along with the complexity of the existing systems. Organisations now operate on the basis of wanting efficient and effective use of information, and changes to current systems are always likely to disrupt this use. Implementation of new software needs to be promoted carefully and so that it is seen to be in line with an organisation's current practices and plans. Ideally, assessors wanted the CENA and its components to have the capacity to be easily built into their current systems.

Carer as client

One common issue raised by assessors was the realisation by carers that their needs were being addressed, rather than just being seen as an adjunct to the service system. In the past, assessments had focused on the care recipient, and the carer was ignored. Some assessors reported that this was positive for the carers, while other carers saw caring as part of their normal role, and did not appreciate all the extra attention.

Modularisation of the CENA

The CENA was used in many different settings in the trial, and used in different ways. For some agencies, the CENA provided too much detail and questions that were redundant, and for others, it did not provide all the information that they needed. Assessors in the evaluation sessions were very supportive of the idea of developing the CENA into modules, which could be developed to meet the particular role of the assessment being done at that point-in-time and for a particular purpose. This would ensure that assessors, for example, at a telephone intake point, would get the right mix of questions that they would need to ask then. Assessors who may be doing a deeper and broader type of assessment would need a different range of questions that could build on the earlier assessment.

Unmet Need

Concern was raised by some assessors about the idea of uncovering needs of carers that their services or other service providers could not meet. They were worried that exploring these needs would make life more difficult for the carer and services would be overloaded. However, it was generally agreed by most assessors that this was important so that needs could be identified, and then resources could be sought to meet these needs.

Training

One common theme from the evaluation sessions was the need for effective and on-going training in the use of the new tools. If the CENA were to be introduced nationally, it was crucial that all users be trained initially, and that this training should continue until it becomes part of normal practice and an agency's normal training program. This training would cover the next version of the CENA and its use and role, and also how it can be implemented in each agency with their differing technologies.

The training of assessors in interviewing and counselling skills was also raised as an important way of increasing their ability to assess carers consistently and effectively.

4.3 Combined Levels Two and Three feedback, including written submissions

There were about 7,000 hits on the CHSD project website in the period from August 2005 to October 2006, half of which were in the field-testing period (August-October 2006). This indicated a level of interest but that did not result in all the interested participants responding to assist the evaluation. Level Three was a useful part of the broader communication strategy, had relatively little impact on the evaluation itself in terms of volume, but did offer some useful commentary.

The Level 2 Trial generated 67 requests for CDs containing the data base version, 2 requests for only the CENA. 60 requested the both ACCNA and CENA and 5 for the ACCNA only.

Agencies and individuals inspected the tools on the web site and gave their comments at Level 3 of the trial. 184 people registered to use the site and look at the web versions of the CENA and ACCNA electronic forms. There were 184 Individual registrations, 12 gave feedback. 5 (21%) were satisfied, 4 (33%) provided more comments and 3 (25%) did not respond. Without a measure of training and support, the task of registering and sampling the software and then offering feedback on the limited experience available over the web was a lot of work.

Some participants also put their views in a submission format in relation to both of the ACCNA and CENA, and many of these went beyond commenting on the data elements and the layout and also provided feedback from a broad “policy” perspective.

The trial also received written feedback in the form of separate submissions from Level Three participants and the comments often were similar for the CENA and the ACCNA. Points that were reinforced were the scope of the domains, and that some of the items were better included in a face to face assessment or inappropriate to ask at first contact.

“Carer strain, mental health and well being may be too intrusive for use at first point of contact, e.g. mental and well being scales, financial, legal and employment.”

“Perhaps rather than 2 separate tools, the ACCNA and CENA could be combined as one tool and streamlined, with only the relevant sections being completed for each client group. The majority of our referrals are generated from ACAT and this tool would generate unnecessary pressure and intrusion on potential clients.”

“Almost felt like I would be interrogating a carer. Difficult to use if a carer is stressed.”

“Some of the carer details questions are very sensitive and, although people may be happy to answer, they may possibly need to build up some trust and be helped to feel it is OK to talk about these things.”

“I wonder if there is a need for so much information about the care recipient, when the carer is the consumer in this instance?”

“Need to have immediate questions on does the carer live with you, how much support can they give you (hours, tasks), has your carer got other people to care for, does your carer also work”

“Looks great to me. Will there be training in its use?”

“The form needs to collect information about person's disability and need”

“Not enough information provided, makes the task harder because the information is still required to be collected”.

Generally Positive

“We commend your team on the excellent achievements to date and offer our support for the direction outlined.”

Software was not the primary focus of the pilots, and was developed as a mechanism to achieve the testing of the assessment data elements. However users acknowledged the value of some of auto-populating features.

“Despite some minor glitches, it is apparent that the intent is that information collected earlier in the assessment will “pull through” and automatically populate later fields. This is an excellent feature and we hope that this will also be possible between the ACCNA and the CENA”.

The lowest support in the feedback from Levels 2 and 3 and in the Focus Groups was for the Financial and Legal profile and exploring the psychosocial domains. Financial and more personal matters were thought to be too intrusive for an initial contact or over the phone.

But the inter-relationships are too limited

The participants saw the obvious next step was two-way compatibility so that:

“... there should be a link between the two assessments so that information could be ‘pulled through’ rather than re-asked and re-entered.”

“Could there be a link from the ACCNA to the CENA and vice versa?”

Participants also noted how the tools did not connect to electronic referral systems:

“Of concern however, was that there does not seem to be any ‘system logic’ in this software, i.e. the information gathered during the assessment does not drive any recommendations in relation to the services recommended in the action plan.”

Ensuring consistent and mappable data elements between the ACCNA and the CENA was the most immediate of the wider system level integration issues that were raised consistently in the field. The prerequisites to wider system reform were recognised as a common language and the development of inter-agency protocols and business rules.

The model and the domains are moving the system in the right direction

The tone of much of the feedback showed an appreciation of the need for a more positive view.

“Currently, the majority of tools developed to assist in planning are heavily geared to the identification of need. This practical focus on identifying one’s need is understandable, as this is a prerequisite in the design of a service support plan. However, over-emphasis on need skews our view of an individual and it alienates a person in contributing to his/her recovery process. The uniqueness and value of every individual with his/her strengths, abilities and desire to live a normal life should not be lost in the course of an assessment.”

Concerns were raised about the appropriateness of some of the domains for inclusion in an entry point tool that should be a preliminary “broad and shallow” instrument: Having a capacity to vary the scope can be a design feature if seen as a set of levels each containing modules that the assessor then navigates along with the consumer.

“Whilst the assessment is designed to provide a holistic overview of needs, clients who are requesting a specific service may have different expectations and expect only to be asked questions that pertain specifically to that service. This can be managed by careful filtering of questions to limit assessment to what is required and appropriate,”

Training was identified as an issue that would have to be addressed

Training in identifying carer issues and consumer issues for rehabilitation, health promotion, mental well-being and healthy behaviours were flagged as areas outside the scope of some agencies' current approaches to service provision.

The scope of interventions in community care is wide and it was felt by some agencies that the CENA could be used to flag interventions prior to the establishment of ongoing services or to arrange residential respite.

"We recognised there would need to be training in how to ask the questions from a cultural perspective, wellness perspective rather than a maintenance perspective."

"Re K10 - Concerns are that staff not adequately trained to ask questions in the mental health and well-being scale."

Most participants who responded wanted the CENA and ACCNA combined, with a specific purpose identified and both with multiple levels. This has major implications for a training strategy.

Feedback was quite specific about how the purpose of the tools needs to be made more explicit and how that relates to the depth of inquiries to be made.

It is also suggested that a clear statement outlining the purpose of the tool be included in the form emphasising that the assessment instrument is designed to bring consistency to the assessment system at a national level and, that the tools are adaptable and designed to serve as a baseline guide to agencies."

"However our primary concern surrounds the conduct of the assessment, primarily that much of it is inappropriate to be undertaken on anything but a face-to-face basis, and preferably after some rapport has been developed between the assessor and the carer."

As with the ACCNA, this issue would be addressed if the key initial screening and eligibility items are identified and undertaken at first contact, with others identified as only appropriate at subsequent stages."

"Good. For our service type we would need to do a little more work around when and under what circumstances we used which parts of the tools. This is consistent with our expectations though."

4.4 Level Four

The Focus Groups included presentations to experienced assessors who had no direct prior experience in using the CENA. The sessions included a presentation and demonstration, and all sessions used paper-based documentation and some also used additional electronic data collection.

Participants were asked to record their ratings of the domains covered in the CENA on a five-point scale from low to high on the three criteria being used for the purposes of the field test evaluation:

- relevance
- appropriateness
- importance

The higher the score, the more relevant, appropriate and important the item was.

There are some caveats to be noted as a result of the focus group methods used and the purpose of the field-testing. By using assessor judgement as the 'gold standard' this is a comparison to

current practice, which is not the same as 'best practice'. So there are implicit assumptions built into the ratings reported here through using the judgements that were applied by the assessors – they will tend to be biased toward the fit with participants'/assessors' own routine practice.

Given the limitations of using averages across different sized groups, the results indicate a satisfactory level of support for the domains included in the CENA. Table 27 shows the average ratings for each of the domains as rated by all the focus groups. Across all domains and focus groups, the average score was 3.95, with the range of scores being from 1 to 5.

Table 27 Overall rating of the CENA domains by the focus groups

Domain	Relevance	Appropriateness	Importance	All criteria
Care recipient details, etc	4.41	4.34	4.61	4.45
Financial, legal, employment	3.58	3.27	3.38	3.41
Knowledge/info	4.13	3.98	4.18	4.09
Care tasks	4.36	4.16	4.50	4.34
Behaviour man	4.28	4.05	4.49	4.27
Health & function	4.23	4.12	4.53	4.29
Psychosocial inc K10	3.88	3.67	4.03	3.86
Personal & social support	4.16	3.93	4.33	4.14
Burden, inc Zarit	3.79	3.45	3.79	3.67
The future, values, preferences	3.66	3.45	3.67	3.59
Positive aspects	3.48	3.48	3.61	3.52
Priority Rating	3.86	3.65	3.95	3.82

There are few new issues raised by these results. As would be expected, the care recipient details, care tasks and health and function of the carer are rated highest. The lowest rating was for the financial and legal domain.

Table 28 to Table 30 break down the global ratings to show the relevance, appropriateness and

Table 28 Rating of the relevance of the CENA domains by the focus groups

Domain	NSW- ATSI	CALD	Tas	Remote ATSI
Care recipient details, etc	4.57	4.36	4.55	4.18
Financial, legal, employment	3.86	3.73	3.45	3.18
Knowledge/info	4.43	4.00	4.09	4.09
Care tasks	4.57	4.40	4.09	4.60
Behaviour man	4.57	4.33	4.00	4.27
Health & function	4.57	4.20	3.90	4.27
Psychosocial inc K10	4.57	3.46	4.00	3.73
Personal & social support	4.43	3.87	4.45	4.00
Burden, inc Zarit	4.43	3.29	4.30	3.40
The future, values, preferences	4.25	3.43	3.60	3.45
Positive aspects	4.86	2.87	3.09	3.70
Priority Rating	4.57	3.20	4.10	4.00

There were mostly consistent responses on relevance and appropriateness, with the main exception being the CALD responses which were lower, and related to positive aspects of care giving, which indicated the potential difficulties of translation of some of the concepts. Financial,

legal and employment issues in remote areas also generated comments because of the need to understand local community arrangements and a mix of employment and income sources that includes the Community Development Employment Program.

Table 29 Rating of the appropriateness of the CENA domains by the focus groups

	NSW- ATSI	CALD	Tas	NT-ATSI
Care recipient details, etc	4.43	4.20	4.55	4.20
Financial, legal, employment	3.38	3.33	3.27	3.10
Knowledge/info	4.29	3.67	4.40	3.70
Care tasks	4.43	4.07	3.80	4.40
Behaviour man	4.43	3.87	3.70	4.30
Health & function	4.43	4.00	3.80	4.30
Psychosocial inc K10	4.00	3.47	4.00	3.50
Personal & social support	4.14	3.57	4.20	3.90
Burden, inc Zarit	3.71	3.07	4.30	3.00
The future, values, preferences	4.29	3.07	3.50	3.20
Positive aspects	4.50	2.73	3.45	3.67
Priority Rating	4.29	3.00	3.80	3.88

Table 30 Rating of the importance of the CENA domains by the focus groups

	NSW- ATSI	CALD	Tas	NT-ATSI
Care recipient details, etc	4.88	4.53	4.82	4.27
Financial, legal, employment	3.71	3.60	3.18	2.91
Knowledge/info	4.50	3.93	4.50	3.91
Care tasks	4.75	4.64	4.40	4.18
Behaviour man	4.75	4.60	4.40	4.18
Health & function	4.88	4.60	4.20	4.45
Psychosocial inc K10	4.75	3.67	3.90	4.00
Personal & social support	4.50	4.27	4.27	4.27
Burden, inc Zarit	4.63	3.21	4.20	3.40
The future, values, preferences	4.57	3.07	3.90	3.55
Positive aspects	4.71	2.80	3.64	3.90
Priority Rating	4.63	3.50	4.10	3.78

4.4.1 National Aboriginal and Torres Strait Islander consultations

4.4.1.1 The processes used in the project and the field trial

The National Aboriginal and Torres Strait Islander HACC Reference Group was given initial information regarding the CENA and ACCNA projects and additional information on the strategies used to get responses in the consultation phase in 2005, and the views of those participants were summarised. The 2006 field trial was described including the opportunities for input at the four levels, plus an invitation was made to provide direct input via submissions. Keeping up with the progress of the trial via the website was promoted as an informative strategy.

The briefings referred to the way the tools were being field tested in parallel and steered by a reference group under the National Respite for Carers Program and Working Group 1 of

community care officials. Most of those consulted were interested in understanding the needs of both the care recipients and the carers.

Advice during the project was focussed on the strategies being used within the CENA and ACCNA field trials to address Aboriginal and Torres Strait Islander assessment issues and to ensure their adequate representation in the findings. The briefings included a request to make recommendations to service providers or other groups with particular expertise that could participate in particular in Levels 2 and/or 3 of the field-testing. This was a strategy to ensure a representative sample was achieved.

An Aboriginal-specific assessment component was included within one agency in Level One, which was also related to a separate project to develop an indigenous assessment strategy. That meant participation in training, advice and support via the hotline and assistance in preparing presentations and strategic advice was included. A Level One evaluation session was specific to Aboriginal assessments and included an assessor with experience in using the CENA in the trial, as well experienced assessors who had not used the tools in practice. Longer meetings with a detailed description and demonstration of the CENA tools took place at the Level 4 the focus groups and the information sessions.

Level 4 of the trial targeted providers for groups with special needs. It covered the acceptability to agencies that provide services to indigenous communities and in regional and remote areas where it may not be realistic for them to try a database or website version. Focus groups specific to rural and remote and Aboriginal issues were held in Alice Springs and Darwin. Torres Strait Islander issues were covered in Townsville and Thursday Island. Information sessions were held in metropolitan Sydney with the HACC Gathering executive group and a carer network. The Sydney meetings included rural and regional agency representatives and included some experienced assessors, as well as service providers and policy people.

The key points for Aboriginal and Torres Strait Islander assessments from the responses to the CENA in the field trial (often covering the ACCNA as well), are summarised under the headings of responses to the tools being trialed and comments on current systems being routinely used.

4.4.1.2 Aboriginal responses to the ACCNA and CENA

The consensus view in Level One (where the experience was in using a phone-based model) was that a modular approach would help, that the layout into more explicit levels made sense and that some domains and items were hardly used at all.

The background of the Level One advice was that apart from a small number of agencies the current assessment practices are not standardised and the tools and processes being used vary widely. In that context the CENA (and ACCNA) could be used with indigenous clients but not in the same way as in the mainstream. Where they had been used they took current practices well beyond the CIARR-type level, and in the small number of cases where both tools were routinely used, the ACCNA was perceived as more useful than the CENA.

The CENA was perceived as frustrating because of its length and depth and its difficulty in being used in phone assessment where few service types (mainly domestic assistance) were being requested. It opened up too many issues (by phone) in areas perceived as intrusive and personal and where the lack of direct referral networks meant no practical action could be easily undertaken to follow them up.

Specifically for the CENA the points to consider for changes or more clarification were identified at the Level One evaluation session as:

- the priority rating did not help if the individual assessor did not capture enough of the context
- the basic functional screen was not practical for most carers, so was not used much
- the availability of open fields and comment boxes was what made the assessment more useful

- social and emotional domains were less useful than the health items and the financial and legal items were not used at all
- health conditions and current treatments of the care recipient should be emphasised as they help to focus the conversation

The key issues (that mirrored the concerns in the 'mainstream') were the current skill and confidence levels and the provision of adequate training and support, especially in using standardised components such as the functional screen, the Zarit and the K10. Regardless of ethnicity or indigenous status the ability to get and retain the right skill sets in remote areas and even in larger regional centres, was a problem.

The important qualification was that there were no real problems in current practice as long as assessors knew whom to refer to for covering assessment areas where they felt their experience or skills were insufficient.

"I believe we have been able to use both our formal assessment / referral tools & conversations with referrers to get plenty of information on both the carers and the care recipient with whom we really have the most contact."

But any 'new' national approach should be seen as an opportunity to raise the levels of competencies and confidence in the sector and be backed up by resources for training and support. This implied a training strategy where agencies within a region agreed on the assessment competencies required for different types of services and at different levels of depth. A roll-out strategy that had these ideas built in would be welcomed.

The major differences between the 'mainstream' assessment tools and those used for Aboriginal and Torres Strait Islander assessments that were noted in the consultations and the field testing were that additional items should cover:

- added questions on literacy and numeracy
- include in the CENA (and ACCNA) some scope for specific attention to local or familial considerations - about *'the way of talking to certain people about certain things'*
- a simple version of the carer items in the ACCNA that allows for a network of care-giving, not just a primary carer, and/or have good links from the ACCNA to the more detailed carer tool
- stolen generation – as an optional part of a psychosocial domain
- a set of teeth in the health profile of the care recipient - oral health is a major issue
- consider an additional profile on home safety and the environment - public health is a major issue

Most responses were not about the ACCNA or CENA per se, as exposure to the tool and its routine use with clients and carers was limited to the Aboriginal assessments conducted under Level One. Most of the focus group discussions and comments were based on experiences shaped more by the assessment tools and systems currently in use.

It was also noted that *"Electronic versions of the tool may not be accessible in remote regions – no IT support."* Many comments were related to system-level issues in the Northern Territory context where necessary costs for staff training and IT support from the government was uncertain.

4.4.1.3 Torres Strait Islander Focus Groups

There were two groups conducted, one in Townsville and one group on Thursday Island. This focus group was linked to the Torres Strait Islander HACC Forum.

In both of the focus groups there was a majority attendance of Torres Strait Islander people who identified themselves as service providers. There were also a small number of carers. There was a mix of both HACC and CRC providers.

Townsville: The group initially identified a number of cultural issues that would have an overarching effect on any process of assessment. These were around the cultural ties of “*who was allowed to address who*” about particular levels of personal information. These levels are dependent on social stature, marriage ties and gender. They also highlighted the difficulty of accessing cultural language or locating an advocate for language within this cultural framework. The other important theme was that it is not an accepted practice to ask for help outside of family ties.

The general comments on the CENA were:

- Too many words / requires simple language
- Concern and frustration about asking all a high volume of questions and not being able to deliver the services identified, which may also create a lack of trust
- Some people felt that their skills were not adequate to complete the K10 or the Zarit but all agreed they would be comfortable to refer out to a more appropriate person
- A number of people felt the Zarit Burden Interview was culturally inappropriate
- The size of the tool was an issue and the group agreed that a modular approach would be both more appropriate for service providers and less arduous for carers
- Skills training was identified as essential and it was emphasised that it needed to be systemic and delivered in a way that was accessible and affordable
- A critical point that was flagged as essential to any implementation was the education of governance / board members to understand the messages from funding bodies about why these system changes were occurring, so they could be better prepared to support staff
- South Sea Islanders were not recognised as a separate grouping even though their organisations received specific funding.

Thursday Island: This group were a mix of Torres Strait Island service providers and non-Torres Strait Island providers. There was a mix of HACC, CACP and CRC program-funded staff. The same cultural context as identified in Townsville applied to the interpersonal relationships, although in this context the existing system is a central referral point for support. Again the emphasis is to maintain strict cultural protocols. The skills of the assessor are aimed at being least intrusive whilst allowing the carer to identify their needs early in the assessment process.

The general comments made on the CENA by the Thursday Island group were:

- Language can be confronting
- Start with positive carer questions
- Skills training is essential
- There was agreement that all aspects of the tool were relevant and that the skills of the assessor determine an appropriate assessment process
- Resource allocation to manage process for those services that would require upskilling of staff
- There was a general sense that this would be a positive component of the overall support system if implemented in smaller bites to carers by skilled staff.

The Torres Strait Islander groups were asked to give a rating of the relevance, appropriateness and importance of the CENA domains. Most participants did not complete the rating of the domains. Where the ratings were made, no areas were rated less than 3 on the five-point scale. The lower ratings were for the psychosocial domain including the K10 (across all criteria), and on

the appropriateness criterion of the personal & social support, burden (including the Zarit), the future, values, preferences, positive aspects domains and the priority rating.

4.4.1.4 Comments on current assessment systems

Feedback comments indicate that many organisations (e.g. those operating in Darwin and the NSW agencies) do not have a formal tool for carer assessment.

“No assessment tool for carer’s but informally discusses their needs and situation with them to ensure sustainable care for the client. The client is not seen as a separate client (to carer).”

Rapport was identified as an important feature of an assessor/client relationship. The CENA was noted as being appropriate over time.

“In remote setting carer’s may not want to discuss information as it may not be a priority at that time.”

“Items 10 and 11 may not be appropriate for our facility – I feel this would intimidate the majority of our carers. We get this information by developing relationships over time with carers.”

The message for assessment reform from the Aboriginal and Torres Strait Islander consultations was that taking a fragmented approach and getting too bogged down in tedious program-specific detail was a problem created by the bureaucracies. That was compounded when not enough effort and resources were put into training and support, so overall, new tools are likely to just add to the overall level of frustration with bureaucracy that is widely felt in the community sector. The CENA (and ACCNA) were seen as valuable tools to create a continuous record of client needs and service provision that could off-set the consequences of high staff turnover.

A list of common assessment tool requirements was described in the course of the consultations:

- It can be simple, but lends itself to expanding where necessary
- Is done in a way that checks back with the client to ensure that the client actively participates as an equal partner in the assessment process and that information recorded is accurate and recorded with the carer’s/recipient’s consent.
- Is formatted to ensure data feeds into formal departmental reporting systems
- Is ongoing throughout the client’s stay on the program
- Balanced - does not entirely rely on scores and reports but gives equal weight to the Carers/Recipient’s, Coordinator’s and other professionals’ considered opinions.
- Flexible - not all sections need to be completed for all carers/recipients..

4.4.2 Culturally and Linguistically Diverse (CALD) Focus Group

This group was held in Melbourne and 25 people attended from a range of organisations and agencies selected by the jurisdiction. They were from Local Government, ethno-specific provider agencies and peak groups, and Departmental officers. Some were assessors and service providers for single service types and others had experience in multiple programs and with packaged care, and others were managers and policy workers.

Key points made about the data elements were:

- The assessment tool as a whole *“must be simple, non-intrusive, and short.”*
- *“Not appropriate for our CALD target group. It is too Anglo Saxon focussed and value based, not culturally sensitive.”*

- There needs to be a client consent section to enforce and protect confidentiality and privacy of clients.
- A telephone-based assessment is not appropriate for CALD communities where face-to-face contact is essential due to language problems. *“Telephone assessments using drop-down boxes electronically re not an option for me.”*
- ‘Care tasks’ domain – hours of care per day should be replaced by hours per week.
- ‘Health and functional needs domain’ – uncertainty about the appropriateness of the word ‘alcohol’ in a Section 9 question.
- Psychosocial domain includes a question on the greatest challenge for care recipient, the space provided for the answer *“should allow for more than one answer to allow a picture of carer’s needs”*. More comment space *here “rather than tick box which could make people uncomfortable.”*
- ‘Personal and social support system’ – remove the word ‘blue’ as this does not translate, and ‘chores’ as this is American.
- Burden/Zarit domain – *“Questions related to doing better job and burden for CALD are not appropriate for he future”*. There is a reluctance to ask questions relating to the carer burden relationship breaking down due to sensitivity concerns.
- ‘The future’ domain uses the word ‘goals.’ This was seen as too severe and suggested replacement was ‘interests/activities.’

The CENA as a whole was identified a *“comprehensive assessment tool”*, that provided a *“history of carers to enable good decision-making and priority access”*. For organisations that did use an assessment tool for the carer, the CENA was perceived as useful in providing a *“more in-depth assessment for service providers”*.

Existing tools were described as being *“very care recipient focussed”*.

“Current tool is SCOTT plus supplements depending on needs...SCOTT until recently has not included enough on carer information.”

“It [the CENA] provides more information about the carer. With our services we tend to focus more on the care recipient. It challenges service providers to support the carer more effectively.”

The detailed nature of the CENA assessment tool was noted as being *“very appropriate as for the information it obtains”*. They also noted that this has implications for language translation.

“To obtain this level of information from the carers it will be vital to utilise and interpreter.”

“Our target group is CALD and this tool may need to be used with an interpreter. The tool is very lengthy and the time taken would be twice as long....some of the terminology would be difficult to translate into other languages.”

System-level comments

National consistency was one key factor as was standardising data and the electronic interchange of information. CENA would only be efficient if the national approach was maintained and regional arrangements supported its common use. A major advantage of a national assessment system is that *“the gathered data doesn’t just stay at the local service level only – it is developed to link into policy and funding level to address systematic issues”*.

- *“Appropriate if all contact services complete relevant sections as needed and isn’t left to one service to complete.”*

- CENA is “*very appropriate if all other services fill out their bits. If this is not done and left to one person who is already looking after clients, it would be too much.*”
- An advantage of CENA is its “*flexibility, only if it was a national database*”.
- “*This tool only encompasses half our target group. Our target group also encompasses the care recipient. Therefore we need a tool that links the CENA and ACCNA.*”
- “*Some items duplicate NRCP, MDS, SCTT V2 items – how compatible is the CENA software when it comes to data analysis, extraction and program reporting?*”

Three major issues were identified with the potential implementation of the CENA. These were training, time and funding.

“DoHA needs to remember that we are not funded for case management or really for our assessment times. We are only funded for service coordination and hours provided. When we have to put in more staff hours to do things like this then they need to be looking at additional funding in conjunction with introducing this type of thing.”

“Lack of funding for this assessment and training, lack of IT skills in employees.” A major challenge identified was “Becoming familiar with the new tool and finding the time to do it.”

“Cost of IT interface/SCOTT/HACC/PCP/On Call.”

Feedback from the trial has identified several areas of concern for potential implementation of this tool. These included length/time issues, appropriateness for CALD assessments, and the limitation of services available in the rural and remote regions. The group appreciated the added focus on the carer’s own goals and self perceptions and the way it allowed more investigation of the reasons for the referral..

4.4.3 Carer Focus Group

This summary has been provided by Community and Aged Services (C&AS) of Hope Healthcare for the purposes of feedback to the trial. The C&AS has a Carer Support Group that has been running for over 12 years with a regular monthly meeting being attended by, on average, 10 – 15 carers, depending on the topic being discussed. The group has a focus on carers of people with dementia.

The October 2006 meeting was used as an opportunity for carers to review the CENA tool, and provide feedback on it. The group was attended by 10 carers, not all of whom had seen the CENA before. C&AS used the CENA as part of Level One of the CHSD trial with carers accessing the DoHA funded services only. Some of the carers attending the group have HACC services only and some have no services at all.

The carers in the Focus Group were a mixed group of primary carers –

- 6 women, 4 men
- 2 daughters, 8 spouses
- 1 carer from a non-English speaking background (Spanish)

Their average length of caring was 3 years, with care recipients having mild – moderate dementia, and one man has advanced dementia.

The group commenced with an overview of the tool, why it was being trialed and the C&AS role within the trial. The core and optional components of the tool were explained, and then the group went through the tool, question by question. Each participant was given a paper based copy of the tool to refer to. The information was collected and mapped to the questions set for the CENA focus group and provided by CHSD.

Which parts of the tool do you think might be most helpful?

A carer asked what the information would be used for, and why it was collected – i.e. “helpful to whom?” The parts that were the main focus were:

- Zarit burden scale
- Psycho-social profile
- K10 burden scale

Carers questioned the need for both the K10 and the Zarit being in the tool, suggesting that one or the other would be better. The carers in the Carer Support Group also felt that the “Functional Profile” was redundant for most of them.

Is there any important information missing?

No. If anything, the carers were concerned about the length of the tool, and difficulties completing it in front of someone with dementia.

Do you think that some or all of the components of the tool could be completed as a self report measure (answering questions in your own time?)

Yes. Carers indicated that completing the tool in their own time, and having the opportunity to think about the answers, such as care tasks and behaviour management would make the process easier. Difficult conversations would not have to be had in front of the care recipient. The option to not answer questions that they may find confronting (i.e. alcohol use) was there.

As part of the technical trial, there were some concerns about some questions being inappropriate. Would you feel comfortable answering the some questions and providing information to the service agency?

This may depend on factors such as the reason for referral and the carer’s relationship with the service provider or assessment agency. Questions that may have been difficult were:

- Cost of living decisions
- Change of alcohol consumption
- K10 mental health screen
- Zarit burden interview

This concern was reflected in the responses of the carers group. The majority of the group felt that questions about cost of living were not appropriate, and older carers were concerned about the alcohol consumption question. Carers felt uneasy about having these questions asked if the service provider was unknown to them, and this was the first visit. They went on to say that when services are required, the carer is usually very stressed, and confronting questions just add to this level of stress.

The question about the future care environment (how important is it that the CR be cared for at home?) was seen as not appropriate. Carers felt uncomfortable about discussing how important it was that the care recipient be cared for at home, lest they be seen as uncaring, particularly at first contact.

Under the financial, legal and employment context, regarding cost of living decisions, carers felt the term “trade offs” was inappropriate, and that questions such as these were invading their privacy.

Carers were pleased with the inclusion of the K10 and Zarit. Until they completed these (which they did privately as part of the group process), many carers did not realise their levels of stress and the enormity of their role. They saw this as a positive in being able to justify to themselves and their families, and perhaps the service provider, their need for services to assist them.

It was felt that the inclusion of the question about concerns for the future was not relevant, as all carers held concerns for the future.

Would you be happy to have your information shared with other service providers for the purpose of referral and service coordination?

This question was not asked of our carers. It should be noted that they currently give permission to have information shared for ongoing referral.

How do you feel about a standard assessment being implemented to assess the needs of carers?

In discussion with carers at the group prior to looking at the tool, one carer indicated that it was about time that carers were seen as an important part of the client/carer partnership, but was concerned at the amount of information collected and the time it would take to complete. Generally, carers were pleased that their role would be recognised with the implementation of such a tool.

Do you feel that any of the questions are unnecessary?

Carers were concerned about:

- Questions about their general health
- The question regarding when they started caring for the care recipient – caring for someone with dementia is a gradual process and so no real start date can be pin pointed.
- Younger carers felt that their date of birth was not relevant
- Under “positive aspects of caring”, the statement “ I feel that caring for CR has made our family grow and work closer together” was distressing, as carers felt that there are always more complex issues surrounding families, particularly when someone has dementia.

4.4.4 Tasmania Focus Group

A Focus Group was held in Hobart to look at issues relating to green-field sites. The issues raised here focused on the broader system issues of funding, technology, agency-cooperation and training issues. These issues were recognised as critical to successful implementation of a new system.

Feedback was positive towards the CENA form, with possible improvements in areas such as consent, and extra contact details required.

4.4.5 Victorian Carers Services Network (VCSN)

The Victorian Carer Services Network expressed a keen interest in the development and trialling of the CENA and asked for a specific visit to give them the opportunity to focus on the key issues and give consolidated feedback. The VCSN relies on an integrated planned approach to state-wide carer service provision and identified the potential compatibility of CENA in such a system.

Careful consideration of the tool led to several concerns being raised. The VCSN commented on the length of CENA and reinforced the need for a modular structure that allows for layered assessment. They recommended that the CENA format be modified to aim carer referrals toward preventative support rather than reactive clinical services for treatment of stress and burden. The VCSN see assessment as an intervention in its own right, and emphasised the importance of the

information gathered by the CENA to generate an informed support plan for carers. This electronic tool must have the capacity for subsequent assessors to add information and show a record of these amendments.

The VCSN identified the areas that need clarification - the priority of access section of the CENA and questions that provide a measure of burden, mental health, and social isolation. They stressed the importance of a common understanding in assigning levels and prompts for specialist referrals. Their comments emphasised their preparedness to be involved in future development work and trialling. As a state wide network of Commonwealth and State funded Carer Support, Respite and Information Services, they are eager to be involved in the future stages of the CENA from the perspective of both an assessment tool and its use as a referral mechanism to specialist services.

5 Discussion of design

The re-configuration described below is in response to the feedback on the results and is reflected in the recommendations.

5.1 Interoperability

A key issue raised at all levels of the field trial is the need for interoperability. Given this, this section starts by defining the various levels at which interoperability can operate. The level of interoperability depends on the amount of human involvement required, the sophistication of the IT and the level of standardisation in how agencies share information:

- Level 1 Non-electronic data** - no use of IT to share information (examples: mail, telephone).
- Level 2 Machine transportable data** - transmission of non-standardised information via basic IT; information within the document cannot be electronically manipulated (e.g. fax or PC-based exchange of scanned documents, pictures, or PDF files).
- Level 3 Machine-organisable data** - messages contain non-standardised data; imperfect translations because of vocabularies' incompatible levels of detail e.g. e-mail of free text, or PC-based exchange of files in incompatible/ proprietary file formats, HL-7 messages.
- Level 4 Machine-interpretable data** - transmission of structured messages containing standardised and coded data; all systems exchange information using the same formats and vocabularies.⁵

There was a clear recognition in the field trial evaluation sessions of the need for Level 4 machine-interpretable interoperability. This applies to interoperability between agencies sharing CENA assessment information (ie, those agencies undertaking CENA assessments as well as those agencies receiving service referrals after a CENA has been completed). It also applies to interoperability with the ACCNA and with ACAT assessments. It is only by achieving this level of interoperability that information can be efficiently shared and information duplication reduced.

5.1.1 Inter-relationship between the CENA and the ACCNA

It is clear that the ACCNA and CENA should be designed so that they can 'inter-relate'. Care recipients and their carers are a duad and their needs to be considered together.

A large proportion of field trial agencies indicated interest in using both the CENA and the ACCNA in the future. The two assessments need to be linked in a way that enables information to be 'pulled through' rather than be re-asked or re-entered. That is, the two systems need to be interoperable. This requires the information about the carer and care recipient to be consistent in both the ACCNA and the CENA. The diagram below emphasises the primary purpose for both assessment systems.

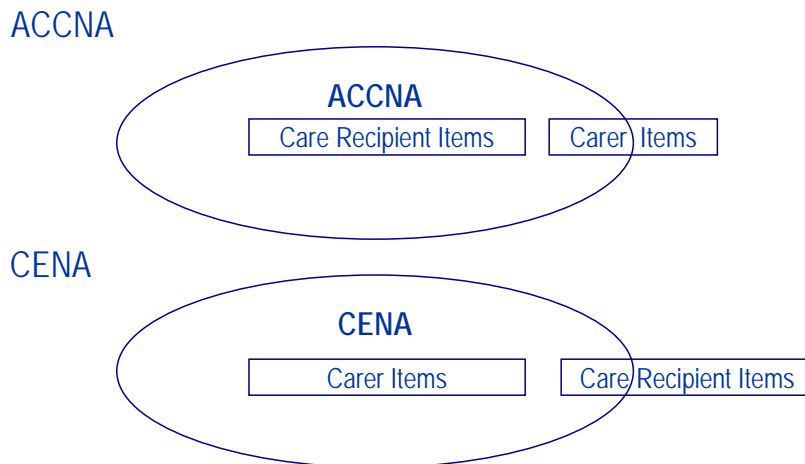
The ACCNA primarily includes data items for the care recipient with a subset of carer items. This subset of carer items should be able to be pulled through to form the basis of a CENA assessment. Conversely the CENA primarily includes data items for the carer with a subset of data items for the care recipient. This care recipient information needs to be consistent with the ACCNA data set so that information can be shared and auto-populated if necessary.

It cannot be assumed at this point that an ACCNA will be completed as part of a referral process from a HACC agency to an NRCP agency. It has thus been necessary to include a subset of ACCNA care recipient items in the CENA care recipient module to meet the needs of NRCP agencies. The relationships are shown schematically in Figure 38.

⁵ Walker J et al *The Value Of Health Care Information Exchange and Interoperability* Health Affairs 19 January 2005

The ACCNA primarily includes data items for the care recipient with a subset of carer items. This subset of carer items should be able to be pulled through to form the basis of a CENA assessment. Conversely the CENA primarily includes data items for the carer with a subset of data items for the care recipient (see Figure 38). This CR information needs to be consistent with the ACCNA data set so that information can be shared and auto-populated if necessary.

Figure 38 Relationship between the ACCNA and the CENA



If the data items are consistent between the ACCNA and the CENA:

- It is likely to reduce the likelihood that assessments will be duplicated
- A subset of carer items in the ACCNA should form the basis for a reliable trigger to identify the need for an agency to conduct a more in-depth carer assessment using the CENA.
- It will reinforce the idea that assessment is not a one-off event but rather a process where information is collected at different points in time and should be based on a combination of the needs of the carer and/or care recipient and agency requirements.

If the information is to be consistent across both tools, then key data items in the CENA should be included in the ACCNA data set. The following CENA data items about the Care Recipient have thus been built into the ACCNA:

- Primary Disability (in Health Conditions Profile)
- Information about medication routine (in Health Conditions Profile)
- Medical diagnosis of dementia (in Health Conditions Profile)
- What are the care recipient's primary care needs? (Action Plan)
- Does the care recipient have challenging behaviours? (FP item as a trigger)
- And if yes, what is the level of support needed? (Action Plan)
- What is the care recipient's level of need? This can be generated by using a combination of the following ACCNA data items:
 - FP score to give level of need/function, with FP questions 8 and 9 indicating level of need
 - Diagnosis of dementia
 - K10 score.

5.1.2 Common definitions

Our parallel report on the ACCNA recommended that the ACCNA and CENA data elements be combined to form an initial version of a Community Care Data Pool to be shared across a range of programs, service types and agencies.

Wide system level integration issues were raised consistently in the field and it was clear that the prerequisites to wider system reform were the development of a set of mappable data items, and a major re-think of the burdens and inconsistencies in the range of reporting requirements imposed on service agencies.

The AIHW reports on the 'Comparability of dependency data items' and the National Community Services Data Committee report on 'Cutting the red tape'⁶ both make the same points about reporting burdens, redundancy and problems of multiple data entry.

In the immediate context of the next stages of work under *The Way Forward*, there is a need to standardise those MDS items that are common between the ACCNA and the CENA. An example of an inconsistency that could be easily resolved is illustrated in Table 32 on page 102. This table shows the inconsistencies in the HACC and NRCP code sets with respect to the coding of referral source. This should be a straightforward item and is just one illustration of the problem.

Reconciling the different items collected on the same clients is a task for program managers. The AIHW has gone a considerable distance in the direction of identifying the various inconsistencies in dependency information and the responsibility for resolving the many other inconsistencies and removing the redundancies lies with the National Health and Community Services Data Committees.

5.2 CENA Layers

A diagram illustrating the CENA in a layered format is included in Attachment 1.

The principles that support this layering are:

- Domains of need and risk are areas of a person's life that are being identified for the purpose of determining a service response, or to prompt further assessment;
- Referral/assessment triggers are key summary questions or derived items from entered data that will prompt the assessor to consider referrals to particular assessments or services, lead into the investigation of need in other domains, or guide greater depth of inquiry in a current domain.
- Specific layers in the assessment process are reached by using triggers in each level to prompt further questions within a specific domain. The purpose is to allow deeper 'drilling down' within domains to encourage the 'flow' of the conversation while investigating needs and risks.

The design implication is that information at one layer would auto-populate the next and comments boxes would be used to summarise and bring forward the relevant contextual information.

The Action Plan is the end result of any assessment, which outlines the immediate next steps for the carer and care recipient:

- The Action Plan summarises the service response and comprises a list of possible triggered referrals to assessments, or assessor judged referrals to other assessments or services;
- Assessors can get to the Action Plan from any level.

⁶ AIHW (2004) *The comparability of dependency information across three aged and community care programs*. March 2004. Australian Institute of Health and Welfare, Canberra, AIHW cat. no. AGE 36.
National Community Services Data Committee (2006) *Cutting the red tape. Preliminary paper detailing the problem of multiple data entry and reporting by service providers*. March 2004. Australian Institute of Health and Welfare, Canberra, AIHW cat. no. HWI 92.

5.2.1 Recommended Changes to the CENA

Based on the data analysis the following changes are recommended:

- Remove redundant items, including the first psychosocial item
- Combine the psychosocial profile and the 4 item Zarit Burden Interview into one domain that measures psychosocial problems for the carer
- Include the functional profile but only complete it if a carer has significant health problems. This is identified as a response of 'moderate' or 'quite a lot' to the question about whether their health interferes with daily activities.
- The data analysis indicates the K10 and Zarit Burden Interview are capturing different types of information. The K10 is not suitable for administration at first point of contact but at a later stage in the assessment process. The K10 may be useful for carers who are at risk due to moderate to high levels of burden &/or stress. The K10 should remain as an optional item. It should not be routinely included in an initial assessment for carers but rather used if triggered by early indicators in the assessment process or judged to be appropriate by an experienced and appropriately trained assessor.
- Replacing the 22-item Zarit with the 12-item Zarit as an optional measure and including the 4 item version in the psychosocial profile in the carer details section.
- Changing the trigger for the 12-item Zarit to a score of 7 or more on the 4-item version. Based on the data in the field trial, this would result in 40.2% of those assessed with the 12-item version being identified as having Moderate or Severe Stress while 2.8% of those who would have been found to have Moderate or Severe Stress (if administered the 12-item version) will be missed.

5.3 Sample CENA Modules

CENA Assessment Modules are particular combinations of data items determined by the purpose of the particular assessment. They are proposed to be built into the next version of the CENA, allowing agencies to select the module that best meets their needs at different times, usually defined by the service type and depth of investigation. Each module should be designed to allow easy access to deeper layers of investigation within domains should that be required as the assessment progresses.

Assessors can over-ride these modules if necessary and collect information that is in addition to a specific module. However a modular design helps to guide assessors to the most appropriate assessment and contends with the assumption that all data items must be completed.

Modules would include service specific assessment modules composed from the pool of data elements, with the assumption that continuous refinements to the layout and triggers and contents could be made over time e.g. for employed carers, for small respite providers, for phone assessment by CCRCs.

5.3.1 Refinement to CENA modules

A set of diagrams illustrating some of the proposed initial CENA modules is included in Attachment 2 and Attachment 3. Not all of the proposed modules have been illustrated in this way and some can be inferred by examining Attachment 1. Possible modules include:

- Care Recipient Module
- CCRC Module/ Phone Assessment
- Crisis Respite Module (used by CCRC's)
- Employed Carers Module (service specific)
- In Home/ Reassessment/ Face to Face

5.3.2 Self-Report Version

Feedback from the field testing and information sessions suggested there were potential benefits to be gained from having a self-report version available:

- Empowers carers through active participation in the assessment process
- Carers can complete it in their own time
- Potentially reduces the length of face to face assessment

The Carer Details would be useful to include, especially the 'future' section. The comment was made that the carer often needs time to think through these questions. The Zarit Burden Interview and the K10 would also be amenable to reliable use in self report versions. Carers would be able to supply their own supporting documentation to add to the context of the scores on the scales.

The development of a self report version would involve some additional complexity as it would require reliable triggers or initial indicators that prompted the assessor to consider which carers might be able to use sections of the CENA as a self report tool. Initial feedback was that sub groups such as employed carers might be interested in this version (and it could be used and evaluated in a trial in 2007), and it might also be useful for carers of younger people with a disability.

5.4 Priority rating system

As noted in Section 4.1.15, the priority-rating model tested in the trial relied on assessor judgements about each of the three components. Given that the model was well received in the field, the final stage of the analysis of the priority rating system therefore sought to identify whether it would be possible to auto-populate the priority rating system based on items collected during the assessment.

The method⁷ involved taking the ratings made on each of the three components and testing whether there were items in the assessment that predicted the rating made. If so, those items could be used as a proxy for the rating. Each of the three components is discussed below.

Carer needs and risks

The two individual items that best predicted carer needs and risks were the following questions:

In general, would you say your own health is?

Excellent Very good Good Fair Poor

How much did your health interfere with your normal activities (outside and/or inside the home) during the past four weeks?

Not at all Slightly Moderately Quite a bit

Individual items in the Zarit and the total Zarit-4 score were also predictive of overall carer needs.

The final model developed incorporates the first health question above but not the second. The answers to these two questions were correlated with each other and adding the second into the priority rating system did not improve the model.

The recommended model uses the following definitions:

A carer is classified as having **high needs and risks** if either:

- Their health is poor OR
- Their health is good or fair AND they have a score of more than 10 on the Zarit-4.

⁷ The statistical method used was classification and regression tree analysis

A carer is classified as having **medium needs and risks** if either:

- Their health is good or fair AND they have a score of between 5 and 10 on the Zarit-4.

A carer is classified as having **low needs and risks** if either:

- Their health is excellent OR
- Their health is good or fair AND they have a score of 4 or less on the Zarit-4.

Care recipient needs

The CENA asked whether a needs assessment had been completed for the CR and, if so, the level of the CR's need based on that assessment (high, medium or low). Assessors used this item to rate this component of the priority-rating index.

If information from the ACCNA assessment of the CR were available, it could be used to populate this component of the priority-rating index. Until such inter-operability is achieved (see Section 5.1), there is little choice but to use this single item in the CENA.

Sustainability of relationship

This component was based on an assessor judgement based on the following item:

Assessor taking into account all information available to you is the relationship between the carer and the CR sustainable without additional services or support?

Record (1) No, arrangements have already broken down (2) No, carer arrangements likely to break down within weeks to months (3) Carer arrangements could break down in the next year (4) Yes, carer arrangements are sustainable without additional support (5) Don't know

There are several items in the CENA that help to inform the judgement of assessors on this component but no single item was found to be a good proxy. This is not surprising. Sustainability is a complex and multi-faceted concept that involves the needs and feelings of both the carer and the care recipient as well as factors in the external environment. Given this, no individual item collected elsewhere in the assessment is adequate.

In summary, the recommended approach in the next version of the CENA is to:

- auto-populate the assessment of carer needs and risks as defined above,
- maintain the use of one item to assess CR needs and risks until such time as there is inter-operability between the CENA and the ACCNA and
- maintain the use of the single sustainability item.

Figure 39 shows the impact on the spread of sustainability scores if this approach is adopted. The overall spread is better than that achieved in the field trial, with about 10%-14% of carers allocated to each rating. There are fewer carers allocated to priority category 1 in the new model and more allocated to category 2. The other difference is that fewer carers are allocated to priority 10.

Our overall assessment is that the priority rating system was seen as useful and had face validity in the field and that this model represents an improvement on the model tested in the field trial. On that basis, it should be included in the next version of the CENA. In doing so, one technical issue to resolve is how to deal with missing data items. This is particularly the case because the items used to assign a priority rating are all optional.

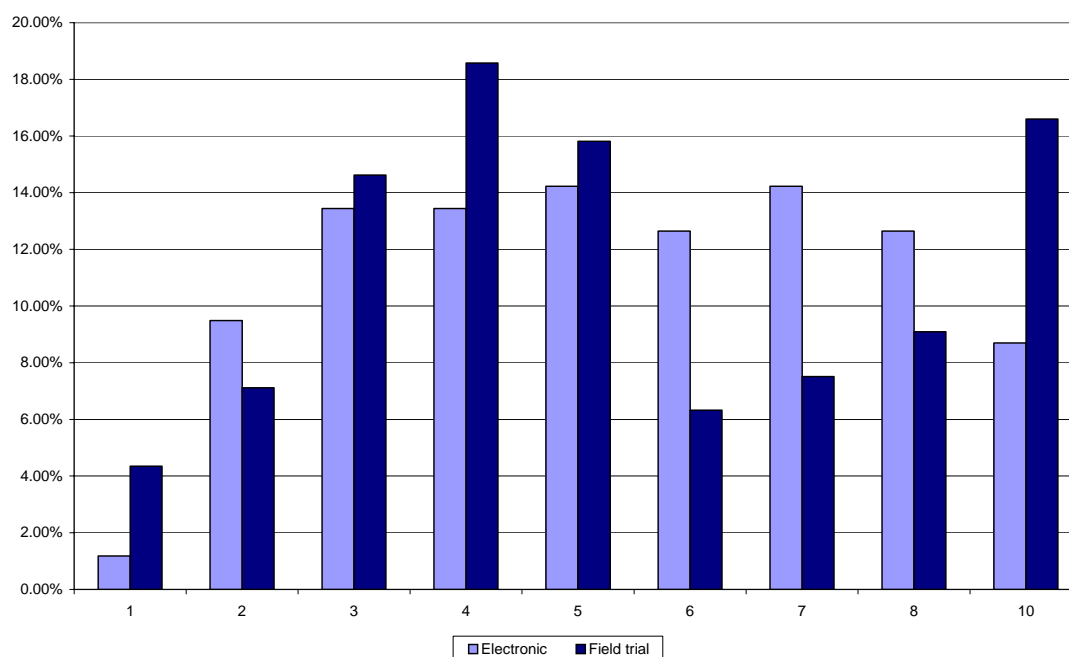
In the ACCNA trial it was assumed that a missing value indicated that a client did not have a problem. For example, if the psychosocial items were not completed it was assumed that the client had no psychosocial problems. This approach was not taken in the CENA field trial, with

only carers having all of the required items being included in the analysis. Whether the approach taken with the ACCNA is adopted will need to be determined.

It is important to note that, while the recommended model represents an improvement over that used in the field trial, there remains room for potential further improvement. How the priority rating system is used needs to be determined as a policy issue. In this regard, the way that the priority rating system in the Queensland ONI tool has been implemented is helpful. In that context, assessors can, with the agreement of their supervisor, override the priority rating if they have other information available to them that justifies overriding it. The priority rating is thus used to assist assessors to make decisions. It does not make the decision for them.

This same approach has merit in the implementation of the CENA. It would be further enhanced if the reasons for over-riding the priority rating could be recorded; as such information would (over time) provide a rich data source to improve the model further.

Figure 39 Comparison of priority rating scores in the field trial and with the auto-populated electronic model



5.5 Guidelines for Care Planning

An implication that follows from the reframing of the CENA into a support interview is that it would more explicitly be part of an intervention that is commonly used in the field for the purpose of 'assessment and care planning', allowing the data elements to be embedded in a care planning framework.

Guidelines for care planning using the CENA would include using something similar to a CCRC type module plus a template for service specific information which may need to be tailored to each specific service type. For example there may need to be an assessment of the home environment for service specific requirements, such as home modifications, and/or there may need to be an assessment of the potential for carer training and support to help in caring tasks such as lifting, mobility, and basic physiotherapy assistance, or in behaviour management.

A package of care may also include in its plan a component of top-up funding to purchase a time-limited placement for respite in a residential aged care facility. Consultations in the field included participants who were from agencies that delivered a range of services including respite programs, care packages and residential aged care. There were also agencies in the trial that included ACAT and CCRC roles involving booking and brokerage for the purchase of short term residential respite places.

The exchange of information between community and residential aged care is an obvious role for the CENA as a short term placement may require an ACAT approval but not necessarily require a full ACAT assessment. A short term care plan based on the CENA could be part of a sifting and sorting process (in either the ACAT or the CCRC or in a combined process and assessment record) that could offset the requirement for a full ACAT level assessment for some care recipients.

5.6 Continuous Development

If the CENA were to be rolled out in a way that was supported by a research and development culture and an explicit research strategy, then continuous refinements to the suggested modules could be coordinated and the lessons from a range of settings and trials could be shared to build a common approach. The effort would ideally be shared across the community (and residential aged care) sector and be driven by a common approach to data analyses.

This would offset the tendency for fragmented and inconsistent developments being driven more by individual agency preferences than by a common national agenda. Relatively rapid development would be possible if a more unified strategy were to be endorsed and supported, and after suitable arrangements were put in place to collect de-identified data in a central repository.

Alternatively, refinements could also be based on suitably controlled trials in particular regions where the results could be generalised and shared with the sector. The key idea is to avoid duplication of effort and a shared approach to service development.

5.7 Final Products Prior to a Roll Out

The final products of the work to date, if they are structured to recognise the diversity of starting points in the sector as a whole, and the diversity of roles and approaches within different agencies, will need to include electronic and paper versions, and possibly a form of hand held electronic device.

Depending on the response to the recommendations and the ability to position further work inside the wider agenda of *The Way Forward*, it may be necessary to commission further work to develop some of the higher priority CENA modules (as detailed in Section 4.3) for use in subsequent trials.

Regardless of decisions on further refinements of modules, in order to support a comprehensive roll-out strategy it will be necessary to complete preparatory work on the range of recommended final products:

- A stand alone version of the software
- Data specifications in a document for software developers
- Paper forms including possibly a self-report version
- A hand held application version
- A web based version

6 Principles for a phased roll-out

This Section of the Final Report emphasises the key ideas leading up to recommendations, including those addressing the design, training and roll-out of the CENA, and they are presented as a set of guiding principles.

The principles are organised under the headings of the CENA tool, its purpose, the culture change implications and practical concerns around role delineation.

This Section is based on explicit assumptions that the CENA will be able to have a process of implementation of its own and also usefully be able to contribute to a more integrated approach. An important caveat around these assumptions are that it may be unrealistic to be too prescriptive about the detail of what is to be done in subsequent steps and proposed trials that are outside the direct control of the carers' programs.

If the carer assessments can both stand alone, and be part of a shared wider system, then it becomes possible for the system as a whole (at marginal extra costs) to move beyond the basic purposes of assessment and reporting. The CENA experience shows agencies and carers themselves will be able to use the information collected to help them plan and (eventually) to evaluate their activities.

6.1 Key principles for the CENA

There are a number of key principles that the assessor should consider as they use these tools.

Principle 1: *The tools should be used to aid decision-making and standardise how the information is collected, recorded and shared*

The tools should be used to assist assessors in their decision making. Assessors need to make informed decisions about service provision based on all information available to them. With the carer's consent, an agency can share the collected information with other care providers to minimise the duplication of assessments.

Principle 2: *The tools are not diagnostic*

The tools may be completed by clinical and or non-clinical staff provided they have received adequate competency based training.

Principle 3: *Not all items or components will be relevant for every carer*

Some carers have complex needs and therefore require a broad and deep assessment followed by a package of services whilst other carers have less complex needs and may only require a shallow needs assessment followed by a basic service response (e.g., two hours of respite per month).

Therefore not all items will be relevant for all consumers and assessors should determine what type of assessment is suitable for each carer. It may also be the case that some assessors choose to conduct a shallow assessment but then add additional components later. The modular approach will help to guide assessors' decision making about the most appropriate depth and breadth of assessment.

In some cases a shallow assessment may function as a starting point and a care plan that has the potential to be built upon over time. In other cases completing all items in the CENA may be too much information, collected too soon, and the assessor may choose to complete the carer registration and contact details and only some of the core items.

The level of carer needs is not the only factor that determines the breadth of assessment being conducted. Agencies will differ in their capacity to conduct assessments. If the tools over-specify what data can potentially be collected, then agencies can adapt the use of the tools to their staff competencies and agency business practices.

Principle 4: *The tools are designed for use over the phone or face to face*

Currently, many carer assessments are conducted in the person's home. This time should be used to collect as much useful information as possible. To improve efficiency, demographic information (Carer Registration and Contact Details) and the core CENA may be collected at first point of contact, which is generally over the phone.

The second point of assessment may be an in-home visit or at periodic reassessment, when further components (depending on the agency's resources and local protocols) may be used. Some carers may receive one-off respite the first time they request a service, and then have no further contact until the next time they require assistance, at which point the face to face module may be completed, with the depth depending upon the carer's circumstances.

Principle 5: *The tools are designed for completion based on all sources of information available to the assessor*

This includes using active listening, observation, answers to questions, information contained in a referral letter, notes or information provided to the assessor by friends or relatives or the referring agency. The modules of the CENA should be capable of capturing additional sources of information as the opportunities arise.

Principle 6: *Do not ask carers about issues in the order that they are listed if they are inappropriate in the context.*

Assessors should keep in mind that some carers may be reluctant to respond honestly, particularly at the beginning of an episode of service provision. Many carers want to protect the dignity and self-image of the person that they care for, and experienced assessors are sensitive to this.

The assessor should make a judgement about the appropriateness of asking some items. For example it may be inappropriate to ask a carer about drug and alcohol usage if the carer is requesting a one off basic service over the phone (e.g. two hours of one-off respite) or alternatively is in a stressed or vulnerable emotional state.

Some scales require a structured approach such as the Functional Profile and the K10 Mental Health and Wellbeing Scale to ensure the ratings are reliable. That makes a conversational style more difficult to maintain, and experienced assessors will have ways of keeping a standardised question intact while asking it inside an ongoing conversation. Some carers may be able to complete self report versions of these components.

Principle 7: *Screen for all the carer's needs, not just those your agency can meet*

A key idea behind the development of national and common tools is that they help the carer and care recipient become part of a bigger service system beyond individual programs. This is so that information can be shared across agencies and sectors and so that carers don't have to repeat their stories and may be more easily referred to other agencies for appropriate services.

Principle 8: *Assessment responses need to be based on the carer's social and/or cultural context*

The assessor should ensure that the standardised ratings that are given to summarise the carer's situation, for example the Functional Profile questions, are based on the carer's and care recipient's own social and/or cultural context, not the assessor's own values and preferences.

Principle 9: *As assessors complete the assessment, they should consider whether the carer requires particular types of assessments and/or urgent services that cannot wait for a formal assessment process to be completed*

Carers should be informed about the range of service responses that are available to meet their needs without unrealistically raising expectations of a service response. This is not limited to the services provided by an assessor's own agency. The assessor should consider the wider range of services, supports and resources available in their regional setting. These include for-profit services, information services, financial entitlements or other alternative services, including how accessible they are likely to be for this carer.

If the relationship between the carer and care recipient has already broken down, emergency respite may be required. An emergency response should not be delayed by the completion of a formal assessment process.

Principle 10: *Assessment should be ongoing and progressive*

Assessment is not a one-off event but rather an ongoing process that will be built upon and expanded at different points in time, including at a point of periodic re-assessment. Assessors should encourage carers to see service provision as a contractual process where they progressively identify their own needs and discuss options that will meet their needs at different stages of the assessment process, including exit strategies at the right time. Contracts (even informal or implicit ones) have a beginning and also have an end.

6.2 Key principles behind collecting assessment information

The principles behind rolling out a more standardised approach have to be clearly stated and somewhat (but not entirely) new otherwise there will be little incentive in agency-level thinking to pay attention to the new information.

- Think broadly about carer (and care recipient) needs but do what is necessary for the right service response, and in doing so, try to look beyond a single agency view
- Collect more information than you might previously done at the first point of contact, but not for its own sake, and not because it is mandatory for the program(s)
- The purpose of collecting information at the entry point is to use it in a practical way— to organise a service response, to share the information and build up a continuous record to preserve what has been learned
- Core information is best thought of as the most commonly collected (and used) items.

6.3 Key principles about culture change

The community care and carer fields of practice, although having much in common, are not by any means uniform. They are highly variable in terms of care settings and regional differences, service types, programs, agency size and approaches to assessment.

The key strategic issue in the development of the CENA/CNA was that the new assessment system would have to be an improvement on current practice, not a lowest common denominator. To be acceptable it would have to add value to the assessment process in the community care sector. The project's national surveys and the systematic collection of tools in routine use showed that the field is already quite sophisticated, but not uniformly so, and that many useful, practical and consumer oriented approaches are already available, sometimes in very sophisticated and expensively developed electronic systems with multiple functions.

Feedback from the field was that Government efforts at reform (at all levels) were often perceived as poorly informed regarding the breadth and depth of experiences in the field, and 'The Way Forward' reform agenda had little to say about what had already been achieved and how the separate pieces of work being undertaken (intake assessment, basic services, packaged care,

comprehensive assessment, access points, the continuous record) could build the past field experience and how the new proposed systems could build on each other.

Requiring a measure of transparency about culture change at all levels (workers, agencies, programs and departments) would be an obvious positive approach to take. The field consultations showed this was an essential pre-condition to support being built up behind a 'new' approach to assessment in a context of more integrated service provision. So an approach to implementation that was cooperative and less reliant on reinforcing a 'compliance' culture would be essential to promote wide support.

The field trial showed that the culture change focus of the CENA roll-out can be potentially very positive rather than needlessly combative. If the approach were to start with the over-riding principle of all questions about reform being focussed by asking 'what works for the carer (and care recipient)?', rather than 'what will work for us (as the government, program manager, agency or as a community worker)?', then the aim of making an improvement on current practice, not a lowest common denominator, could well be achievable.

The CENA is not intended to form a 'minimum data set' in the sense that all items would be collected on all carers. The dominance of a program reporting mentality, rather than a client-centred assessment focus was the major fear in the field.

The training and the consultations emphasised that the CENA was 'too big' to be universally applied in a single format as not 'one size fits all'. The message from the field trial was consistent – the CENA needs to be, in essence, a smorgasbord of data items from which assessors can select to meet the individual needs of the carer.

And the message from the field was that promoting the CENA as an adaptation to existing systems, and not as an entirely 'new' system in itself, would take considerable and well-planned investments from within and outside the program.

To apply this message to the recommended design of the CENA and any strategy to roll out the approach in the community care sector implies a broader service development agenda organised around the idea of shared and complementary roles in community care assessment. And that implies a 'system' level of integration that really has to be beyond any one program if it is to be efficiently and effectively capable of being implemented. Integrating a common approach to assessment within one program, no matter how well planned, will only lead to further fragmentation across community care, if it is not planned along with the efforts in a range of other aged care and disability programs that share essentially the same broad population of people who require services.

6.4 Key principles about role delineation in assessment

The project and the field trial showed there is a clear way through many of the issues discussed above, where a common language of assessment, a common pool of standardised data elements, and agreed processes to share information can all come together.

An approach that focuses on better networking of agencies makes sense, where there is explicit agreement about different roles in assessment of carer needs, depending on the skills and competencies of the assessors and the purpose of assessment. This might be applied *between* agencies in a region where logically the starting point might be between CCRCs and providers. It could also be logically applied *within* agencies where not all assessors are at the same level of comfort and competence, and where different disciplines cooperate through an agreed approach based on formal role delineation.

At both levels (between and within agencies) the aim would be to recognise different levels of experience and skill and comfort with the different depth of investigation that is required to respond to the range of needs and expectations of carers.

The aim would not be to simply impose increasing uniformity over time. Rather, to acknowledge the reality of different starting points and allow for the continuing development and growth of competencies to take place at a pace appropriate to the purpose of assessment, the type of agency and the competencies of the individual assessor.

Role delineation in assessment has to also take into account the starting point of the carer and the nature of the service request. Some carers will be 'self navigating' and require only basic information and referral with minimal guidance, while others will require significant 'navigation support'.

It is recommended that, over time, a more formalised system for delineating the assessment role of each agency be established. An outline of different roles is shown below.

Level One – An agency that does its own service based assessment but does not use the CENA.

An example could be a small ethno-specific service with a part time coordinator who uses volunteers and operates a centre-based respite service and coordinates a relatively small number of service types, say food services and diversional therapy, or 'Holiday Explorers' where the client is primarily the care recipient.

A Level One agency would not use the CENA. Rather, they would have a formal link to a Level Three agency (see below) and would refer on to this agency for a CENA assessment as required.

Level Two – An agency that does its own CENA assessments. Level Two agencies would have defined competencies that are maintained by its staff.

An example might be a respite service provider with full time staff and a more complex mix of service types, say a HACC-funded respite service and a dementia carers' support program. They would both do their own service specific assessments and additional investigation of carers' needs as appropriate to the competencies of the staff and refer on for additional assessments beyond what is need for organising their service responses.

Level Three – An agency that does its own CENA assessments, as well as those referred from Level One agencies. These agencies would also be promoted as access points for new referrals.

Level Three agencies would have the 'full skill set' and could provide a 'train the trainer' role for other agencies.

An example of a Level Three agency might be one that has a mix of basic services (day programs, personal care and home maintenance) and packaged care (flexible options, CACP, EACH), as well as CCRC-type brokerage and booking roles, or carer counselling services.

7 CENA phased roll-out strategy

This section is more prescriptive and covers in more detail the important factors to consider for a staged roll-out, which is recommended to take place over three phases. The coordination of a phased roll-out with other stages or projects within the context of *The Way Forward* agenda would be ideal but may not be possible, given the complexity of timetables and the constraints and rigidities of other decision-making structures.

Some of the pre-conditions for a successful roll-out are described in the following points. They come from the consultations, surveys of current practice, conferences, information sessions and submissions, as well as the field testing experiences that were all part of the project:

- Wherever possible, build the next stages on the existing momentum and goodwill created by the research, consultation and field testing of the CENA
- In phase one, identify a small group of change leaders that can act as role models and assist with articulating and refining the culture change goals
- Build the culture change goals into the content of a training and implementation support strategy
- Jurisdictions should be encouraged to nominate their candidates for leadership roles and help to choose national demonstration sites in the proposed phase two
- The training implications and the proposed structures to support a *longer term* training strategy should be explored with the change leaders and in close consultation with demonstration sites – driving as much as possible from the bottom-up, with support and encouragement coming from the top-down.

It will be important to explicitly build on lessons from other jurisdictions where they have achieved the state-wide roll-out of new programs. In particular the Queensland Ongoing Needs Identification tools roll-out has documented its strategy and drawn out useful lessons, and carer-specific program work in Victoria has included the Victorian Carer Services Network which developed a carer assessment add-on to assist with the roll out of the second version of the Service Coordination Tool Templates.

7.1 Phase One

This would include *volunteers* from the Level One agencies in the CENA field trial, plus some invited agencies involved in the employed carers' projects, particularly those with a strong evaluation interest. It would also be strategically useful to invite others with a research interest such as agencies providing HACC respite services and a small number of residential respite providers in order to make use of a range of interest groups from a mix of service types with a diversity of systems in place. This would serve to demonstrate to the community care sector (and residential care) that there is potentially a wide applicability in the approach.

It will be useful to plan national demonstration sites with the jurisdictions based on a selection of agencies with good distributed networks of connections into local and regional systems, such that an individual agency will have the future capacity to provide training and support for their local networks.

Phase one should involve the refinement of the field tested CENA system into different versions (stand alone, web-based etc) and include the development of the priority CENA modules such as the crisis respite module and the CCRC phone module. The rationale for the strategy in this phase is:

- Focussing the initial effort would enable further practical work in the refinement of the layers and modules in order to make them attractive to a range of agencies in later phases

- A measure of tight control and systematic evaluation will provide an opportunity for further lessons to be learned and also for agencies within the demonstration sites to build up assessor competencies and specific expertise in the use of the CENA
- It will be more efficient to have a well-selected but small number of demonstration sites in phase one (rather than a wide selection of agencies in all jurisdictions) in order to focus the initial effort, draw out lessons in establishing a learning culture, and identify an initial group of 'champions' to use as role models in subsequent phases.
- The initial relatively narrow focus would provide the opportunity to test information sharing and role delineation in assessment between agencies, ideally as part of wider 'system' or access point trials under *The Way Forward*
- A small number of demonstrations could explore different assessment roles *within* agencies so as to show a flexible and developmental model and to not imply the roll-out will be an imposition of too much uniformity, especially early on in the phased implementation process.

7.2 Phase Two

Change leaders would be selected by all interested jurisdictions in order to build the CENA into regional referral systems (exploring wider interoperability issues) or other state-based trials. It may be possible to integrate the CENA into some stages of the electronic continuous community care record agenda and the proposed system-level or access point trials.

Phase two would continue to support the agencies participating in phase one and the development pathway may have progressed sufficiently to allow some useful comparisons between different models created within demonstration sites for the purposes of evaluation.

Depending on the quality of the data that is able to be collected and consolidated, and the structuring of evaluation activity within a common research and development framework, it would be possible to move some agencies in phase two in the direction of using their assessment information to measure outcomes for carers and make limited comparisons between interventions, agencies and models of carer support.

7.3 Phase Three

A common national approach would ideally be based on a culture that encourages the adoption of innovation that improves services and support to carers, rather than imposing uniformity for its own sake. The proposed research and development agenda should support this culture change by a focus on improving outcomes for carers. In turn, the national implementation will be made more robust and resistant to the natural tendencies towards fragmentation and inconsistency if it can be driven good quality research in support of service and sector development.

If a common and standardised approach is capable of being maintained, then phase three would result in the wider adoption of the CENA on a national basis with an emphasis on a more voluntary and research based culture and a developmental approach to improving routine assessment practice.

8 Training and support

It is recommended that the training model to be used should build on existing models that have evidence that they have proven to be effective. The implementation of the Queensland Ongoing Needs Identification Tool and the use of the Functional Independence Measure in the rehabilitation sector provide useful lessons about training and support for the field agencies. These are not competing systems to the CENA but are examples where there is evidence to support the practical value of the approaches that were used and where there are known to be some generalisable lessons. The examples in this section do not imply that either of these tools should be used for carers, but rather that their implementation has generated useful lessons for the development of a similar approach under the NRCP.

In consultation with agencies in the field trial, recommendations were made about the type of training and support that will be most useful:

- Further education of agencies in the sector as well as program managers is required on the distinct needs of carers and the importance of the role of carers in supporting the care recipient
- Training requirements will vary within and between agencies according to the type of service, years of experience and/ or the existing skill level of assessors
- Training and support should be ongoing and developmental, rather than being seen as a one-off training session - training sessions are necessary but not sufficient in themselves
- Other resources should be provided for enhancing the quality of ongoing support, i.e. research to find out what works best and for whom (via a training needs analysis), and this would provide direction to build the content and style of self-directed learning packages
- Given the nature of the community care sector, a training strategy needs to accommodate experienced assessors and 'entry-level' workers as a recognition of the rate of staff turnover
- It is important for the training strategy to acknowledge the importance of within-agency support to back up training sessions and other self-directed learning by models such as debriefing and mentoring.

As well as using comparable and effective training strategies, attention will also need to be given to assuring there is compatibility with the required competencies for community care assessment as delineated by the Industry Training Advisory Boards in each jurisdiction.

8.1 Development of competencies

One of the pre-requisites for a CENA roll-out included the development of necessary training modules and, if deemed appropriate, the development of national competency standards.

8.1.1 Definition of Unit of Competency

A competency standard is an industry-determined specification of performance which sets out the skills, knowledge and attitudes required to operate effectively in employment. Competency standards are made up of units of competency, which are themselves made up of elements of competency, together with performance criteria, a range of variables, and an evidence guide.

Competency standards are an endorsed component of a Training Package⁸. The National Training Information Service (NTIS) is the official national register of information on Training Packages, Qualifications, Courses, Units of Competency and Registered Training Organisations (RTOs) and has been developed for supporting experienced training sector users.

⁸ <http://www.ntis.gov.au/Default.aspx?glossary>

Carers Victoria developed a training program called “Orientation to Carer Friendly Practices”⁹. This training package includes elements of competency that address relevant areas of knowledge and skills for comprehensive carer need assessment. Each unit of competency is accompanied by training modules that are made available to students. They developed a framework of ‘carer needs for support’ and key principles for carer needs assessment.

These elements of competency provide a useful basis for determining gaps in existing practise for competencies related to carer needs assessment.

8.1.2 The roll-out of the Queensland ONI tool

The CENA Interim Report, Part 2 summarised key lessons from the Queensland ONI experience. One of these was the focus on building skills and competencies across programs at two levels: “State-wide Guidelines for implementing consumer screening using the Ongoing Needs Identification Tool in Queensland”¹⁰, and competencies specifically related to the ONI. The selling points were its emphasis on the ONI not being an expanded MDS, and how it was promoted as being broader than just one program (HACC and beyond), plus it could reduce reporting burdens.

The Queensland roll out also emphasised it did not have to replace existing skills and local system investments in protocols and training strategies, but could build on them. This process involved a number of key steps:

- Initial agreement was reached on the policy framework, the business case and the training strategy, with considerable flexibility to change as lessons were built up and as evaluation evidence was analysed
- Then there was agreement that was reinforced on the model of assessment and the aim of the culture change being from a perspective based on programs and the ‘service system’ to an explicit ‘client and carer’ focus
- A range of attractive training options was offered and there were regional roles created just for the purpose of effective and efficient implementation – it was not just an extra role added to busy people’s jobs
- Clear manuals on ‘How’ and ‘Why’ were written and were constantly revised and refined in response to field consultations and coordinated back through the regional trainers to a central support unit
- Self-directed learning packages (paper and CD) were refined and promoted
- Experts and local champions were not only linked through to a central support system, but were also linked to existing structures and they supported local referral processes.

8.1.3 Brief description of the FIM model

The Functional Independence Measure (FIM) is the set of core data elements that ensures a measure of standardisation of assessment is achieved for the Australasian Rehabilitation Outcomes Centre (AROC), which is a joint initiative of the Australian rehabilitation sector (providers, funders, regulators and consumers)¹⁰. Over 95% of rehabilitation services in Australia voluntarily collect this measure and use it to benchmark their services.

The FIM assessment training model is one that could be adapted for the community care sector. Training in the FIM includes a workshop prior to attempting a credentialing exam. The workshop provides education in how to score the FIM. The FIM Instrument is used to track patients from admission to discharge and follow-up. It assesses self-care, sphincter control, transfers, locomotion, communication and social cognition on a seven-level scale.

⁹ VBN 826 Orientation to Carer Friendly Practices, Student Resource Book. Carers Victoria, Australia, 2006.

¹⁰ For more detail see <http://www.uow.edu.au/commerce/aroc/training.html#facility#facility>

A person who attends the workshop will receive a FIM training attendance certificate and if they have passed the credentialing examination, a credentialing certificate.

The Facility Trainers workshop is designed to train participants how to teach the FIM to staff at their facility. In order to attend the Facility Trainers workshop, a candidate must have satisfied all pre-requisites. A certificate is issued after this workshop

There are two trainer levels - Master Trainers and Facility Trainers. Master trainers are contracted to AROC and train outside their facility for payment. Master trainers train in all facilities (public and private) and they conduct both the FIM workshops for clinicians and the Facility trainers' workshops. Master trainers have in-depth experience with the FIM and training expertise. Facility trainers train staff within their facility, as part of their job description and in their normal paid time (i.e. not as an independent contractor).

While this model would need to be modified to make it appropriate for the community care sector, it has the strong advantage of ensuring that the assessment data collected are of a uniformly high standard. Further, as part of the training, assessors are taught not only how to collect the information but also how to use it.

9 Recommendations

Recommendation 1. Change of name to the Carer Needs Assessment

The CENA should be renamed as the Carer Needs Assessment (CNA) to highlight its usefulness as an intervention in its own right for the purpose of care planning as well as information gathering. The change of name is a way to reflect this potential broader role and to emphasise that the CENA was a field test version in order to start a continuous improvement process. Having the concept of 'eligibility' in the name reflects a single program view. Eligibility is just one initial point in a much longer process and the term implies a gate keeping rather than a supportive approach.

Recommendation 2. Clear Principles

An implementation strategy for the Carer Needs Assessment should be based on a set of key principles derived from the lessons learned in the background research, consultation surveys, design and field testing of the CENA.

Recommendation 3. A Phased Roll-Out

The implementation strategy should be carried out over three phases in the context of a research and development strategy to support the national roll-out. The first phase should use volunteer agencies from the field testing and employed carers projects, the second phase should involve additional agencies nominated by Jurisdictions and the third phase should be the national roll-out.

Recommendation 4. Link between the ACCNA and CENA

The inter-relationship between the Australian Community Care Needs Assessment and the CENA is the first basic step to be taken in achieving a system where data collection does not have to be duplicated. It is not just a question of reducing the burdens on assessors and providers. Helping the carer to be as healthy as possible sustains the care recipient and promotes a prevention focus.

Recommendation 5. Training and Support

Implementation should pay attention to the larger change management agenda, use a research and development strategy and a centrally organised network of trainers, and use attractive training materials based on principles of adult learning.

Recommendation 6. Credentialing

The implementation strategy should develop a credentialing framework within an agreed set of competencies over the three phases of the roll-out and in the context of a research and development strategy. The development of an agreed set of competencies will help to overcome barriers such as distrust of another agency's assessment information. Standardised training and credentialing will help to foster confidence about the quality of carer assessment between agencies.

Recommendation 7. Role delineation in assessment

Individual assessors and agencies need to recognise their role in assessment as being an active part of a bigger system. This requires agreement on the roles of different agencies and the technical and cultural capacity to share information between agencies.

Recommendation 8. Research dissemination

One of the outcomes from the field trial was a wealth of information from routine assessment practice that had not been collected on such a scale before. Once a degree of standardisation is achieved, many useful comparisons can be made. Timely disseminating of research findings to

participating agencies is a practical way to demonstrate the valuable insights to be gained from turning routine data into useful information.

Recommendation 9. Connection with residential respite

As an extension of the inter-relationship between the NRCP and other programs, there is a useful role for the CENA in sharing information with providers of residential respite. This issue arose in feedback from some level one agencies, in the information sessions and some submissions from respite providers.

Aged Care Assessment Teams and Carer Respite Centres book respite admissions in residential aged care facilities and do not always require a comprehensive assessment of the care recipient. But they do need a short term care plan. The CENA is well suited to this purpose. CCRCs will broker services and use top-up funding to purchase short-term places in residential care, and again the CENA in its proposed modular form could be a useful adjunct to these functions.

Information exchange between community support services and residential aged care will become a practical issue in the near future as a result of the review of Australian government subsidies and services.

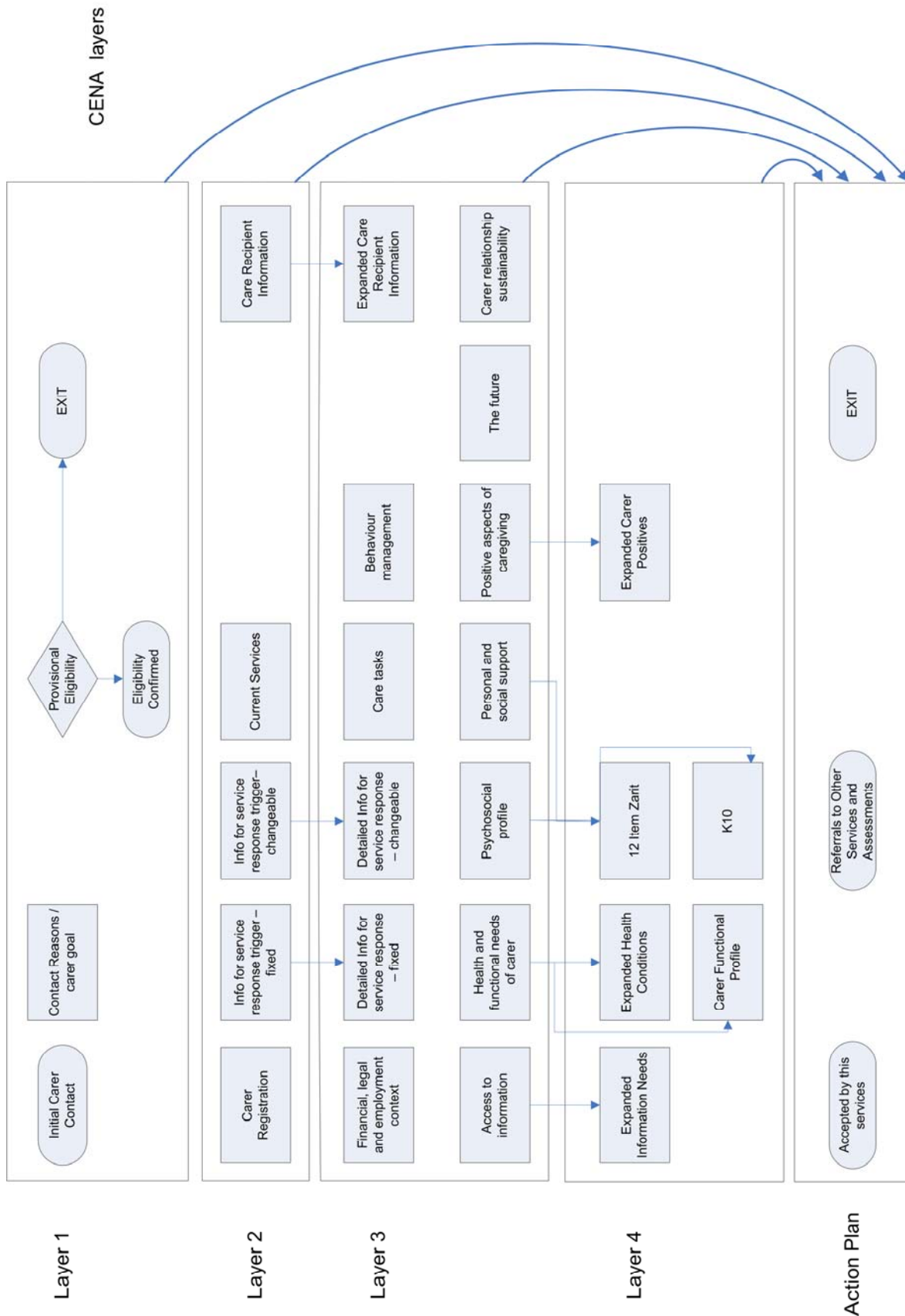
As part of the field testing, a number of NRCP funded agencies have indicated their willingness to be involved in further testing of the CENA in a 'system' context, and the opportunity to test this level of inter-relationship should be build into planning the next steps.

Recommendation 10. Towards the measurement and analysis of the outcomes of interventions

When used for both assessment and re-assessment, the CENA captured needs, risks and relationship factors that change over time. That is the basis for a continuous record that, in turn, is a pre-condition for measuring the outcomes for carers (and care recipients). Over time, and with good quality data and sensible analysis, it provides useful information about the effectiveness of the interventions that were put in place. The recommended phased roll-out of version 2 of the CENA gives the program an opportunity to move in that direction in a logical and planned way.

Attachment 1

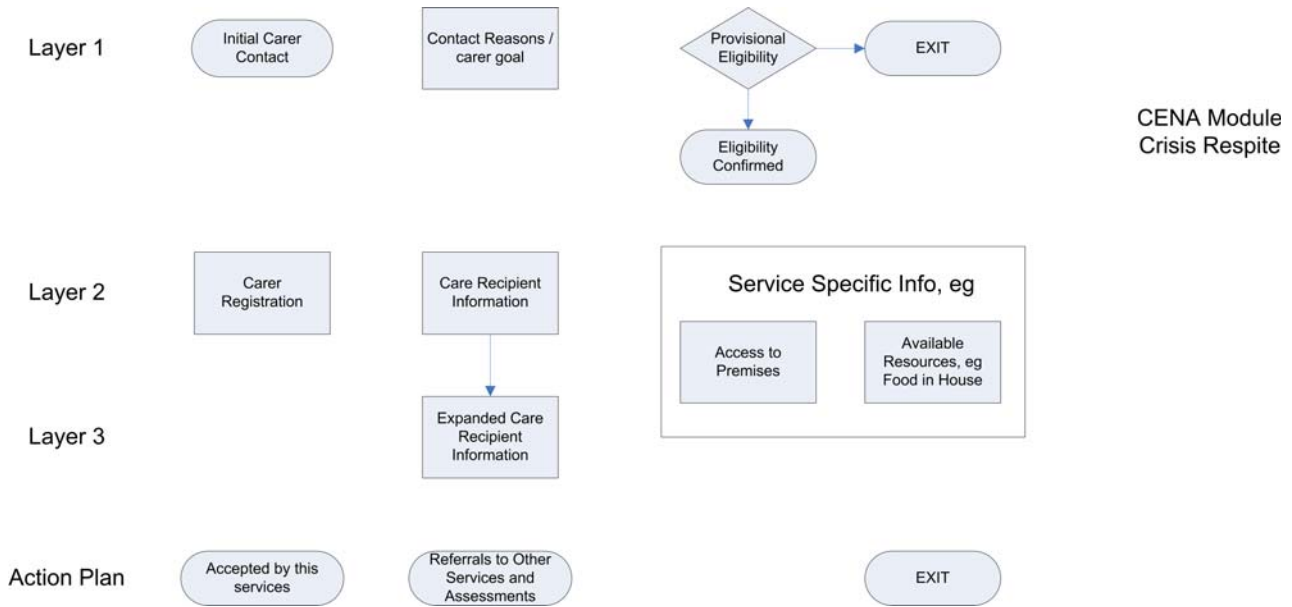
The CENA model as recommended following feedback from the Reference Group



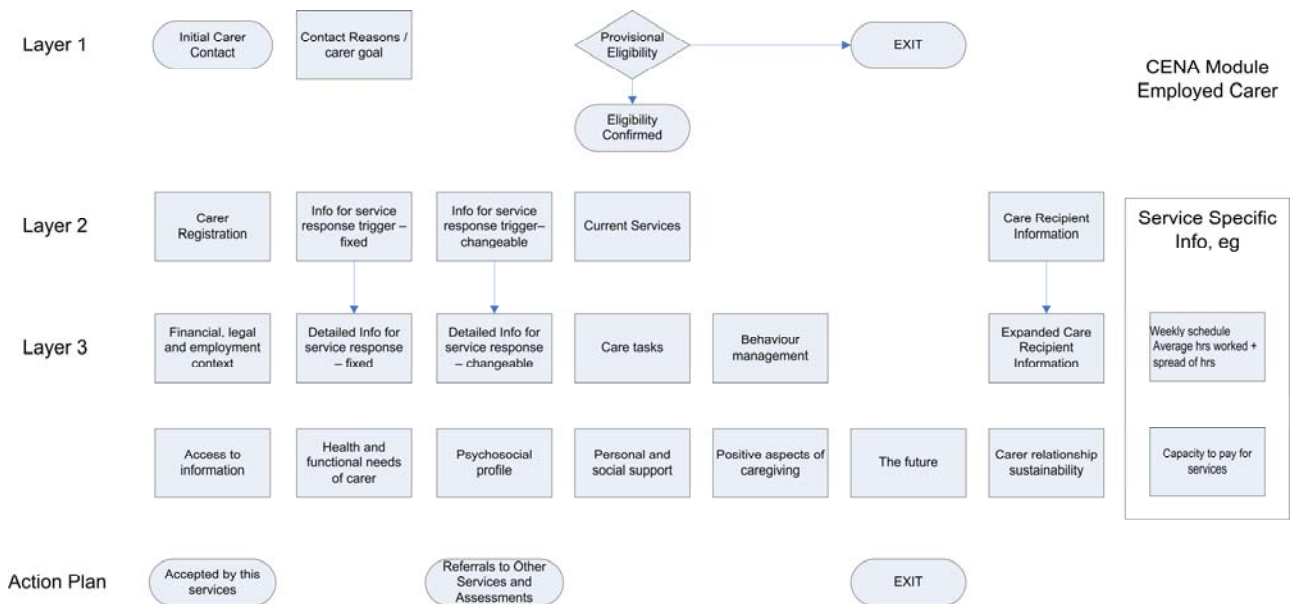
Attachment 2

Crisis Respite and Employed Carer Modules

Crisis respite module

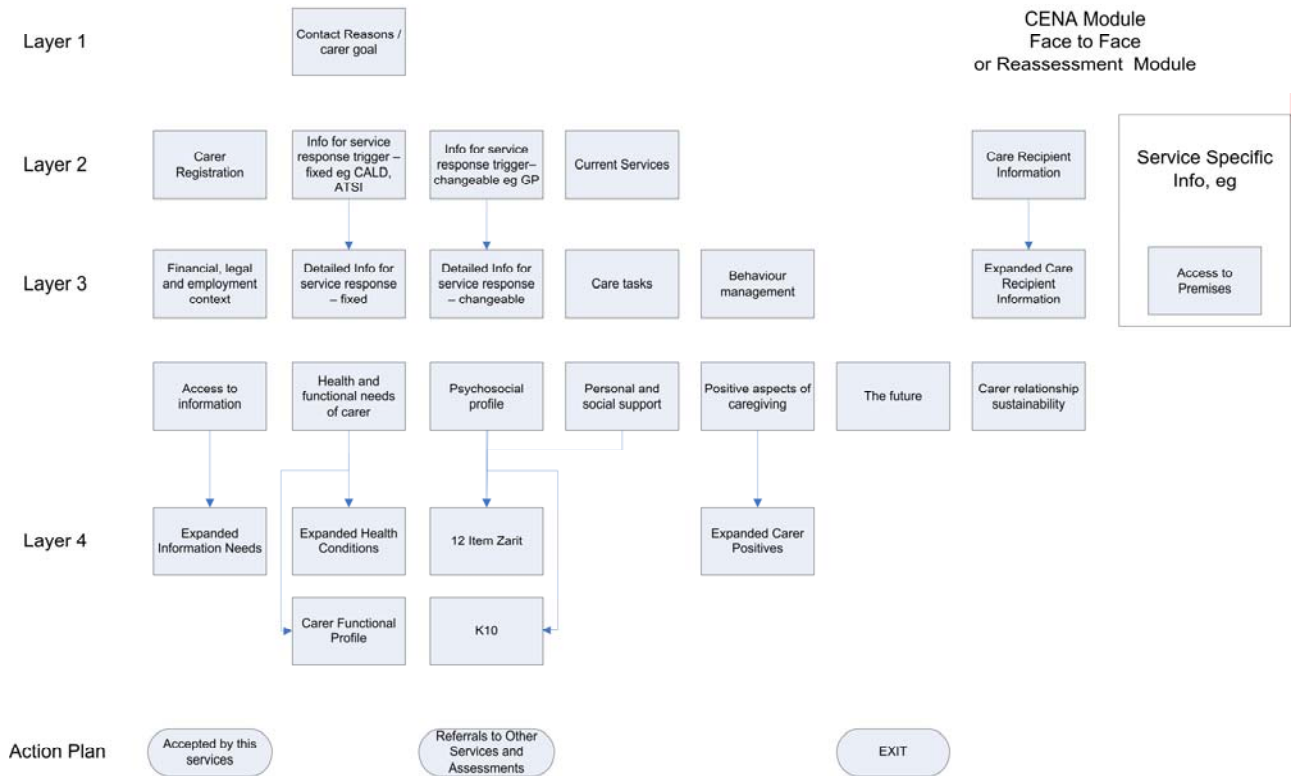


Employed carer module



Attachment 3

In Home/ Reassessment/ Face to Face Module



Attachment 4

Recommended CENA Data Elements

This table shows:

- the Layer of each Domain,
- whether Assessor Judgement (AJ) is required to decide whether to ask the question
- the type of information in the response
- whether the element is an assessment item (AAS), or is information relevant for service response (ISR)
- whether the element is recommended for the ACCNA

Table 31 Data elements in the CENA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
1 Initial Client Contact				
Assessment Purpose		Initial Re-assessment	ASS	
Contact date		date	ISR	
Carer First name		Text	ISR	ACCNA
Carer Family name		Text	ISR	ACCNA
Referral Source		Self Family, significant other, friend GP/medical practitioner – community based Specialist aged or disability assessment team/service (eg ACAT) Comprehensive HACC assessment authority Community nursing service Acute care hospital Psychiatric/mental health service or facility Extended care/rehabilitation facility Palliative care facility/hospice Government residential aged care facility (nursing home or aged care hostel) Aboriginal health service Commonwealth Carelink centre Other community-based government medical/health service Other government medical health service Other government community-based services agency Hospital (private) Non government residential aged care facility Other non-government medical/ health service	ISR	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Other non-government community-based service Law enforcement agency Carer respite/resource centre Other		
Referrer First Name		Text	ISR	
Referrer Second Name		Text	ISR	
Organisation		Text	ISR	
Postal Address		Text	ISR	
Telephone		Text	ISR	
Fax		Text	ISR	
Email address		Text	ISR	
Referral Consent		Yes No	ISR	
Comments	AJ	Text	ISR	
1 Contact Reasons				
Why has Carer contacted this service?		Text	ASS	
Record services requested?		Day care -centre based Daytime respite - in-home Overnight respite - in-home Community access – individual Community access – group Host family – day Host family – overnight Overnight community respite houses Overnight –other Liaison/ advice/ support/counselling Information provision (written/ spoken) Education/ training Direct respite care Assessment Case management/ coordination domestic Social support Nursing care Allied health care Personal care Centre based day care meals Other food services Provision of goods and equipment (specialised) Home maintenance Home modification Provision of goods and equipment (generic)	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Formal linen service Transport Other (specify) - including employment support, primary or acute health care, or rehab.		
What were the key circumstances triggering contact	AJ	Carer – emotional stress & strain Carer – acute physical exhaustion/ illness Carer – slow physical health deterioration Carer – factors unrelated to care situation Carer – maintain regular activities Carer – employment issue Carer – return to work/study Care Recipient – increasing needs Care Recipient – other factors One-off event	ASS	
Comments	AJ	Text	ASS	
What is Carer DOB?		date	ASS	
What is Carer age?		Text or Autocalc from DOB	ASS	
What does Carer expect the outcome to be?		Text	ASS	
Comments	AJ	Text	ASS	
1 Provisional Eligibility				
Has carer been caring, or is likely to be caring, for more than 6 months?		Yes No	ISR	
Number Of Care Recipients		Carer of one person Carer of two people Carer of three people Carer of more than three people Not stated/inadequately described	ASS	
Comments	AJ	Text	ISR	
2 Carer Registration				
Preferred Name		Text	ISR	
Sex		Text	ISR	
Date of Birth Estimate Flag	AJ	Yes No	ISR	
Type of Address		Text	ISR	
Street number		Text	ISR	
Street name		Text	ISR	
Suburb/locality		Text	ISR	
State		Text	ISR	
Phone type		Text	ISR	
Phone number		Text	ISR	
Preferred phone flag		Yes No	ISR	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
Message flag		Yes No	ISR	
Email		Text	ISR	
2 Info for Service Response Trigger - Fixed				
Carer Born in Australia		Yes No	ISR	
If Yes, ATSI status		Aboriginal but not Torres Strait Islander origin Torres Strait Islander but not Aboriginal origin Both Aboriginal and Torres Strait Islander origin Not indigenous	ISR	
If No to Australia as COB, what is country of birth		The Australian Bureau of Statistics Standard Australian Classification of Countries (SACC) ABS catalogue No 1269.0 1998	ISR	
If Yes to Australia as COB, does Carer have CALD background		Yes No	ISR	
2 Info for Service Response Trigger - Variable				
Does Carer receive an Australian Govt Pension/Benefit?		Yes No	ISR	ACCNA
Are there other people that the agency can contact?		Advocate Case Manager Emergency Contact Friend GP Guardian Next of kin Relative	ISR	
Comments	AJ	Text	ISR	
2 Current Services				
Is Carer currently receiving services?		Yes No Unsure	ASS	
What is the Carer's current use of formal services		Is receiving one or more formal services that are primarily focussed on meeting the needs of the carer Is receiving one or more formal services that are primarily focussed on meeting the needs of the care recipient Is receiving a 'package' of formal services which is primarily focussed on meeting the carer's needs Is using a 'package' of formal services which is primarily focussed on meeting the care recipient's needs Is not receiving and has not received services that are focussed on either meeting the needs of the carer or the care recipient	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Not stated or inadequately described		
Type of formal assistance		Text	ASS	
From which agency?		Text	ASS	
How many hours per week		number	ASS	
Comments	AJ	Text	ASS	
Are there other people who provide care? (e.g. network of carers, shared caring arrangements)		Yes No Not sure	ASS	ACCNA
Type of informal assistance		Text	ASS	ACCNA
From whom (eg family, friends)?		Wife/female partner Husband/male partner Mother Father Daughter Son Daughter-in-law Son-in-law Other relative – female Other relative – male Friend/neighbour – female Friend/neighbour – male No informal support Not stated/inadequately described	ASS	ACCNA
How many hours per week		number	ASS	ACCNA
Comments	AJ	Text	ASS	ACCNA
2 Care Recipient Information				
CR First name			ISR	ACCNA
CR Family name			ISR	ACCNA
What is CR DOB		date	ASS	ACCNA
What is CR age		Text or Autocalc from DOB	ASS	ACCNA
Relationship of Carer to CR		Wife/female partner Husband/male partner Mother Father Daughter Son Daughter-in-law Son-in-law Other relative – female Other relative – male Friend/neighbour – female Friend/neighbour – male	ASS	ACCNA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
Co-Residency Of Carer		Co-resident carer Non-resident carer Not stated/inadequately described	ASS	ACCNA
Carer Role		Primary carer Other carer Not stated/inadequately described	ASS	ACCNA
When did Carer start caring for this CR		date	ASS	
Comments	AJ	Text	ASS	
3 Expanded Care Recipient Information				
Preferred Name		Text	ISR	ACCNA
Sex		Text	ISR	ACCNA
Date of Birth Estimate Flag	AJ	Yes No	ISR	ACCNA
Type of Address		Text	ISR	ACCNA
Street number		Text	ISR	ACCNA
Street name		Text	ISR	ACCNA
Suburb/locality		Text	ISR	ACCNA
State		Text	ISR	ACCNA
Phone type		Text	ISR	ACCNA
Phone number		Text	ISR	ACCNA
Preferred phone flag		Yes No	ISR	ACCNA
Message flag		Yes No	ISR	ACCNA
Email		Text	ISR	ACCNA
Is CR Currently receiving services		Yes No Unsure	ASS	ACCNA
Agency		Text	ASS	ACCNA
Service type		Alternate Therapists Aged Care Alcohol and drug Community health Counselling Dental care Disability Emergency accommodation Family planning Home care Hospital inpatient Hospital outpatient Hospital emergency	ASS	ACCNA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Maternal and child health Medical (GP) Medical (specialist) Men's health Mental health Palliative care Rehabilitation Residential Aged Care Respite care Self help groups Sexual health Women's health Youth services.		
Service Description		Text	ASS	ACCNA
Are there other people who provide care? (e.g. network of carers, shared caring arrangements)		Yes No Not sure	ASS	
Type of assistance		Text	ASS	
Who from (eg family, friends)		Text	ASS	
How often (hrs/week)		number	ASS	
Comments		Text	ASS	
Care Recipient's Primary Disability		Developmental delay Intellectual (including Down's syndrome) Specific learning (including Attention Deficit Disorder) Autism (including Asperger's syndrome) Physical Acquired brain injury Deaf blind (dual sensory) Vision Hearing Speech Psychiatric Neurological Other Not stated/inadequately described	ASS	ACCNA
Care Recipient's Primary Care Needs		Specific primary health care needs Acute health care needs Palliative care needs Rehabilitation needs Needs for ongoing management of chronic conditions Extended (long-stay in special-purpose facility) health care needs	ASS	ACCNA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Geriatric evaluation and management needs Maintenance care needs Other and unspecified needs Not stated/inadequately specified		
Medical diagnosis of dementia		Yes No	ASS	ACCNA
Care Recipient's Level Of Need		High (no additional factors) High (plus additional factors) Moderate (no additional factors) Moderate (plus additional factors) Low (no additional factors) Low (plus additional factors) Not stated/inadequately described	ASS	ACCNA
Challenging Behaviour		High level of support required for behaviour Medium level of support required for behaviour Low level of support required for behaviour No support required for behaviour No challenging behaviour Not stated/inadequately described	ASS	ACCNA
CR Born in Australia		Yes No	ISR	ACCNA
If Yes, ATSI status		Aboriginal but not Torres Strait Islander origin Torres Strait Islander but not Aboriginal origin Both Aboriginal and Torres Strait Islander origin Not indigenous	ISR	ACCNA
If No to Australia as COB, what is country of birth		The Australian Bureau of Statistics Standard Australian Classification of Countries (SACC) ABS catalogue No 1269.0 1998	ISR	ACCNA
If Yes to Australia as COB, does CR have CALD background		Yes No	ISR	ACCNA
If CR born overseas What is migration status		Citizen/Permanent resident Business & Skilled Migrants Temporary Protection Visa General Sponsorship Proposed Entrant Humanitarian Refugee	ISR	ACCNA
or has CALD background, what is CR's ethnicity		text	ISR	ACCNA
If ATSI, what is skin name		text	ISR	ACCNA
Main language spoken at home		Australian Bureau of Statistics adaptation of the Australian Standard Classification of Languages Catalogue No. 1267.0 1997	ISR	ACCNA
Interpreter required		Yes No	ISR	ACCNA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
Preferred sex of interpreter		No preference Male Female	ISR	ACCNA
Preferred language (if not spoken English)		Australian Bureau of Statistics adaptation of the Australian Standard Classification of Languages Catalogue No. 1267.0 1997	ISR	ACCNA
Comments	AJ	text	ISR	ACCNA
Does CR receive an Australian Govt Pension/Benefit?		Yes No	ISR	ACCNA
Australian Government Pensioner/Benefit Status		Aged Pension Veterans' Affairs Pension (complete details below) Disability Support Pension Carer Payment (pension) Unemployment related benefits Other govt pension or benefit	ISR	ACCNA
Other government pension or benefit, specify		Text	ISR	ACCNA
Health Care Card Number		Text	ISR	ACCNA
DVA Card Status		No DVA Card Yes – Gold Card Yes – White Card Yes - Other DVA Card	ISR	ACCNA
If other DVA card, specify		Text	ISR	ACCNA
Are there other people that the agency can contact?		Advocate Carer Case Manager Emergency Contact Friend GP Guardian Next of kin Relative	ISR	ACCNA
Is there any evidence of previous difficulties between the CR and health and community service providers?	AJ	Yes No	ISR	ACCNA
Is the CR receiving medication?		Yes No	ASS	ACCNA
Does the CR generally look after and take their medication without reminding		Reliable with medication Slightly unreliable Moderately unreliable Extremely unreliable	ASS	ACCNA
Webster Pack or similar used for medicine?		Yes No	ASS	ACCNA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
What is the schedule for medication?		Text	ASS	ACCNA
Does the Mental Health Act affect CR?		Yes No Not sure	ASS	ACCNA
Comments	AJ	Text	ASS	ACCNA
Are there any other relevant legal issues	AJ	Yes No	ASS	ACCNA
Details	AJ	Text	ASS	ACCNA
How important is it for carer that CR be cared for at home?		Very Important Somewhat Important Not at all Important Don't know	ASS	
Does carer have any concerns for the future?			ASS	
3 Detailed Info for service response – fixed				
If Carer was born overseas What is migration status		Citizen/Permanent resident Business & Skilled Migrants Temporary Protection Visa General Sponsorship Proposed Entrant Humanitarian Refugee	ISR	
or has CALD background, what is CR's ethnicity		Text	ISR	
If ATSI, what is skin name		Text	ISR	
Main language spoken at home		Australian Bureau of Statistics adaptation of the Australian Standard Classification of Languages Catalogue No. 1267.0 1997	ISR	
Interpreter required		Yes No	ISR	
Preferred sex of interpreter		No preference Male Female	ISR	
Preferred language (if not spoken English)		Australian Bureau of Statistics adaptation of the Australian Standard Classification of Languages Catalogue No. 1267.0 1997	ISR	
Comments	AJ	Text	ISR	
3 Detailed Info for service response – changeable				
Australian Government Pensioner/Benefit Status		Aged Pension Veterans' Affairs Pension (complete details below) Disability Support Pension Carer Payment (pension) Unemployment related benefits Other govt pension or benefit	ISR	ACCNA

Data element	AJ	Response Information	ASS or ISR	ACCNA item
other government pension or benefit, specify		Text	ISR	ACCNA
Health Care Card Number		Text	ISR	ACCNA
DVA Card Status		No DVA Card Yes – Gold Card Yes – White Card Yes - Other DVA Card	ISR	ACCNA
If other DVA card, specify		Text	ISR	ACCNA
Other contacts -type		Advocate Carer Case manager Emergency Contact Friend GP Guardian Next of kin Relative	ISR	ACCNA
Title		Text	ISR	ACCNA
Surname or Family Name		Text	ISR	ACCNA
Given Names		Text	ISR	ACCNA
Organisation		Text	ISR	ACCNA
Address		Text	ISR	ACCNA
Suburb/Town/Locality		Text	ISR	ACCNA
Postcode		Text	ISR	ACCNA
State/Territory		Text	ISR	ACCNA
Phone		Text	ISR	ACCNA
Mobile		Text	ISR	ACCNA
Fax		Text	ISR	ACCNA
E-mail		Text	ISR	ACCNA
Comments	AJ	Text	ISR	ACCNA
3 Financial, Legal and Employment Context				
Paid Employment Participation		Full time Part time Casual Seasonal Not in paid employment Not stated/inadequately described	ASS	
Has providing care for CR put a financial strain on carer?		Yes No Don't know	ASS	
If 'yes', consider cost of living decisions (optional question below).		Yes No Not sure	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
<p>Assessor: Because of limited income, has the carer during the last month made any trade-offs among purchasing any of the following:</p> <p>Prescribed medications; necessary medical care; adequate food; necessary home care for the care recipient; necessary transport?</p> <p>If 'yes', discuss issues with carer and consider need for counselling (e.g. financial, gambling, drug or alcohol) and need for material support.</p>				
Did care-giving responsibilities cause carer to leave work or retire early?		Yes No Not applicable	ASS	
Has providing care for CR interfered with carer's job or study?		Yes No Not applicable	ASS	
3 Access to Information				
Has carer been given information about available support services and financial entitlements?		Yes No Not sure	ASS	ACCNA
In addition to the kinds of amounts of information that carer already has, what additional or new kinds of information would be valuable to carer as a caregiver?		Comments	ASS	
Does Carer need practical training in lifting, managing medicine or other tasks?		Yes No Not sure	ASS	ACCNA
3 Care tasks				
In a typical 24-hour day, how many hours does carer provide help, care, or supervision for CR in person?		Number	ASS	
Comments		Text	ASS	
3 Behaviour Management				
In a typical 24-hour day, please estimate how much time carer has spent managing behaviour problems of CR? Please consider the following as examples of behavioural problems: keeping a person who is wandering or pacing under		Number	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
constant supervision in order to ensure they do not get lost or injure themselves supervision of a person who is restless or agitated giving emotional support to a person who is fearful and anxious intervening with a person who disturbs other people by being noisy, or being physically or verbally aggressive				
3 Health and functional needs of the carer				
Carer estimate of own health is?		Excellent Very Good Good Fair Poor	ASS	
How much did carer's health interfere with carer's normal activities (outside and/or inside the home) during the past four weeks?		Not at all Slightly Moderately Quite a bit	ASS	
Has carer had any difficulty sleeping?		Yes No	ASS	
Comments	AJ	Text	ASS	
3 Psychosocial Profile				
Does carer face any challenges in care-giving role?		Yes No	ASS	
What would carer say is the greatest challenge carer has faced in care-giving?		affected their financial situation affected their time for themselves affected their family affected their work affected their health Other Specify No Difficulties	ASS	
Comments	AJ		ASS	
Has caring for CR caused strain and/or friction in carer's relationships with CR or close family members?		No obvious problem Slight problems Moderate problems Extreme problems	ASS	
If problems, specify:		Other family members Care recipient	ASS	
Zarit Carer Screen (Australian Modified)	AJ	Scores are 1) Never (2) Rarely	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
Do you feel that because of the time you spend with CR that you don't have enough time for yourself?		(3) Sometimes (4) Quite frequently (5) Nearly always		
Do you feel stressed between caring for CR and trying to meet other responsibilities for your family or work?			ASS	
Do you feel strained when you are around CR?			ASS	
Do you feel uncertain about what to do about CR?			ASS	
Subtotal Assessor: If total score is 5 or more, consider completing full 22 item Zarit (page 17).		Total	ASS	
Comments	AJ		ASS	
3 Personal and Social Support				
During the past 4 weeks, was someone available to help carer if they needed and wanted help? For example, if carer ... Felt very nervous, lonely or blue Got sick and had to stay in bed Needed someone to talk to Needed help with daily chores Needed help just taking care of themself		No, not at all Yes, a little Yes, some Yes, a quite a bit Yes, as much as I wanted	ASS	ACCNA
Comments				AJ
3 Positive aspects of care-giving				
In carer's experience as a carer, what would carer say are the most positive aspects of care-giving?		Helping CR Helping carer's other family members Feeling a sense of accomplishment Caring for someone who cared for them Being appreciated Other (e.g. enhancing self-esteem, provides meaning, satisfaction) None Don't know	ASS	
Comments			ASS	
3 The Future				
Does carer have any concerns for the future?		Yes No Don't know	ASS	
Comments			ASS	
Is carer able to identify any goals that they would like to		Yes	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
achieve in the near future?		No Don't know		
Comments			ASS	
What if anything, might place carer's situation at risk of breakdown?		Carer – emotional stress and strain Carer – acute physical exhaustion or illness Carer – slow physical health deterioration Carer – factors unrelated to care situation CR – increasing needs CR – other factors response to assess both	ASS	ACCNA
Comments on risk or urgency			ASS	
What type of support would make the biggest difference for the future?			ASS	
For who – carer or CR?			ASS	
Who from (eg. agency, family, friends)?			ASS	
How often (hrs/wk)?			ASS	
3 Carer relationship sustainability				
Assessor, taking into account all information available to you, record a score for each of the following:				
Is the carer relationship sustainable without additional services or support?	AJ	(1) No - carer relationship likely to break down within weeks to months (2) No - carer relationship likely to break down within the next year (4) Yes - carer relationship is sustainable without additional support	ASS	ACCNA
Carer needs and risks	AJ	High = 1 Medium = 2 Low = 4	ASS	
Care recipient needs	AJ	High = 1 Medium = 2 Low = 4	ASS	
Priority rating		(Total score minus 2)		
Comments	AJ	text	ASS	ACCNA
4 Carer Functional Profile (complete only if health interferes with daily living)				
Can carer do housework...		Without help (can clean floors etc)? With some help (can do light housework but need help with heavy housework)? Or is carer completely unable to do housework?	ASS	
Can carer get to places out of walking distance...		Without help (can drive own car, or travel alone on buses or taxis)? With some help (need someone to help carer or go with them when travelling)? Or is carer completely unable to travel unless	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		emergency arrangements are made for a specialised vehicle like an ambulance?		
Can carer go out for shopping for groceries or clothes (assuming carer has transportation)...		Without help (taking care of all shopping needs themselves)? With some help (need someone to go with carer on all shopping trips)? Or is carer completely unable to do any shopping?	ASS	
Can carer take their own medicine...		Without help (in the right doses at the right time)? With some help (able to take medication if someone prepares it for carer and/or reminds them to take it)? Or is carer completely unable to take their own medicines?	ASS	
If not without help, is reason		Physical Cognitive	ASS	
Can carer handle their own money...		Without help (write cheques, pay bills etc)? With some help (manage day-to-day buying but need help with managing their chequebook and paying their bills)? Or is carer completely unable to handle money?	ASS	
If not without help, is reason		Physical Cognitive	ASS	
Do not ask the following 2 questions if the carer scored 3 on all of the above 5 items (ie, can do all 5 activities without help). Can carer walk...		Without help (except for a cane or similar)? With some help from a person or with the use of a walker, or crutches etc Or is carer completely unable to walk?	ASS	
Can carer take a bath or shower...		Without help? With some help (eg, need help getting into or out of the bath)? Or is carer completely unable to bathe themselves?	ASS	
These 7 questions are qualified by if carer has difficulty, who helps carer		No-one, Service Provider Other	ASS	
and To what extent is this need met		N/A - no need Fully met; Partially met Completely unmet	ASS	
Does the Carer have any memory problems or get confused?		Yes No	ASS	
Does the Carer have behavioural problems (eg aggression, wandering or agitation)		Yes No	ASS	
Total		Total		

Data element	AJ	Response Information	ASS or ISR	ACCNA item
Comments	AJ	Text	ASS	
4 Australian modified 12 item Zarit Carer Interview				
(responses to these questions are)	AJ	0 = Never 1 = Rarely 2 = Sometimes 3 = Quite frequently 4 = Nearly always		
Do you feel that because of the time you spend with CR that you don't have enough time for yourself?			ASS	
Do you feel stressed between caring for CR and trying to meet other responsibilities for your family or work?			ASS	
Do you feel angry when you are around CR?			ASS	
Do you feel that CR currently affects your relationship with other family members or friends in a negative way?			ASS	
Do you feel strained when you are around CR?			ASS	
Do you feel your health has suffered because of your involvement with CR?			ASS	
Do you feel that you don't have as much privacy as you would like because of CR?			ASS	
Do you feel that your social life has suffered because you are caring for CR?			ASS	
Do you feel you have lost control of your life since you began caring for CR?			ASS	
Do you feel uncertain about what to do about CR?			ASS	
Do you feel you should be doing more for CR?			ASS	
Do you feel you could do a better job in caring for CR?			ASS	
Overall level of stress: Total 0-20 = Little/No Stress 21-40 = Mild/Moderate Stress 41-60 = Moderate/Severe Stress 61-88 = Severe Stress		Total	ASS	
4 K10 Mental Health and Wellbeing Scale				
In the past 4 weeks about how often did you feel (responses to these questions are)		None of the time A little of the time Some of the time		

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Most of the time All of the time		
tired out for no good reason?			ASS	
Nervous?			ASS	
so nervous that nothing could calm you down? (not asked if the CR answered "none of the time", to the preceding question)			ASS	
hopeless?			ASS	
restless or fidgety?			ASS	
so restless you could not sit still? (not asked if the Cr answered "none of the time", to the preceding question)			ASS	
depressed?			ASS	
that everything was an effort?			ASS	
so sad that nothing could cheer you up?			ASS	
worthless?			ASS	
Total score		Total	ASS	
Comments	AJ		ASS	
4 Positive aspects of care-giving				
I am going to read out 6 statements about being a carer. After I read out each statement, I would like you to tell me whether you strongly agree, agree, disagree or strongly disagree. These statements are about how you are feeling at the moment.		Strongly Agree Agree Disagree Strongly Disagree		
I am capable to care for CR			ASS	
I feel I have become a stronger, more tolerant, and/or patient person			ASS	
I feel that caring for CR has made our family grow and work closer together			ASS	
Caring for CR has made me more confident in dealing with others			ASS	
Helping CR has made me feel closer to him/her			ASS	
Overall, I feel that I am a good care-giver			ASS	
4 Expanded Health Conditions				
Self-reported health conditions Include all relevant issues e.g. allergies, acute medical conditions, disabilities, continence,			ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
dental, vision, hearing, developmental, anxiety, depression				
Has Carer's use of alcohol and/or other medicines changed since Carer has started caring?	AJ	Yes, increased Yes, decreased No change	ASS	
4 Expanded Information Needs				
In addition to the kinds of amounts of information that carer already has, what additional or new kinds of information would be valuable to carer as a caregiver?				
A help line (or central place to call to find out what kind of help is available and where to get it)		Yes No	ASS	
Someone to talk to or counselling services or support group		Yes No	ASS	
Information about CR's condition or disability		Yes No	ASS	
Information about legal issues that might affect their situation		Yes No	ASS	
Information about residential care		Yes No	ASS	
Help in understanding how to pay for services		Yes No	ASS	
Help in getting services, or		Yes No	ASS	
No additional information needed?		Yes No	ASS	
Other (specify). Assessor: Prompt for information on carer's health needs		Text	ASS	
Action Plan				
Accepted by service for this agency		Yes No	ASS	
Assistance – Type		Indirect respite – domestic Indirect respite – social support Indirect respite – nursing care Indirect respite – allied health care Indirect respite – personal care Indirect respite – centre based day care Indirect respite – meals Indirect respite – other food services Direct respite care Assessment	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		Case management/ coordination Indirect respite – provision of goods and equipment (specialised) Indirect respite – home maintenance Indirect respite – home modification Indirect respite – provision of goods and equipment (generic) Indirect respite – formal linen service Indirect respite – transport Liaison/ advice/ support/counselling Information provision (written/ spoken) Education/ training Other – including employment support, primary or acute health care or rehabilitation		
Assistance – Reason Not Provided		Carer preference Care recipient preference Residential respite unavailable Respite care/ support unavailable Formal or informal staff support unavailable Funding unavailable Other	ASS	
Agency to be referred to		No referral GP/medical practitioner – community based Specialist aged or disability assessment team/service (eg ACAT) Comprehensive HACC assessment authority Community nursing service Acute care hospital Psychiatric/ mental health service or facility Extended care/ rehabilitation facility Palliative care facility/ hospice Government residential aged care facility (nursing home or aged care hostel) Aboriginal health service Commonwealth Carelink Centre Other community-based government medical/health service Other government medical/ health service Other government community-based services agency Hospital (private) Non-government residential aged care facility Other non-government medical/health services Other non-government community-based services Residential facility (respite house, short term or	ASS	

Data element	AJ	Response Information	ASS or ISR	ACCNA item
		crisis respite accommodation) Carer respite/resource centre Other		
Reason for referral		Text	ASS	
Referral Text		Text	ASS	
Priority for referral		Low - hold over during peak demand Routine - attend in date order Urgent - cannot wait	ASS	
Consent for referral		Yes No	ASS	
Referral Status		Not Made Sent Accepted Rejected	ASS	
If referral not made, reason		Carer ineligible for service Referred elsewhere Advice / information provided. No further action required Carer declines further referral or service Carer issues resolved. No further action required Service not available Requested service not accessible - long waiting time Requested service not accessible - inaccessible location Requested service not accessible - other Other	ASS	
Comments	AJ	Text	ASS	

Table 32 An example of inconsistencies in current code sets - source of referral codes for HACC and NRCP

HACC Referral Source	NRCP Referral Source
Self	Self
Family, significant other, friend	Family, significant other, friend
GP/medical practitioner—community based	GP/medical practitioner – community based
Aged Care Assessment Team	Specialist aged or disability assessment team/service (e.g. ACAT)
Community nursing or health service	Comprehensive HACC assessment authority
Hospital	Community nursing service
Psychiatric/mental health service or facility	Acute care hospital
Extended care/rehabilitation facility	Psychiatric/mental health service or facility
Palliative care facility/hospice	Extended care/rehabilitation facility
Residential aged care facility	Palliative care facility/hospice
Aboriginal health service	Government residential aged care facility (nursing home or aged care hostel)
Other medical/health service	

HACC Referral Source	NRCP Referral Source
Other community-based service Law enforcement agency Other:	Aboriginal health service Commonwealth Care Link Centre Other community-based government medical/health service Other government medical health service Other government community-based services agency Hospital (private) Non government residential aged care facility Other non-government medical/ health service Other non-government community-based service Law enforcement agency Carer respite/resource centre Other